

Assisted Reproductive Treatment Policy Manager  
50 Lonsdale Street  
Melbourne, VIC – 3000  
Australia

10 August 2015

## Nuffield Council on Bioethics response to Government of Victoria Discussion Paper ‘The Right to Know’

### KEY POINTS

- The extent to which donors are open to meaningful contact with donor-conceived people is not something that can simply be changed by law.
- Donor-conceived people should not be misled as to the likelihood of the identifying information they receive leading to meaningful contact.
- If a donor has a ‘no contact’ preference, donor-conceived people should be informed of the donors’ wishes as soon as they make any request for identifying information.

### COMMENTS

The Nuffield Council on Bioethics is an independent UK body that examines and reports on ethical issues in biology and medicine. We welcome the opportunity to comment on the Government of Victoria’s Discussion Paper ‘The Right to Know’.

The Council published its own consideration of these issues in its 2013 report *Donor conception: ethical aspects of information sharing* (available online: [http://nuffieldbioethics.org/wp-content/uploads/2014/06/Donor\\_conception\\_report\\_2013.pdf](http://nuffieldbioethics.org/wp-content/uploads/2014/06/Donor_conception_report_2013.pdf)) which carefully analysed the interests of all those concerned with donor conception: donor-conceived people, parents and prospective parents, and donors.

We took the view that "there is no one right place to start when analysing [any potential] conflicts of interest; and in particular that the interests of one party to a relationship should not, as a matter of principle, automatically take precedence over any others. Accordingly, the interests of different parties always have to be weighed." (para 5.40)

In the specific context of retrospective identification of donors who had donated at a time when anonymity was guaranteed, we noted that:

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Hugh Whittall

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“Clearly, some donor-conceived adults experience a very strong need for information about their donor, which they are currently unable to meet. Equally clearly, some past donors will feel very strongly that retrospective legal change in this area is both potentially harmful to their current relationships and fundamentally unfair, given that the assurance of anonymity was a standard part of the terms on which they had agreed to donate at the time. These interests do not, and cannot, coincide, and action to meet the interests of one group will inevitably be damaging to the interests of some of the other.

“However, we suggest that a constructive way forward from this impasse may be achieved by considering in more depth the nature of the interests of donor-conceived adults who desire, but do not have, identifying information about their donor. Those interests lie in obtaining information in order to find out more about their donor as a person (for example to help them assimilate the fact of being donor-conceived into their sense of self), and potentially also in the hope of developing a meaningful relationship. However, it is hard to see how these interests would be promoted in any significant way if the state were to provide the identifying details of a donor who was not open to further information exchange or ongoing contact.

“In other words, in order for the interests of donor-conceived adults in this position to be furthered, the donor must be willing and able to engage in at least minimal contact. Yet, such willingness is simply not something that can be created through legislation. **Thus not only does retrospective legal change potentially damage the interests of some donors, it would also, in at least some cases, fail to achieve its objective of promoting the interests of donor-conceived adults.**” (paragraphs 6.54-6.55)

In the UK context, we therefore recommended renewed effort on the part of the state to increase awareness among past donors of the value placed by some donor-conceived people on obtaining identifying information, in order to encourage donors to consider providing identifying information via voluntary contact systems.

We recognise that the Victoria proposals take a different approach when balancing the interests of donor-conceived people and donors, by offering all donor-conceived adults the opportunity to obtain identifying information, but at the same time enabling donors to register ‘no contact’ preferences in response to such requests. **We welcome the focus in the discussion document on the importance of counselling and support, and we agree that it is very important that donors have the opportunity to register a ‘no contact’ preference if they wish to do so.**

However, we remain concerned about the expectations that will be raised among some donor-conceived adults by the offer of ‘identifying information’ - since from the evidence we received it seemed clear that the desire for identifying information was in fact the desire for contact. **It will be very important, if these proposals are implemented in their current form, that donor-conceived people are not misled as to the likelihood of the identifying information they receive leading to meaningful contact, since this clearly cannot be guaranteed.**

We are also concerned about the impact of these changes on donors, who will have to make their 'no contact' preference known on each separate occasion that their identifying details are requested.

It seems likely that, once alerted to the fact of the change in law, donors will either take the view that they will contemplate contact (with appropriate support), or that this is not something that they are able to do. In this second case, it would seem fairer both to the donor and to the people conceived as a result of their donation for this preference to be registered upfront.

**It cannot be in the interests of donor-conceived adults who wish to obtain identifying information to have their expectations about the possibility of contact raised and then dashed, if this situation could be averted through prior notification of the donor's wishes.**

If such a system were to be implemented, it would, of course, be important that donors were made aware that they could, at any point in the future, change their minds and register a different preference.

We would like to thank the Government for issuing their call for evidence, and look forward to reading its conclusions. If we may be of further assistance, please contact us at [bioethics@nuffieldbioethics.org](mailto:bioethics@nuffieldbioethics.org)

Yours sincerely,

A handwritten signature in black ink that reads "Hugh Whittall". The signature is written in a cursive, flowing style.

Hugh Whittall  
**Director**