

Consultation with donors who donated gametes in Victoria, Australia before 1998:

Access by donor-conceived people to information about donors.

Victorian Assisted Reproductive Treatment Authority
in collaboration with Monash University

Report to the Victorian Government

May 2013



VARTA

Victorian Assisted Reproductive
Treatment Authority

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VARTA contracted researchers from Monash University to conduct the consultation interviews with pre-1998 gamete donors and analyse the findings. This report has been prepared by VARTA in partnership with Monash University.



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***Consultation with donors who donated gametes in Victoria, Australia before 1998:
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Victorian Assisted Reproductive Treatment Authority.

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Executive summary

The report of the Victorian Parliament Law Reform Committee (LRC) of the *Inquiry into Access by Donor-Conceived People to Information about Donors* was published in March 2012. Among the LRC's recommendations was that information identifying donors should be released on request by donor-conceived people, irrespective of whether donors had been assured of anonymity when they donated or had donated at a time when their consent was required for the release of identifying information.

The Victorian Government sought further knowledge of the views of donors directly affected by potential legislative change: those who donated before 1998. It commissioned the Victorian Assisted Reproductive Treatment Authority (VARTA) to consult those donors about their opinions of some of the key recommendations, particularly about suggested changes to the release of identifying information. VARTA contracted Monash University researchers to interview donors and analyse the results in order to ensure confidentiality, rigour, and neutrality. In an extensive publicity campaign in January and February 2013 sperm and egg donors who donated in Victoria before 1998 were invited to take part in the consultation.

The 42 donors (36 sperm donors, six egg donors) who participated were diverse in age (40-73), place and year of donation (1970-1997), disclosure patterns, outcome of their donations, and whether or not they had been approached by donor offspring or joined the Voluntary Register (see page 8). Only seven reported having made a submission to the LRC inquiry. Because records of donations are incomplete, the total number of donors is unknown and it is impossible to assess whether these 42 donors constitute a representative sample. However, the diversity of characteristics, the range of opinions, and the inclusion of donors who have not previously made their views known suggest that the results represent more than a narrow segment of donors. The number of participants exceeded expectations.

Semi-structured interviews were used to explore donors' opinions of the LRC's recommendations and their thoughts about the effect on their lives of introducing these recommendations into legislation. Factual information was also collected. Researchers were careful not to initiate discussion of any specific organisation including VARTA and the Victorian Registry of Births, Deaths and Marriages.

Key findings

LRC Recommendation 1: That the Victorian Government introduce legislation to allow all donor-conceived people to obtain identifying information about their donors.

- A little fewer than half of the donors supported the recommendation. These donors emphasised the needs of donor-conceived people to understand their genetic heritage and the responsibility of donors to do all they can to assist their donor offspring. It was suggested that donors should also have access to identifying details of their donor offspring.
- A little more than half of the donors rejected the recommendation. These donors said it would violate the terms of a contract and undermine trust in guarantees of privacy and confidentiality, as well as harming them and their families. Some said they would seek redress through the courts. Current legislation against (for example) financial claims on donors was not seen as protective if a precedent were to be set of retrospective change.
- About half of the donors who rejected the recommendation suggested the compromise of persuading donors voluntarily to release information (whether identifying or non-identifying) to donor-conceived people.

These donors were themselves willing to supply information to their donor offspring and advocated encouraging parents to tell their children about their donor conception; a stronger view was that, if donors are compelled to release identifying information, parents should be compelled to tell their children they were donor-conceived. The model of voluntary engagement derived from donors' suggestions encompassed:

- publicity about the Voluntary Register to urge donors (and donor-conceived people) to join it;
- an intermediary organisation contacting a donor personally to seek permission for release of identifying or non-identifying information to a donor-conceived person who had made an enquiry.

Concern was expressed that the threat of retrospective removal of anonymity via the release of identifying information, may dissuade donors from making non-identifying information available through the Voluntary Register, because of fears that this leaves a trail of identifying information.

Other LRC recommendations

Donors' opinions were diverse and not consistently aligned with their attitudes to Recommendation 1.

- A donor contact veto, in which donors can refuse contact (for five years) with specific donor offspring to whom they have been identified, was accepted by some donors as a reasonable compromise. It was rejected by others as unfair to donor-conceived people (on the one hand) and both as putting donors in a difficult position and as unenforceable and therefore inadequate protection for donors (on the other hand). Some said that a veto could not prevent the comprehensive gathering and sharing of information about donors and their families, friends, and occupations through the internet and social media.
- A contact preference form was accepted by some as a basic courtesy to donors. Other donors who supported Recommendation 1 rejected the preference form as symbolising donors' wishes to remain distant from their donor offspring, and some donors who rejected Recommendation 1 rejected the preference form as part of an unwelcome package that undermined donors' privacy.
- Allowing donor-conceived people to have access to information about their donors' potentially heritable medical conditions was endorsed by some as providing essential information and rejected by others as beyond the original terms of agreement and because donors' own children have no right of access to their parents' medical files.
- The use of DNA matching for donors and their donor offspring was welcomed by some, particularly if applied only to those on the Voluntary Register; others doubted the accuracy of DNA testing or feared future compulsory testing.

Different circumstances surrounding donation, including recruitment, collection, and record-keeping, influenced donors' attitudes, although attitudes did not vary strictly according to era.

- Some donors described being well informed and supported.
- Some practices were reported as less than ideal. There was evidence of absent or inadequate record-keeping and identity-checking for semen donations. Male donors told of being almost expected to donate as young, often teenage, university students, with assurances of perpetual anonymity. Donations were solicited from men who were having their semen tested or stored for personal reasons. Not all donors thought they had given fully informed consent.
- Donors conceptualised their role across a wide range, from being akin to a blood donor to being a parent to their donor offspring.

Donors made suggestions for managing the legislative changes proposed by the LRC

- Strategies for notifying donors and the community of legislative changes ranged from personal communication to advertisements and included publicity about personal stories from donors and donor-conceived people. Some donors said that missing records and changed addresses would limit any attempts at comprehensive personal contact; others stated that attempts to make personal contact would violate donors' privacy.
- There was near consensus that approaches from donor-conceived people to their donors should be mediated by an organisation with expert staff who can provide professional counselling and is experienced in managing the complexities of these new relationships. Donors often spontaneously mentioned the Infertility Treatment Authority (now VARTA) as the model of an appropriate intermediary organisation and the place where information about donors and donor-conceived people should be stored.
- The provision of accurate information to donors was identified as part of the intermediary organisation's role, as was the education of donors and the community about donor-assisted conception and the rights and responsibilities of all parties.
- Donors with a range of attitudes to Recommendation 1 advocated the provision of counselling and support as an essential accompaniment to any contact between donors and donor-conceived people. It was also seen as important to the families of both parties. Some donors who rejected Recommendation 1 also rejected counselling and support services as inadequate compensation for any compulsory release of information about donors to donor-conceived people.

All participating donors acknowledged the profound significance of the decisions to be made about the release of information about donors for themselves, their families, and donor conceived people.

Background

The use of donor gametes (sperm and eggs) and embryos to conceive is an integral part of assisted reproductive technology (ART) treatment practices. Donor sperm has been used to treat couples with male infertility since at least the 1960s (Hill 1970) whereas egg and embryo donation became possible some 25 years ago (Hammarberg et al 2011). Until the 1980s, a culture of secrecy about using donor sperm prevailed and gamete donation was anonymous (Johnson et al 2012).

The 1980s saw a shift in attitudes towards more openness as the view that children have a right to know their biological origins began to gain acceptance. As a result, in 1988 the Victorian Government, was one of the first jurisdictions in the world to enact a law [*Infertility (Medical Procedures) Act 1984* (Vic)] mandating that identifying information about donors, recipients and children born as a result of the donation be recorded in a Central Register to allow donor-conceived children access to information about their biological parents when they reached adulthood. As a condition of donating, donors between 1988 and 1998 agreed to have their identifying information recorded on the Central Register. However, the release of the information to the recipient parents or the donor-conceived person could only occur with the donor's consent.

Subsequent legislation, *Infertility Treatment Act 1995* (Vic), enacted in 1998, did not require the donor's consent to release information to the donor-conceived person. Hence, those who have donated gametes since 1998 have been aware of, and agreed, that children born as a result of their donation can access identifying information about them when they become adults.

The 1995 legislation also stipulated that two voluntary registers for information exchange between the parties involved in donor conception be established: one for those who were involved before the introduction of laws regulating donor treatment and one for those involved after the 1984 legislation was passed. The two voluntary registers became operational in 2001 and are currently managed as one. The Voluntary Register allows donors, donor-conceived people and their relatives and descendants to lodge information about themselves and apply for information about a related party. If two or more related parties lodge information, they can be matched and information exchange between them facilitated. The Voluntary Register was managed by the Infertility Treatment Authority (now VARTA) until 2010 when the responsibility for the Central and Voluntary Registers was transferred to the Victorian Registry of Births, Deaths and Marriages (BDM).

In the year ending 30 June 2012, 174 donors, 70 donor-conceived people, and 142 recipient parents had registered their details on the Voluntary Register (VARTA Annual Report 2012). Two possible explanations for the relatively small number of donor-conceived people on the Voluntary Register are that: a person has to be at least 18 years of age to register; many parents of children conceived before 1988 have not revealed their children's donor origin to them. By June 2012, 79 matches between donor, donor-conceived persons or recipient parents had been achieved.

Many donor-conceived adults who have not been able to trace their donor through the Central or Voluntary Registers express significant distress and frustration about their lack of access to information about their biological origins due to donor anonymity (Law Reform Committee 2012). Research from other jurisdictions also indicates that access to information about the donor and the donor's family is important to donor-conceived people (Turner and Coyle 2000, Mahlstedt et al 2010, Beeson et al 2011, Rodino et al 2011, Blyth et al 2012).

Societal views and opinions increasingly support the right of donor-conceived people to be able to access information about their donor (Allan 2012). There has also been a shift towards greater public acceptance of the use of ART (Kovacs et al 2012) and recognition of the need for parents to disclose their donor origins to donor-conceived children (Hammarberg et al 2008, Kirkman 2003, Kirkman 2004, Kirkman et al 2007).

Evidence suggesting attitudinal changes towards openness in relation to donor conception include studies that have found that: increasingly parents disclose the use of a donor to their donor-conceived children (Blake et al 2010, Söderstöm-Anttila et al 2010); parents of donor-conceived offspring want to be able to connect with ‘donor siblings’ (Freeman et al 2009); some anonymous donors welcome removal of anonymity (Daniels et al 2012); and change in donor anonymity legislation has not resulted in a decline in the number of men willing to donate sperm (Shukla et al 2013). Donor-conceived people’s right to medical and genetic information about the donor is argued (Lindheim et al 2011, Ravitsky 2012) and the internet is seen as a powerful tool in improving donor-conceived people’s access to information about their donor (Braverman 2010).

To date little research has investigated the psychosocial needs and experiences of donors and there are few follow-up studies of donors (Van den Broeck et al 2012). However, one study found that some donors wish to know the outcome of their donation, including identifying information about children conceived as a result of their donation (Jadva et al 2011). Debate about the rights of donors to access information about those conceived as a result of their donation is emerging (Raes et al 2013).

In response to changing community attitudes, the Victorian Parliament asked the Law Reform Committee (LRC) to consider a number of matters related to donor-conceived persons, under section 33 of the *Parliamentary Committees Act 2003* (Vic). This included:

- a) the legal, practical and other issues that would arise if all donor-conceived people were given access to identifying information about their donors and their donor-conceived siblings, regardless of the date that the donation was made;
- b) the relevance of a donor’s consent or otherwise to the release of identifying information and the National Health and Medical Research Council’s ethical guidelines on the use of assisted reproductive technology in clinical practice and research;
- c) any practical difficulties in releasing information about donors who provided their gametes before July 1988, because in many cases records are not available, either because the procedure was carried out privately or records were not stored centrally;
- d) the options for implementing any changes to the current arrangements, including non-legislative options;
- e) the impact that any such changes may have on the donor, the donor-conceived person and future donor programs;
- f) the impacts of the transfer of the donor registers currently held by the Infertility Treatment Authority (now VARTA) to the Registry of Births, Deaths and Marriages; and
- g) the possible implications under the *Charter of Human Rights and Responsibilities Act 2006* (Vic).

After considering submissions and views expressed during public hearings, one of the LRC’s recommendations was for the Victorian Government to introduce legislation to allow all donor-conceived people to obtain identifying information about their donors. (Law Reform Committee 2012). An executive summary of the LRC’s report is provided as Appendix 1 and the full list of its recommendations as Appendix 2.

The nine donors who provided submissions and/or appeared in public hearings during the LRC inquiry expressed a range of views about whether identifying information should be accessible to donor-conceived people, and under what circumstances:

“All but one of the donors empathised with the circumstances of donor-conceived people and supported providing at least non-identifying information to them” (LRC 2012, p 68). “Six of the donors that the Committee heard from were open to, or indeed hoped for, contact from their donor-offspring. The remaining three donors were opposed to any release of identifying information about them” (LRC 2012, p. 68).

The LRC reported on fears held by some donors: about contact, their donor-status being revealed and publicised through the internet, and the impact on their families who did not know that they donated. In contrast, the LRC also reported on the views of three donors who had positive interactions with their donor-conceived offspring and two donors who actively desired contact (LRC 2012, p 69). Most donors reported to the LRC that “they had often wondered what had become of their offspring” (LRC 2012, p 71).

Reactions to the LRC’s recommendation to retrospectively remove donor anonymity ranged from labelling it as “unfair” and having the potential to undermine trust in government (Pennings 2012) to welcoming it as a “move towards openness and honesty” (Allan 2012).

Although retrospective release of identifying information has occurred with adoption [*Adoption Act 1984*, (Vic)], retrospective release of identifying donor information has no precedent anywhere in the world. The implications for donors and their families of introducing a law that facilitates the mandatory retrospective release of identifying information about donors are unknown. While acknowledging the value of the views stated by the nine donors who made submissions to the LRC or attended its public hearings, the Victorian Government wished to canvass views from a broader donor community before deciding whether or not to implement the LRC’s recommendations. To assist the Victorian Government find a balance between the conflicting rights of gamete donors who presumed they would remain anonymous and donor-conceived people who want to learn about their biological origins, VARTA was asked to conduct a consultation with donors who donated either prior to the introduction of legislation in 1988 or under the conditions of the legislation that operated between 1988 and 1998.

VARTA has statutory responsibilities to provide public education about matters related to ART and conduct community consultation [*Assisted Reproductive Treatment Act 2008* (Vic)]. VARTA’s public education program provides information to all parties involved in gamete donation about matters relating to disclosure of the use of donor gametes. VARTA’s website and information promote openness and disclosure of donor origins to donor-conceived offspring. To ensure consultation rigour and neutrality, VARTA contracted independent researchers from Monash University to conduct the consultation with pre - 1998 gamete donors. (See Appendix 3 for details of the backgrounds and roles of VARTA staff members and Monash University researchers involved in the consultation).

Method

People who donated sperm or eggs before 1998 were sought to give their opinions of the LRC's recommendations and to provide insight into the effect on their lives of introducing these recommendations into legislation. In the absence of complete records of these donations, it is not possible to specify how many donors (either in total or still alive) donated sperm or eggs before 1998. Therefore, the most appropriate approach for enabling in-depth discussion of the recommendations and in recognition of the impossibility of describing the donor population was to adopt a qualitative research model in which volunteers were sought to participate in semi-structured interviews. It was considered unethical to contact donors directly using information on the donor registers or clinic records because this would have constituted an invasion of their privacy; it was also inappropriate to do so because it would have excluded donors not identified on these data bases.

Ethics Committee approval

The consultation was given out-of-session interim approval by the Chair of the Department of Health Human Research Ethics Committee, Fr Michael Elligate, on 21 December 2012. This decision was ratified at the full committee meeting on 6 February 2013 (Appendix 4).

Recruitment

Community awareness of the consultation was raised through the announcement that the Victorian Government wanted to consult with donors before responding to the LRC's recommendations and a comprehensive advertising and media campaign about the consultation which ran in January and February 2013. An advertising company was consulted to craft sensitive print and radio advertisements that conveyed the scope of the consultation and reassured potential participants that confidentiality would be assured (Appendix 5a and 5b). Full-colour advertisements appeared in two newspapers (*The Age* and *The Herald Sun*) and audio advertisements were played on radio station 3AW. Information about the consultation was included on the VARTA website, VARTA Facebook page and in the VARTA e-Newsletter. A Facebook post describing the consultation was placed on the Monash University Alumni website. A request to place the same Facebook post on the University of Melbourne website was declined. A media release generated substantial interest from print media and radio (Appendix 6). Feature articles appeared in *The Herald Sun* and *The Age*. VARTA CEO Louise Johnson and one of the Monash University researchers, Professor Jane Fisher, were interviewed on Radio 774 in a special segment dedicated to discussing the consultation; a podcast of this interview was prominently displayed as the story of the week on the ABC website. A radio interview with Louise Johnson on 3AW with presenter Tom Elliot was also broadcast. (See Appendix 7 for consultation-related media coverage.)

Potential participants were requested to contact VARTA for information about the consultation. Those who chose to proceed after reading the information material (Appendix 8) and Participant Information and Consent Form (Appendix 9) were asked for permission to give their contact details to the Monash University researchers who then sought an appointment for an interview in person (at Monash's Alfred Hospital campus), by telephone, or via Skype, or to arrange a written response to the interview questions.

Interview guide

The interview guide (Appendix 10) was devised from the Law Reform Committee's report in consultation with VARTA staff and the Victorian Government. In addition to requesting an account of each donor's experience of donating and of subsequent related events and reflections, donors' opinions were sought on:

- the LRC's recommendations about donor-conceived people's access to information about their donor;
- how donors' needs can best be met if the recommendations are included in legislation;
- how potential legal changes should be communicated to donors and the general public; and
- the personal consequences of implementing the recommendations.

Factual information was also collected, including whether the donor had joined the Voluntary Register.

Procedure

All interviews were conducted in a private, sound-proof room by one of two researchers (Dr Maggie Kirkman and Dr Karin Hammarberg), apart from one interview that was conducted at the donor's workplace. With the donors' consent, telephone and face-to-face interviews were tape-recorded and transcribed by an experienced transcriber who had signed a confidentiality agreement. One of the researchers (MK) removed or disguised any identifying information from the transcripts before analysis. All participants were asked to choose a pseudonym for use with quotations. Demographic details were recorded separately, without names or addresses, in order to summarise information about participants as a group. Donors who elected to respond in writing were sent the questions by email.

Analysis

Thematic analysis of transcripts and written responses was conducted by one of the researchers (MK) who is a qualitative methods specialist, in consultation with the research team.

Results

1. Recruitment and participants

1.a. Recruitment

VARTA received 55 inquiries about the consultation. Six were deemed ineligible to participate for the following reasons:

- two were oocyte donors who had donated after 1998;
- one was a parent, not a donor;
- one was a former IVF patient who was concerned that some of her excess oocytes might have been donated without her knowledge;
- one was a man who had provided an initial sperm sample but did not become a donor;
- one had donated sperm interstate but not in Victoria.

Of the remaining 49, two people who made enquiries did not receive written information: one rang while the staff member responsible for enquiries about the consultation was on another call and declined to leave contact details; the other decided not to proceed because of concern about privacy, despite being offered the options of using a pseudonym, creating a non-identifying e-mail account, or contacting the researcher directly.

The remaining 47 people who contacted VARTA elected to receive information about the consultation. An information package including the Information and Consent Form was sent by email or post to 45 donors; the remaining two preferred not to provide contact details but to download the information from the VARTA website. Two participants created non-identifying email accounts for participation in the consultation.

After reading the information, two potential participants did not give permission to be contacted by the researchers; one of these potential participants had said that he wanted to discover the outcome of his donation before participating. The remaining 45 donors agreed to have their contact details forwarded to the researchers.

1.b. Participants

Of the 45 potential participants who were contacted by the researchers 42 were interviewed. Of the remaining three, one could not be found at the given telephone number, one responded two weeks after the closing date for interviews, and one did not return his written responses to the interview questions.

Interviews were conducted from 24 January to 4 March 2013; most were by telephone. Three donors took steps to ensure that their contributions were unidentifiable: one by arranging to telephone the interviewer, one by establishing a special email account, and the third by mailing his written responses. In addition to the interviews, some participants sent subsequent emails (one of more than 6000 words) and made follow-up telephone calls to ensure that they had said all that they wanted to say. Information about those who were interviewed is presented in Table 1.

There is no way of knowing whether participants are representative of all pre-1998 donors. However, the diversity of the sample in age, year and place of donation, disclosure patterns, knowledge about the outcome of their donation, and whether or not they had been approached by their donor offspring or joined the Voluntary Register provides some assurance that their views reflect a broad range of donors. It is important to note that the majority of participating donors had not made a submission to the LRC and have therefore supplied new information. It appears that the procedures adopted for the consultation have reached a new audience as well as encouraging previously unwilling donors to come forward.

Table 1:
Information about the 42 participants

TYPE OF DONOR	
Sperm	36
Oocytes	6
Embryos	0
AGE AT INTERVIEW (RANGE)	
40-73	
DONATION YEAR (RANGE)	
1970-1997	
Donated before 1988	28
Donated between 1988 and 1999	13
Declined to answer	1
PLACE OF DONATION	
Royal Women's Hospital	11
Prince Henry's Hospital	9
Queen Victoria Hospital	9
Epworth Hospital	6
Monash IVF	5
Melbourne IVF	1
Declined to answer	1
PRESENT FAMILY AWARE OF DONATION	
Yes	26
No	9
Partner but not children	6
Declined to answer	1
DID BIRTHS RESULT FROM DONATION?	
Yes	32
No	1
Unsure	9
NUMBER OF BIRTHS (RANGE)	
0-36	
JOINED THE VOLUNTARY REGISTER	
Yes	25
No	11
No but considering	6
CONTACTED BY DONOR OFFSPRING	
No	32
Yes	10
MADE SUBMISSION TO LRC	
No	34
Yes	7
Declined to answer	1
TYPE OF INTERVIEW	
Telephone	30
In person	6
Written (email, post)	6

2. Donors' opinions, perspectives, and experiences

Because the population of donors cannot be identified and we cannot know how representative of all donors the participating donors are, results of these interviews cannot legitimately be reported by the numbers of people who expressed a particular point of view. A single person with an opinion not shared by anyone else in the consultation might or might not actually reflect the majority of donors who did not come forward. The value of this consultation lies in identifying the range of opinions held by those who took part and the variety of circumstances in which they donated, from which can be inferred the likely effect of legislative change on those with similar opinions and circumstances.

In the following sections we describe the results of our analysis, presenting the categories of opinions, perspectives, and experiences relevant to the recommended legislative changes. We also describe the context within which donations were made and how donors understand these experiences as influencing their attitudes to the recommendations. Brief quotations from the interviews are included in the text. Longer extracts, enabling greater appreciation of the complexity and diversity of the donor experience, accompany each section of the results and are provided following the conclusion on page 34.

2.a **Recommendation 1: That the Victorian Government introduce legislation to allow all donor-conceived people to obtain identifying information about their donors**

Donors' opinions on the recommended legislative changes covered the range from strong agreement with all changes to equally strong disagreement with all changes. Recommendation 1, concerning the release of identifying information about their donors to donor-conceived people, was pivotal. Although it could be misleading to specify numbers of donors expressing particular points of view, the distribution of donors' attitudes to Recommendation 1 is worth revealing to demonstrate that agreement and disagreement were both strongly represented. A little fewer than half of the participating donors supported Recommendation 1 and a little more than half rejected it. About half of those rejecting Recommendation 1 suggested a compromise position in which steps would be taken to persuade donors to reveal information about themselves voluntarily.

2.a.i. **Agreement with access to identifying information**

Donors who supported the proposed release of identifying information tended to do so out of consideration for the rights of donor-conceived people. For example, Jack B said, "I think the recommendations are probably very sensible. I'm in favour of the donor offspring being able to get in touch with and contact their donors." Quentin said, "My sympathy comes down with the donor-conceived children. Somehow or other I think they should have the right to know". Quentin was married with children when he donated; he discussed it with his wife at the time and told his children as teenagers. Quentin and one of his children are curious about his donor offspring; Quentin accepts that whether or not they have contact is up to each donor-conceived person. Egg-donor Sharon wrote, "While I am aware of people who believe this is all morally wrong and an invasion of people's privacy, I just think they need to walk a mile in someone else's shoes and then make their decision." Sharon added that her children, conceived from donated sperm, will have her support should they want to find their donor, "so I hope the system is not too difficult to navigate come what may!" Owen read an article in the paper about donor-conceived people seeking their donors which provoked him to consider "if there were any children and they wanted to find out information and genetics, so I just thought it was appropriate to make contact and register [with the Voluntary Register]". Evan said, "I honestly believe the child needs to know everything about its conception." Jill thinks that donor-conceived people should have a legal right to know their biological origins; whatever the circumstances when the donation was made, donor-conceived people's interests are more important than the donors'. Jill asserted that donors have a responsibility

to the people they help conceive, even if they did not consider that when they donated. Bruce was scathing about donors who reject the removal of anonymity and said that he cannot understand them. David P believes that the donor-conceived person's rights are paramount and is prepared for a relationship with his offspring based on respect for their need to know their genetic origins. David P has already met one of his offspring without developing a continuing relationship. As a 1970s' donor, David P reminds us that there is a range of views in each era.

Michael B, who also donated in the 1970s, not only supports Recommendation 1 but now opposes the practice of gamete donation, writing that "Donating one half of the means to create human life to the medical establishment to do with as they wished was a grave moral error and I would never do it again." Furthermore, he argued that donors should have unfettered access to "their children": the identification should operate in both directions, with both donor-conceived people and donors having access to identifying details about each other, no matter when they donated or what agreements were made at the time.

Adoption was a frequent analogy among this group, with parallels identified between adoptees seeking their birth parents and donor-conceived people seeking their donors. Some emphasised the need to find genetic heritage, others spoke also of the ultimate connection with the parents who raised the child and still were central to their adult children's lives.

Donors who have put their names on the Voluntary Register, such as David P, tended to say that changes to the law will not affect them, although Wayne commented that an outcome of the changes for him would be that "any future contact with other donor-conceived would probably be a lot easier". A donor who wants to be known as Utnapishtim has put his name on voluntary registers in NSW and Victoria, having donated in both places in the late 1970s and early 1980s when he was told that there was no way that he could ever be contacted. He has learned recently that there are no records of his donations in either place. Utnapishtim is moved by stories of unhappy donor-conceived people searching in vain for their donors and supports the proposed legislative changes because they are important to donor-conceived people, especially if they have an inherited disease.

Donors who supported Recommendation 1 were prepared to meet their donor offspring; some had done so. Not all are emotionally invested in the potential for a relationship. Utnapishtim, for example, said that, "If someone wants to make contact, I'm happy to make contact. If nobody ever does, I'm not going to go to my grave with a huge regret about what's out there and what's not out there." However, some donors endorse Recommendation 1 not only for the sake of their offspring but also because they long for a relationship with them. James even declared that he would have made more sperm donations had he thought there was any chance of meeting "my children". Bruce would "absolutely" like to know his donor-conceived offspring, saying, "I could go on living for another 10 or 20 years but, if for some reason I don't, I would like to have met them or have them meet me." Being on the Voluntary Register gives no guarantee of contact, which some donors who endorsed Recommendation 1 thought might surprise donors who reject the recommendation. Jack B knows that there are more than 20 people conceived from his donated sperm; he is disappointed that none has contacted him through the Voluntary Register, although he has met the mother of one child. Jack B spoke of reading about relationships developing between donor-conceived people and their donors, and said, "My dream would be one day to appear in one of those news stories with a happy reunion". After donating, Noel married, had children, and did not think of his donations until he received a letter in the late 1990s telling him that there were still straws in storage that would be used only for additional children in families already containing his donor offspring. Noel wept during his interview as he relived this shocking, emotional moment, saying that he suddenly realised that there were people in the world as genetically close to him as his children. Noel said, "Just once I'd like to look into their eyes and see them, and to see me", but thinks the degree of information and contact is entirely up to the donor-conceived people. One of Noel's donor offspring asked for information about him through the Voluntary Register a few years ago but has not made contact; he would like to have deeper personal knowledge of all his donor offspring.

Egg donor Jenny chose not to be a mother but donated eggs in response to an advertisement in the 1990s. Jenny now regrets going ahead with the donation to a woman who, the counsellor told her, was determined never to reveal to her children that they were donor-conceived. Jenny talks of her love for the child that grew from her egg, although they have never met and she knows nothing about the child except the sex. Jenny has a friend who was adopted and whose adoptive mother severed their relationship when he was 21. Jenny is convinced that parents whose children were donor-conceived will similarly reject their children when they reach adulthood, and declares that she will welcome the child born from her donation when he is set adrift by his family.

Donor-conceived people and their donors could also develop significant relationships, as Michael B has with two of his donor offspring. Brett described his family as “best friends” with the family of one of his donor offspring; he has also had many contacts with another family, and inquiries have been made by a third family which has not yet initiated contact. David Q received letters (vetted by the clinic) written by the mother of a young adult conceived from his donated sperm; the mother had been open with her child, who is now aged about 30. David Q has developed a relationship with the young person, which he thinks has been limited by the fact that his offspring’s sibling’s donor has refused contact, causing profound distress.

Relationships between donor and offspring can illustrate the ramifications of the release of information. Jill was originally told that one child, now an adult, was born as a result of her donation. Jill received a registered letter from the Victorian Registry of Births, Deaths and Marriages (BDM) asking her to contact them, and had “a weird phone call” with BDM staff which resulted in her agreeing that the young person be given her email address. Jill was contacted by her offspring and, after months of emails, they met once and are planning to meet again. Jill wants to take things slowly to make sure that it works out well for everyone; she is aware of vulnerabilities, especially in the young adult and in one of her own children who is about the same age. Jill considers herself lucky that her donor offspring is well adjusted, and volunteered that it could be difficult for a donor to be contacted by someone who is “angry” or “miserable with their life”.

2.a.ii. Disagreement with access to identifying information

Donors who oppose Recommendation 1 said that it is unethical to change the rules retrospectively via the mandatory release of identifying information and that there would be adverse consequences of doing so. For example, Chris wrote, “I donated on the basis of assurances of anonymity. It would feel like a dreadful betrayal of an altruistic act to have the situation changed now. ... I regard this as, essentially, a complete breach of contract.” Michael A would not have consented to donate without a guarantee of anonymity and wants nothing to do with his donor offspring. He wrote, “My offspring owe their very existence to this guarantee which is why they should not feel cheated or offended by it. I consented to donate sperm with a view to assisting a couple to conceive. I did not consent to a relationship with my offspring at some future time nor did I accept the responsibilities that accompany any such relationship.” Peter X adamantly objects to changing the law with retrospective effect to the extent that he did not answer most of the questions about other recommendations because everything hung on his objection to the mandatory retrospective removal of anonymity via the release of identifying information. Peter X also said that he would not have donated had he known that he would ever be identified. Tony wrote that the effect on him of being identified would be “The incredible risk of destroying my family, and I will sue heaven and Earth if that happens.”

Among the harms predicted to families were the unwelcome “knock on the door” by someone claiming family membership, thereby damaging the family’s understanding of itself and of the donor’s loyalty; “stalking” of the donor’s children and extended family in person or through the internet; and demands or “emotional blackmail” from a “needy” or “unstable” donor-conceived person. Some donors, however, did not feel required to give reasons beyond the propriety of upholding promises that their donation would always remain anonymous. Adverse consequences for donor-conceived people of legislated access to identifying information about donors were also

suggested. Michael A said that, if a person conceived from his sperm donation came to his house, “As soon as they say who they are and why they’re here, I will shut the door”. He asked whether this person might not be better off being left in ignorance of his donor’s identity. Other donors were aware of great suffering on the part of donor-conceived people whose donors refused to have contact with them; in this group, donors tended to say that it would be better not to put a reluctant donor in this position rather than to force the donor to be identified and then refuse contact.

It was claimed by some donors that the possibility of legislating with retrospective effect would disrupt community confidence in parliament and the rule of law. For example, Peter X asked, if they change this aspect of the law, what else will they change? Might they decide that donors are financially liable? It was notable that one donor (Owen) who supports Recommendation 1, is on the Voluntary Register, and is prepared to be identified to his donor offspring, nevertheless has a lingering concern about any potential legal burdens on the donor, such as claims on his assets. Concern about demands on the donor—financial and legal, as well as emotional—were raised by donors despite apparent awareness that financial and legal claims are not valid in law. Given that donors expressed fears about potential outcomes of being identified such as demands for money from donor offspring or claims for child support from recipient mothers for which there are specific legislative safeguards, the point made by Peter X and others is that the current safeguards have no power of reassurance once the rules on release of information are changed. And, according to Michael A, if a government can make this legal change with retrospective effect, how can anyone who is guaranteed confidentiality, such as a whistle blower, be confident that such assurances will be kept?

Andrew attributed the proposed changes to campaigning by a few donor-conceived people who feel they have the right to know their donor, whom he described as “selfish, short-sighted, belligerent, irresponsible, overly-optimistic and intrusive” and “wilful violator(s) of the donor’s privacy”. According to Andrew, these legislative changes would be of minimal benefit because only a small proportion of donor-conceived people from that era know that they are donor conceived and because the available records are limited. The impact on the “aggrieved party” (the donor), according to Andrew, far outweighs any benefits to the few donor-conceived people who want and are unable to gain access to identifying information about their donor. Andrew said that donor-conceived people should be able to find out who their half-siblings are in order to avoid consanguinity but suggested that this could be done through VARTA without revealing the donor’s identity. DC, who thinks he might once have been told there are two or three people conceived from his donations, is interested in having non-identifying information about them only to help his (adult) children avoid relationships with them. DC is not concerned about donor-conceived people having non-identifying information about him, although he wants no contact and feels apprehensive about the possibility that they might attempt to contact him and about any claims they might make on him. Chris is on the Voluntary Register and is also willing to supply non-identifying information. He wrote: “I support the notion of donor-conceived people receiving some information. I have done what I can to help in this regard. But a loss of my own privacy, which could have severe implications, would be most regrettable. I did this (donated) to help others. I hope I did help. Why should I, and my family, potentially be harmed now?”

A donor using the pseudonym Anon rejects any change to legislation with retrospective effect, asserting that mandatory release of information identifying him would be severely detrimental to him and his family. Anon donated in the early 1990s as a young university student, attracted by “travel costs” for the expected 10 donations and the prospect of genetic survival should he have no children of his own. He recalls two sessions of counselling before he donated, in which it was emphasised that there would be no chance for him to meet or find out about his donor offspring. Anon was happy with that rule then and remains so, and was glad of the assurances of anonymity and confidentiality. At the time of donation, Anon gave the requested information about his health and history and wrote a letter for his file; in the letter he said that he and his donor offspring would never meet and wished them “a nice life”. When Anon told his wife-to-be about his earlier donating, “it was nearly a deal-breaker”. Anon’s wife feels responsible for any children created from her eggs and

thinks Anon should feel the same about his genetic material; she believes he should never have donated. In contrast, Anon equates his donations with “a one-night-stand”. Anon contacted the clinic about a year after his donations to find out if his samples had been used; he was told they had and that there had been births, but he wanted to know nothing more. Ten years later, Anon was contacted by the clinic seeking permission to conduct a gene test for which they would require an additional sample; he agreed but did not want to know the results. Anon now thinks that his initial contact was “one contact too many”, which has set a “dangerous precedent”, establishing the impression that he is “willing to be contacted”. He thinks it is “unreasonable” to take away his promised anonymity, and said that the possibility of losing it arises only because the clinic has his details on file and because of publicity about “unhappy” donor-conceived people.

Some donors who reject Recommendation 1 welcome the prospect of being contacted by their donor offspring. Jim, for example, is “interested” in finding out about his offspring, although “It’s not vital to my existence or anything...I’m not emotionally attached to the idea of revealing or not revealing”. Jim is willing to put his name on the Voluntary Register if he learns that he has any offspring, to enable them to satisfy their curiosity; he has already notified the clinic that he has changed his name. Over the years, George rang to check whether there had been any births from his donation in the 1990s and learnt that there were a few, all from about 10 years after the date of his donation. He has joined the Voluntary Register, saying, “I’m interested to make contact in any way...and I’d be happy to talk to the parents tomorrow. Even though the children aren’t 18. If they wanted. I mean, they might learn a lot from me, and they might be interested to meet me. I don’t know. I don’t know if that’s legal in the system at the moment. ... I registered years ago with that, and I haven’t heard from them; I guess that means that they haven’t asked.” Dennis was contacted (through the ITA) by one of his offspring and has since put himself on the Voluntary Register, prepared to be identified. As a result, he has become curious about the (unknown number of) others. Nevertheless, despite stating that these changes to the law will not affect him, Dennis, in common with the other donors in this category, thinks it is wrong to change the law with retrospective effect, as proposed by the LRC.

2.a.iii Preference for the compromise of persuading donors voluntarily to release information

Donors who reject Recommendation 1 fall into two categories. About half rejected it outright; their views are summarised in the previous section. The other half, whose views are described here, emphasised the value of encouraging the voluntary release of information. This latter category consists of donors who, while themselves willing to give information to people conceived from their donations (often to the extent of being identified), nevertheless were not happy with the recommended mandatory release of identifying information. They advocated education and persuasion rather than compulsion in encouraging other donors to make themselves accessible. They tended to say that the proposed changes would not affect their own lives.

Ian, who supports the donor-conceived person’s right to know, is happy to be identified to any of his donor offspring, but disagrees with Recommendation 1: “You can’t change the rules after you’ve made them”. He is proud of having donated in the early days of assisted conception. Another donor, Ewan, thinks donors have a right to privacy that should not be overturned by any right of donor-conceived people to know the identity of their donors. According to Ewan, “the donor has the right to remain anonymous if they want to”, and consent is necessary before information can be released. However, Ewan recently put his name on the Voluntary Register. Edward said that no legislation should have retrospective effect, although he would be prepared to reveal himself to a donor-conceived person with appropriate support and mediation. Edward wrote, “It would do well for those who are writing any new laws to remember that the donors gave a great gift—and it would unkind if that gift came back to cause them grief or angst.” Gary also disagrees with Recommendation 1 but said that, should it happen, he will accept and live with the outcome and that he has confidence in the process that has led to the changes. Gary said that the needs of donors’ immediate families trump those of donor-conceived people, for whom he nevertheless feels

sympathy. He understands that some donor-conceived people may want to know about their donor, and agrees that medical and other non-identifying information should be available to them. Gary has considered joining the Voluntary Register but has not done so because his wife is concerned that there may be offspring who want to form a relationship with him. Gary feels sorry for donor-conceived people who look for “their biological father” but, on balance, decided that his wife’s preference that he does not join the register is more important. Gary is troubled by donors who donated 30 years ago and now seek a relationship with their donor-conceived offspring, describing them as “weird”.

There are two components of the preference for voluntary identification. The first is that the Voluntary Register should be actively promoted; Jack A, for example, thought this might “encourage” donors to “participate”. Among donors expressing this view were those who thought that the donor-conceived people they had met or read about who were distressed about being unable to find their donors would not be helped by the recommended release of identifying information because the relevant records were not available; they had either never been created or could not be found. Donor-conceived people, some donors said, would best be helped by persuading donors to join the Voluntary Register and undergo DNA matching. The views of at least one donor in this category are informed by his experience of being adopted.

The second component of the preference for voluntary identification is that, upon receiving an enquiry from a donor-conceived person, the relevant donor (who may or may not be on the Voluntary Register) could be contacted by the appropriate authority to ask whether he or she is willing to release any information, either identifying or non-identifying. Donald said he was happy to provide all information short of his name and address, but is prepared to reconsider should he be told that a donor-conceived person is suffering in the absence of identifying information. Emily donated eggs in the early 1990s after seeing an advertisement about a shortage of donors; she does not know whether any children were born as a result. She was a mother and wanted to help other women achieve motherhood. Emily was asked in pre-donation counselling whether she was prepared to be identified to children born from her eggs and said no; she has since changed her view, writing that “I do not have any desire from my end to meet up with any children that may have resulted from my donation, but would not object to meeting up with a child if it was their wish to meet me for whatever the reason.” Emily explained that “My change of heart comes from the fact that I now believe children should be able to obtain medical and genetic history.” Roger, too, is willing to be identified but does not think that donors should be compelled to do so, although medical information should be available. In his late thirties, Roger developed medical conditions that he thought might be relevant to his donor offspring, so he contacted the clinic where he donated and was told that, although the conditions were unlikely to be significant to any offspring, notes would be made on his file. Roger wants his donor offspring to be able to find him and is considering joining the Voluntary Register but said that he is deterred by the paperwork and the perceived difficulty of the requirements. Michael A, who opposes Recommendation 1, nevertheless entertained the possibility of being contacted confidentially to ask whether he is prepared to reveal any information following a request from a donor-conceived person, as long as he can decline and not be troubled further. (Others in the same category as Michael A—against Recommendation 1—rejected this direct approach to donors who are not on a register as an unacceptable breach of privacy.)

Donors in this category (preference for voluntary release of information) may seek an exchange of non-identifying information. Peter Y, for example, wants to avoid having any connection with his (about 10) donor offspring, but sought information about them and put his name on the Voluntary Register because of concerns that his children might form a liaison with one of them. Donald, too, wanted information only to the extent that he could prevent consanguineous relationships.

Other donors are prepared to be available to their donor offspring under certain circumstances. About 15 years ago, Jerry T was contacted by the infertility clinic because one of his donor offspring

had developed a problem known to be inherited; Jerry T does not have the problem in his family but was happy to provide any useful details. Jerry T then asked and was told how many offspring he had (more than 10); none has made contact. Jerry T is concerned that parents might not tell their children about their conception by donor.

A few donors have stronger feelings about their donor offspring. For example, Elka has always been curious about the person she helped to conceive, saying “I wonder who this person is, and what they’re like and what they do”, adding, “then there’s the issue of, well, what if they don’t know that they’ve been conceived in this way?” John, who has no children of his own, said that he hesitates when asked if he has children. He knows that he has a few donor-conceived offspring and hopes that they will contact him; none has. He described himself as thinking of them about four times a week. John’s sister, who “disapproved strongly” of his donations, is “irritated about the possibility of family money going out of what she saw as the family”; he has consulted a solicitor to ensure that his will specifies that they can make no claims on his estate. Another donor, who also has no children of his own, was notified by the clinic almost 10 years ago that a young donor-conceived woman wanted to contact him, and met her several times. He said, “It was a positive thing; a father: that was great, and all those things. And it was interesting, my own reaction to the whole thing. But again, you know, I sort of think it’s because I’m gay. That changes your whole perspective on that sort of stuff.” This donor does not know whether he has any other offspring, but wonders whether his sexuality, which was not a problem for his donor “daughter”, might be difficult for a young man.

Jerry T described himself as “sitting on the fence” about the proposed legislative changes; he would not have donated without assurances of anonymity, but “times change”. Jerry T is not worried about access to non-identifying information but is concerned about being identified, although he is considering the possibility. His wife refuses to accept losing anonymity and “always feared, you know, children knocking on the door and things like that”. Nevertheless, he planned to tell his adult children in the six weeks following the interview about his history as a sperm donor and will then sign on to the Voluntary Register. Jerry T is interested in genealogy and thinks that donor-conceived people might be similarly motivated to know their genetic history. He donated because “becoming a father really changed me. You know, being allowed in the room and witnessing the birth of your child. I just thought the joy, and the sensation, and, you know, the outpouring of emotion; I thought, well, why should people be denied that?” Jerry T said, “It’s all right for them to, you know, the legislators and the do-gooders coming out and flushing out donors and saying, you know, ‘We want you to come out of the closet’, so to speak, when some of the children don’t even know that they’re donor conceived. You know, if they’re going to make it compulsory for us, it should be compulsory for the parents, too.” Other donors spoke of the need for parents to be honest with their children about being donor-conceived.

Peter Y also has an equivocal attitude to the recommended changes, arguing that the law should take account of the circumstances at the time of donation and that donors should be able to give or withhold permission for identification or contact without being compelled in either direction. Peter Y is worried about what would happen if the donor-conceived person is “desperate”, or “has problems” that become his problems or his children’s problems; his anxiety extends to the next few generations rather than being focused on himself. Although Peter Y is concerned about the effect of donor-conceived adults on his family and himself, he wanted to record his thought that there might also be problems arising from legislative change for a donor-conceived adult who does not want to know about the donor or acknowledge his existence, especially if donors are given reciprocal access to their donor offspring.

Donors in both categories of those who reject Recommendation 1 expressed concern that the threat of mandatory release of identifying information could dissuade donors from making non-identifying information available through the Voluntary Register, because of fears that this leaves a trail of identifying information. Andrew, for example, said that the only way in which he and other donors could protect their privacy was never to make contact with an organisation such as VARTA which

might leave behind an email address or a telephone number. Some donors who participated in this consultation had not responded to previous requests to express their views because they felt that stepping forward would lead to their identification. They volunteered for this consultation only under the strictest conditions of anonymity, prompted by publicity about what seemed to them to be the imminent legislated removal of anonymity.

2.b. Other LRC recommendations

Donors' opinions on other recommendations are varied, complex, and not consistently aligned with their attitudes to Recommendation 1 on access to identifying information.

2.b.i. Contact veto

Donors were asked whether a five-year contact veto should be available in the event that the Victorian Government introduces legislation to allow all donor-conceived people to obtain identifying information about their donors. The contact veto as described in the LRC recommendations would be specific to each request made by a donor-conceived person. That is, a donor would be notified that a person born as a result of their donation had enquired about them and been given his or her name; the donor would then be given the opportunity to refuse contact with that person. The veto could be renewed by request when it expired after five years. An approach by another donor-conceived person would require a separate veto, should it be desired. The proposed contact veto was accepted by some donors as a reasonable compromise. It was rejected by others as unfair to donor-conceived people (on the one hand) and both as putting donors in a difficult position and as unenforceable, and therefore inadequate protection for donors (on the other hand). Some said that a veto could not prevent the comprehensive gathering and sharing of information about donors and their families, friends and occupations over the internet and social media.

Those who agreed with the contact veto and supported Recommendation 1 did so because it seemed like a necessary concession to donors who hoped to remain anonymous. According to Noel, a person's right to know her or his genetic origin is paramount. Nevertheless, Noel wrote that "Removing anonymity from those who were promised it 25/30 years ago is not a step to be taken lightly. I've made a moral decision—for myself—to remove anonymity. Many other [sic] have as well—hence the numbers on the Voluntary Register. But, some are nervous, even frightened of this potential action. In this context the contact veto (modelled on that used in adoption circumstances) is critical." James wrote unequivocally of the contact veto, "That makes perfect sense." Luke accepted the veto only reluctantly, saying, "I suppose it's fair enough, given the sort of contract they went into in the past. But it's not really fair on the children, is it?" Jack B suggested that the contact veto should be active for a maximum of two years before the donor must reconsider it.

Those who agreed with the contact veto while rejecting Recommendation 1 did so because it gave donors at least some protection from unwanted intrusion into their lives. Elka said, "If a donor wants to remain anonymous, and wants to be not contacted, I think that that should be respected." John thinks the contact veto should be comprehensive and permanent rather than specific and renewable every five years, because otherwise "you could never ever say, 'This is done'." John, who has put his name on the Voluntary Register, is against legislative change with retrospective effect. He does not think changing the law would affect him, saying, "I don't expect anybody to contact me after 30 years. I wish they would, but I don't expect it". Michael A supports the contact veto but doubts that it would be effective; he thinks he would be demonised if he took out a restraining order on anyone who ignored his veto.

Others with contrasting attitudes towards Recommendation 1 rejected the contact veto. Ian, for example, who prefers the compromise position of encouraging donors to release information voluntarily, understands that some donor-conceived people would like to know the name of their biological father so they could "do some detective work" on genealogy without contacting the donor, but is "dubious" that a contact veto would prevent contact with reluctant donors and is concerned about the effects on the donor's wife and children. Peter X, who rejects Recommendation 1, thinks that the veto should not arise because he does not want his privacy to be breached at all. Anon, who also rejects Recommendation 1, does not accept the idea of a renewable, person-specific contact veto and wants to be able to assert a blanket rule of no contact. To Gary, the idea of a contact veto is "laughable" because anyone with identifying details can find and contact a donor. Andrew also

believes that the contact veto is completely inadequate and has virtually no value; he, too, finds it “laughable” that anyone would consider that such a veto would make it easier for donors to accept being identified to their donor offspring, and that “once the cat is out of the bag” there are many potential abuses of privacy. For example, if a donor-conceived person found out their donor’s code, he or she could share that on Facebook and elsewhere on the internet. Andrew stressed that it is easy to search the internet for information about the donor’s immediate and extended family, who may not be aware of the donation and “may not approve”. He envisages a “family album” being compiled with photographs of the donor and his family found on the internet. According to Andrew, there are many more forms of contact than directly approaching the donor, yet this appears to him to be all that is vetoed; the “only protection”, in his assessment, is for the state to maintain its promise of anonymity. Andrew is concerned that even the action of notifying an organisation such as VARTA that you do not want to be identified or contacted will leave a trail of information that might (deliberately or inadvertently) be used to enable contact in the future. He concluded that, “Due to the long-term nature of the donor’s need for zero information disclosure, the only prudent option is probably to have no contact at all with VARTA.”

In contrast, Brett is an advocate of openness and the right of the child to know her or his donor; he supports all the proposed changes, with reservations about the contact veto because it limits the donor-conceived person’s rights. Similarly, Michael B wrote of the contact veto: “This denies the offspring the ability to form a complete picture of their genetic inheritance. In fundamental human relationship terms the donor is their father. The donor, and legislators, should affirm that he is their father and not exercise or allow right of veto.” David P is in the same category: “I don’t really agree with the donor being able to veto. I think, if you were a donor, you did it because you wanted to help someone and, at this stage, to sort of put up a wall when someone really wants to know, I don’t think that’s right.” Jenny said of the veto, “That should be illegal. That’s cruel. I have seen, I’m telling you, I’ve seen adults bawling their eyes out, knowing they’ll never ever get to meet their father, know their father.” Others who support Recommendation 1 dismissed the veto as worthless. One example is Evan, who said of the veto, “That’s rubbish, anyway. ... That part of the law could never be maintained. ... But look, it’s politically correct, what they’re saying, because they are politically doing what they have to do, but everybody knows if you want information bad enough, you can find it.” Egg donor Shelby thinks the contact veto is both too hard on the donor-conceived person and impossible to enforce. In endorsing Recommendation 1, Shelby said, “Why should there be a time span, that, ‘You can’t’, and ‘You sort of can’, and ‘You can?’”, depending on the period of donation. Sharon cautioned that “when you tell someone they can’t do something, you make them want to do it more”.

Jerry T, who prefers to persuade donors to come forward voluntarily, was not able to make a firm decision on the contact veto, saying, “I think, at this stage, I’d have to wait until I get the reaction from my children. Because, I mean, it’d be silly, wouldn’t it, if my children wanted to meet them, and I didn’t. I’d want to hear what they have to say first.”

2.b.ii. Contact preference form

The proposed contact preference form, in which donors could state how they would prefer to be contacted by their donor offspring, was less controversial than the contact veto. It was accepted by some donors as a basic courtesy and rejected by others either as keeping an unwarranted distance between donors and donor-conceived people or as part of an unwelcome package that undermined donors’ privacy.

Most donors who agreed with the contact preference form saw it as an appropriate courtesy. Jenny, who supports Recommendation 1, said, “Everyone should choose how they would like to be contacted; that’s respect.” Jack B also supports Recommendation 1 and said of the contact preference form, “I think that’s a good proposal, because if—you know, for many people, a letter arriving is a lot better than a telephone call out of the blue, so that’s fair enough.” Michael B, another supporter

of Recommendation 1, wrote that contact should be “Any way possible, as long as the donor realizes what true contact should entail.” Jim, who rejects Recommendation 1, said of the contact preference form, “Yes, that makes sense.” DC, who also rejects Recommendation 1, said “if I couldn’t avoid it, I certainly would like to choose how it’s going to happen. ... My preference would be to avoid it altogether.”

A few donors disagreed with the contact preference form. Donors who rejected Recommendation 1 tended to consider the preference form as representing part of the same unwelcome package. Peter X said that the question of stating a preference should not arise because he does not want to be identified to his donor offspring, and Michael A said, “What have my preferences got to do with it if my offspring can contact me any way they choose with impunity? What have my preferences got to do with it?” Tony, who is adamantly opposed to Recommendation 1, wrote of the contact preference form that it could be acceptable to donors “If they’re foolish enough to entertain that.” On the other hand, Evan, who supports Recommendation 1, thought that allowing donors to express a contact preference related to “the donor wanting to be anonymous.” His response to the question about the acceptability of the contact preference form continued, “I do believe that, if you’re going to be a donor, you’re not anonymous. You’re doing it for the good of the child, or the future good of future children. ... What are you doing wrong that you don’t want them to know who you are? God, I would be thinking you should be quite proud that you could turn around and say you brought extra children into the world that needed to be loved. You know, people wanted it, so why hide behind a screen? No, I’m not for that.”

2.b.iii Release of information about potentially heritable medical conditions

Responses to the question of whether donors should be compelled to release information about medical conditions that could possibly be inherited by their donor offspring depended, to a large extent, on attitudes to Recommendation 1 on access to identifying information.

All donors who supported Recommendation 1 said that, if any medical conditions had arisen that were not known at the time of donation and were thus not in the donor’s record, donors had a responsibility to ensure that their donor offspring had access to this information. Jack B, for example, said, “I think that should happen a hundred per cent. I really think it’s an absolute fundamental human right to understand if there’s any hereditary condition that you should be aware of, in order that you can receive treatment. In fact, I think it would be almost criminal to conceal that information that could help somebody with a serious condition.” Other donors who disagreed with Recommendation 1 were nevertheless willing to concede that donor-conceived people could learn about potentially heritable medical conditions as long as the donor’s identity was not revealed without permission. John, who prefers to encourage voluntary disclosure, said “I think it would probably be withholding important information if they were not notified”. Edward, who also advocated voluntary disclosure, rejects the contact veto as too intrusive and yet said, “I have no troubles with my medical records being passed on to people who have got my genetics; that’s perfectly fine with me.” Peter Y, another donor who prefers the voluntary approach, has a potentially heritable late-onset condition about which he would be happy to tell his donor offspring. He argued that there should be updates on donors’ health every five years, initiated by an intermediary body managing contact, to ensure that all hereditary diseases are notified to donor-conceived people.

Some donors who disagreed with Recommendation 1 also rejected the idea of disclosing medical information. Anon, for example, said that, if he’d had a one-night-stand in a nightclub, anyone conceived as a result would have no access to such information; Michael A said that his own children have no legal right of access to his medical records, so why should anyone conceived as a result of his donation have access?

2.b.iv DNA matching

One recommendation from the LRC is that DNA matching could be used to identify the correct donor for donor-conceived people when records are inadequate or missing. Donors across the spectrum of attitudes to Recommendation 1 were prepared to accept this possibility, most on the understanding that both donor and donor-conceived person had voluntarily enlisted themselves on the Voluntary Register and that they gave permission for the DNA matching to be conducted. Michael B, who supports Recommendation 1, wrote, “Yes, some medical advances actually serve to affirm genetic inheritance rather than obfuscate it.” Jenny, who also supports Recommendation 1, said, “Fine! Absolutely. I’m willing to give my blood to prove that definitely we’re related, and that it was the right egg that went into that woman and it’s my child.” Jim, who rejects Recommendation 1, said, “I can’t see any drawbacks in that, so I think that’s a good idea.” Jerry T, who prefers encouraging voluntary disclosure, said, “I think I would agree to that. DNA matching is vital in solving crime, it’s vital in ascertaining identities of people, so I can’t see any problem with that.”

Not all wholeheartedly endorsed the recommendation, however. DC opposes both Recommendation 1 and DNA matching and, according to John, DNA testing is acceptable but unreliable. Some donors who opposed Recommendation 1 postulated that DNA matching could be caught up in the move to mandated identification of donors; for example, Chris’s reply to the question reflected his anger and suspicion about the recommended changes: “But would such matching be voluntary or compulsory?”

2.c Different circumstances may influence donors' views

Differences in the circumstances under which donations were made, including recruitment, collection, and record-keeping, appear to have influenced attitudes to the recommendations. There was no direct correlation between era and donors' attitudes to Recommendation 1. It was not necessarily more likely that donors who had been guaranteed anonymity in the 1970s, for example, would say that they did not want the legislative changes than those who donated in the 1990s, when the topic of donor-conceived people's need to know about their donor was being publicly discussed and legislative changes were already being implemented. However, those who donated in the 1970s who objected to Recommendation 1 appeared to do so with far more vehemence and tended to have spoken up for the first time to this consultation. The earlier donations often involved university students, including medical students, who were recruited as sperm donors almost as an expected part of their student experience. Some of them were teenagers. Later donations were more likely to be as a result of publicity about people who had experienced infertility; donors' empathy was aroused and they volunteered with the intention of providing altruistic assistance. This is not to say that earlier donors lacked empathy and altruism; they spoke of having these motives. However, early donor recruitment tended to present semen donation as a do-and-forget activity in which donors said they were warned that no knowledge of or connection with the offspring of their donation would be countenanced or possible. Donors such as Ewan and Gary from the 1970s equated being a semen donor with giving blood. Bruce, too, said, "I'd been a blood donor for a long time, heard they were after sperm donors, so I thought, 'Why not?'" On the other hand, some later donors objected to Recommendation 1 on the grounds that they had altruistically contributed a valuable gift to people who wanted to be parents and rejected the notion of having to give more by having their identity available to people conceived as a result of their donations.

Some Victorian donors from the 1970s, such as Bruce, told of knowing or suspecting that their sperm samples had been sent interstate without their permission; a donor from interstate (who was not interviewed nor part of this consultation) wrote to say that he had reason to suspect that his samples had been exported for use in Victoria. Ian was surprised to discover when he contacted the clinic that he has a donor offspring conceived and born interstate, because he did not know that sperm were exported from Victoria. Ian is shocked and disappointed that the interstate records are too poor to enable linkage. Ramifications of legislative change are not confined to Victoria.

Jerry T made almost 60 sperm donations over three years in the early 1980s and thinks (although he can't recall being told) that some might have been used for research. He was not alone in this claim.

Robert donated as a teenage university student in the 1970s, recalling that male students of science and medicine were encouraged to do so, as did Jim and Gary, all of whom spoke about the emphasis on perpetual anonymity. Michael A described how he and his cohort of medical students did 10 weeks residence in obstetrics at a hospital in the 1970s where they were expected to donate to the infertility program. They were notified when a woman needing sperm was in the clinic and would make a fresh donation which was immediately transferred to her. Michael A can recall no documentation, but the students were given firm assurances that they would remain anonymous and could never be traced. He now feels "angry and betrayed" by the potential loss of anonymity.

Noel donated when he was young, single, and childless in the 1980s; he now thinks that the process amounted to uninformed consent because he was not told to consider the outcome of his donation and what might happen in the future. John described as "clever amateurs" those who collected his sperm donations, saying that they had no insights into human needs and no psychological training. David Q donated as a teenage university student in the early 1980s and was told that there were unlikely to be any births resulting from his donations. He was therefore surprised a few years ago to be contacted by a counsellor from the clinic with a request to provide information about himself for one of the children born from his sperm. David Q has since learnt that he has several other donor offspring, about whom he knows nothing. David Q said that the medical profession "has a lot to

answer for” because they gave inadequate information to donors, because of their poor record keeping, and because “It was a business back then; it’s a business now”. In contrast, Donald was “pleased” and “impressed” with the counselling he received in the late 1980s.

Not all donors set out to donate sperm. Peter X had supplied semen to enable a diagnostic test for himself in the early 1980s; he was found to have a high sperm count and invited to be a donor to families of a specific ethnicity. Clinic staff emphasised that he would remain anonymous, which persuaded Peter X to agree. Peter X wanted to make it clear to us that family is important to him and that he has a parental relationship with a child conceived with a girlfriend before his marriage, but insisted that sperm donation is different and that he should retain his promised anonymity. Peter X believes that most families of the ethnicity to which he donated would not have told their children. George wanted to store sperm before a vasectomy in the early 1990s; he reported being told that there would be no storage fee if he also donated sperm, so he did. A few years later he was notified that the clinic had changed hands and that he was now required to pay for storage; the only way to avoid paying was to donate the stored sperm, so once again he did so. George thinks that the potential legislative changes are further examples of renegeing on a deal.

Egg donors tended to be more willing to be identified to their donor offspring than sperm donors, possibly because of both their later time period and the different process of retrieval. Sharon, for example, gave birth to children with the help of sperm donation in the 1980s and donated eggs in the early 1990s as a way “to give back”; she does not know if any child was born as a result, but agrees with Recommendation 1. Shelby became an egg donor in the mid-1990s after seeing a newspaper article about women who needed donor eggs; she already had the children she wanted, and told them and her husband what she was doing. She also supports Recommendation 1. However, egg donors also reported problems with record keeping and management. Jill became an egg donor in the 1990s after seeing an advertisement in the paper from an infertile couple. Jill’s relatively recent inquiries about the number and sex of children born from her donations were, in her view, not handled well. She was frustrated that staff of the Victorian Registry of Births, Deaths and Marriages were unable to provide her with non-identifying information about her donor offspring, and upset that the clinic at which she donated gave her inaccurate information after a cursory check of records. Having finally learnt the truth, Jill now regrets that her years without accurate information have left her with responsibility for telling her own children and the one young donor-conceived person she has met that there is another person born from her eggs to whom they are genetically related; this undermines what Jill thought of as the truth that she has been telling them from the beginning.

2.d Understanding themselves as parents or non-parents may be associated with donors' views

Donors conceptualised their role in the creation of donor-conceived people across a very wide range. At one extreme were those who saw it as akin to donating blood; at the other were those who understood themselves as a parent to any person conceived from their donation. Those in the former category were more likely to reject Recommendation 1, while those in the latter category were more likely to accept Recommendation 1.

Anon, for example, defines himself as a sperm donor and not a parent; he thinks that donor-conceived people should be satisfied with the parents who raised them: “One of the things was that I wasn't intending to become a parent, and this was not me becoming a parent; this was me providing a service to other people who would be parents.” Similarly, Andrew denied that a sperm donor can be a parent, and described his efforts as “minuscule” when compared with the work of parenting carried out by the child's acknowledged social father. Jerry T said, “I've considered those children are their mum and dad's children, not mine”. When Donald wrote to the clinic asking whether there were any births as a result of his donations (in order to avoid consanguineous relationships for his children) he was angry that the letter appeared to imply that these children were his family and equivalent to his own children. According to Donald, the letter said, “You have one family of [several] children, and possibly another [child]”. And I thought, ‘I don't have a family of donor-conceived children. I've got a family of my own’. They should have said, ‘There are [several] conceived children’.” He was not prepared to consider that the use of the word ‘family’ in the letter referred to siblings with the same parents, saying that the letter, in conjunction with the proposed changes, meant that “they're trying to impose a family on me”. Egg donor Sharon, who supports Recommendation 1, said, “I'm not a parent. I would never consider that I was any sort of parent, but certainly I've got a role in their life in just letting them know what their genetic heritage is”.

Donors can characterise themselves differently in relation to each of their donor offspring. For example, Wayne has developed a relationship with one of his (about 10) donor-conceived offspring; he considers himself to be the father of this person, who lived with his family for a while, but does not need to develop a parental relationship with the remaining offspring, should they contact him. Wayne said that he thinks his wife and children are becoming accustomed to the idea of this new person in the family.

Michael B is at the ‘parent’ end of the parental distribution. He wrote unequivocally that “In fundamental human relationship terms the donor is their father. The donor, and legislators, should affirm that he is their father and not exercise or allow right of veto.”

2.e Managing legislative change

Donors were asked about how best to manage the implementation of potential legislative changes recommended by the LRC: how to notify people that the changes had taken place and how to manage any resulting contact between donors and donor-conceived people. As can be seen from the interview guide (Appendix 10), questions did not specify options nor invite donors to choose between named organisations that might manage the requirements of legislative change. Because these interviews sought a more in-depth response than a questionnaire would allow, there was frequently discussion around each question, especially in order to ensure that the donor's perspective was clearly understood. However, researchers were careful not to initiate discussion of any specific organisation including VARTA and the Victorian Registry of Births, Deaths and Marriages.

2.e.i Notifying donors and the community

Donors' suggested strategies for notifying donors of any legislative changes covered the range from personal communication to press releases and advertisements. Some donors recognised that missing records and changed addresses would limit any attempts at comprehensive personal contact. Others stated that attempts to make personal contact would in themselves violate their privacy, and there was some preference among these donors for keeping any unwanted legislative change as quiet as possible.

Donald recommended a direct mail-out and added that his own experience demonstrated that it was possible: he recalled receiving letters in two direct mail-outs, one about the establishment of the Voluntary Register and the other about the initiation of VARTA. Michael A suggested sending letters to every alumni of the medical faculties of the universities from which donors were commonly recruited in the 1970s and 1980s. Jill advised electoral roll searches as the basis of personal communication, and DC thinks legislative change would be "a big deal", requiring attempts to contact donors individually as well as extensive publicity. While sharing this view, John was puzzled about how to overcome the curiosity that might be aroused in family members by an official envelope. A few donors said that there needs to be extreme sensitivity in contacting donors because letters and emails might be opened by other family members who might not know about the donor's history of donation, so the initial approach by an intermediary organisation should refer just to the need to contact the organisation without specifying why. Wayne appreciated that he had first been approached by the Victorian Registry of Births, Deaths and Marriages in a carefully-worded letter that invited him to contact them to see whether he was the correct person; he thought this would enable the recipient of the letter to tell his family that he was not the person sought. In some cases, sperm donors said that they saw no point in mentioning their history as donors to their wives or children until they were asked to make contact, because otherwise they would merely be arousing unnecessary anxiety in their family members.

Taking this concern a step further, Andrew (who opposes Recommendation 1) argued that it is wrong to try to contact all donors to notify them of legislative change and to attempt to persuade each one of the value of being identified to their donor offspring because the contact itself amounts to a violation of privacy. Instead, widespread advertising could be used to persuade donors to come forward and put their names on the Voluntary Register. This publicity could include stories from specific donor-conceived people, which he thinks have worked in the past to raise awareness. He warned that, if the stories are too extreme, they may "scare off" donors. Jack B (who supports Recommendation 1) suggested that publicity should emphasise how few donor-conceived people actually make contact and that the resulting association is limited; he suspects that some donors are deterred by the assumption that all their offspring will want an intense relationship with them.

Among those who think that it is not possible to contact all donors individually is Utnapishtim, who said, "How do you do that? I mean, I've shifted about 15 times since. ... I think that would

be very cost-inefficient and very time-wasting. I think you could try, but I would probably find out from television and from papers more than anything.” Those who emphasised widespread press and internet publicity include Sharon, Luke, and David Q as well as people such as Shelby, who said that she was not aware of earlier attempts to consult donors for the Parliamentary Law Reform Committee inquiry. Peter Y said that he doubts whether more than five per cent of early donors would be aware of any publicity, including about recommended changes to legislation, and Jim thinks there is no sure way to contact everyone; he spent years not reading a newspaper or watching television.

On the whole, publicity of all sorts was recommended for notifying the community of legislative change, although a few donors preferred not to spread the word, presumably to limit the approaches to donors that might ensue. Some donors who advocated for change hoped that such publicity would encourage parents who had not done so to tell their children about their donor conception.

2.e.ii Managing contact

Donors were asked how contact should be managed if legislation is introduced that allows access to identifying information. There was near consensus among the donors that approaches from donor-conceived people to their donors should be mediated by an organisation with staff who are expert in the area, able to give accurate information and advice, professionally trained in counselling, and competent to manage the complexities of these new relationships.

2.e.ii 1. Intermediary organisation

It was common for donors to mention the former Infertility Treatment Authority (ITA) as the appropriate intermediary organisation and the place where all information should be stored. A single agency was widely preferred. Jill, for example, was insistent that specialised intermediary services are essential to ensure adequate support for all parties and that they should be designed for maximum convenience, with “one place you go to, and that’s it, and they provide all the services”. Donald also advocated a single intermediary organisation based on the ITA model rather than maintaining registers at one place and providing counselling and support at another. He was “unsettled” by the termination of the ITA and the distribution of its responsibilities between VARTA and the Victorian Registry of Births, Deaths and Marriages (BDM): “I thought, ‘That’s just crazy!’ You know, they said, ‘Oh, talk to these people if you want to do this; talk to these people if you want to do that.’” Donald said that mediation should be by staff with psychological expertise who could ensure that all participants avoid having unrealistic expectations about what may come of the contact, saying “I think the emphasis should be on the protection [of all parties] rather than the administration.”

Jenny, who yearns for a relationship with the child conceived from her donation, is not on the Voluntary Register because, according to her, the paperwork is daunting. Brett, who donated both before and after the 1998 amendments and agrees with the later system of disallowing anonymous donation, prefers the old ITA system to BDM which he finds “so impersonal”. Quentin concurred, disliking the “bureaucracy” of BDM. Jack B, too, said, “I personally think that the way the ITA did it in my case was actually a model for how it should be done. ... I got a letter which I’ve kept. ... And it was from [a staff member]; ... it was factual but gave a number of steps that were very clear and helpful, [... including] making a time to talk to a counsellor. ... I think it’s really important that there be counselling and people be offered some support, because people’s emotions can take them away from some of the realities.” He described his recent dealings with BDM as “like dealing with India, the Indian Passport Office or something. Or the Complaints Department.” When Jack A approached BDM (in 2013) to put his name on the Voluntary Register, he was asked by a clerk whether he had considered the implications for his will; Jack A thought that the clerk was trying to be helpful but it appeared that he or she was unaware of legislation on donor-assisted conception. Jack A’s opinion is that a well-informed and well-resourced specialist organisation would be a more suitable intermediary for linking donor-conceived people and their donors.

2.e.ii 2. Accurate information and education

The provision of accurate information to donors was identified as part of the intermediary organisation's role, as was the education of donors and the community about donor-assisted conception and the rights and responsibilities of all parties. One goal of education, according to donors such as Sharon, should be to encourage donors to volunteer to be identified to their donor offspring. Similarly, Jim (who disagrees with Recommendation 1) said, "Without consultation, I think your privacy should be kept, because that's what you agreed to in the first place. However, I think you should be encouraged to, and counselled about, the benefits to the offspring of revealing who you are, especially in terms of family history and all that sort of stuff." Jack A suggested that part of the education for unwilling donors could be meeting other donors who had voluntarily allowed the release of information to their donor offspring; this could also be coordinated by the intermediary organisation. He suggested setting up groups and arranging meetings. Some donors spoke of having been involved in and valuing the meetings already held by the ITA and VARTA, with donor-conceived people, parents, and donors. Utnapishtim was among those who advocated the provision of accurate information to donors, because "I think you'd want to understand what your rights and obligations were". From another perspective, Michael B wrote that donors "need to be educated about their moral right to accept true parentage of their donor-conceived children."

2.e.ii 3. Counselling

The provision of counselling and support was seen by many donors as a necessary accompaniment to any contact between donors and donor-conceived people. Some, such as David P, spoke from experience and told of how much they valued counselling from a skilled professional who understood donor-assisted conception. Many said that provision of counselling was one of the vital roles of the intermediary organisation. Jack A thought that counselling could be reinforced by meeting other donors.

When he donated, Edward was pleased to be told that there would be mediation and counselling if a donor-conceived person tried to contact him. Edward was so shocked when he received a letter from the Victorian Registry of Births, Deaths and Marriages to say that the mother of a donor-conceived child was trying to communicate with him that he contacted a member of parliament to protest about the lack of appropriate support. Edward said that expectations and outcomes need to be managed and that caution had to be exercised in making contact; his wife is concerned about effects on their children of contact from his donor offspring and would also need counselling, as would their children. Others also said that counselling and psychological support need to be available for the families as well as to donors and donor-conceived people.

Donald, however, did not see the need for counselling as long as a professional mediation service guided the exchange of information and potential contact between donor and donor-conceived person. He was especially concerned that the intermediary organisation manage expectations with care, without promoting the idea that a close relationship was the desirable outcome of any donor linking. Donald wrote: "Going through the VARTA website and listening to the donor-linking podcast reinforces this 'best outcome' assumption in a very obvious way. It is almost as if VARTA is saying 'not only is it "not bad", it is "good, healthy and you get an extended family as well"'. Other donors saw counselling as a necessary component of mediation in managing expectations and spoke of valuing the accounts of donors' experiences.

A few donors did not see counselling as valuable. Anon does not want to be counselled and said it would be "an insult" to his wife to be offered counselling; she would seek it herself should she need it. Anon said, "I don't want my family involved... It causes so much stress at it is, this wouldn't help."

Conclusion

This consultation was successful in encouraging participation by donors who have not previously made their views known. Some had been unaware of earlier attempts to consult them and came forward as soon as this consultation came to their attention. A few became aware of discussion about donor identification only after reading in a newspaper about the Parliamentary Law Reform Committee's recommendations. Others were reluctant to put themselves in a position where they might be identified, and either trusted that VARTA and Monash University would protect their privacy or were satisfied with the steps they were able to take in this consultation to retain complete anonymity.

Although it is not possible to know how representative these donors are, the 42 participants offered a full range of views on Recommendation 1, that all donor-conceived people should be allowed access to identifying information about their donors. Donors who agree with the recommended change are willing to be identified to any donor offspring and say that they will not personally be affected should the recommendations be implemented. Donors who disagree claimed not only that their lives would be disrupted and even damaged but that confidence would be undermined in any current legal protection should legislation enable the overturning of past assurances of confidentiality and privacy. A compromise position was occupied by donors who, while disagreeing with Recommendation 1, were prepared to entertain ways of encouraging donors to make identifying or non-identifying information available to their donor offspring. The two suggested approaches were to promote the Voluntary Register as widely as possible with the aim of encouraging donors (and donor-conceived people) to join it; and to contact donors individually after each enquiry from someone conceived as a result of their donations, to seek permission for release of information and to allow donors to specify what information could be released. Donors who urged compromise (and some who rejected Recommendation 1 without suggesting compromise) were themselves willing to agree to the release of information; some were willing to be available for contact from their donor offspring or had already been contacted by them. Attitudes to other recommended changes, including the contact veto, contact preference form, release of medical information, and DNA matching, covered a similar range but were not consistently correlated with attitudes to Recommendation 1.

There was some evidence that practices of recruiting donors, maintaining records, and managing requests for information about or contact between donors and donor-conceived people had not always met desirable standards. Donors' varied experiences of these practices could be understood to play a role in their attitudes to the recommendations, although complex variables in individual lives were also powerfully influential. Donors who were concerned about the possibility of identifying information being released were sometimes not specific about the kind of harm that they envisaged but talked about disruption to their own and their family's lives. Some were concerned about having their own or their family's privacy invaded by donor offspring, especially by those who had expectations of their donor; others spoke of harm to marital relationships caused by a wife's regret or anxiety over the husband's history as a donor.

Should the recommendations be included in legislation, most donors suggested that the changes should be widely advertised through various media. There were divergent views about whether attempts should be made to contact each donor individually.

There was a very strong preference for a single intermediary organisation with appropriate expertise and experience to manage approaches by donors and donor-conceived people for information about or contact with each other and to provide counselling and support, as well as to provide information, advice, and education to those not yet seeking contact and to the community in general.

Donors made it clear that they recognise the profound significance of the decisions to be made about donor anonymity for themselves, their families, and donor-conceived people.

Bruce

[Sperm donor, 1970s]

“I’m not sure why anyone would really want to remain anonymous from the resulting children, because they have a responsibility to tell the kids about their medical history, and the medical history of the family that has produced the child. So, if only for that reason, I believe that, yes, they certainly have a right. As far as hearing that the kids may come around and want to borrow money off them or something like that, well, why did they originally do the donation? Was it only to get the \$10 for each donation? I don’t know. I question how some people can say they changed their mind, you know. It’s a very serious commitment that you make when you get involved in any process like this, and, if you haven’t thought it through, well, you must be aware that the other people do have rights to know about you, and know about your past. ... [If these changes came about, how would they affect you personally?] “Just make me happier, hopefully. I’ve been through so much trial and bullshit in recent times, I’m looking for the good side of it. I understand there could be some grief; I understand that the person may not be willing to—I wish they were—I’m quite ready to handle that. Should the person be in gaol, I’m quite willing to go and visit them. If the person is well-adjusted and successful, I’m happy to, you know, participate in that person’s life if they would like me to. ... Many times in my life I’ve looked at people walking around the streets as I pass in various places around the world, thinking, ‘Could you be one of my children?’ And in no way in the world am I able to contact them, because I signed away all rights. But should they ever wish to know about me, ‘Here I am; come and see me’.”

David P

[Sperm donor, 1970s]

“I don’t think it [Recommendation 1] would affect me, because I volunteered to be contactable, and one child appeared, and we managed that relationship on the way it felt after an initial consultation. ... I just think that it’s really bad if a person doesn’t really know where they came from, and that’s why I never had—I sort of went out of my way to offer myself if one of these children came forward. ... I don’t really see that [Recommendation 1] as a great problem. ... If people were donors in the first place, ... I can’t really see what serious reasons there would be that they would want to sort of hide that; why, in any current relationship they may be in or something, where they wouldn’t want that to be known. ... It doesn’t really seem like a big deal, because I just think the rights of the child should take precedence over that desire for anonymity. Yeah, I’m sort of a bit ambivalent about it, because legally the early donors did go into it on that understanding. ... It’d be interesting to actually know how many—I mean, obviously, there’s probably no mechanism for this, but to know how many children there were born by donations. ... I think I was just told, ‘Oh yes, there’s a couple’. ... I believe that a high proportion of children are never told that this happened, that they were the result of a donation. ... I don’t want to actively seek them out, and in the case of ones who were never told, well, you can’t really do that anyway, can you? ... So no, whatever happens, happens.”

2.a.i. Agreement with access to identifying information

James (in writing)

[Sperm donor, 1970s]

“I read in *The Age* that there was a long waiting list for families to receive sperm donations due to a lack of donors. I was amazed at this. For the slightest inconvenience on my part, I could help a childless family fulfil what is probably their greatest wish. It was a no-brainer to donate. I accepted the anonymity I was required to contract to, although my preference then, as now, would be to have some contact with my children. About 10 years ago I read in the paper that a donor knew how many donor children he had. I made enquiries and found out I had [several] donor children. Had I received more feedback when donating, I would have donated more and, if I knew there was a chance of meeting some of the children, I would have donated even more. ... The legislative changes are courageous, possibly controversial, but will ultimately be of benefit to the people who matter. I fully support all of the changes and do hope that all of these recommendations are supported by Parliament.”

Noel

[Sperm donor, 1980s]

“I’d come out of a fairly long-term relationship and I’d been single for about a year, and didn’t see any prospect of a future relationship and having children. I mean it seems odd now, because I’ve got my own children now, but at the time I can recall quite clearly that I thought, well, this is something useful I could do. I had had ... a good friend ... who’d been trying to conceive via IVF, and so I was sort of aware of IVF and aware of the issue of people needing donors, and so that was a motivation for me. And so I thought, well, I can help. And it seemed fairly straightforward at the time. I know now it’s not straightforward at all. ... After I had made the last donation, I ... married [my girlfriend]. ... She was quite aware of the fact that I’d been a donor, and had no problems with that. ... It [being a donor] was just something that I didn’t think about until, it was, I think, about [the late 1990s] I got a ... registered letter that had come from [the clinic], ... to say, ‘We’ve still got vials of your semen here in storage’. ... And telling me that they would only use them in the case of families where there were already existing children. ... And I {breaks down}. ... It still makes me emotional. ... It was a registered letter, and I can remember it quite clearly and sort of picture it in my mind reading it, and [my wife] was standing there, and I read it, and I, ‘Oh, oh! So there are children’. And so that was how I found out that I had this other offspring. ... By that stage I had my own children. ... I think I was shocked. Not sort of dismayed, but shock was the reaction, because I had not thought about it. ... And then, to all of a sudden have this realisation that, ‘So there are people that have been born’. ... I wrote back to them and asked for more information, ... what they could tell me about how many children had been born; were they still alive? ... There was some further correspondence with the doctor, and I explained to him that ... one of the things that most concerned me was the possibility of consanguinity, because my children are of similar and overlapping ages with the children from the donations. ... I think the next point at which I then sort of started to think about the issue was when the ITA ... started some advertising around the issue of donors, and I think it would have been when they were first starting the Voluntary Registry. ... As soon as it was created, I put my name on the Voluntary Registry. I put on to the registry also an open letter {breaks down}. Here I go again. ... It was quite hard to try and write that letter, ... to say what I wanted to say to those people if they ever get a chance to look at it. ... I know one of them was alive at least a couple of years ago, because one of them has made initial contact through the Voluntary Registry. I went through a phase of sort of thinking about them and I’d find myself sitting on a tram or a train sort of looking at somebody and thinking, ‘You’re about that age, and maybe it’s you’. ... One of the things that’s been really fundamental for me in my reaction to it is having my own children, ... having seen them grow and see them ▶

2.a.i. Agreement with access to identifying information

Noel *continued*

[Sperm donor, 1980s]

as half of me, to know that there are [about 10] other people out there ... who are as much a half of me as the ... children who live with me. And that's quite a profound thought. ... I talk in the letter about this experience of meeting, for the first time, this grandfather who I'd never known, and I describe it as being like having a missing piece of the jigsaw. {Breaks down} Now there were sort of family characteristics that you were so familiar with. ... I talk about that in my letter, and I say that, if we do ever have a chance of meeting, I think it might be a bit like that. ... Notwithstanding the fact that we were promised anonymity, I think the right of an individual to know their genetic, their family origin, overrides that other right to anonymity. And I don't say it lightly, because I think that's quite a significant thing to override. And although I've thought this through really thoroughly, and carefully, and I'm quite willing for any of those people to know about me, to make contact with me if they wish, I know that there are men who are, who want to retain that anonymity, and I can understand that. I can understand that it could be deeply threatening and frightening, this prospect of: you did something all those years ago, and you were told you'd be anonymous, and now, you know, whatever it is years later, 25, 30 years later, they turn around and say, 'Oh no, sorry, you're not'. That's a pretty significant thing to do. But I do think you're weighing up two sets of rights there, and I think the right of those people to know their origin is paramount. ... The thing that has really impressed that on me is meeting people like [my donor offspring]. ... I've met a number of other people who are searching for their genetic parents, and I can see the depth of the anguish that they feel at not knowing that."

Utnapishtim

[Sperm donor, 1980s]

"I can understand that donors may or may not wish to have identifying information put out there. I can only comment from a personal point of view. ... I've had a couple of friends who have basically found out on death beds that they've got siblings that have a common parent elsewhere, and it's upset them and hurt them, and then it's created this issue of them trying to find each other. So, from my point of view, as a personal thing, I would rather tell them upfront, and that's what has kind of motivated me here, because if I do have children, they'd be in their thirties now, and my [children] are [in their twenties] now. I think they're old enough to handle finding out that perhaps they've got half-brothers and half-sisters around. And I don't think it would necessarily be a bad thing for them to know. ... I guess I started reading things about children who had issues and health problems and were desperately trying to locate biological fathers to either exclude or at least get a better picture for themselves about what their background was. I mean, I didn't do it necessarily to start meeting a whole heap of people, but I figured, if it helps someone, that was the reason for going in in the first place, to try and help couples. Well, if you could help the offspring, then I had no problems with it."

Jack B

[Sperm donor, 1980s]

“The reason I became a donor was because I had a very, very good teacher ... in high school, a lovely man, and he confided to some of his students. He said that he wanted to start a family and he was unable to have a family, so he went to the doctors and they found that there was a problem and he wasn’t able to father a family, but that, through the assistance of donors, he was able to have children, ... and he was a great dad and a lovely man. And we thought, ‘Well, that’s a great thing. Those are the people who should have children’. Anyway, and I didn’t ever think about where the donors came from until I got to university, and somebody mentioned to me, ‘Have you heard about this?’ And I think it was a bit of a joke at the time. But I thought about it, and it sort of landed with me, because I remembered this story of my teacher, ... and I thought maybe that’s something I could do. ... At the time, if they’d asked me, would I have wished would I have looked forward to having donor-conceived children getting in touch with me in the future, I probably would have said yes. I would have thought, ‘Where’s the harm?’ But I know that some people probably were a bit more concerned about their privacy. But then, I also feel: what were they doing this for? They know, they knew what they were doing. ... You weren’t doing it for the money, so I can’t understand why people would be surprised that they may have children who are real people, real living, breathing people with feelings and thoughts, who wouldn’t want to find out about them. Now I could understand why it could be a little bit complicated if your relationship was sensitive in that way. ... Some people may fear that the children are going to come and want to live off them, or borrow money off them, or that kind of thing, or be bad people. I guess there is always that risk, as there is with any single person that you may encounter, but again, that’s a pretty remote kind of risk. And, in the worst case, surely there’s ways that you can actually distance yourself from people you don’t like or wish to see. ... Having read some of the testimonies of the people who really, really strongly wanted to get in touch with their donor parent, I would feel really sympathetic to them, and I could understand why they would want to get in touch, and I think their rights should be really, really respected. I can really see very little downside for a donor if one of their donor offspring gets in touch. ... But for those who said, ‘No, I don’t want to be contacted’, I think you have to balance up that wish for privacy with the feelings—and I would say, probably, the rights—of the offspring. And I would lean on the side of the offspring actually being able to get in touch. People do need to be able to confront their past and not just hide it forever. ... I haven’t told the children, because I feel that, if I told them, they’d want to know more. They’d want to meet them. ... I did tell my dad before he passed away. ... I was always a bit sad that none of these donor offspring ever got in touch and met him, because he was a great man. ... A few years ago, I got an email ... which said, ‘There are [more than 20] children.’ ... I thought, ‘Great. When they turn 18 ... I expect that some will get in touch’. And, you know, quietly I was thinking, ‘Well, I wonder what they’ll be like’. And then there was a resounding silence, so you know, I didn’t hear anything about it for years. ... I’ve sort of come to terms with it, I suppose, but I’m a bit sad, if I’m honest. ... I hope they have loving family lives and all that, but there is something about knowing your, what you’re like. ... I guess that some of them just probably haven’t been told, and that means, I assume, that they’re just happy and grown up and all’s going well for them in their lives. So that’s nice; I feel good about that. ... There is one that’s indirectly been in touch. ... It was actually [the child’s] mum who got in touch, and said she wanted to find out about me. ... Actually, this lady, [name], had two donor-conceived children: [one] who wasn’t one of my ones and [another] who was. ... Basically, she put both of them on the Voluntary Register, because she wanted to find out [the other child’s] natural father. And he isn’t on the Voluntary Register, apparently, but I was. So she said that [my offspring] has all the luck. ... [An ITA staff member] was very, very helpful, very good, and said, ‘Look, these things sort of unfold over time. [Your offspring] may not wish to get in touch’, and basically prepared me for what may happen or may not happen. And, as it turned out, I haven’t been in touch. ... What I recently found, as recently as this new year, because I got a letter from [the] mum, was the first really good photograph I’ve seen of [my donor offspring]. ... And my partner saw it and burst into tears. [The offspring] looks exactly like me, ... more like me than any of my own children do. ... I have that kind of, that sort of, you know, pride that one does have in your children. ... I personally wouldn’t have any problem with any of the offspring, any of the children, being in touch with me at any time. I would be really, really happy if they did. I feel really warmly disposed to them.”

2.a.i. Agreement with access to identifying information

Quentin

[Sperm donor, 1980s]

“I sort of do agree with it [Recommendation 1], but I just have some respect to donors who feel very, very strongly about their privacy. And I don’t know how you get around that. I think maybe they should be educated! ... Donors who are resistant, then, I think all the support you can give them to maybe help bring them around. Maybe the law does need to, at the end of the day, say, well, ‘The children as a result of your donation do have rights which are stronger than your rights for privacy only. It’s their right to have information about their parent’. And I think that’s probably the way I’d come down. ... I just think that children have the overwhelming right, and the privacy issue for the donor comes second, to my mind. ... I think it’s a pretty straight case. If donor-conceived people need, want, information about their biological parent, I think that’s fair enough.”

Evan

[Sperm donor, 1980s]

“Oh god, look, I’d like to see what my biological child is. ... I’m going to treat him like a person I don’t know; I will have to, but I think any biological father or even a mother would like to know what their biological child is all about, and see if you have any of the traits of his own children, you know? And it’s not that you’re welcoming him, them, into your family as, ‘Oh, this is your stepbrother and stepsister’. That you don’t do, but I mean, who knows what will happen down the track? ... If I had one of my biological children call me tomorrow and say, ‘Can we meet?’, I would open my front door, welcome them in, sit down, talk to them. The kids walk in, I would introduce them to the children, to my other half; I would introduce them as I would introduce anybody else. I would not ostracise them and keep them in a sterile corner of the room and not introduce them at all. ... If they want to find out, I’m more than happy to say yes, and, ‘Come and have coffee. Come and have dinner with us and just see who we are’. For me to chase, I don’t think it’s the right thing to do, because it’s not my claim. ... If the child hadn’t been told, oh god, what ramifications are you going to have on that? We’re talking about adults, 18 or whatever, but I mean what ramifications? You’ve lived your life 18 to 20 years, and all of a sudden I knock on the door saying, ‘Hello, I’m your biological dad!’ You can imagine, you know, ‘Are you a nutter?’ Where did they let you out of, and what drugs are you taking?’ So, you know, if the shoe’s on the other foot, if they want to see my socks, they’ve got to come and find me.”

David Q

[Sperm donor, 1980s]

“It caused huge ructions in my family when I decided to have contact with [my donor offspring], and then when I went and actually met [my offspring], I did that outside of the Treatment Authority umbrella, and that caused huge ructions as well in my family, but, at the end of the day, as far as I was concerned, it was a human rights issue. ... It’s not a close relationship by any stretch of the imagination, but, you know, we went to [my offspring’s] wedding, and we see them at Christmases, and they come at birthdays and we sort of—it was a bit difficult, because, as I said, we did it outside of the Infertility Treatment Authority, and that was a mistake on my part. It didn’t perhaps go as smoothly as it should.”

Wayne

[Sperm donor, 1980s]

“In my family, it was open. My children knew, my wife knew, but to meet someone new and then—as far as Mary and I were concerned, we were family. ... Mary is a daughter by donor conception. ... My wife and other daughters started feeling a little put out by that, I suppose. So it’s those sort of things that you can get into trouble with without the counselling, without sort of someone to say, you know, it’s not as bad as it seems. ... [I’ve had my DNA mapped for medical information.] ... It was also testing to see if Mary and I were actually related, or whether it was a mistake in the paperwork. ... [So you did that testing, and you found out that you were indeed her sperm donor?] No, we were indeed father and daughter, and that my other daughters are my daughters, and my cousin is my cousin. ... That was the relationship that she wanted. ... It’s a difficult thing when you actually meet someone, and you realise, ‘No, this is family’, and it’s hard to feel that you haven’t given away your children. ... Mary actually came to live with us so that she could go to a local campus for a university. And it’s a bit like adoption, in that the relationship starts right back at the beginning, and then has to progress forward; you know, like you’re establishing a bond. And if you see it between, say, a parent and a child, you go, ‘Well, that’s normal and wonderful’. If you see it between two adults, it’s like as we were strangers. It’s weird. And, of course, looking at it over a period of time, you can say, ‘Oh, I can see it exactly’: ... contracting what would be a normal 20-year relationship into three or four years. It comes out all right at the end, but everyone else goes, you know, ‘This is not really your daughter’. ... This is the perspective I gained having gone through it. I really expected that I would have, you know, lunch sometime and maybe a few photos exchanged. ... I mentally prepared myself as being available to whatever was required; you know, if it was just some information, if it was some contact, if it was something a bit closer. But I didn’t actually expect a father-daughter relationship.”

Shelby

[Egg donor, 1990s]

“I would have told [my children] that they were conceived through a donor egg or sperm; I would have. I’m very open. ... But I wouldn’t condemn or—that’s a very harsh word—but I wouldn’t think anything if the person who received my eggs didn’t tell the [children]. Like—I don’t know; I guess that’s an individual thing for her and her partner or husband to decide to do. ... I thought, you know, when they’re 18—and I’m on the register—when they’re 18, if they do try to make contact with me, then I would be fine to do that via letter or Skype or personally. I wouldn’t have a problem with that, but I never really had any expectation. ... I think back then it was all sort of a bit hush—well, not hush-hush, but I don’t know whether the parents were encouraged to tell the children when they were of an age to understand, or not. So I kind of think I just put it into the back of my mind that they probably don’t know, so I never really thought about it. ... I think about them once or twice a year when I think, ‘Oh yes; they’ll be that age now’. ... That’s the way I’ve treated this whole thing ... I’d be quite delighted, I think, to meet them, and my [children] often say, ‘I wonder if they look like us’, and. It’s strange to think, you know, that they’re sort of out there in the world and that I may never cross paths with them.”

Brett

[Sperm donor, 1990s]

“That was one of the stipulations I made with mine. I said, ‘If there’s any little ticks and crosses I can put in that makes sure that they can contact me, I want to do it’. ... I’ve got an open letter in my file that basically says, ‘If you want it, come and get it’. ... Since my kids’ birth, I’ve written a family diary; ... it was written with two intents: for my children to know about their childhood and for any donor children to be able to know about the years that they didn’t know me. ... I think that child deserves that right, and I think people going into it who wanted to be anonymous really have not considered the child. They’ve brought a child into the world, and then don’t want to know about them. That to me is wrong, personally, and I mean, that’s a violation of that child’s right. So personally, I think that, if that happens, that the person who said they didn’t want to needs to have a little bit of counselling to sort of like say, ‘Well, this is why we need; this person wants to know your details. This is why’. You know, because the child has that right. ... It’s your responsibility as a— I’ll use the word ‘parent’. But yeah; it’s your responsibility as a parent to provide that child with information that would help either potentially save their life or make their life a little easier. ... Way back in [the mid-2000s], I went through the Infertility Treatment Authority, the ITA, and they went and basically interviewed or asked over the phone or by mail whether or not all of the families would be interested in contacting me, because I’m interested in contacting them. ... I’ve got everything from sort of like, ‘Can’t find them’, to ‘Our children know that they’re donor-conceived. We’ve put provisions in so that they can find out. We’ve made everything transparent’, to, yeah, all over the place, and, like I said, there’s one family that did show an interest, started doing some paperwork, and then just didn’t continue with it, for some reason. ... One family I’m in regular contact with; ... another family, I’ve been in contact with the mother ... And I’ve had one family get my details, but not give me theirs, because they wanted more donations and stuff like that, and I provided that, and what-have-you. But they’ve stopped that contact. ... I was a little disappointed, but that’s their choice. ... I was aware when I got into it that, you know, there’d be people just using it and not wanting to talk about it; ... everything from people who want their children to know, and want their children to, you know, be part of my life. ... I’m fully open with my family; with anyone. ... Of any of the families that contacted me, I’ve collected the photos. I have people say, ‘Oh, are they your kids?’ ‘Well, yes and no. Those two are mine; I go home to those ones, but those ones? Yes, I’m genetically, but, blah, blah, blah’. And we go off into the whole donor thing and what-have-you with people. ... I’m so happy that I’ve got at least one of my families that [has a relationship with me]. And one of the other families: they’re a little hesitant to do that. ... They may get there eventually when the kids get older and what-have-you, so I can always hope.... The family we’re in contact with, ... we just consider it natural; sort of like best friends coming around. ... I send birthday presents, I send Christmas presents. ... I actually got a phone call on Father’s Day from one of my [donor offspring]. ... And it made me feel so special, that [the child] actually considered me as part of that. Because, I mean, [s/he]’s got a birth father; [s/he]’s got a stepfather, and [s/he]’s got me. ... It’s been a beautiful experience. I highly recommend it to everyone I talk to, which possibly annoys the crap out of them! But having been on both ends of the spectrum, having been—my wife had fertility problems, and so we actually contemplated an egg donor, and we were in that same situation; we contemplated adoption. ... I find it amazing that people would want to keep theirself anonymous. ... If that child wants to know you, they don’t want to move in with you; they don’t want your money; they want to just know you. They want to know where they come from, and, for god’s sake! The poor kids; they deserve that. ... This is why I get a little pissed when I see that adoption laws are different than the donor laws. You know, that the children have totally different rights, but they’re basically in the same situation.”

2.a.i. Agreement with access to identifying information

Owen

[Sperm donor, 1980s]

“I’ve gone on the Voluntary Register and ...the ART Team at the Department of Justice, Registry of Births, Deaths, and Marriages, ... let me know that none of the children born as a result of my donation had actually registered on the Voluntary Register. ... I don’t believe that it’s appropriate that they have, you know, that they’d be regarded as a child of the donor from a legal asset perspective. ... But I wouldn’t have any issue about donor-conceived children that resulted from my donation contacting me, if that’s what they wanted to do. It wouldn’t concern me.”

Sharon

[Egg donor, 1990s]

“It’d be nice if we lived in a world where people did the right thing and whatever, but what one person’s right is, you know, is obviously not someone else’s, so if it needs to be protected in the law, then yeah, I sort of think—I know of some men that I’ve spoken to over the years who donated sperm prior to ever having their own families. And their families—you know, afterwards, when their families have gotten together and talked about it, one of them, the wife actually got really upset about it, and said, ‘No, there should be no contact,’ categorically. So I don’t think that you’ve got the right to say that. You know, she was concerned about the effect that any children would have on her family relationships.”

Jill

[Egg donor, 1990s]

“What we have to consider above all is the young person who’s involved in this, the young person who’s been born as a result of this, you know? And I think that their needs override any other needs, really. I think that need in a person to know and to understand about themselves is very strong, and we know the results in terms of what it does to people who don’t know, and it’s not good. And so I think ... we have to meet that need. And, as an adult who donated, we have to take that responsibility on it, even if that means that we now understand that we should, you know, that we were wrong in that belief that you could do it anonymously. I think we’re the adults, and we should take that on and say, ‘No, here it is. This person needs to find out’. ... I personally went into this program, the donation program, knowing that I was clear that I had a responsibility in the future towards any young person that was born as a result of this. And I kind of think that’s the mindset we have to take on as a society. There’s no such thing as an anonymous donor, and you walk away. There are always consequences. And, as a society, we have to kind of take that on; we have to understand what that means, and we have to understand that core concept of people needing to know who they are, with all the consequences that go with it. And, you know, if we’re not prepared to do that and give young people the support they need, then we are going to have potentially—because, you know, IVF is so successful compared to what it used to be. We’re going to have a generation of young people who are going to be lost. You know, lost in an emotional sense, and it’s not good. It’s no good, and we have to be really upfront about it and do the work we need to do around it, and, you know, make it possible for them to find where they came from. ... It’s a really kind of basic human need, and I think it’s a really basic human right. And we should just be doing it, so if that means we change the law, then so be it, but we can’t just change the law; we have to provide the support around it as well. Because this is not going to be a rare thing; this is more and more common.”

2.a.ii. Disagreement with access to identifying information

Michael A

[Sperm donor, 1970s]

“It [Recommendation 1] is a breach of a contract. I had an explicit undertaking when I entered it. For noble reasons I entered into those arrangements to help people. I did it on the basis of promises given, and now the proposition is that those promises be discarded. So I feel, firstly, betrayed, cheated. Secondly, I think there’s a public policy issue here, in—and remember, I regard [the doctor] as being representative of the [hospital], and that hospital was an agency of the Department of Human Services, and governed by the relevant Public Hospitals Act. And ultimately, the State of Victoria, the Government, the Minister are parties to this agreement that I entered into. And it just strikes me that, as a public policy issue, people are entering contracts with government, the government of the day. It’s nothing to do with medicine or infertility, but it might be something like whistle blowers. And if you go into an agreement with government around some sensitive issue, whether it be sperm donation or whistle-blowing or whatever today, on the strict understanding of anonymity and confidentiality, the idea that that can be overturned on a whim by legislative reform at some point down the track, in my view, creates a real problem for government, because a whistle-blower cannot rely on guarantees of confidentiality and protection, because look what happened with the sperm donors. They thought that was confidential too, and look what happened to them. So I do think there’s a public policy issue, that if prospectively government want to change things around confidentiality and so forth, then people go into those arrangements eyes wide open. But to retrospectively withdraw undertakings around confidentiality has a whole raft of implications for government dealing with citizens. ...I’m a fairly robust individual, so it would be gilding the lily to say I would be fearful, but the prospect of that knock on the door—I’m not being melodramatic here—the prospect of that knock on my door and all that might follow: you know, why wouldn’t my biological offspring then knock on my kids’ doors? They’re as easily contactable as me. You know, what’s to stop them stalking them? What’s to stop them making claims on my estate? What’s to stop them, you know, complicating my life at a time of my life where I have put those complications of parenthood largely behind me? And I have no protections and no—other than, you know, apprehended violence orders, I have little protection against that intrusion into my life and the life of the people I love. And, as I say, I think that’s just a gross betrayal of me by someone—I hesitate to use the word—but by someone whose very existence is owed to me. So it’s not enough that I’ve given them life; they’re now able, if they’re of that inclination, to make my life uncomfortable. Haven’t I done enough for them? ... As I understand part of the thinking, and certainly Mr Newton-Brown’s public reported comments, this ethical issue is cast in terms of the rights of children as opposed to the rights of adult donors. Now—and that, because of their status as children, they need certain leg-ups and assistance and special consideration from the State, because they are not, you know, they’re not capable, in a way that a mature adult is, of looking to their own interests. Now what really pisses me off about this is that this is not about the rights of children versus the rights of a grown man. This is the rights of [someone aged in their thirties] versus the rights of [someone aged in his sixties]. They are biologically my offspring. They are very mature adults, the recipients of my information. So they don’t have any special standing, in my view, in their dealings with the State, over and above my own rights to dealings with the State. They are not children; they are, in my case, adults. ... I think that one iteration of the legal background of all of this I’m actually very comfortable with; if the recommendations are enacted in a way that it says, ‘We’ve been to the records of [the hospital]. We’ve identified that, in that 10-week period that you were a donor, Michael, that your sperm was used on couples Smith, Brown, and Jones, and, as a result of those inseminations, there are two biological children that you fathered. And a Betty Jones [aged in her thirties] wants to make contact with you’. If I can say, ‘Yes, happy to have that contact made, and let’s talk about how to do that’, then I think that’s great. Because a lot of people in my position, I suppose, will say ‘yes’. They don’t have my views on the importance of the anonymity promise. However, my belief

2.a.ii. Disagreement with access to identifying information

Michael A *continued*

[Sperm donor, 1970s]

is that if I say 'no', then that's the last word in the matter. So I'm not saying there shouldn't be any attempt to bring biological parents and offspring together, and where the offspring want it, and the donor is comfortable with it, then happy days. ... I was very hesitant to participate in this consultation, not because of any sensitivities around it, but simply because I felt powerless. I don't believe this interview, I don't believe this consultation will have any influence whatsoever on the outcome, and, as such, it was nothing more than a waste of time and emotional energy even having this discussion. That's born of a lifetime of cynicism of many in the public health system. ... And I think its [the government's] mind has been driven up, its mind has been made up, as Mr Newton-Brown admitted during the course of that enquiry, where he said, 'We all changed our mind. We started off thinking this, and of course anonymity should be protected and preserved, and we all changed our mind'. ... They changed their mind, I dare say, because of the passionate and well-intentioned and touching representations of a small number of highly-motivated people, to wit, the offspring for whom this is very important. But I'm telling you, there are hundreds of people like me who didn't even know it was happening, let alone did they not therefore put to Mr Newton-Brown and his colleagues the views that I'm putting here today."

DC

[Sperm donor, 1980s]

"I've been a blood donor for many years, and back then I just thought it was a way of helping people, but back then, I'm pretty sure I signed some paperwork, and it was always going to be confidential, and we sort of didn't expect the laws to change. ... If I had have known that it may have changed, I probably would have changed my thoughts about doing it. ... As I've been discussing with my wife, our children are the result of our love for each other, whereas those other children are the result of just trying to help somebody. So no, I certainly would be very—wouldn't like anybody trying to contact me. But in saying that, it would be handy to know when some children have been born from my donations, and what sex they were, just so that we know on the off-chance that either of my children happen to—you know, it's a very minute chance, but it's always a possibility that they could come across one of these other people and choose them as a partner. That would be the only reason. ... People try to identify, and then they might say, 'Look, I need to have a kidney', and that sort of thing, and that can cause all sorts of problems, because, whereas you definitely would feel sorry for them, if I'm going to donate a kidney to save someone's life, it's going to be my own two children in the first instance. That's for sure. That's going to an extreme example, of course."

2.a.ii. Disagreement with access to identifying information

Tony (in writing)

[Sperm donor, 1980s]

[In your view, should donor-conceived people have a legal right to have access to information about their donor?] “NO, NOTHING, under NO circumstances. The recipients knew what they were getting into at the time and the breathtaking audacity of them expecting to be given access to sensitive information like that retrospectively would be like me, for example, gaining revealing access to information about people infected with HIV. ... [T]rying to mess around with laws retrospectively is asking for big trouble. ... I was naïve at the time and didn’t understand the long-term implications, but I knew that my anonymity was assured. Now I have my own family and I will NEVER, EVER share this information with them. My family is my life and we are at peace with each other and the world. These proposed changes in legislation will threaten the health of many innocent families in Victoria or Australia. It might become law, but in my opinion it will be the first law ever passed in history with the deliberate intent of stripping away an innocent person’s privacy. Convicted criminals have more rights! I hope those ultimately responsible for changing the law have good lawyers.”

Peter X

[Sperm donor, 1990s]

“I did it out of respect. I had a very good doctor at the time, who, they thought I had glandular fever, and he was part of the IVF program, and just by chance, the only way they could tell glandular fever is to get it through your sperm, to know whether to treat it. And then when it came back, I think it was three and a half times the norm. ‘As part of the IVF, would you like to be a donor for these families who cannot become parents? And you’d be doing them a favour, but it’s your choice’. ... I think the whole reason of doing it in good faith was to stay anonymous and to help couples. If it was put to me at the time that, ‘Look, they can access your information’, well then, I would never have done it. ... They can change the rules with commencement from now, so all donors can make that judgment call, but they shouldn’t just change it because it suits other parties or it’s more convenient and so forth. They were the rules on the day, and that’s what people should respect. ... It would be an impact [on my wife and children], and also it could be an impact later on. You don’t know what laws are going to change again. ... They might turn around and change laws by saying, ‘Well, because it’s your biological father, then you must pay child support’. You know, it could be a snowball effect. ... I think it should remain as private, and that’s how it was conducted at the time, and they should respect the law and respect the donor. ... They actually helped their parents out at the time and that’s that. That’s where it should stop.”

2.a.ii. Disagreement with access to identifying information

Andrew

[Sperm donor, era not stated]

“This is my opportunity to speak to a whole bunch of people, and ... it’s my potential opportunity to speak to my offspring. And also I think it’s reasonable to say that I’m not just thinking of myself, but I’m thinking of other donors who for whatever reason they—and it’s entirely up to them—don’t want to have contact. I’m going to try and give you some idea of the kind of reasons that might be, because people don’t always think of all the complexities and possibilities of life. ... They think, you know, ‘Oh, the donor’s blah, blah, blah. Why shouldn’t he want contact? I’m sure if we contact him he’ll like us’. Or, ‘I’ve got the right to contact him. It’s more important than his right to privacy’ and all that kind of crap. ... I can’t write a letter to the editor, or I don’t want to identify myself either to you or to VARTA. This is a pseudonym, but you can tell that I’m a genuine person. ... It’s really, really important for me not to give out identifying information, because once the cat is out of the bag, it’s out. ... [The contact veto] doesn’t prevent her [the donor-conceived person] from following his activities on the internet, searching for his name, finding out his relatives, from sitting outside his house and watching him come and go, from getting other people to take photos of him. It doesn’t prevent a whole series of things, which are really gross invasions of the privacy and arguably security, ... and completely at odds with the contract with which he entered into this whole thing. ... There’s a kind of a literalism going on here that contact means contact. ... There’s plenty of other different kinds of contact, and other things which are even not contact: just watching or knowing, or therefore being able to look up the person’s relatives. ... Once [the donor’s] name has been given to [the donor-conceived person], she could be in contact with other donor-conceived people. She may know the donor code, ... and that may well be given out as part of the package; who knows. ... The parents might have said, ‘Look, we don’t know who the donor is, but the donor code is XYZ’ or whatever. ... And here obviously I’m looking for worst-case scenarios. Which is a reasonable point of view from [the donor’s] point of view in contemplating changing the law. You know, one of the worst-case scenarios is [the donor-conceived person] joins a group of people who are dedicated to finding their donor. ... Once they’ve got a donor code, then releasing it to one person opens it to every other recipient who’s got a donor code; ... I could speak for hours on the number of different channels by which information can flow. ... Once the cat is out of the bag, the potential for abuse of this information ... is absolutely boundless, and it does not go away; it just gets worse and worse and worse. And it’s archived forever, and searchable forever, and, you know, people can just go to a web forum and ask a question and say, ‘I’m looking for so-and-so, semen donor’, or something like that, and it becomes a searchable, you know, anyone who searches for his name will find that. So that means that anybody else with Bob’s name will find that, so it’ll actually impact other people’s lives, or search for ‘Blah, blah, blah’, and they’ll say, ‘Oh, this guy’s a semen donor’, and other people, some other Bob, you know, Bob2, people will ask him, ‘Well, gee, are you a semen donor?’ ... People could turn up on the doorstep, or they could see him in the street. They could be walking past when he walks out of his gate just to see him. Or maybe Bob has a business. Maybe he runs a shop, or maybe he’s a doctor or something like that. They could make an appointment to see Bob, and they wouldn’t necessarily disclose who they are. They just want to see him and get a feel of who he is. ... And it’s not just Bob which is the issue here. ... [His] parents might get a visit, or they might be searched for, or people can search for people’s photos, ... and photos of Bob’s parents, and photos of Bob’s brother and their children and all this kind of stuff. And this is just so pernicious, and ... she might do that on her own computer, or make her own little scrapbook or alternative family album or something like that. But maybe she’ll do it on Facebook as well. Or on her own website. ... [The donor-conceived person] may claim, ‘Oh no, I don’t have any expectations of him; I don’t have any emotional need to see him; it’s just—’, and I’d say that’s probably bullshit. I know you can’t write the word bullshit in your report, but it’s bullshit.”

2.a.iii. Preference for the compromise of persuading donors voluntarily to release information

John

[Sperm donor, 1970s]

“I think the whole thing [proposed legislative change] is rather unfortunate, because you can't sort of re-negotiate marriages, for instance. And causing the new life of a donor-conceived child is just as important as a marriage, it seems to me. ... I'm not remotely worried for myself by the possibility of being contacted by a donor child; in fact, I would like it. But I think that it's rather like if you make a major purchase, you buy a house; you don't expect the purchase to be invalidated 20 years down the track. ... The formulated rules are always behind the zeitgeist. ... I'm very glad indeed to have done the job; I'm delighted by it. It crosses my mind about four times a week, I would say, that I have [several] test-tube children. ... The legislation evolved, as you know, and I wrote asking if they would tell me what children I had. ... I've never made any further enquiries since then, because I didn't feel it was my affair.”

Robert

[Sperm donor, 1970s]

“I'm sure I'll do it [join the Voluntary Register]. ... I should, because [my donor offspring's] sister was also sperm-donor-conceived, and, unfortunately for her, she ... was allowed to contact her donor, and he refused to have anything to do with her; ... wouldn't even tell her his hair colour. ... And I just find that really, oh, I don't know, morally wrong. ... He said, 'Oh, I'm married now with a family and kids'. Well, that's got nothing to do with the price of chips, as far as I'm concerned. ... Because he said, 'No, I don't', that's it; she has no recourse. ... I can understand that he may not want some girl in his life because of his family and so forth, but to not give her anything, as in, you know, 'My hair's brown, my eyes are blue' and whatever, I just found that really quite unbelievable. I don't know why you'd donate sperm in the first place if you weren't prepared to give them that, at least. ... I don't recall being asked about any genetic history or any of those sorts of things, which are really more important anyway. So they need to know there's mental instability in the family or the family has cancer or any of that sort of stuff. ... I actually think it should be law, that if you're going to donate sperm, then the ... child should have ... in-law rights to basic medical background history-type questions. And not personal history; you don't need to know the personal stuff. ... They should be able to go ahead and ask now, 'Have you found anything else that's popped up?' Because [as a teenager] I had no idea if I had some genetic disorder or something or other which I may have since found out. ... I have no issue with it whatsoever, and I don't really understand why people would have an issue, other than if a donor is trying to contact you in the hope of financial gain or with some emotional instability or so forth. And I was lucky, because with [name], my [donor offspring], the first letter [s/he] wrote was, 'I'm not looking for money, I'm not looking for a father; I'm just looking to understand where I'm coming from'. And so we clicked straight off, and it was great, without that sort of carry-on, whereas [the] sister's donor apparently said, 'I've got a family; it was done before I was married; I won't have anything more to do with you, because I don't know what's going on'. ... She was more needy about the whole thing. So she was sort of looking for something beyond finding out some information. So I think I was lucky because my [donor offspring] was quite stable ... whereas [the] sister was ... looking to find somebody to help her out of this horrible place in her life. So I can understand how ... you wouldn't want that. ... I mean you deal with people on all sorts of levels. You can meet anybody and they can be a weirdo. ... I guess there could be some sort of law about stalking; there is laws about stalking. ... There's got to be some sort of mutual agreement about whether you want to go further or whether, you know, that's as far as they need to go. ... I'm thinking more from the kid's side than the donor's side. I guess if you're a donor—well, not for me, ▶

2.a.iii. Preference for the compromise of persuading donors voluntarily to release information

Robert *continued*

[Sperm donor, 1970s]

but some people might be quite interested in finding out if they've got kids and whatnot. So I guess it's a two-way street. So if it means protecting the child as well; you know, some guy coming along and saying, 'Oh, my child. You're my daughter. I need blah, blah, blah', I guess that it is actually a two-way street. I sort of think of it as being the other way, more about the kids than about you. ... Back when I was doing it, you were allowed to be anonymous, and if you were donating with that in your mind, then I think that should be respected, because perhaps they wouldn't have donated at that time. And they were really pushing for donations. They were asking all the kids at uni who went through, you know, these walks through the hospital and stuff. So if you want to donate, it's going to be anonymous, and then you do it, fine, but if you then find out however long later that suddenly you're not anonymous, I think that's ... probably a step too far. You know, you donate on one condition, and then they turn the conditions around, and I think that's probably harsh. ... I totally understand ... where the donor child's coming from, because if I was in that situation, I would want to know where I came from. It's probably like adopted kids trying to find their natural parents, their birth parents. ... My [donor offspring told me], 'I used to think, people walking down the street, oh, maybe he's my dad'. And [s/he]d stand and stare and try and figure out what I looked like from what [s/he] looked like, and things like that. And I think that'd be an awful thing to hang over your head your whole life. It'd be quite difficult to put it aside in some ways. I can see how you'd become fixated."

Ian

[Sperm donor, 1970s, 1980s]

"I honestly cannot see people in my era being forced to meet or have on-going contact with the donor-conceived offspring. ... [Donor-conceived people] have a right, and ... I bet you ninety per cent of people: the curiosity factor alone. Probably very few necessarily would want to have a long-term relationship on a periodic basis. And that wouldn't concern me, but I think it's shameful that we're not in a position to offer every donor-conceived child the opportunity to meet their biological father. And yes, I would be delighted—a little bit on top of that—of course I would, but particularly given that I haven't got children of my own. And were I to have children of my own, the delight would still be there, but it wouldn't be quite as intense, one imagines. ... I would just be happier that anybody that I conceived this way ... would have the opportunity to contact me and that, in, I would suggest, a very high percentage of instances, would make their life richer, whether it was only putting their mind at rest. Even if they didn't want to continue some sort of periodic long-term connection, they would at least say, 'Well, I've met him. He's a dickhead, but, you know, I've met him, and I can now see where I get, perhaps, a couple of my—whether it be physical or personality traits or my bents in life skills or interests or whatever', like that. ... That may be all the person wants. However, they would have lived a life in a vacuum in that area were it not for—and that would always be in the back of their mind, and it would mean their life wasn't quite as fulfilled in their knowledge. I'm not saying it would enrich their life, necessarily, but it would—there would be this nagging doubt or query that was in the back of their mind, such that they would be a more content person if they knew, and pursued the contact as long as they, or I, or any donor wished to do so."

2.a.iii. Preference for the compromise of persuading donors voluntarily to release information

Donald

[Sperm donor, 1980s]

“My wife is unsettled by a knock on the door. I mean, as I was walking out the door today, she said, ‘Tell them we don’t want any knocks on the door’. You know, she laughed when she said it, but she’s deadly serious about it, and, I mean, she’s a little bit concerned about, you know, ... monetary claims or something like that. And, I mean, she’s very, very protective, obviously, of the family unit, and look, I think if you talked to her, she’d know that she’s being a little bit irrational about that, because she knows all the disclaimers and everything that are signed by everybody. I think what she is really saying is, a bit like me, she’s a little bit worried about the possibility of emotional blackmail. You know, what happens if one of the kids was a drug addict? How guilty would I feel? What happens if they were destitute? What happens if they’d been bashed or worse by their parents? ... I didn’t think about it at the time I donated. It’s just that, every time these articles come up, yeah, I think about it: ... Why is it always about the donor-conceived children? What about the reservations or everything that the donors have? ... Non-identifying, absolutely. Ask questions. If I got a letter saying they’re a little bit concerned about such-and-such; is there any history in your family of such-and-such, I’d happily communicate back. I think I feel quite strongly about this issue of having a bond forced upon me, okay? And once you know and talk to a person, then you can’t help but have some form of bond, and I think I react against almost prurient interest; you know, that they just want to see what the donor looks like, just for the sake of, you know, having a geek at them. ... I wonder what they look like and everything like that. But, I mean, I have to say, ‘Well, no; hang on, that was a transaction’, or whatever you want to call it, ‘that didn’t involve forming a bond or a relationship’. ... I think the thing is, if somebody from VARTA or something rang up and said, ‘Look, this person is absolutely desperate; they’re in a total mess. You really do need to meet them’, I’d meet them. I mean, I’ve put things in balance. I mean, there’s my uncomfortableness and concerns, but, if somebody’s totally devastated by the fact that they’ve just discovered they’re a donor-conceived child, whereas they thought these people were their natural parents, and they need to meet me, that’s fine; I’d do it. But if it was just somebody with prurient interest or hangs their hat on the fact that everyone has a right to know something, everything, about somebody else, then I’d sort of get my back up a little bit” [In writing]: “A lot of the arguments to do with full disclosure relate to ‘rights of the child’, But these rights are being extended to people who are no longer children which then raises the issue of whether the question ‘what is in the best interests of the child’ is appropriate when the donor conceived person is say 30yo and the donor is, say, 55yo. I think this matter needs to be considered as there are two types of cases, one where the child (under 18yo) asks her social parents about the donor and the other where a donor conceived adult asks the same question. The answer may be the same but the reasons for doing so need to be appropriate and not assume it is always a child asking the question. ... My hesitation with full disclosure is the assumption/expectation that some form of ‘bonding’ will occur and that the ‘best outcome’ is an ongoing ‘relationship’.”

2.a.iii. Preference for the compromise of persuading donors voluntarily to release information

Gary

[Sperm donor, 1980s]

“I think that, in reality, for most people in my situation, [Recommendation 1 would] just be something that we face and, in fact, it won’t be probably as big as a deal for any of us as we think it might be. ... I think that what people like my wife are afraid of is that the children will want to have a relationship. And that’s what you read about in the paper. ... I get worried about people who want to have that sort of relationship, not from the point of view of the children; I can understand from their point of view, although I would imagine most of them think of their social parents as their parents and aren’t interested in the biological parent. ... So for a donor to want to have a relationship, I think is just a bit funny. Not if they donated now, because we live in a different age, and there’s different expectations, and all of this has been thought about a lot more, but someone who donated 30 years ago who thinks they want to have a relationship with their biological son or daughter, I think that is weird. ... I was just a vehicle to help those people. I was not about me fathering children or wanting relationships with other children. I don’t agree that that’s a healthy thing at all. ... I don’t think the donors should be allowed to have information. I would think that that is completely wrong. ... Now if the children want information, I can understand that, and if there were one of the children who resulted from my sperm, if they felt quite strongly, well, you know, as a person in the community, I feel really bad for them, and I would feel that I’d have a responsibility to help them, but it’s not what I want. I mean I definitely don’t want that. ... I’m hoping that no-one wants to get this information about me or my family. And, you know, my amount of feeling sorry for them hasn’t been enough that I’ve said, ‘Well, I’ll go against my wife’s wishes and contact VARTA and put myself on the Voluntary Registry’. So I’ve weighed up those two things, and, at the moment, I’ve come down on the side of those closest to me, but I accept that there’s a possibility that’s causing harm to someone else, and I’m sorry for that.”

Edward

[Sperm donor, 1990s]

“The government made a promise and that was 20 years ago, or 15 years ago; for some people, obviously, a long time ago. And they said, ‘Here are the terms’, and someone has agreed to those terms. And then for them to turn around 15 years later and say, ‘Oh, actually, sorry; we want to change those terms’: I really think, you know, it is wrong. I understand why they want to do it, and I understand on behalf of the donor children who have obviously had serious illnesses and what-have-you that might have been able to be avoided if they’d been—I understand that. But I really think it’s dangerous ground for the government to be able to retrospectively go back and change rules. Otherwise, why can I ever trust any contract or any field that I agree to with someone or any person if there’s this right to go and change it 10 years later or 15 years later? ... I think it should be voluntary. ... Someone comes up and says, ‘We’ve had a request. Is this OK?’ Then I’m free to say, ‘Well, yes, it is; I’m comfortable with it’, and obviously, if I wasn’t, I could say ‘No’. But I really have an issue with the fact that, ‘Here, the deal’s on the table’; I agreed to it, and now retrospectively they’re trying to change it. And I really don’t think that’s fair or right, and I understand how you could really say, ‘Oh, the child’s rights’, and all this, but hang on! I just don’t think the world can go around saying someone’s rights are more important than the others. The world’s a tough place if you want to argue it like that, and, you know, the world’s not fair sometimes, but I really don’t think they can do it. I really think it takes away a lot of trust in the process if someone’s free, or people are free, to just change the terms, because, as I said, perhaps they didn’t quite get it right 15 years ago. ... I actually understand the other side of things quite well, because my mother was an adopted child. ... I suppose she spent her life wanting to make contact ▶

2.a.iii. Preference for the compromise of persuading donors voluntarily to release information

Edward *continued*

[Sperm donor, 1990s]

with her mum just to say hello, and how things are going, and what's happened to me, and everything's alright, and has probably always had something missing in her life. ... I didn't know about the [LRC] investigation for quite some time, and I think I'm certainly worldly-wise, so there must be plenty of people out there who have obviously participated in the program over the years who were not aware of the changes, and if they do come into place, are going to get a knock on the door or contact that they were not ready for, or weren't aware of. ... We've been contacted, or, you know, requested, by one family, and we agreed to pass details, which we did, and so I have regular email contact with the donor [offspring, whose] mother's ... been very open with her [child] about [donor conception], and so was very keen at a very early age to then introduce [the child] to the fact that, you know, here is this person, and so we've had very—you know. I mean, I think [the child]'s only [primary school age], so obviously we've just corresponded by email. ... We haven't met, but I've seen photos, and they've had photos of our children, and I've sent them photos of myself when I was a kid, and so then people go, 'Oh, I can see why I look like that, because there's my dad'. ... I was really worried when I first got contact, I really did feel as though I was standing on the edge of the cliff and anyone could just walk up and push me over. I had no idea what the intentions were or what they wanted. And now it's turned out fine; but I think there was a lot of chance involved in that. ... My wife, who I may say is a [professional], so she's very worldly-wise and what-have-you, ... actually had some issues with it, as in especially when the family wanted contact: ... Would I put her and her family second? ... It's definitely an issue for her. And it's something we discussed frequently, and, as I said, now that this ... donor child would like to speak to [my children]; and for my wife, she's still got a bit of issues as to, well, how are we explaining this. ... It's easy for me to be thoroughly engaged in the topic, because obviously there's a direct link. ... I mentioned this all before we got married, so it was all open, but she's still very much—I mean, you know, she married me planning on our family and our kids, so, as far as she's concerned, I'm number one to them. And so ... they should be number one to me. So for someone else to want to come and knock on the door and say, 'Oh, g'day; you're my real dad' or something, is confronting."

Dennis

[Sperm donor, 1970s. Disagrees with Recommendation 1]

“I think the current system where, if you want to voluntarily sign the register, that’s fine. And if you don’t want to do that, you shouldn’t. ... The way I understand it is, the current legislation, one of the suggestions is that the children who have been born from donations can find out about their donor and that they can then sign a veto saying they can’t contact them. I don’t think that’s right either. Because, I mean, they will know; they can work out who they are if they want to. And I know that they’re all medical students and all that sort of thing, so I just don’t think that’s right. ... I’m talking about the ones who donated anonymously. .. I’m just talking about my own group that were anonymous; I think it should stay anonymous. [*So it should stay anonymous, and therefore the contact veto is irrelevant?*] Yes. But they can find out about the Voluntary Register, and register if they want to. I think that sounds fair to me.”

Peter Y

[Sperm donor, 1980s. Prefers voluntary release of information]

“If they’re interested enough to find out who their donor is, then I think it’s going to be hard for them not to delve further [even with a contact veto]. ... My concern is that the person that’s making the enquiry might be desperate for money, have a mindset that’s a problem, and then create all sorts of other mental anguishes into my family, which was not there before, because this person might have some hang-ups that have bugged them for so long, one of which could be that their parents have only just recently told them that they’re the result of a donor, and they might get some major hang-ups. That is my main concern. A normal person would be fine, but there’s always the five per cent that have got problems that are going to inflict their problems on other families which was never the intention of the situation in the first place. ... Now if there was somehow that the donor-conceived person could be checked out, and I don’t know how you’d do that, but that is my biggest concern. I don’t want more problems of the world brought on me late in life, let alone my whole family and my wife, that was never intended. And that is my biggest concern about the whole change in the law.”

Jack B

[Sperm donor, 1980s. Agrees with Recommendation 1]

“I think that’s probably a pretty good start, a pretty good mitigation for those individuals who don’t wish to be contacted, because I think it does give a reasonable period of time. I think that certainly, for me, addresses any concern they may have. And in fact, how they deal with it then is up to them, because they’ve then got five years in which to sort it out for themselves. Five years is quite a long time. I think, you know, would I be in favour of that being in the law? I suppose I’m fairly neutral on it, because I wouldn’t object to being contacted. But for those who do have an objection to being contacted, I would imagine that should be plenty. And, in fact, there are protections under law anyway if you don’t wish to be contacted by people, if you’re being bothered by them: restraining orders, if you need to, but I think this sounds like a very practical and simple way of doing it.”

Michael A

[Sperm donor, 1970s. Disagrees with Recommendation 1]

“[The contact veto is] a pile of crap.... Say that my offspring have my information, my particulars; I can find you. I can find out where you live. I can find that in three minutes, and I’m not even techno-savvy. ... So the kid says, ‘Okay now, I’m [in my thirties], so he would have been a donor in [the seventies], and here’s his unusually-spelt surname, so let’s look for a guy [in his sixties] with this name’. Bang! Find it in a minute. Now the problem with that is, I say, ‘Well, look, he knows me, but I don’t want any contact, so I’m going to sign the veto thing’. And next Saturday afternoon, there’s a knock on my door at my home, and there he is, or she is. Now, it’s all well and good to say I’ve vetoed that contact, but, in practical terms, if my offspring ignore my wishes in the matter, ignore my veto, what am I going to do? Am I going to ring the police? Is the person who ignored my veto going to be prosecuted? Hauled up in front of a magistrate? Fined or convicted or jailed for some slap-on-the-back-of-the-wrist-with-a-wet-lettuce-leaf breach of the prohibition on contacting me? What’s the newspaper reporting of that scenario going to look like? You know, poor Michael’s Saturday afternoon was disrupted by his loving child wanting to—you know. It’s a farce. It is an absolute farce! So once the particulars are in the hands of the offspring, then, if the offspring are so minded, personal contact with me, my family—and god knows where that will go—is inevitable.”

Noel

[Sperm donor, 1980s. Agrees with Recommendation 1]

“I think [the contact veto] is a good idea, because it flows from the fact if you’re breaking that promise of anonymity, I think you do have to put some degree, then, of protection in there for people who don’t, who just don’t wish to be contacted. ... I think it’s a good safeguard. I know that there will be donor-conceived people who won’t like that. ... At least they will get the core information that they want. They may not be able to meet that person, and they won’t be happy, potentially, with that, but I think it’s about weighing up the rights of both parties, and I think, if you take away that anonymity, there will be a small proportion, I think, of men who will be, for sound reasons, frightened and threatened by that prospect, and the contact veto allows a degree of protection for those people if they want it. ... I know this from other reading, that a similar kind of thing was done when they changed the adoption laws. And my understanding there is that there’s a fairly small number of contact vetos, and the number of breaches of those vetos is tiny.”

Brett

[Sperm donor, 1990s. Agrees with Recommendation 1]

“I think that [contact veto] needs to be with the proviso that that person has an amount of counselling. You know, like, yes, we wanted contact. We had to go through counselling to be able to do that. And I think that, if this person wants to do a veto, then they need that counselling to say, you know, to understand, you know, ‘Don’t just do this on a whim because you’re scared. Do this because that’s what you wholeheartedly believe and feel’ and what-have-you. ... That that person, you know, if they they’re going to veto it, they can only veto it after they’ve gone through an amount of counselling, or something of that nature.”

Anon

[Sperm donor, 1990s. Disagrees with Recommendation 1]

“I never want to be contacted. ... This sort of crap is going to come into my life and I will have to discuss it with my wife, and it’s going to cause a huge amount of tension in my relationship, you know? And potentially the relationship I have with my children. So the idea that I’ve got to do it for a single person, and I’ve got to renew it every five years! I mean, I don’t know how many children there are. We’re probably talking about an environment where I’m going to be continually reminded of something that I did—the rules have been changed on me—repeatedly. If we’re going to go down that path, then I want the contact veto to be permanent, and I want it to be across everything, so that I can, one time, say, ‘I do not under any circumstances want to be contacted by anyone’. And if I change my mind, I’ll come back and change my mind, but I don’t want to have to do it every five years, and I don’t want to have to do it for each person. ... I don’t want to set rules for, you know, for stalkers versus people who are satisfied with their relationships. I just want to get on with my life.”

Shelby

[Egg donor, 1990s. Agrees with Recommendation 1]

“I think if the person, the child came and then contact was made from the agency and then I said, ‘No, I don’t want any contact’, and put the veto in, then I don’t think the child should know my name, because, in this day and age, with multimedia and Facebook, and, it’s very easy to actually track somebody. Not that I do, but I know that my [children] would go, ‘Oh yes, that person’, and then the next thing, there they are on the screen and all their pictures, and their lives there before their very eyes. ... If that was the case, I think it should be the contact made from the child, then the contact from the donor, and then, if the veto’s put in place, well then, I don’t think any identifying information should be handed over.”

Edward

[Sperm donor, 1990s. Prefers voluntary release of information]

“I understand why they’re putting that [the contact veto] in: ... If someone then comes and knocks on the door, that could put someone in an uncompromising situation, so they’re recognising that problem and, by putting in this back-door veto. ... To me, they’re not getting it right in the first place. So it’s almost like—so, in part one, they’re saying everyone’s got the right to get some identifying information, but then, ‘We understand that, actually, now, because we’re changing the deal for the people who gave this donation in anonymity, we could be really doing the wrong thing by them, so we’ll just give them this back door no veto’. I actually think it’s bad law, or bad legislation. ... It’s like the first bit’s just not quite right, but here’s this sub-clause (b) to try and fix what might not be right about the first bit. So yes, I agree with the veto process, but I actually don’t agree with the fact as to why it’s there. I’m saying the reason why it’s there is because the first bit isn’t correct. ... They’re putting the onus onto us: ... we’re the ones who would then have to turn around and say no to a contact. Otherwise, ... we’re open targets for whoever our donor children are, and we’re the ones who have to put up the security shield, and so we need to be made aware that we’ve got this option, and we’re the ones that have to say, ‘No contact’.”

David P

[Sperm donor, 1970s. Agrees with Recommendation 1]

“That sounds all right, because I just think there should be some channel of communication, even if it’s sort of anonymously by email or something like that, where, you know, [the donor-conceived person] can get information and maybe try to enter into some sort of relationship. But yeah, there should be something.”

Utnapishtim

[Sperm donor, 1970s. Agrees with Recommendation 1]

“I wouldn’t like to have someone lob on my doorstep, and knock on my door and say, ‘Hey, I’m your daughter’. But I would certainly want that person to establish contact with me so that we could meet in perhaps neutral territory and discuss how we wanted to progress things. So yeah, I’ve got—I think that’s important that the first—and the initial contact really needs to be a little bit formal.”

Noel

[Sperm donor, 1980s. Agrees with Recommendation 1]

“I think that’s a good idea, yep. Because it gives the donor some control over the flow of information. It’s not just, ‘Okay, we’ve removed your anonymity; too bad’. You know, if you have those sort of safeguards built in, I think it gives a degree of protection. And so, if you are going to remove that anonymity, which I think should be done, there’s some safeguard there.”

Peter Y

[Sperm donor, 1980s. Prefers voluntary release of information]

“That’s assuming a one-on-one contact. Is it possible that—I’m just thinking aloud. I guess contact doesn’t necessarily mean face-to-face contact. I mean a phone is virtually face-to-face contact. [*Well, you could say, ‘I want it not to be face-to-face. I want it to be just by letter or just by telephone’.*] Yes, I suppose. That would be fine, subject to—the curiosity will probably get the better of the donor-conceived person. But, as I say, if there is some way of assessing, if the five per cent of people have got hang-ups, that could impose on the donor, problems—and the donor’s family—problems which was never intended from Day One. That’s my biggest concern. Now, if there was somehow that the donor-conceived person could be checked out, and I don’t know how you’d do that, but that is my biggest concern. I don’t want more problems of the world brought on me late in life, let alone my whole family and my wife, that was never intended. And that is my biggest concern about the whole change in the law.”

Shelby

[Egg donor, 1990s. Agrees with Recommendation 1]

“I think that’s probably a good idea initially. I guess that puts the—especially for the people back then that were told there was no, there would never be any contact; I guess then those people have the right to have that bit of empowerment to say, ‘Well, yes, you can send me an email or a letter through the agency’, and then that kind of allows them to then take the next step, I guess, or not. So yes, I think that’s probably a good idea.”

2.b.iii. Release of information about potentially heritable medical conditions

Michael A

[Sperm donor, 1970s. Disagrees with Recommendation 1]

“If, at the initiation of the donor, information about hereditary diseases and predispositions and so forth can more readily make its way into the knowledge of the recipient, then I think that’s good. And, if the donor initiates that process of informing the offspring of a predisposition, then that’s fine. But the proposition about, ‘Well, what about coming at it from the other end? What about coming at it from the offspring’s point of view?’ If the proposition is, ‘Because of the possibility that my biological father has given me a genotype which predisposes me to illness, then I need to contact him and find out about all his medical information’, no. ... My own children, my biological, conventionally-raised children, have no statutory right to my health information. If I want to give it to them, if I think they need to know it, I will. But they can’t go, under the laws of this country, to my medical records, or the records of Medicare. So why should my, what exercisable right to my health information should my biological offspring have?”

Jerry T

[Sperm donor, 1980s. Prefers voluntary release of information]

“My slate’s clean in that regard, so I don’t have any problem with that. I mean, a few years ago, when I started my family tree, I got death certificates to find out the cause of death, and there’s no cancer in my family. There’s no serious illness. ... I offered to send, you know, an A4 sheet of the family tree with the causes of death, and I sort of don’t remember the answer I got. ... I don’t have any problems with that. As I said, I just want them to have happy, healthy lives like I’ve had a happy, healthy life.”

Evan

[Sperm donor, 1980s. Agrees with Recommendation 1]

“I’d agree with that, but there shouldn’t be any hereditary diseases, because I know the program I went through with them at [the clinic]. That took me six months, with several blood tests in between, you know? In the end I thought I was a pin cushion! [*Yeah. Some things happen later in life, I suppose.*] Well, the only onset that can happen later in life is becoming a diabetic. Possibly Alzheimer’s or whatever, but that shouldn’t be passed on to the child, because ... nowadays, those diseases shouldn’t be a problem, because nowadays they’ve got the technology to see them in the DNA structure. Back in my days, they probably didn’t have the technology to be able to read that very well. So yes, it would be very important that the donor child understands it may have to look at maybe one or two of the congenital diseases that come down the line.”

Jim

[Sperm donor, 1980s. Disagrees with Recommendation 1]

“Yes. ... Without consultation, I think your privacy should be kept, because that’s what you agreed to in the first place. However, I think you should be encouraged to, and counselled about the benefits to the offspring of revealing who you are, especially in terms of family history and all that sort of stuff. You know, genetic history and potential medical histories and stuff.”

2.b.iii. Release of information about potentially heritable medical conditions

Peter Y

[Sperm donor, 1980s. Prefers voluntary release of information]

“Well, without a name; I mean you just send some medical history. I agree. I agree that’s important, but hang on, just let me think. If they’ve got a problem—but my belief is that, if I have a problem, it might be convenient to have that on the records so that, if that person enquires and they say, ‘Well, I maybe should be having myself checked out for this’. So I guess, I’m happy with that, but does that also include the donor’s name details? ... There are two questions there. The first is, has the donor advised the authority, whatever that might be, of their health situation anyway? That’s the first part. And the second—and in my case I’ve voluntarily chosen to do that. Secondly, so what happens if something happens? Like myself, I’ve had [a health problem] now. Which I guess—I put it down, anyway. But I believe the causes were stress and my job, but it might be handy for one of those males to know at least that I have had [this health problem]. And that that has occurred since I’ve given the details to the authority, whatever that is. So that is not, I believe it’s not recorded on my record. So, direct need to do that is fine. ... But if I, in my vintage, haven’t given you the information in the first place, then what do you do with those that have got no medical records of donors anyway? ... Maybe the authority, whatever it is, should, every five years or something like that, contact—well, first, are the donors still alive? Secondly, has anything occurred that might be of benefit to update the history for any potential enquiries? [*Oh, so you’d have five-yearly automatic contacting of donors just to update their health records?*] Well, I mean, if they’ve got health records, it might be reasonable. I mean I’m going to forget to do it. But if—it all takes time and it all takes money, but if there were some sort of follow-up within the authority for people who they have records for to send out a letter every five years and say—well, ‘Nobody’s enquired yet, but, this is what you did last time. Has anything changed since the year blank that you want to add to your medical history?’ At least it forces contact. Are they still alive? Are you still at the right address? Potentially, we’re all getting old, so you won’t have, so therefore you can’t do anything about it, but most of us tend to—well, I guess we forget about it, and every five years we just need a prod. But that all takes time and money, but at least if the authority is wanting to provide as much detail for potential recipients, then that’s one thing that could be done.”

Peter X

[Sperm donor, 1990s. Disagrees with Recommendation 1]

“I feel for the people who are offsprings from the donation, but, at the end of the day, they should respect the fact that, you know what? If it’s a medical thing, you could sort of bend a little bit and say, ‘Well, what’s the problem?’ But they did that screening 20 years ago. They took blood samples; they asked a lot of series of questions. ... Of course you want to say yes, because of that big case that some problem that no-one knew about. But it doesn’t change the fact that, again, it’s going to be known who the donor is, so it will be a snowball effect from there again. So where does it stop? Say if—there has to be, obviously, extractions from the law, and it could be implemented where, if there’s an illness, they be advised, but the person’s identity not to be advised.”

Michael A

[Sperm donor, 1970s. Disagrees with Recommendation 1]

“If, as a starting point, a donor says, ‘I am happy to be identified as my offspring’s biological father, and I am happy for my identity to be disclosed to my biological offspring’, then anything that facilitates or expedites that wish, that agreement, is fine. But I’m only talking about the people who wish to stay anonymous. So that’s my—I’m not speaking for those, quite possibly, contemporaries of mine who don’t have a problem with this. I’m speaking as a sample of one, and I did it anonymously. I want it to stay that way.”

David Q

[Sperm donor, 1980s. Agrees with Recommendation 1]

“I believe in the case of [the clinic] that all the records have survived, so, I mean, in my own case, I don’t think that would be necessary. However, I understand at other clinics that that’s not been the case, so yes, DNA would be the only way. Yes, I would agree to that. There’s going to be a lot of people there; it’s the only way they’re really going to know. ... The private clinics and some of the records that have been lost because of negligence or theft. What do you do? You’ve got to give them a chance.”

Peter Y

[Sperm donor, 1980s. Prefers voluntary release of information]

“Interesting; hadn’t thought of that. But that—oh, okay, so what you’re almost saying is, ‘I’m the result of a donation. Can I find out who my other parent is by doing a DNA check and going into the lottery?’ sort of speaking. And the answer is I don’t have a problem with that, but, of course, the question then is, is it going to be forced to make the donor provide the DNA sample, or is that going to be voluntary? [*And what’s your view on that?*] In my case, because I donated not expecting to be followed up, I would say it should be voluntary. In my case, it doesn’t worry me doing that, as long as it’s—I guess other people always think that the so-called wrong persons might use it for other situations. But I guess it has to be voluntary everywhere, because everybody donated based on the law at that time, and they knew what they were doing, and this is now something else, which has now become available, which was not in their mindset at that time. ... For the past I think it ought to be voluntary, but, for future legislation, it maybe should be provided as part of future donations.”

Jack B

[Sperm donor, 1980s. Agrees with Recommendation 1]

“I don’t have any objection; I wouldn’t have any objection to that if there is any doubt. And, in fact, in some cases, people may wish to have that certainty. I’m sure that the record-keeping at the [clinic] is really good. I have a lot of confidence in them, but there’s nothing like having seen a photograph that looks exactly, or very much, like part of the family. You know, then that’s an obvious sign, but if somebody were to come and look completely different, you may well want to have that confirmed. So I personally wouldn’t object to that.”

Jill

[Egg donor, 1990s. Agrees with Recommendation 1]

“I think it’s an appropriate way of kind of managing, well, I suppose it’s managing the situation. I mean, you know, people want, as much as possible, certainty. And, you know, I guess I see it from the perspective of: wouldn’t it be awful if you thought this person was your parent, or your child, and you went along with that in the belief—and then suddenly you realised they weren’t. You know, I think that’s really tough. And so the more certain that you can be, the better. So if DNA testing is the way to go, well, absolutely.”

2.c. Different circumstances may influence donors' views

John

[Sperm donor, 1970s. Prefers voluntary release of information]

"I often think back to the donations time. It wasn't actually a pleasant experience. I used to do it before work. And I remember thinking that the people running the scheme were—this sounds discourteous—but they were very clever amateurs, I felt. ... They didn't have any particular mechanism for, or particular rules for, collecting donations. In fact, I used to walk in there with my little jar, and somebody would say, 'Put it down there, please'. He was a smiling young man, but I felt that the end of the whole thing was not particularly well handled. They didn't offer me any on-going contact, for instance. If I had been upset by doing the whole thing, I'd have had to organise some sort of relief for my upset myself, I felt."

Utnapishtim

[Sperm donor, 1970s. Agrees with Recommendation 1]

"I remember vividly sitting opposite a lady like you, and all she had was a bunch of cards, and she was writing details on cards. So I'm not surprised that things have vanished and been misplaced. ... Because of the anonymity at the time, they probably didn't concern themselves too much if they lost things. ... When I signed up, I asked the nurse ... 'Will I ever know if there are any offspring?' And she said to me, 'You will never know; it's completely anonymous. You will never know, even if there's a conception'. So ... I never expected that I would ever, ever find out of any conceptions. Since the laws have been starting to change, then my paradigm's shifted a little bit, in that I'm not expecting a knock on the door, but I half expect to be contacted by either VARTA or a registry or someone saying that, you know, 'Someone wants to make contact with you'. But that's only been in the last, probably, five years, I guess, since this has all started to bubble up a lot more. But certainly not from years ago. ... I've never lived in fear of that happening. And in some ways, I would have welcomed it, but, but I'm kind of ambivalent; not that I don't care, but that I respect the rights of that other person to have it anonymous if they want it to be."

Michael A

[Sperm donor, 1970s. Disagrees with Recommendation 1]

"I was a medical student ... in the fifth year of the [university] program. At that time, there was a mandatory 10-week residential block during which we did obstetrics at [a hospital], and I'm pretty sure that every student at [the university] did that 10-week stint. ... A doctor there [and colleagues] ... introduced themselves to the new student group, as I imagine they did with every new group that passed through one after the other, and told us about her program, said that the program was always looking for sperm donors. As I recall it, there wasn't any storage or freezing step, so basically they'd have a recipient in the clinic and I think we even had a beeper, and someone's beeper would go off, and half an hour later they had to sort of produce the donations. So that was the source of some amusement amongst the group. ... And there was no screening of any kind that I can recall, health screening or medical assessments or family history or certainly not transmissible diseases or other things that I think would preoccupy a donor program these days. ... I don't recall any documentation, any agreement, any contracts. ... And it seemed to us to be a fairly harmless and praiseworthy thing to do. We lived there 24-7, which was another reason why the medical student group was so attractive ▶

2.c. Different circumstances may influence donors' views

Michael A *continued*

[Sperm donor, 1970s. Disagrees with Recommendation 1]

to the IVF program people, because we were Johnny-on-the-Spot, and given that sort of timeframe in which, you know, the collection and the insemination, to have someone on site, or have the donor pool onsite, where the patients were being treated, was a great plus, rather than ringing someone to come in from home or work or wherever. ... I think we were paid \$5 for it, which wasn't—you know, \$5 even in those days wasn't going to make any material contribution to your standard of living, so that was more a gesture than a source of income. ... I do well recall the sure and certain undertaking that this was totally anonymous. It was simply a matter of providing the specimen. There would be no contact with us in the future from the program people, and certainly not from the recipient couple, and certainly not from the offspring. ... So we were absolutely certain, as we believed at the time, that this was no more than a specimen of biological material and with no downstream implications or complications that would flow from that. ... Over the years I've made no secret of this. I was quite proud of my modest contribution to the happiness of families and infertile couples, as they were at the time. ... I'm not in the least bit embarrassed or ashamed of what I did, and really, the first negative thought I've had about that whole episode occurred around March of last year when I picked up *The Age* and saw a report on the findings of the Victorian State Parliamentary Law Reform Committee and reported comments from the Chairman of that committee, Mr Newton-Brown I think his name was, about the findings of a 20- or 22-month enquiry into IVF programs and the rights of the offspring of those programs to knowledge of, and even contact with, their biological parents, and that the committee were unanimously of the view that donors, including people who donated under my circumstances, should be identified to our biological offspring. And, as I said, that was the first negative thought I've had about my lifetime involvement in that, through the course of my entire life. And when I say 'negative', in my case that's a major understatement. ... If anonymity wasn't guaranteed, or, as has been the case in more recent legislative iterations, or if the donor donates in the knowledge that the offspring will be given certain information about the donor, then that's eyes-wide-open stuff. But my problem was that there was a rock solid, explicit, hand-on-heart, swear-on-a-stack-of-bibles undertaking that this would be anonymous, and we would have no contact with the recipient couple and no contact with the recipient offspring. And if that was the circumstance under which the donor agreed to donate, then I think it's appalling that, you know, with the passage of time, that undertaking is discarded. I feel cheated and I feel betrayed, and I'm deeply distressed by it. And I do accept, by the way, that others in my position couldn't care less."

2.c. Different circumstances may influence donors' views

Ian

[Sperm donor, 1970s, 1980s. Prefers voluntary release of information]

“It started off really childishly, as a joke, and it may sound silly that way. I wouldn’t be here now if I considered it a joke, obviously, but, bottom of page 3 of *The Age*—and I bet you I could find you the exact date—there was a photo of a lady, a young lady; I reckon she was in the Bourke Street Mall, soliciting donors, and I woke up after a big Thursday night at the North Melbourne Disco, I’d say, with a mate of mine staying in the spare bedroom. I said, ‘Have a look at this, [name]. It’s a bit of a joke. I might become my cricket club’s first sperm donor’. You know, because I used to like to muck around and be a bit of a dickhead, and it really was based on that, because it provided a great story, of course, for the boys, as you can understand. And, now, we’re all serious about it. ... I did think about it on the basis of the fact that, you know, now I was told, in all honesty: high sperm count. They were as happy as Larry with me, so I thought, ‘Well, it’s a badge of honour there. How lucky am I?’ But I did soon think about the whole reason for doing it, given that some people, by no fault of their own, are in a different situation, and so I did take it seriously, in that I came back, I don’t know how many times. But see, then I re-located in [the late seventies to another state], to start a brand new career. ... Then I went overseas ... and I may not have donated again until [the early eighties]. ... I don’t think they’ve even got the records now. ... I was told some time in this period ... that I had a live birth, and I’m told—I do recall the terminology correctly, because a lady ... confirmed that that’s exactly the terminology they would have used—in [another state]. Now I was intrigued about this. [*But you hadn’t donated in [the other state]?*] No, no, no. But I had been told that that was where I had had a live birth as a result of these donations. ... I’m told that the record-keeping situation has been atrocious, quite possibly in Melbourne as well. ... I would like to absolutely ensure that I’ve done everything possible, and I did suggest DNA, which I’m pleased to see here, such that, if the records are totally lost in [the other state] and can’t be found in any way, that I’m quite happy to provide whatever DNA is necessary for someone who may chance to come in and say, ‘Well, look, your records are lost, but here’s a lock of my hair or a vial of blood, and go to it, and if you can find someone who matches that, then I’d like to meet them’, and, as I say, I have no desire to intrude in any person’s life. ... There may be other offspring; I don’t know. ... I was quite furious that the records had been lost. [Would you like to know how many people have been born as a result of] Absolutely; of course I would. There’s no doubt about that, because, as I say, apart from the first time going there, I wasn’t doing it for a lark, obviously. And, as I say, I regret I didn’t do it more often, particularly because of my—all the qualities of both the sperm and the lack of genetic thingos. I mean, you know, I should have been encouraged, probably more proactively; a phone call: ‘Hey, you haven’t been in for a while’. It’s almost like blood donations, isn’t it? ... My main thing is I think the [interstate] situation is shameful, and it seems that the record-keeping—because it seems to have been [a clinic] thing rather than any state government regulation.”

2.c. Different circumstances may influence donors' views

Donald

[Sperm donor, 1980s. Prefers voluntary release of information]

“What I was impressed about was that they gave me a certain amount of time when they were interviewing me to start with, and said, ‘Well, what do you think any conceived children would want to know about you?’ So I mean I gave them a bit of health history for the broader family, and I gave them a bit of background, historical background, saying the ancestors came from [overseas] and sort of things like that, and I was quite pleased with that, because, you know, I didn’t expect that; I thought it would just be very clinical. ... I just assumed I’d be anonymous, because I was aware that, previously, that 10 or 15 years earlier, they used to mix it all up together, you know, so that nobody would ever know who the donor was.”

Noel

[Sperm donor, 1980s. Agrees with Recommendation 1]

“One of the things that I feel very strongly is that people like me did not give informed consent for what we were doing. ... We had a very valuable commodity that those people wanted, ... because this is in the early days of IVF, and ... people like [fertility clinicians] and so on, were excited by the potential of the science, and I don’t think they wilfully failed to do the informed consent thing. I mean, you know, you could say, if you wanted to be very legalistic, I signed a form saying I was agreeing to do this. You know, I’ve got a copy of it. ... But I don’t believe it was truly informed consent. ... They didn’t sit us down and say, ‘Look, have you thought about the implications of what you’re doing? This is not just like you’re giving blood.’ ... I’ve subsequently met or talked to probably about 10 or 12 donors from the era that I was at, and almost all of them say the same thing; that, you know, you felt like, ‘Oh, I’m a blood donor; here’s something else I could go and do’. ... It’s not something that’s unpleasant to do, so, you know, it’s not even as uncomfortable as having a blood transfusion. And I’m not sort of being gratuitous; it’s just the reality of it. ... We had a valuable spare part that they needed; a critical spare part. And they were really keen to get people in, and so the thing that was missing was not saying, ‘Have you really thought about the implications of this? You’re going to create people. There’s going to be half of you out there somewhere’. And I, you know, when I look back at it, I think, ‘How can I not have understood that?’ And, I mean, I did understand that, but the thing for me that’s made the huge difference is having my own children. ... There are another [number] that are just as much a half of me as those are. And, you know, if I, I can go down a pretty sort of dark and unhappy train of thought which says that, really, I’ve given away [about 10] of my children, and I did it with the best of intentions, absolutely, but I’ve given away [about 10] of my children, and I have no idea what their fate has been. And I can’t change that. ... I know that, and I know that that’s a choice I made back then, and it goes back to this informed consent business. Would I have made the same decision? I think not. ... I know that I did it for the, with the very best of intentions, and in some sense I’m really glad that, you know, I’ve given the gift of life to a family who wanted a child.”

Tony (in writing)

[Sperm donor, 1980s. Disagrees with Recommendation 1]

“To register with the IVF in the 1980s was very simple. There weren’t any formal, binding legal documents to sign. It looked more like a survey. I was in my early 20s and naïve in my approach to filling out the form, but I did make it clear that I didn’t want any contact from recipients under any circumstances.”

2.c. Different circumstances may influence donors' views

Luke

[Sperm donor, 1980s. Agrees with Recommendation 1]

“It was an advert on the radio, which I got the number from. ... I was getting old at the time, mid-thirties. I didn't have any children, and I had a girlfriend, but she couldn't have children, and I just wrote the number down. ... Back in the eighties, they didn't have any rules, as they said in the brochure they gave me [recently]. I just used to ring up the clinic. They'd let me know [how many children had been born]. Every two years I'd give a ring, and they'd tell me how many. And it seemed to just grow and grow. And there was a bit of a spurt one year; there was a lot in one year. I don't know why. ... [I haven't told my partner I was a donor] because, at the time, it says in the brochure again, when you got involved, they told you it was all anonymous, and there won't be any meetings, as though they were just imaginary people I was never going to meet. ... I haven't met anyone. No-one's contacted me [even though I'm on the Voluntary Register]. ... Well, not surprising, because I learned by the papers that most children are not told anyway.”

Brett

[Sperm donor, 1990s. Agrees with Recommendation 1]

“My wife and I were on the IVF program for [more than 10] years, and, during that program, ... I thought I'd never have kids. And so I asked my wife about it, and she said, 'Look, as long as you don't tell anyone, you can go on the program'. She said, 'I don't want my family to think that you went elsewhere to have kids'. ... There was a period there that, you know, we, I had kids through the program, but not in my own family. And then we eventually did, and once we did have that, then we made the decision that, 'Well, okay, we've got our own kids now. We're not worried about it. We're happy to tell the world about it'. So then, after that, we told everybody and everyone's sort of like, 'Yeah, okay, whatever'.”

Anon

[Sperm donor, 1990s. Disagrees with Recommendation 1]

“I was at university in the early nineties, and there was an article—in fact there might have been a couple of articles—in the paper about the fact that there weren't very many donors. And so it was more or less a bit of a call-out for donors. ... I was certainly going through a phase where I thought, you know, it was possible I'd be hit by a car, you know, and therefore, what the hell, my DNA can go on if I donate, and it's picked up by some, a couple or whatever, who wants to use it. And, of course, the other thing is that they wanted to pay travel expenses, which I—and I—it sounds like it's a trivial amount of money these days, but, of course, you know, I was going to do it 10 times, so it was going to add up to, I don't know, it might have been—it was a few hundred dollars, anyway. ... So I phoned up or whatever; I can't remember the exact details. I filled in the forms; I got some counselling. ... Essentially that I was going to have no contact with the future—I don't even know what to call them. [*Donor-conceived people; will that do? Offspring? Some people talk about offspring.*] Yeah, no, I refer to my own children as offspring. [*Okay, well, donor-conceived people.*] DCP. DCPs. Not that we referred to them as DCPs at the time; they probably were referred to as children, but let's, anyway. And essentially I said no, I was a hundred per cent behind that. One of the things was that I wasn't intending to become a parent, and this was not me becoming a parent; this was me providing a service to other people ▶

2.c. Different circumstances may influence donors' views

Anon *continued*

[Sperm donor, 1990s. Disagrees with Recommendation 1]

who would be parents. ... As far as I was concerned, this was the equivalent of meeting someone for a one-night stand and never seeing them again. ... And that was the limit of my involvement, and I was very comfortable with that. And maybe point out that basically, you know, if people were trying to contact you in the future, it was typically unbalanced ones. ... This is probably what I thought.... If you're satisfied with your upbringing and your parenting, then, well, you're satisfied with your parenting. And if you're not, then you're going to be looking, you know, for reasons and excuses, blah, blah, blah, which is why you'd reach out. ... So I signed all the forms and certainly they did try and put a bit of emphasis on, 'You realise you're not going to have any right to have any contact?' and all that, and I said, 'Yep, I'm a hundred—definitely'. ... Because, you know, I was in university and I was still a virgin, there was definitely a point of, 'Well, what if I never have sex with anyone?' So this was kind of, this was perhaps a bit of a dodge to get my DNA to go on. ... I don't talk about this stuff very often, ... so it's not particularly well formed."

Sharon

[Egg donor, early 1990s. Agrees with Recommendation 1]

"When I made up my mind to do it, I had ... children myself through donor sperm. ... We went through ... years of injections and heartache, and, you know, you live your life on a roller coaster. ... There was like a 10-year window of my life that was waiting to find out if you were pregnant; waiting to find out if you had eggs that were viable; waiting to find out, you know, whether you were on the list for that month; whether you could afford it; whatever. There was always something waiting, so if I could avoid that for another family, I would do that in a heartbeat. ... I spoke to my specialist ... and said to him, 'One day, I'll try and return the favour.' ... And they always said, 'Well, you can't do that until you've completed your family. Then you can'. So ... I ... went back and did that, and it really didn't worry me whether I found out or not. When I was in the hospital, you know, waiting for the egg pick-up, the family had this massive bunch of flowers delivered to me. ... And I actually just got some of those roses out of that bunch of flowers, and wrote a letter at that time that I put away, and my kids know where that is, so that if anyone every knocks on the door and I'm not there, and my reasons for what I did, why I did it, who I am, and pretty much that's it. ... I think my kids have been brought up pretty much knowing who they are and, you know, where they sit in the grand scheme of things within their family and things. ... I've moved a couple of times, and when I've moved, you know, this damned letter with flowers pressed into it has gone with me. I've said to them, 'Well, it's there'. And I've always made sure that they know that, if I'm not around and someone comes and they have to do that for me, that's something that I want them to do. And they accept that, and they've sort of said, 'Well, we don't want to know [our donors]. Why would we want to know?' Maybe when they're older they might want to know, or when they're having their own children. ... I would hate to see that laws get made that make it impossible for families to go down this road. There are some people that are never going to be able to have a family unless they can do it through donor semen. So, you know, I would advocate it as a good option for some people, certainly, and hope that they do the exploring before they decide."

2.c. Different circumstances may influence donors' views

Jenny

[Egg donor, 1990s. Agrees with Recommendation 1]

“I saw an advertisement in the paper for egg donating. I didn’t understand what it meant, and I was asking questions, and people explained to me it was like sperm donating, which I understood. I didn’t realise you could take your egg. And I thought, ‘All right, then’. So I contacted the hospital and they told me to come in, and speak to [a person], who was a counsellor at [a hospital], and she said she was very happy, really happy, that I came in, because they needed egg donors. There weren’t enough, and she had a perfect match for me. Somebody that looked like me. Hair colour, skin colour, eye colour, height, and so on. That it would look, that the child would look similar to her in that way. ... The thing that I didn’t like what she said next, but I continued to do it anyway, was she said, ‘We try and get the donors—the recipients, sorry, to tell the child they’re from a donor ovum, but this woman just doesn’t want to tell the child, ever’. And that really upset me. You know, that she had no plans at all in telling the child. ... They put two embryos back in, and only one egg took, because it was a live, a live—you know. ... There were six embryos still frozen, and every single implant failed. ... So out of all my hard work, the pain and suffering I went through, only one child was born, sadly. ... I suppose I didn’t plan on having any children; that’s why I did it. ... It would be nice to meet [my donor offspring] and see what [s/he]’s like, and I know that [s/he]’ll be like a stranger when [we meet], but you know, we could get to know each other. But if it happens, great; if it doesn’t, it doesn’t, but it would be nice if it did. ... I don’t think anybody should give if they don’t allow that child to find them whenever the child wants to. That’s what I think the law should be. ... If I was to meet [my offspring] it would be more like friendship, but family as well, because we’ve got blood. ... If I met [my offspring], I would love [them] so much; as much as any mother could love a child. I would not give [them] up, or do anything cruel or wrong to [them].”

2.d. Understanding themselves as parents or non-parents may be associated with donors' views

Michael B (in writing)

[Sperm donor, 1970s. Agrees with Recommendation 1]

“They [pre-1998 donors] need to be educated about their moral right to accept true parentage of their donor-conceived children. ... [D]onors should also have unfettered access to information about their children. I, for one, would like to have further information about, or even make contact with, my three remaining children. It should be a two-way street. Legislated denial of paternity or maternity simply because the creation of the child involves medical mediation, rather than actual copulation, should be avoided.”

Andrew

[Sperm donor, era not stated. Disagrees with Recommendation 1]

“These guys [recipients of donor sperm] knowingly go into this because they love their wife, and, more than that, that they love children who haven't even been born yet. So these guys, the fathers of these children, as far as I'm concerned, are really special people. And I think one of the things that offends me about the likes of [donor-conceived people], which are what I might regard as the pernicious pursuers of donors, is that they, I suspect—I can't say for sure—but I suspect that they are not giving due credit to their father.”

Brett

[Sperm donor, 1990s. Agrees with Recommendation 1]

“If I provide the genetic material, I am a, you know, a parent, as in I provided that genetic material. That person is genetically part of me, just as my children are. ... I consider all of them my children, but—and I feel that responsibility towards them as, like a parent would. But I'm not their parent because they've got a mum and a dad. ... I am their donor, but a donor just sounds sort of—it's like artificial insemination; it just doesn't have that ring of parenthood to it.”

Anon

[Sperm donor, 1990s. Disagrees with Recommendation 1]

“I think it [Recommendation 1] is unreasonable, okay? I don't think the benefits—okay, I understand, you know, because the whole issue around adoption, that some parts of society think, of course, we should know where we come from, ... but honestly, I don't think that's tenable. We've got two conflicting rights here. ... I donated in good faith with the agreement that I was never going to be contacted. That they would never know. ... And the fact that people are now changing the rules on me, as far as I'm concerned, that's only because we can, right? If—you know, it's not like there's a push by society for mandatory paternity testing so that everyone knows where everyone came from. We're only doing this because there is a database, there is a list of names which people want access to. ... My name is only in that list because it was private. ... The only thing I can think of is that there are unhappy DCPs, and I understand that, you know, that there's not—but they have parents. And I would urge them to have strong and happy relationships with their parents, and to understand where their parents come from, because I am not their parent. Just a guy who looked at some porn and, you know, masturbated into a cup 20 years ago.”

Dennis

[Sperm donor, 1970s. Disagrees with Recommendation 1]

“If the Parliament decides it’s fair to change the rule, then they’ll want to publicise it a bit, and I’m sure they will publicise it a bit, but if I don’t like the law, I wouldn’t want it publicised. That’s a sort of selfish answer, but that’s my answer.”

Noel

[Sperm donor, 1980s. Agrees with Recommendation 1]

[People should be notified] “In a sensitive fashion, and in such a way that it doesn’t frighten or alarm people. And so, I would think, certainly for people where there are records, in contacting those people, in a discreet fashion, because some men won’t have told their families what’s happening. So contacting them, explaining what has happened and why. ... I think a letter would be the best way to do it, ... a personal letter that tells you what’s happened, and it gives you time to process and think about that, rather than getting a phone call out of the blue from somebody, or seeing something in the paper that just announces, ‘OK, this has all changed’. ... I guess the next step would be ... some sort of mass media advertising to explain what was happening, why it was happening, and, importantly, explaining what people could do, where they could go for advice and support. Because, again, going from my experience of—I expect that many men who had been donors, particularly from that far back, will, like me, they will have just put it out of their mind. Which is not to say they’ve forgotten about it, but it just won’t be front of mind. And then, all of a sudden, to find out, ‘Oh, wow; this has changed. Okay’. And, at that point, I think that’s when people will need support, advice; you know, advice about, ‘Okay, so what’s likely to happen next?’, And people to talk to who can, you know, who understand the complexities of the thing.”

Gary

[Sperm donor, 1980s. Prefers voluntary release of information]

“I think that, if the law is going to be that there is identifying information, then we should be contacted pre-emptively by someone within VARTA or something to say that, you know, ‘On such-and-such a date, this is going to become available, and if you want to choose support or counselling or discussion, we’re going to provide it’.”

Tony (in writing)

[Sperm donor, 1980s. Disagrees with Recommendation 1]

[If the law allowing donor-conceived people access to identifying information about their donor were introduced, what would be the best way to communicate this to donors and the general public?] “Advertise as broadly as possible and make it very clear that donors who are unwilling to be contacted must be left alone or recipients will risk unpleasant retaliatory action.” [What support could be provided to those who donated prior to 1998 if legislation to allow donor-conceived people access to identifying information about their donor is introduced?] “Make it very clear that donors who are unwilling to be contacted must be left alone or recipients will risk unpleasant retaliatory action.”

Brett

[Sperm donor, 1990s. Agrees with Recommendation 1]

“Very touchy issue; very touchy. Send a personal letter to them, a personal private letter to them, for their eyes only, addressed to just them. But, you know, you’ve got the whole, what if their spouse opens it and didn’t know? ‘What is this? What is that?’ ... From my understanding, they’re able to use electoral rolls or electoral stuff, which is a bit of a bummer, because of their privacy. ... [*So an attempt should be made to contact people individually?*] Oh god, yes. It’s a no-brainer. Yes, you know, ‘This has happened; this is what can happen. Be aware of it, and this is your options if choose to do this’. [*And what about notifying the community in general and those donors who can’t be contacted individually?*] Yeah, definitely; a dirty great big media thingy. I definitely think, really, so many people have so many bad conceptions of the donor program. Every time I talk to people about it, I always get, ‘Oh, they’ll want my money and they’ll want this and they’ll want that’, and, no, no, no, no, no. You’re talking about the other ones, the mercenary donors. That’s not what I am. I’m a legal donor, not a mercenary donor. Because it’s the mercenary ones who go out there and say, ‘I’ll donate for you’, and then they take them to court and say, ‘Well, you know, that’s the same as having a child, so you’re responsible’, whereas, in my case, it’s sort of like, ‘No, the birth father is the father legally because of the procedures that person’s used’. ... Donors have got a bad name, inasmuch as people are scared of it because they think the whole coming back for money and legal wrangling: it’s got two different—yes, it’s the wrong side of it.”

Andrew (in writing)

[Sperm donor, era not stated. Disagrees with Recommendation 1]

“VARTA could attempt to contact all donors to provide them with arguments why they may want to allow the release of their personal information, subject to counseling [sic] and other constraints. This should not be attempted because the very act of phoning, or posting a letter to, the donor is likely to involve information release which is contrary to their desires and needs. For instance, if Bob receives a letter or a phone call from VARTA or from any other government agency and his wife, or children, or workmates enquire about this, then the information is released: Bob’s anonymity and privacy would be violated by the initial form of contact. // A second approach would have no such privacy or security concerns and might help to resolve difficulties for donor-conceived children. ... This would be to advertise widely within Australia, by all effective methods including newspapers, television and Internet advertising methods, that some semen donors from Australia in the relevant years now have adult donor conceived offspring who are keen to get in touch with them. This would enable such donors to make contact with VARTA and explicitly allow this contact to be made, if they so choose.”

Bruce

[Sperm donor, 1970s. Agrees with Recommendation 1]

“There would possibly be a counsellor speak to the person and find out where they’re coming from and ask what they’re hoping to achieve and where they want to go. As I understand, it’s currently handled in such a way that the two people would be introduced in a neutral environment. ... If it’s done by one central agency, feedback can be given and things can be observed. It’s a lot cleaner, there’s a lot more care involved, and generally everything works a lot better.”

Utnapishtim

[Sperm donor, 1980s. Agrees with Recommendation 1]

“I think the only really critical thing to me is that it is properly managed. That there is someone in the middle, whether it’s VARTA or whoever. Births, Deaths and Marriages doesn’t sound right to me, to be honest, but VARTA sounds right to me; that there’s someone in the middle that manages the process. That’s all. Because it could get out of hand.”

Peter Y

[Sperm donor, 1980s. Prefers voluntary release of information]

“They’d obviously need a central authority to go to, is the first part. And then secondly, they’ll need—I was going to use the word ‘counsellors’; I don’t know what you’d say. But some sort of people in the office that understood and had empathy with both sides, that would be the equation, and to talk to them, and explain the law to them and encourage them to cooperate. Of course, you might get a third of them, or you might get a half of them, in my mind, to agree and the other half will say nice and politely, ‘Up your jumper!’ ... My first thought would be for the recipient to maybe initially write me a letter, send it to the authority, pass it on to me, and then I would do my response through that authority for the first time, and pass it on to them, so there’s somebody keeping an eye on it, in my mind. And then seeing how that goes and then the first face-to-face contact could be either in the rooms or a convenient place; doesn’t necessarily has to be with the authority in the background, but I’d rather do it through some formal intermediary than just meeting on the street, sort of thing, willy nilly, because—that’s why I’d need some sympathetic intermediary to—at least they know how it at least starts, anyway.”

Wayne

[Sperm donor, 1980s. Agrees with Recommendation 1]

“A letter was sent to me from what was then the ITA. And then I had contact with one [donor-conceived person] and I’ve had a request for information from another just recently. ... [The process] was excellent. At the time, it was one of those things that they just got right. Subsequent legislation, I think, got it all wrong, because there was a chance to have a letterbox; there was counselling available for both sides and not just the donor and the donor-conceived; it was also for family members. And that was really necessary, because it’s family members that actually have the most problem, in my experience.... It should definitely be central. At the time, I had contact with [someone at the ITA], and she was able to sort to pull all the threads together and keep everything on board all heading in the right direction. And if it’s divided up—because, at the current stage, I don’t know whether the person who’s tried to make contact has tried to make contact. I’ve sent away the forms to say that I’m open to it, but received no contact, so what’s happened? Has an email gone wrong, or, you know, they think I don’t want contact now? Should I make contact with them? [*So are you saying that, because it’s not centrally managed, you don’t know at which point there’s been a breakdown, if there’s been a breakdown?*] If there’s been a breakdown. Because they maybe just say, ‘I know that it’s Wayne. That’s all I need to know. I don’t need to know medical history, other than what’s already available. I don’t need to know family history other than that there is a number of siblings and that’s it’. Or they may just think that I’ve given as much as I’m going to give. ... What I’ll probably do is: I think it’s still available for me to request identifying information from them, and I’ll probably try that, to see if they want—because obviously, they’ve started the process and they may want further contact, or they can say, ‘No, that’s enough’. But it was a lot more streamlined. I would have been able to just ring up [the person at the ITA] and say, ‘What’s happening?’ and she’d be able to tell me. ... [Now], I get in touch with Births, Deaths, and Marriages. ... It’s divorced from the counselling. ... So [the BDM staff member] won’t know any more than be able to say, ‘Okay, you can go ahead and request identifying information’. ... When I received a letter from the Births, Deaths and Marriages, they did it in the way, ‘We have some information, but unfortunately we’re not sure whether it’s you; could you get in touch with us?’ And I thought, well, that’s not too bad. It lets somebody get out of it if some other family member opens it and says, ‘What’s this?’ They can say, ‘Oh, I just had to get in touch with them, and no, it wasn’t me’. ... It probably did quite well coming from Births, Deaths, and Marriages, because if it comes from, say, VARTA or something, it would ask more questions. [*Right, so having that initial letter come, it would be best from a far more general, anonymous organisation?*] Yes.”

Shelby

[Egg donor, 1990s. Agrees with Recommendation 1]

“I think it should be all uniform and in one spot. So then, therefore, people know that that is the place that you can go to if you want this sort of information. And so I guess, if the donor child made an enquiry, then that agency would contact the donor and then, as I said before, by a letter or email or there would have to be sort of a process of contact, and then to see, you know, how comfortable both parties are, I guess, as to whether they eventually meet face to face. But I think, if there’s one body that people can go to, like if you know you want a certain thing, you go to a certain professional. The same, I think there should be like just one place, rather than the registry here, and like some of the records are here and some are there. And then that gives everybody the opportunity. And you know, there would have to be, I guess, some type of counselling, because a lot of people would be fearful, I guess, of the expectations of the child or—and the child might have greater expectations of the donor, or the donor might—and so all that would have to go through a process, I would imagine, until everybody was comfortable, and then decide what to do. And I guess, if it was in one area, it could be regulated step by step to see how far it goes, or where it goes.”

Jill

[Egg donor, 1990s. Agrees with Recommendation 1]

“I got a letter from Births, Deaths, and Marriages. I got a registered letter saying, ‘Please contact us’. Something like, ‘We have some information that may be relevant to you’. Well, I knew what it was straight away. And so I contacted them, and then I had this kind of weird phone call with this person who said to me ... ‘Did you donate to the IVF Program?’ I said, ‘Yes’, and then she kind of said, ‘Oh yes, well, the person who resulted is now seeking information and possible contact. So I’m going to send you some information about them. I’m going to ask you to fill in the form about whether you are prepared to have contact or not, and what level’. So it was actually that question about, you know, mobile number, email address; what are you prepared to give? ... They apparently gave that information back to ... this young [person], and it was up to [the person] to contact me. ... I waited quite some time, and then suddenly there was an email. And I suppose my thoughts on that were, ‘Look, I suppose that’s all appropriate’. I mean, ... I knew that ... Births, Deaths and Marriages would have done their work, and therefore I felt confident that we had the right person. ... But for me, what was missing was any intermediary or any support in that whatsoever. ... I contacted VARTA. The only help that they could give me was over the phone: ‘Think about this, think about that, this is what it means, this is what might happen’. Fabulous support, but nothing in terms of there being an intermediary. I think that’s really tough, that, you, you know, that young [donor-conceived person] is left on [their] own to contact me. And then I’m potentially left on my own to manage it. ... [We need] someone at VARTA who’s got a real expertise who could perhaps directly work with the young person; do a little bit of counselling, you know, and support for them in what they might want to do and how they should manage it, and perhaps a little bit of support for me. I mean, I was able to seek out my own support, but I think I’m lucky that I can do that. And I could imagine that there’s real potential for a first meeting to be quite difficult. Now in our case it wasn’t. But I’m lucky. [The person] is a well-adjusted young [adult] who’s known since [s/he] was very young the method of [their] conception, so [s/he]’s all right. But, you know, I know there are cases where, for young people, it’s not been easy for them, and they’ve suddenly found out, and they’re all, a bit all over the place. And I think that, you know, it’s a big thing in your life to do this, and I think that particularly the young person deserves the support of someone professional around them, and possible support in organising, you know, at the very least an initial meeting or something like that. Because I think it’s really hard. ... I know how to meet young people and talk to them. You know, I’ve got a [sibling] who’s adopted. I know all about this area, as much as is possible for anyone to know. But, you know, for someone who didn’t have the kind of luck that I’ve had and resources that I’ve got: very difficult to know how to manage it, and what do you do if you’ve got an angry young person on your hands, who’s miserable with their life, because they’ve just found this information out, or they’re, you know, things aren’t going well with their parents. ... I think that young people especially deserve more than just, ‘Here’s a phone number; off you go’. ... I’m not suggesting that it necessarily needs to be on-going, because, in most cases, I believe these things work out very nicely with them. But, if it’s not going to, then we’ve got a young person who deserves some help, and possibly someone at the other end, you know, as in the person who’s donated might be thinking, ‘I’m really concerned about this young person, but I don’t have expertise in this’.”

Utnapishtim

[Sperm donor, 1980s. Agrees with Recommendation 1]

“I think a lot of people would be concerned about strangers popping up all of a sudden, and the families being threatened about what rights these people do have. So I think, yeah, I think it’s important that we actually understand what’s the implication of what we are doing. You see, I actually don’t. ... I’m not saying this is my wife’s thing, but wives might think, you know, these kids come along and all of a sudden their inheritances are threatened and all these sorts of things; I don’t know. I mean, those things to me are sort of secondary to the initial thing about the welfare of people, rather than whether they’re going to get one-tenth of your inheritance or one-fiftieth of it, you know?”

Sharon

[Egg donor, 1990s. Agrees with Recommendation 1]

“I think that there’s a lot of people go through their life, and they don’t ever have any thought about how it’s going to affect someone, or because they’ve just gone through and had their children without even thinking about it, that that’s the way it is, and they don’t sort of think about the effects that they’ll have on other people and on the wider community, and you know, their children and all of that. I don’t think it’s a bad thing to educate the community that there are people that do things in a roundabout way to get to the same end result. And, you know, it takes all kinds to make up a world. And I think that, I still think that the ultimate protection is to ensure that the children are brought up in a safe environment, and make sure that checks are in place before everything happens.”

Elka

[Egg donor, 1990s. Prefers voluntary release of information]

“One thing which has sort of concerned me a little bit, and which has made me very careful in kind of wording my will, was what if somebody sort of popped up and said, ‘Hey, I’m part of your offspring’, so that my will was previously fairly generic because it was written before we had children, and it said, ‘Or any of my children—’? So I’ve sort of tightened up the wording of that so that I actually name my children. ... So I think some kind of legal advice in those sorts of areas would be helpful.”

Jack A

[Sperm donor, 1970s. Prefers voluntary release of information]

“Fundamentally I believe that it’s best for folk to know their biological history and, if it’s possible and agreeable to all parties, to actually, you know, meet. ... I think that there should be a lot of counselling on both sides, particularly for the donor. I know that, for myself, the counselling, when I was on the search regarding my adoption, I know that the counselling that was provided was of immense support and carried me through. ... If a donor feels that he doesn’t want to be identified, then that has to be worked through very, very carefully, and it may be right at the end that his rights are upheld, but that the medical information, given the advances technologically and scientifically and all the rest of it, with regard to DNA and so forth over these years; that there’s been so much progress in that area. And there are some, there are some, there are good medical reasons why information should be shared. ... I think the donor should, over a period of time, receive counselling and information, and be encouraged to participate in—I suppose it’s a soft option in a sense, but I just feel that it may be that, you know, a donor does not want to be identified. ... I’d hate the situation to develop where the name is divulged. If the donor doesn’t want to be identified, you’ve got a situation where the donor-conceived person may spend an incredible amount of effort and time and emotion trying to find that person, and that person just doesn’t want to be found. I just feel that it’d be extremely healthy to work with the donor to see if it’s possible to get a change of heart, you know, over a period of time. It may take a couple of years. ... I tend to adhere to the belief that we can do the right thing if we’re given support and encouragement and particularly where we can meet other folk who are in the same situation as donors and who have consented. ... I am so much of the belief that, if we can listen to other people who’ve gone through a situation similar to our own, that will give us a lot of insight that we’re not alone. I felt, initially with the adoption thing, I felt, you know, I was the only adopted child I knew. And it was finding others in a similar situation that really opened up my eyes and my heart. ... The donor, in the final analysis, if he doesn’t really want to reveal who he is, and doesn’t want to make contact, then I think he should have that right. But I would stress that every opportunity should be made to get that person to see how others are coping in the situation.”

Ian

[Sperm donor, 1970s, 1980s. Prefers voluntary release of information]

“In the unlikely event that people who didn’t want to be contacted—and I am not in that case—and they’re married, and their wife was particularly unhappy about this, maybe, and it’s been foisted upon them. I find that most unlikely; I don’t think that’ll happen, but if that were the case, then clearly they must be offered counselling to be able to handle it, as should the spouse, the wife, concerned, and the children. Anyone who might be affected by this. But I just can’t see that happening. ... If it were to happen, well, quite clearly you’re going to have to have counselling, because there are people who are reluctant, if they haven’t voluntarily registered, or given that they know about the Voluntary Register. Now you may find that there are heaps of people who don’t even know about this, and would be quite happy to, and it may be a very small percentage who, even with all this knowledge, say, ‘Ha, ha, ha; I don’t want any of that; my wife’d go spare if she knew’. And I think it would be more the wife, but it may be a husband who’s had four kids of his own and he’s quite happy; ‘Thanks very much; I just haven’t got the time’. You know, that’s another thing: ‘You’re being brought up by other people. That was the whole idea of it. I’ve got my own life, my own family; I’ve no desire’. In fact, his wife might be most interested. ... I’d just find that very strange if they were forced. I couldn’t see that happening. There’d be uproar about that. ... The more people who learn about the Voluntary Register, the better.”

Donald

[Sperm donor, 1980s. Prefers voluntary release of information]

“I don’t see the need for a person-to-person contact to exchange that information. ... [I’m willing to exchange information] as long as it’s mediated and there’s not an intention to form a bond. ... I’ve got no interest in forming a bond with the people conceived. ... I would just need a professional mediation service. You know, I mean, I don’t think I need counselling, and I don’t think it would be terribly traumatic or anything like that. It doesn’t consume me in that way or anything like that. ... If there was any form of emotional blackmail or something like that, then I’d probably need some support or something like that.”

Brett

[Sperm donor, 1990s. Agrees with Recommendation 1]

“Provision of counselling; definitely they need that, sort of; you know, if they want to veto it, try to veto it; that ‘five years’ business. Definitely I think they need to attend some sort of sit-down-and-talk-about-it counselling, even if it’s only half an hour. You know, just sort of like, ‘This is how the law has changed, blah, blah, blah’. You know, just to make them aware of it. If they’re going to sign it, then they’ll sign it, but at least you’ve had a go at pricking their conscience as to what it means to the other people, especially if they’re, you know, if they’re trying to contact. How would they feel in that situation? I mean, stuff like that. ... This person only just wants to talk; you know, they’re not going to hunt you down like some criminal and, you know, put you in the media and force you to do things and stuff. They only just want to know. I mean, jeez! ... It would be handy to have it available, as in, sort of like, this counselling service specifically designed for these people, for their situation, because you go to a standard counsellor, and they say, ‘Oh, I’ve got no idea, no experiences in this. I generally do this, this and this’. You know, if you’ve got somebody like that; yes, clearly, ‘These are the approved government ones that we know of, and you can go to these people’. You know, ‘We recommend that you go to this one or this one’, and stuff like that. ... I think [counselling should be centralised in] the mediating organisation, because that way they can control it all; they know what’s, you know, the sort of—how can I put it—the current—not social—the current best practice. ... Other than that, you get these horrible little side ones all over the place that it just gets out of control.”

David P

[Sperm donor, 1990s. Agrees with Recommendation 1]

“Something similar to what I had, with just the offer of a consultation with a psychologist or some person of that sort to just work through the issues and—I can’t remember, because it’s quite a few years ago now when I took part, but, you know, it can be helpful to go through things, and they may point out things you hadn’t thought about, or just to help you prepare for a meeting with the child. ... I’d given it a lot of thought myself about meeting with the child, but yeah, I think it would be helpful, unless the donor doesn’t see any point in being prepared to meet the child or have direct contact.”

Sharon

[Egg donor, 1990s. Agrees with Recommendation 1]

“Things change so much, you know? ... I think that, if you’re going to be contacted, you just be contacted, and whichever way you go about getting initial contact, it’s obviously going to come out the blue and bring up a lot of things. So I would just sort of hope that there was some sort of counselling or something that can be in place. ... I think it’s fraught with issues, certainly for the donor and for the children, but I still think it’s not insurmountable, that they, you know, if they’re well-adjusted and they’ve got back-up with some support, then it should be okay. ... I think there could probably be a support circle set up that they [donors] could meet with other people who don’t have an issue with it, and maybe just before some of that stuff—or, you know, a third party that’s actually going to look at what their actual issue is, whether it’s privacy or, you know. ... My mum gave up a child before my [sibling] and I were born. ... We think was taken away from her forcibly, so, you know, put up for adoption. ... As she started to get dementia, we started to work with a psychiatrist, and we started to find out more that she had these secrets that she was hiding. And it’s not good for anyone to live in that sort of constant state of fear that there’s going to be something that’s going to damage them so badly. If they need some help adjusting, of course, it’s going to be—you think, well, maybe their rights are taken away from them a little bit because they made that decision based on that there was always going to be that anonymity. But if you put it in the context of, ‘This is what we now know for children, that they’re going to be safe and they can resolve their issues earlier in life’, then maybe they would come around. ... I think with education and talking through the process of things, I think people can actually—. ... I’ve seen some people who’ve been very rigid in their ideas initially, and they’ve, you know, 10 years down the track, they’re very different.”

Anon

[Sperm donor, 1990s. Disagrees with Recommendation 1]

“Given the conversation I’ve had, the idea that I can somehow make things better by saying, ‘Oh look, I know you’re very upset, Darling, but why don’t you talk to this counsellor at some government authority, and you’ll get over it’. I mean, that’s crap. She made it abundantly clear that this was almost a deal-breaker, and I can’t—you know, I’m not going to tell her how to do that. ... I think that would make a bad situation even worse. She’s an adult; she’s got to decide how she wants to handle this sort of stuff, and if she needs counselling, she’ll be counselled. But the idea that there is this bureaucracy to enable services for something that I didn’t want, that I made it abundantly clear I didn’t want, and, at the time, the rules were, this is, you know. And, in fact, they were really more concerned—you know, they seemed to be more concerned about the fact that I was never going to have contact with them, and would I wonder, you know, would that make me sad? ... And I said no. ... I really don’t want any contact. This is a good thing, as far as I’m concerned.”

Edward

[Sperm donor, 1990s. Prefers voluntary release of information]

“I was probably contacted about this time last year, ... with obviously a legal request in the mail for, you know, contact details. ... It always had been explained to me very clearly that if anyone wants to make contact, there was a very clear policy about counselling. There was a counselling service, and an official set of counsellors and, you know, it was explained sensationally well to me that obviously I would go to see a counsellor and explain that someone wishes to make contact with me, that wants to make contact, and explain our reasons, and then, of course they would then speak to ... the child’s family. And they said it was actually extremely important for them, you know, to actually then go back to that family to say, ‘Well, actually, this is what is possible, and this is what isn’t possible’. ... Maybe the child is expecting an uncle relationship, a father’s relationship, a whole variety of different things, and, of course, that’s not actually possible. So quite often that counselling process can tone that down for them, to make clear, just saying to them, ‘This is the actual position of your donor. They’ve got a family with kids. Their wife is uncomfortable about it’, or let them know that they’re happy to say just a quick ‘hello’ or a one-off meeting, but they probably can’t offer any more than that. And that way, it’s sort of like no party’s going in with their expectations too high, and then actually have a bit of a disappointing sort of result, because their expectations aren’t met. ... And that’s actually where I got involved with [a member of parliament], when the new legislation got passed four or five years ago, and that counselling process somehow had been looped out, and somehow it said it wasn’t now a part of the actual process. So the way it works now is, if one of my donor children wants to make contact, they’ve got to apply to the Department of Justice, who monitors the register. They send a form out to me, saying, ‘There’s been a request for contact details’, or, you know, ‘You can choose’. And I can choose what information to release, but that is it. So I could pass an email address, and then that is passed back to the child’s family, and then that is it; we’re left to our own accord. ... When that became apparent that was now the process, that’s when I went and approached the member of Parliament, saying, ‘Hey, this isn’t right and this is not what I was told what was happening. There is the counselling process’. I explained why the counselling process is, because I don’t know what [the family that has contacted me] want. ... It could be that the family’s broken up, and now the mother’s hoping that maybe the child can have a father-figure through this all, or maybe there’s a request for money, saying, ‘Oh, your child’s very bright; we want to send him to this school, but we can’t afford it; we’re hoping you might be able to help out’, you know. And then, of course, I turn around and say, ‘That’s not part of the deal’, and then they can just reply back, ‘Don’t worry about your real dad. He’s, you know, a deadbeat; not going to pay for anything’. ... So the Department of Justice, literally, they’ve just got a stock standard form, and it just says I can send the name or medical records or whatever; there was a list of four or five different things. And when I actually phoned up the registrar who’s in charge of this process, and said, ‘This is actually not giving me any control at all. I’m just—’. And she said, ‘Oh, no. You can choose what information you release, so yes you do have control’ and I went, ‘Actually no; it’s not actually like that at all. It’s simple on black and white paper, but no, I’ve actually got no control over the situation at all’. And so I went and spoke to [the parliamentarian] and said, ‘I actually think I’ve been put in quite a difficult position, because this counselling process seems to have disappeared’. And I did speak back with the [clinic] and their program, and they agreed that, yes, there was a counselling service. The counselling service as such did exist still, or the counsellors did exist still, but they, as I said, weren’t part of a formal process. And so I still would very much like that. ... My wife is happy with what I did, but at the same time, she sees it that I’m a dad to [several] kids, and, you know, perhaps uncomfortable that perhaps some other kid may come along and expect, you know, some sort of meaningful relationship, when in actual fact I’m obligated to, obviously, my own family. And so—and once again, that could be communicated back to the other side. But then I’ve

Edward *continued*

[Sperm donor, 1990s. Prefers voluntary release of information]

also got a clear picture of what the other side wants. And it might be just as simple a thing as, 'Thank you very much for what you've done for us. You've given us a wonderful child. And here she is; here's a photo of her; she's 8, and she just wants to say hello once, and we just want to say thank you and that's it'. In which case, you'd be happy to say hello and do all those things. Whereas, as I said, you just—you know, when I don't know what the other side wants, and that's the thing; I'm being asked to say or expose myself without knowing what the other side actually want. So I know nothing about the other side. I don't know who they are, and I don't get any details of what they are or who they want, you know. ... I'm being asked to basically stand in an open paddock and say, 'Well, hello, here I am', and then anyone could walk out and say, 'Oh, you're my real dad'. And it's probably not the way it should be. ... I don't think the government can change their—they promised us that, you know, we'd be anonymous, and I think for them to go back and renege on a promise they'd made 15 years ago or 20 years ago: I have real issues with that. You know, here was a promise made, and then, for them to say, 15 years later, 'Well, actually we want to change the terms, and bad luck for your other different terms': I'm not convinced that's right. But, having said, that, if they re-introduced the counselling process, where the parties all go and see a counsellor first, and so there's quite some transparency for me to now know what the opposite side wants; then it's a bit easier, or I feel more comfortable then, saying, 'Hello, here I am. I now know that you just want to say hello'. Because, if they're looking for a much more meaningful relationship, then I might be able to say to them, 'Well, that's not quite possible today, because my children are young', and what-have-you, 'but as they get older, and I can explain it all to them, that may change'. And that way, they're entering into the deal not expecting so much, and then perhaps they won't get disappointed. And I really do think that's the process that seems to have, as I said, was meant to be there, and was there, and it's disappeared, and I'm hoping they return back."

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Executive summary

Chapter One: Introduction

This Inquiry is concerned with the rights of donor-conceived people to access information about their donors. Currently, donor-conceived people have different rights in this regard, depending upon the date of donation of the gametes from which they were conceived.

Assisted reproductive procedures help people to conceive a child through a means other than sexual intercourse. Donated gametes are often used in these procedures where partners have had difficulty conceiving, when a person carries a hereditary disease or genetic abnormality, or when women without male partners wish to have children. This is referred to as donor-conception. There are likely several thousands of donor-conceived people who were conceived in Victoria prior to 1988, and more than 5500 have been born since then. Many of these people will be unaware that they are donor-conceived.

The Committee heard views from a wide range of individuals and organisations in the course of this Inquiry, through submissions and public hearings. This report has been informed by the evidence of donors, donor-conceived persons, recipient parents, academics, and representatives from government agencies, fertility clinics, medical associations and support groups.

Chapter Two: A history of donor-conception in Victoria

Victoria was one of the leading international sites for the development of assisted reproductive technologies such as IVF during the 1970s and into the 1980s. Victoria was also the first Australian state, and the first jurisdiction in the world, to enact legislation regulating assisted reproductive treatment. This legislation – the *Infertility (Medical Procedures) Act 1984* – came into effect in 1988. The legislation has been significantly amended twice, with the *Infertility Treatment Act 1995* effective from 1 January 1998, and the current *Assisted Reproductive Treatment Act 2008* coming into effect on 1 January 2010.

Prior to 1988, donor-conception was unregulated, and was entirely in the hands of the medical profession. A culture of secrecy was pervasive in the early days of donor-conception, despite contemporaneous changes to adoption laws to eliminate secrecy. Donors and recipient parents were required to sign anonymity contracts agreeing that they would not seek to discover each other's identity. Parents undergoing treatment were advised not to disclose the manner of their child's conception to their child or to others, and clinics attempted to match the physical characteristics of the donor and the prospective father, so that the child would not look too different from the father.

Donor-conception practices in Victoria have evolved significantly over time to encourage far greater openness. Legislation regulating donor-conception has incrementally introduced provisions allowing donor-conceived people to access information about their donors, with the *Infertility (Medical Procedures) Act 1984* allowing post-1988 donor-conceived people to obtain identifying information with the donor's consent, and the *Infertility Treatment Act 1995* introducing the right for all post-1998 donor-conceived people to obtain identifying information about their donor in all cases.

Chapter Three: Access by donor-conceived people to information about donors

Not all donor-conceived people want to know who their donors are, or desire more information about their donors. However, donor-conceived people who want to know who their donors are can experience distress when they are unable to obtain information about them. This distress may be exacerbated when a donor-conceived person learns of the circumstances of their conception later in life.

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Under current legislation in Victoria, rights for access to information by donor-conceived people are determined by the date at which the gametes used in their conception were donated. People conceived from gametes donated before 1 July 1988 have no rights to access information about their donors under legislation, although they may obtain information through a voluntary register. People conceived from gametes donated between 1 July 1988 and 1 January 1998 are entitled to receive non-identifying information about their donors, and identifying information with their donors' consent. People conceived from gametes donated after 1 January 1998 are entitled to obtain non-identifying and identifying information about their donors. Legislative change will be required to provide people conceived from gametes donated prior to 1 July 1988 with access to identifying information about their donors.

There are a number of arguments in favour of providing access to identifying information to all donor-conceived people in Victoria. These include: providing for communication of medical information between donor-conceived people and their donors; ensuring that donor-conceived people are able to exercise their rights under the *Charter of Human Rights and Responsibilities Act 2006*; and ensuring that the principle articulated in the *Assisted Reproductive Treatment Act 2008*, that "the welfare and interests of persons born or to be born as a result of treatment procedures are paramount", is applied. On the other hand, donors were promised anonymity when making donations prior to 1 January 1998, and providing donor-conceived people with access to identifying information may constitute an unreasonable breach of donors' privacy.

On balance, the Committee determined that the right of a donor-conceived person to have access to identifying information about his or her donor is paramount. The Committee therefore recommends that the Victorian Government introduce legislation to allow all donor-conceived people to obtain identifying information about their donors. However, in order to provide some assurance to donors and donor-conceived people that they will not consequently experience unreasonable interference in their lives, the Committee also recommends that both parties be able to lodge a contact veto to prohibit contact with each other.

Chapter Four: Donors' access to information

Donors have a wide range of views on whether donor-conceived people should have access to identifying information. The Committee heard from donors who were happy to have identifying information provided to donor-conceived people and others who did not want identifying information shared with others. Some donors were worried about the effect that contact with their donor-offspring would have on their families and careers.

Under current legislation in Victoria, donors who provided gametes prior to 1 July 1988 have no right to access identifying or non-identifying information about their donor-offspring. They may obtain information from the voluntary register (if other parties have also volunteered information), and may obtain non-identifying information from the treatment clinic, if it is still operating. Donors who provided gametes after 1 July 1988 are able to obtain non-identifying information about their donor-offspring from the central register, and identifying information with the consent of their offspring (or if that person is a minor, his or her parents or guardians).

The Committee determined that all donors should be provided with access to non-identifying information about any person conceived from their gametes. The Committee considered that providing all donors with a mechanism to obtain identifying information about their donor-offspring was not necessarily in the interests of the donor-conceived person, as evidence suggests that it is preferable that donor-conceived people learn of their status from their parents. In the Committee's view, existing arrangements for donors' access to identifying information should remain.

The Committee also recommends that a mechanism be introduced to allow medical information to be passed from a donor to their donor-offspring, if a significant genetic or hereditary risk to the donor-conceived person exists.

Chapter Five: Access to information about donor-conceived siblings

A number of donor-conceived people expressed an interest in knowing more about their donor-conceived siblings. Some donor-conceived people also expressed concerns about forming relationships with people in their age group, fearing that they may discover their partner or spouse is their half-sibling. Some donor-conceived people find it difficult to form relationships for this reason, even though the likelihood of forming such a relationship is low.

Donor-conceived people are not currently entitled to receive any information about their half-siblings. The only mechanism through which contact can be made is the voluntary register, which requires the participation of both (or all) of the half-siblings.

The Committee recommends that non-identifying information about half-siblings be made available to donor-conceived people. This would provide some means for donor-conceived people to assure themselves that a person they formed a relationship with was not related to them.

Access to identifying information on half-siblings should not be provided to donor-conceived people. The Committee recommends that a mechanism be introduced to allow medical information to be passed from a donor-conceived person to his or her half-siblings should a significant genetic or hereditary risk to the half-sibling exist.

Chapter Six: Counselling and support services

Contact between donor-conception stakeholders – including donor-conceived people, their parents, half-siblings, and donors – is still very new and uncharted territory. All parties will feel vulnerable throughout this process, and will struggle to determine the appropriate way to proceed. It is important that particularly leading up to and during this process, comprehensive counselling and support services be available to these people and their families. The arrangements that were in place when the former Infertility Treatment Authority was responsible for providing these services (up until the end of 2009) were far superior to the limited and fragmented services currently available.

While it operated, the Infertility Treatment Authority was responsible for managing the donor registers, and provided a range of related services. These included donor-linking and counselling services for those seeking information about their donor or donor-conceived offspring, and operating a letterbox service. The letterbox service allowed donor-conception stakeholders to communicate and gradually develop a relationship before revealing their identities to each other.

The introduction of the *Assisted Reproductive Treatment Act 2008* in 2010 dramatically changed the services available, by transferring the donor registers to the Registry of Births, Deaths and Marriages, and conferring a limited counselling role on a section within the Department of Human Services. The Committee heard much evidence to suggest that these changes have markedly reduced the services available to donor-conception stakeholders, and have made it difficult and confusing to access those services.

It would be preferable that all donor-conception stakeholders are able to access the information, counselling and support services that they require through a single agency with relevant expertise.

Chapter Seven: Protection and management of records

Victoria has had reliable and centralised donor-conception records from 1988 onwards, as since this time, clinics and doctors have been required to provide details about donor-conception procedures to be recorded on the central register. However, pre-1988 donor-conception records are held in disparate

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locations, and some may be inaccessible, incomplete, inaccurate, or may no longer exist. In addition, where these records are held privately, they are legally able to be destroyed at any time.

As donor-conception records are a type of identity record, they should be protected and preserved indefinitely. To ensure that all donor-conception records are accessible, it is critical that they all be held and managed centrally. Ideally, the managing agency would be the same agency that is responsible for providing counselling and support services to donor-conception stakeholders.

It is important that information in donor-conception records is verified before it is released. Where there are gaps and uncertainties in the records, a DNA matching facility could assist to overcome these. It is also desirable that a national donor-conception register be established, and the Victorian Government could play a role in championing the development of consistent donor-conception legislation in all Australian states and territories.

Chapter Eight: Other issues in donor-conception

In the course of this Inquiry, a number of issues were raised that do not fall within the Committee's Terms of Reference. The Committee did not make findings or recommendations on these issues, but considers that it is important to note the issues raised. These include:

- the number of families who should be permitted to use gametes donated by a single donor;
- the 'reasonable expenses' that donors should be entitled to receive, if any;
- whether potential donors should be subject to police checks before they are accepted as donors;
- whether the importation of gametes from overseas should be banned; and
- whether the legislation should be amended to clarify that a donor does not have the right to make decisions about embryos resulting from his or her gamete donation.

Inquiry into Access by Donor-Conceived People to Information about Donors

Recommendations

Recommendation 1:

That the Victorian Government introduce legislation to allow all donor-conceived people to obtain identifying information about their donors.

Recommendation 2:

That, in implementing Recommendation 1, the Victorian Government require that a child applying for identifying information about his or her donor only be provided with that information if:

1. the child's parents have consented to the application; or
2. a counsellor has provided counselling to the child and has confirmed in writing that the person is sufficiently mature to understand the consequences of the disclosure.

Recommendation 3:

That, with the introduction of the legislation described in Recommendation 1, the Victorian Government require donor-conceived people to attend counselling prior to obtaining identifying information about donors.

Recommendation 4:

That, with the introduction of the legislation described in Recommendation 1, the Victorian Government introduce provisions for contact vetoes that may be lodged by a donor or a donor-conceived person following counselling, with the following features:

- that contact vetoes only be available to people conceived from gametes donated prior to 1998, and the donors of those gametes;
- that donors may only lodge a contact veto after they have been informed that a donor-conceived person has lodged an application for identifying information about them;
- that a veto prohibits contact between the donor and the donor-conceived person;
- that suitable penalties be established for breach of a veto;
- that a veto lapses within five years if not renewed by the person who lodged it; and
- that the person who lodged a veto may withdraw it at any time.

Recommendation 5:

That, with the introduction of the legislation described in Recommendation 1, the Victorian Government introduce provisions for donors to lodge a contact preference form for presentation to a donor-conceived person.

Recommendation 6:

That the Victorian Government introduce the measures proposed in Recommendation 1 through Recommendation 5 following a period of time sufficient to publicise and inform the Victorian community of retrospective changes to donor-conception arrangements.

Recommendation 7:

That the Victorian Government encourage organisations, agencies and persons holding information on donor-conception to release, upon request, non-identifying information about a donor to a donor-conceived person, his or her parents, and his or her descendants.

Recommendation 8:

That the Victorian Government encourage organisations, agencies and persons holding information on donor-conception to release to a donor upon request, non-identifying information about his or her donor-conceived offspring.

Recommendation 9:

That the Victorian Government introduce a mechanism for medical information from a donor to be provided to a donor-conceived person, where there is evidence of hereditary or genetic disease or risks to the health of the donor-conceived person.

Recommendation 10:

That the agency managing the donor registers be empowered to release to a donor-conceived person, upon request, non-identifying information about his or her donor-conceived siblings.

Recommendation 11:

That the agency managing the donor registers be empowered to release to the parents of a donor-conceived person, upon request, non-identifying information about that person's donor-conceived siblings.

Recommendation 12:

That the voluntary register remain the only means for donor-conceived people to seek identifying information about their donor-conceived siblings.

Recommendation 13:

That the Victorian Government introduce a mechanism for medical information from a donor-conceived person to be provided to that person's donor-conceived siblings where there is evidence of hereditary or genetic disease or risks to the health of the donor-conceived person.

Recommendation 14:

That the Victorian Government introduce legislation to empower one agency to provide all services relating to the provision of information, linking and counselling services related to donor-conception, including management of the donor registers, a letterbox service, education and public campaigns.

Recommendation 15:

That the agency referred to in Recommendation 14 be granted access to the Victorian register of electors in order to conduct its functions.

Recommendation 16:

That VARTA assume the responsibilities of the agency referred to in Recommendation 14.

Recommendation 17:

That the Victorian Government introduce legislation to transfer ownership of, and responsibility for, the donor register databases currently held by the Victorian Registry of Births, Deaths and Marriages, to the agency referred to in Recommendation 14.

Recommendation 18:

That the agency referred to in Recommendation 14 offer comprehensive and ongoing counselling and support services, in association with managing the donor registers, to all donor-conceived people, recipient parents and donors, and their relatives, and that counselling be compulsory for:

- a donor-conceived person who is seeking identifying information about his or her donor;
- a donor who is seeking identifying information about his or her donor conceived offspring; and
- a donor or donor-conceived person who applies to lodge a contact veto.

Recommendation 19:

That the Victorian Government introduce a mechanism by which identifying information about a donor can be released directly to a donor-conceived person, in appropriate circumstances.

Recommendation 20:

That the agency referred to in Recommendation 14 provide a letterbox service for donor-conception stakeholders, based on the service previously provided by the ITA.

Recommendation 21:

That if the Committee's recommendations are implemented, VARTA conduct a public information and awareness campaign advising the public of relevant changes in the provision of information to donor-conception stakeholders, particularly targeting pre-1998 donors.

Recommendation 22:

That VARTA continue its education and public campaigns role, with a particular focus on encouraging and supporting the parents of older donor-conceived children to tell their children about the circumstances of their conception.

Recommendation 23:

That the Victorian Government introduce legislation to provide that destruction of, falsifying or tampering with, any records that identify parties to donor-conception, is an offence.

Recommendation 24:

That the Victorian Government introduce legislation to require that persons or organisations that hold records containing information on pre-1988 donor-conception provide copies of the records to a central agency, and in the case of PROV, that pre-1988 donor-conception records be transferred to a central agency.

Recommendation 25:

That the legislative changes proposed in Recommendation 24 be advertised in a public campaign targeting the medical profession.

Recommendation 26:

That the agency referred to in Recommendation 24 approach individual doctors who are known to have provided donor insemination services and obtain copies of records held by them, if any, containing information on parties to donor-conception.

Recommendation 27:

That the Victorian Government introduce legislation to transfer responsibility for the central and voluntary registers from the Victorian Registry of Births, Deaths and Marriages to the agency described in Recommendation 14.

Recommendation 28:

That the Victorian Government provide a facility within the voluntary register for DNA matching.

Recommendation 29:

That where records for donors or donor-conceived people are unavailable, incomplete, or ambiguous, the Victorian Government offer a concession for DNA testing if that person wishes to lodge DNA matching data on the voluntary register.

Recommendation 30:

That the Victorian Government provide regular reports to an appropriate inter-jurisdictional body, such as the Standing Committee of Attorneys-General or the Council of Australian Governments, on progress with the development and implementation of reforms to donor-conception legislation.

VARTA Staff

Ms Louise Johnson

CEO

Louise Johnson has been CEO of the Victorian Assisted Reproductive Treatment Authority (previously known as the Infertility Treatment Authority) for eight years and has over 25 years management and public education experience. She had overall responsibility for the consultation process including the adherence to time lines and the timely completion and communication of the report of its findings to the Victorian Government.

Ms Kate Bourne

Senior Community Education Officer

Kate Bourne has over 20 years' experience in infertility and donor-linking counselling and chairs the Australian and New Zealand Infertility Counsellors Association. As the VARTA Senior Community Education Officer, she is responsible for the development of resources to assist patients undergoing infertility treatment, donors and those born as a result. Kate was the liaison person for the consultation process and the contact person for donors who approached VARTA about participating in the consultation. She provided them with written and verbal information about the topics to be covered in the interviews.

Monash University Researchers

Dr Karin Hammarberg

Postdoctoral Research Fellow

The Jean Hailes Research Unit, School of Public Health and Preventive Medicine, Monash University

Karin Hammarberg is a Registered Nurse with a PhD. She has clinical and research expertise in the psychosocial aspects of fertility, infertility, and assisted reproductive technology treatment, including donor conception. In consultation with VARTA staff she designed the consultation process. Together with Dr Kirkman she conducted the interviews, interpreted the data and prepared the report of the findings of the consultation.

Dr Maggie Kirkman

Senior Research Fellow

The Jean Hailes Research Unit, School of Public Health and Preventive Medicine, Monash University

Maggie Kirkman is an academic with extensive experience in qualitative research methods and a special interest in the psychosocial aspects of donor conception. Together with Dr Hammarberg she conducted the interviews, analysed and interpreted the data, and prepared the report of the findings of the consultation.

Professor Jane Fisher

Director

The Jean Hailes Research Unit, School of Public Health and Preventive Medicine, Monash University

Jane Fisher is a clinical psychologist with extensive research experience in the psychosocial aspects of infertility and infertility treatment. She assisted in the interpretation of the data and the preparation of the report of the findings of the consultation.



Department of Health

Incorporating: Health, Mental Health and Senior Victorians

HUMAN RESEARCH ETHICS COMMITTEE

15/12

Ethics Committee Secretariat
Telephone: (03) 9096 5239 Fax: (03) 9096 9176
50 Lonsdale Street
MELBOURNE 3000
Email: research.ethics@dhs.vic.gov.au

50 Lonsdale St
 GPO Box 4541
 Melbourne Victoria 3001
 DX 210311
 www.health.vic.gov.au
 Telephone: 1300 253 942
 Facsimile: 1300 253 964

6 February 2013

OUR REF:

UR REF:

Dr Karin Hammarberg
 Jean Hailes Research Unit
 6th Floor, Alfred Centre
 99 Commercial Road
 MELBOURNE VIC 3004

Dear Dr Hammarberg

**Re: 15/12 – Consultation with donors who donated gametes prior to 1998:
 Acceptability of retrospective release of information about donors to
 donor-conceived people**

The Department of Health Human Research Ethics Committee (DH HREC) at its meeting of 6 February 2013 considered and ratified the earlier, interim out-of-session approval for this project given by the chair on 21 December 2012.

The project is now approved in full from **6 February 2013 to 30 June 2013**

If the study has not been completed by the nominated completion date, you will need to request an extension and submit a progress report.

To enable the Committee to fulfil its obligations in relation to monitoring the programme, you are asked to provide a report within 12 months or on completion of your project, whichever is earlier. Additionally, the Committee requests a summary of the research findings of less than half a page, including when the study was completed.

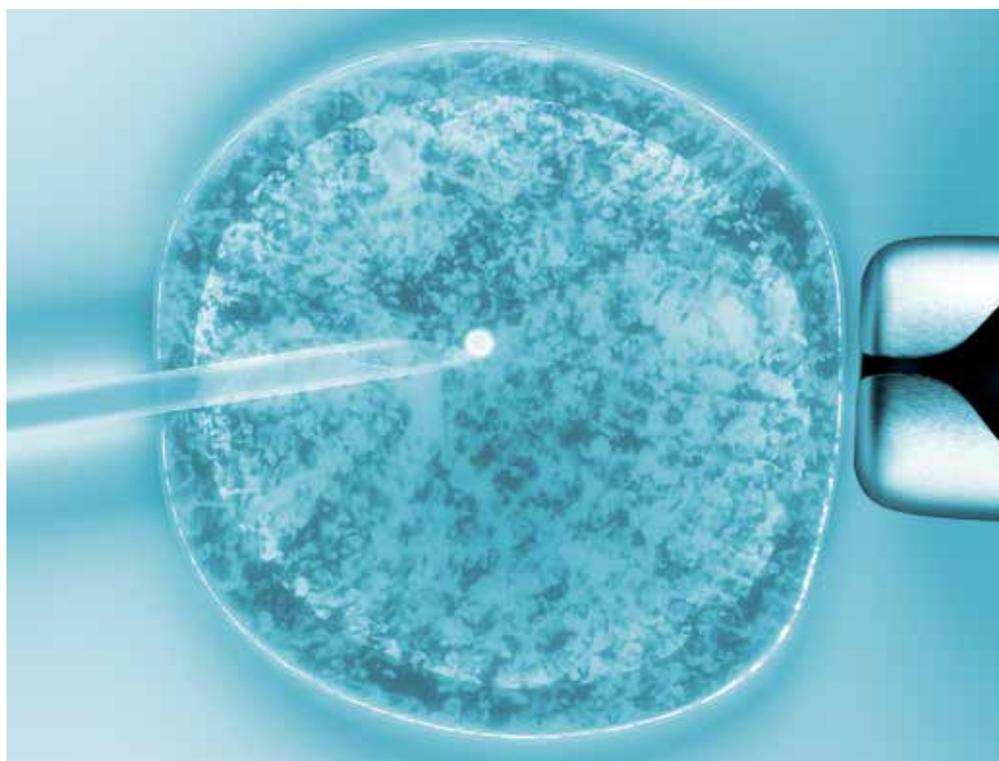
It is important to note that researchers carry substantial responsibilities in monitoring their research. You must ensure that the Department of Health Human Research Ethics Committee is notified immediately of any matter that arises that may affect the conduct of the approved program. In addition, prior to the implementation of amendments to approved research, researchers are required to advise the Committee of such amendments and seek approval for these.

Should you have any queries please do not hesitate to contact Mr Jeffrey Chapman, on 9096 5239 or email research.ethics@dhs.vic.gov.au.

Yours sincerely,

Rev Fr Michael Elligate
Acting Chair





You gave life. Now give voice.

Did you donate eggs or sperm in Victoria before 1998?

The Victorian Government wants to hear what you think about the possibility of the law being changed, allowing your donor-conceived offspring access to identifying details about you. *Contact VARTA in confidence to have your say. All feedback will be kept private.*

Phone (03) 8601 5250 or kbourne@varta.org.au



CLIENT: VARTA
FEATURE: You Gave Life. New Give Voice
KEY NO: VAR/051212/1
START: 13/12/12
DETAILS: Male voice aged 50-60
REP: Peter W
WRITER: Supplied
DUR: 30-sec
END: 14/12/12

Before 1998 you did something amazing.

You donated your sperm or eggs and you gave life.

You can make another valuable donation... your opinion.

The Victorian Government is considering changing legislation to allow all donor-conceived people access to their donor's identity.

The Victorian Assisted Reproductive Treatment Authority, VARTA, is handling consultation with donors.

All feedback is private and your opinion will help to inform decisions about law.

Visit [varta dot org dot au](http://varta.org.au) to have your say.

You gave life. Now give voice.



MEDIA RELEASE – Embargoed until 6AM Monday January 14

VARTA invites pre-1998 donors to have their say on possible law change

The Victorian Assisted Reproductive Treatment Authority (VARTA) has invited people who donated eggs or sperm in Victoria prior to 1998 to have their say about possible law changes which would remove donor anonymity.

Among 30 recommendations of the Inquiry into Access by Donor-Conceived People to Information about Donors, the Victorian Law Reform Committee recommended that *all* donorconceived people have access to their donor's identity. The Victorian Government, in an initial response to the committee's report, asked VARTA to consult with donors who currently can choose to remain anonymous.

Many donors who donated sperm or eggs in Victoria prior to 1988 did so under condition of anonymity. Under the *Infertility (Medical Procedures) Act 1984*, implemented in 1988, parents of donor-conceived children, or donor-conceived people if they were over 18, could apply for identifying information about their donor, but it would be given only with the donor's consent

In 1998 a revised Act, the *Infertility Treatment Act 1995*, was implemented, bringing an end to anonymous donation in Victoria. Since then, donors have donated with the knowledge that their identifying details would be available to donor-conceived offspring aged 18 or over, upon request. This was maintained within current legislation – the *Assisted Reproductive Treatment Act 2008*.

VARTA estimates that prior to the introduction of the *Infertility (Medical Procedures) Act 1984* in 1988 there were more than 1000 sperm donors, the majority of whom would now be aged in their 50s and 60s. Although very few women donated eggs in the 1980s, VARTA encourages egg donors to come forward and have their say during the consultation.

Donors can give their feedback in confidence and all donor feedback will be private – information recorded will be de-identified and the report VARTA prepares for the Victorian Government will not contain any identifying information. The consultation will be conducted with sensitivity and VARTA welcomes all views.

'This is an important opportunity for pre-1998 donors to convey what they think about the possibility of their identity being made available,' VARTA CEO Louise Johnson said. 'We encourage all donors who would be affected by a change in legislation to contact VARTA by Friday February 15.'

Donors should contact VARTA on (03) 8601 5250
or VARTA's Senior Community Education Officer, Kate Bourne, at kbourne@varta.org.au

MEDIA ONLY:

For comment or interviews, contact VARTA CEO Louise Johnson on (03) 8601 5250
or ljohnson@varta.org.au

Media	Australian Associated Press	Date	11/10/13
Title or content	Vic donor kids upset at finding dad delay		
Author/Interviewer	Melissa Iarla and Sarah Malik		
Media	The Age	Date	12/10/12
Title or content	More time needed for egg, sperm donor decision		
Author/Interviewer	Kate Hagan		
Media	Radio National, The World Today	Date	15/10/12
Title or content	Government delay for donor conceived people 'appalling'		
Author/Interviewer	Eleonor Hall		
Media	The Age	Date	9/12/12
Title or content	Sperm donor steps up for offspring who want to know		
Author/Interviewer	Julia Medew		
Media	The Project	Date	13/12/12
Title or content	Interview with donor, Roger Clarke and donor-conceived person, Riley Knight		
Media	Herald Sun	Date	20/11/12
Title or content	Donor-conceived kids deserve truth about who their biological parents are		
Author/Interviewer	Susie O'Brien		
Media	Herald Sun	Date	14/1/13
Title or content	Donors: to ID or not to ID		
Author/Interviewer	Lucie van den Berg		
Media	The Age	Date	3/2/13
Title or content	Sperm donor privacy 'not protected'		
Author/Interviewer	Farrah Tomazin		
Media	The Age	Date	5/2/13
Title or content	Listening to donors (Letter to the Editor)		
Author/Interviewer	Louise Johnson		
Media	ABC Radio 774	Date	4/2/2013
Title or content	Drive program, Life and other catastrophes		
Author/Interviewer	Raphael Epstein		
Media	Radio 3AW	Date	14/1/2013
Title or content	Drive program		
Author/Interviewer	Tom Elliott		



Q&A on donor conception and identity in Victoria

Q: What was the Victorian Government's response to the report of the Inquiry into Access by Donor-Conceived People to Information about Donors by the Victorian Law Reform Committee?

A: The government announced on Thursday October 11, 2012, that it wants to consult further with donors about the committee's recommendation that all donor-conceived people should have access to information about their donors, regardless of which law was in place when their donor donated sperm or eggs (see 'What are the inconsistencies of access to information?'). The government has asked the Victorian Assisted Reproductive Treatment Authority (VARTA) to conduct this consultation.

Q: How will VARTA conduct the consultation with donors?

A: Donors will be consulted with the utmost respect for their privacy and interviews will be conducted sensitively and confidentially. For further information contact VARTA on 03 8601 5250 or varta@varta.org.au.

Q: Can you give me more background about the Inquiry?

A: The Inquiry into Access by Donor-Conceived People to Information about Donors by the Victorian Law Reform Committee addressed inconsistencies within Victoria around donorconceived people's rights to information about their donor and how information could be accessed.

The committee's report was released in March 2012, with 30 recommendations relating to the rights of donor-conceived people to information about their donors, the rights of donors to information about the people they helped to conceive, and the rights of donor-conceived people to information about siblings. The committee also recommended introducing provisions for contact vetoes for donors or donor-conceived people who did not want to be contacted. Some of the recommendations concerned changes to services related to information management and counselling.

See: <http://www.parliament.vic.gov.au/lawreform/article/1468#intgovtresp>

Q: What are the inconsistencies of access to information?

A: There have been three Acts relating to donor conception within Victoria, each of them having different implications for the rights of donor-conceived people to information about their donor. These Acts were:

- *Infertility (Medical Procedures) Act 1984* (implemented in 1988)

Under this Act, hospitals had to maintain a register recording details of each gamete donor, recipient parents and any children born as a result of a procedure. They were also required to forward these details to the Victorian Government for inclusion on a central register.

Under this legislation, a donor-conceived person, regardless of age, can apply for obtain non-identifying information (e.g. hair and eye colour, height, complexion, build) about their donor from the Registry of Births, Deaths and Marriages.



Q&A on donor conception and identity in Victoria

If over 18, a donor-conceived person or a parent of a younger child can apply for identifying information about their donor but the donor would have to consent to its release.

- *Infertility Treatment Act 1995* (implemented in 1998)

This Act recognised the welfare and interests of donor-conceived people as paramount and brought an end to anonymous gamete donations in Victoria. Under the Act, when a donor consented to the use of his or her gametes, he or she had to be advised in writing of the right of a person conceived from the gametes to obtain identifying information about the donor. A donor-conceived person conceived from gametes donated after the start of the 1995 Act (i.e. post-1998) can obtain identifying details about their donor at the age of 18 – or at a younger age through a parental application and the consent of the donor.

- *Assisted Reproductive Treatment Act 2008* (implemented in 2010)

Under this Act, donor-conceived people had the same rights to access information about their donor as under the 1995 Act. However a mechanism was introduced to allow a donorconceived person to obtain identifying information about their donor prior to 18 with parental consent or on recommendation from a counsellor if the child is sufficiently mature.

This Act also introduced a requirement that where a child is born as a result of donor treatment, the Registrar of Births, Deaths and Marriages must mark the child's birth entry to note that he or she is donor-conceived. When issuing a birth certificate to a donor-conceived person the certificate must include an addendum stating that further information is available about the birth entry.

This Act also introduced a limit on the use of donated gametes from a donor to the creation of 10 families. This limit was previously in place as part of the regulation of the ART industry but this was the first time it was legislated.

Q: How many donor-conceived people are there in Victoria?

A: About 5500 donor-conceived people have been born in Victoria since 1988. VARTA estimates that pre-legislation there were more than 1000 sperm donors, the majority of whom would now be aged in their 50s and 60s. There were very few egg donors who donated in the late 80s.

Q: How many people wouldn't know they were donor-conceived?

A: We don't know but it's likely that the majority of donor-conceived people born prior to 1988 would not know because there was a greater culture of secrecy around donor conception.

Q: Who would be affected if the recommendations proposed by the committee were implemented by the Victorian Government?

A: Donor-conceived people and the donors who donated prior to the first Victorian legislation (passed in 1984 and implemented in 1988) and those who donated during the life of that legislation (until 1998, when the second legislation was implemented).



Q&A on donor conception and identity in Victoria

Please note that if a donor donated under the 1984 legislation but their sperm wasn't used until after the second legislation was implemented in 1998, the children they helped to conceive would have the 1984 legislation rights to information about their donor.

Q: How can donor-conceived people currently find information about their donor?

A: Details about donors are stored on a central register. Donor-conceived people whose donors donated under the 1988 legislation can apply for identifying information from this register and their donor can either grant or deny permission for the information to be released. They are entitled to non-identifying information without the donor's consent.

Donor-conceived adults whose donors signed consents under the 1995 legislation are entitled to identifying information about their donor. Parents and donors are also able to apply for identifying information but consent of the other party is required.

A voluntary register was established under the 1995 Act (in 1998) so that people who could not access information through the central register (e.g. those born, or those who donated, prior to legislation being introduced; parents wanting to link with other parents who used the same donor; or half-siblings wanting to link with others) have the opportunity to access information, if a related person has lodged information with the register.

The donor registers are managed by the Registry of Births, Deaths and Marriages.

For information about making an application:

<http://online.justice.vic.gov.au/CA2574F700805DE7/page/Births-Donor+treatment+registers?OpenDocument&1=10-Births~&2=20-Donor+treatment+register~&3=~>

Q: Is there a limit on how many families a donor can help to form?

A: A donor's sperm can be used to form up to 10 families, including his own. However, a donor may have more than 10 donor-conceived offspring if his sperm has been used to conceive siblings within one or more families.

This limit has been legislated in Victoria since the 2010 implementation of the Assisted Reproductive Treatment Act 2008. However, the limit has been in place as a licensing condition for assisted reproductive treatment clinics since 1998.

Q: Who can people contact if they want further information about donor conception in Australia?

A: They can contact VARTA at www.varta.org.au, varta@varta.org.au or 03 8601 5250.



Participant Information Sheet/Consent Form

Title:	Consultation with donors who donated gametes before 1998: Access by donor-conceived people to information about donors.
Protocol number:	
Project sponsor:	The Victorian Department of Health
Principal Investigator:	Dr Karin Hammarberg
Associate Investigators:	Dr Maggie Kirkman, Ms Kate Bourne, Ms Louise Johnson, Professor Jane Fisher

Part 1 What does my participation involve?

1 Introduction

You are invited to take part in this research project, which is called 'Consultation with donors who donated gametes before 1998: Acceptability of release of information about donors to donor-conceived people'. You have been invited because you donated gametes before 1998 and have contacted VARTA expressing interest in being part of a consultation process with donors.

This Participant Information Sheet/Consent Form tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or local health worker.

Participation in this research is voluntary. If you don't wish to take part, you don't have to.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read
- Consent to take part in the research project
- Consent to be involved in the research described
- Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.



2 What is the purpose of this research?

The Victorian Parliamentary Law Reform Committee's (LRC) recently recommended retrospective release of information about donors to donor-conceived people who request it. To assist the Victorian Government find a balance between the conflicting rights of anonymous gamete donors and donor-conceived people who want to learn about their biological origins, consultation with donors who donated either prior to the introduction of legislation in 1988 or under the conditions of legislation introduced in 1988 is needed (donors who donated between 1988 and 1998). The Victorian Department of Health has requested that VARTA undertake consultation with donors to canvass their views of the Law Reform Committee's recommendations. VARTA has commissioned researchers from Monash University to conduct this consultation. The aim of this consultation is to ensure that donors' views are heard before considering legislative change that may have significant impact on them and their families.

This research has been funded by the Victorian Department of Health.

This research is being conducted by VARTA in collaboration with researchers from Monash University.

3 What does participation in this research involve?

If you agree to take part in this consultation you will be interviewed by Dr Maggie Kirkman or Dr Karin Hammarberg. Depending on your preference the interview will be conducted over the telephone, via e-mail or face-to-face. The interview will take 30-60 minutes and canvass your understanding of, and views about: donor-conceived people's right to information about their biological origins; current and past legislation; the LRC recommendations and the implications of these for you and your family; how potential changes to legislation could be communicated to donors and the general public; what support could be provided to those who donated prior to 1998 if legislation to allow donor-conceived people access to identifying information about their donor is introduced; and ways in which agencies could assist with the potential linking between donors and their offspring.

The interview will be recorded and transcribed. After transcription the digital recording will be deleted and any identifying details that can link an individual to a transcript destroyed. Beyond that point it is not possible to access any personal information. The information you provide will be used in this project only and this project does not involve the establishment of a data bank.

This research project has been designed to make sure the researchers interpret the results in a fair and appropriate way.

There are no costs associated with participating in this research project, nor will you be paid.

4 Other relevant information about the research project

Approximately 30 interviews will be conducted and at the end of the consultation process, the content of the transcripts will be analysed and summarised by the researchers. A report outlining the range of views on the topics covered in the interviews will be prepared for the Victorian Department of Health.



5 Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your relationship with staff at VARTA or Monash University.

6 What are the possible benefits of taking part?

We cannot guarantee or promise that you will receive any benefits from this research; however, possible benefits include the opportunity to be heard and to express your views about the implications for you and your family of potential legislation enabling all donor-conceived adults to apply for identifying information about their donor.

7 What are the possible risks and disadvantages of taking part?

Psychological distress

You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. If you become upset or distressed as a result of your participation in the research project, the research team will be able to arrange for counselling or other appropriate support. Any counselling or support will be provided by qualified staff. This counselling will be provided free of charge.

8 What if I withdraw from this research project?

If you do consent to participate, you may withdraw at any time. If you do withdraw, you will be asked to complete and sign a 'Withdrawal of Consent' form; this will be provided to you by the research team.

If you decide to leave the research project, the researchers will not collect additional personal information from you, although personal information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law. You should be aware that data collected up to the time you withdraw will form part of the research project results. If you do not want your views to be included, you must tell the researchers when you withdraw from the research project.

9 Could this research project be stopped unexpectedly?

While it is unlikely, this research project may be stopped unexpectedly for a variety of reasons. These may include reasons such as the Victorian Health Department requesting the consultation process be terminated.

10 What happens when the research project ends?

At the end of the consultations process a summary of the results will be sent to you if you wish. We expect to have the summary complete by the end of April 2013.



Part 2 How is the research project being conducted?

11 What will happen to information about me?

The interview will be recorded and transcribed. After transcription the digital recording will be deleted and any identifying details that can link an individual to a transcript destroyed. Beyond that point it is not possible to access any personal information. In all reports and other publications or presentations of the findings of the consultation process, only summary data where no individual can be identified will be presented. A pseudonym will be used if we quote you directly.

The electronic copies of the non-identifiable transcripts will be stored on a password protected computer and paper copies in a locked filing cabinet only accessible to the researchers. The data will be stored for seven years after the last publication of the findings of the consultation process, after which time electronic files will be permanently deleted and paper copies destroyed by the researchers.

By signing the consent form you consent to the research team collecting and using personal information about you for the research project. Any information obtained in connection with this research project that can identify you will remain confidential. Only group data where no individual can be identified will be published. Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law.

The personal information that the research team collect and use includes your name, age, where you donated and your views on the topics covered in the interview.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your express permission.

In accordance with relevant Australian and/or Victorian privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information. Please note that once the recording of the interview has been deleted, personal information can no longer be accessed.

12 Complaints and compensation

If you have concerns about the conduct of the research project you can contact the Secretary of the Department of Health Human Research Ethics Committee, Mr Jeffrey Chapman on (03) 9096 5239. If you have any other questions or want to discuss details of this study please contact Karin Hammarberg at karin.hammarberg@monash.edu or on 0418 306023.

If you suffer any distress or psychological injury as a result of this research project, you should contact the research team as soon as possible. You will be assisted with arranging appropriate treatment and support.



13 Who is organising and funding the research?

This research project is being funded by the Department of Health and conducted by VARTA and Monash University

You will not benefit financially from your involvement in this research project. Monash University will receive a payment from VARTA for undertaking this research project. No member of the research team will receive a personal financial benefit from your involvement in this research project (other than their ordinary wages).

14 Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC).

The ethical aspects of this research project have been approved by the HREC of the Department of Health.

This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007). This statement has been developed to protect the interests of people who agree to participate in human research studies.

15 Further information and who to contact

The person you may need to contact will depend on the nature of your query.

Name	Karin Hammarberg
Position	Research Fellow
Telephone	0418 306 023
Email	Karin.hammarberg@monash.edu

Name	Kate Bourne
Position	Senior Community Education Officer
Telephone	03 86015250
Email	kbourne@varta.org.au

Research contact person

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Mr Jeffrey Chapman, Secretary of the Department of Health Human Research Ethics Committee, on 03 9096 5239

Reviewing HREC approving this research and HREC Executive Officer details

Reviewing HREC name	Department of Health
HREC Executive Officer	Jeffrey Chapman
Telephone	03 9096 5239
Email	research.ethics@dhs.vic.gov.au



Consent Form

Title: Consultation with donors who donated gametes before 1998:
Access by donor-conceived people to information about donors.

Protocol number:

Project sponsor: The Victorian Department of Health

Principal Investigator: Dr Karin Hammarberg

Associate Investigators: Dr Maggie Kirkman, Ms Kate Bourne, Ms Louise Johnson,
Professor Jane Fisher

Declaration by Participant

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future care.

I understand that I will be given a signed copy of this document to keep.

Name of Participant (please print) _____

Signature _____ Date _____

Declaration by Researcher†

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Researcher (please print) _____

Signature _____ Date _____

† An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.



Form for Withdrawal of Participation

Title: Consultation with donors who donated gametes before 1998:
Access by donor-conceived people to information about donors.

Protocol number:

Project sponsor: The Victorian Department of Health

Principal Investigator: Dr Karin Hammarberg

Associate Investigators: Dr Maggie Kirkman, Ms Kate Bourne, Ms Louise Johnson,
Professor Jane Fisher

Declaration by Participant

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my relationships with the researchers, VARTA or Monash University.

Name of Participant (please print) _____

Signature _____ Date _____

In the event that the participant's decision to withdraw is communicated verbally, the Senior Researcher must provide a description of the circumstances below.

Declaration by Researcher[†]

I have given a verbal explanation of the implications of withdrawal from the research project and I believe that the participant has understood that explanation.

Name of Researcher (please print) _____

Signature _____ Date _____

[†] An appropriately qualified member of the research team must provide information concerning withdrawal from the research project.

Note: All parties signing the consent section must date their own signature.

Consultation with donors who donated gametes before 1998: Access by donor-conceived people to information about donors.

Interview guide

[Thank participant for volunteering; go through informed consent process.]

[Reminder that they can stop at any time and choose not to answer particular questions]

[Check that they agree to be recorded.]

Focal story or opinion

1. First, can you tell me your story about being a donor, including where and when you donated?

About you

(i) *[Note the following details as they arise in the initial account; ask any specific questions that do not arise]*

(ii) Just to get some background, if you are willing, could you tell me a little more about yourself:

- a. your current family and whether they are aware that you were a donor
- b. when you were a donor
- c. where you donated
- d. if you know how many children have resulted from your donation
- e. if you have registered with the Voluntary Register
- f. if you have been contacted by any of the people who were born from your donation
- g. did you make a submission to the 'Law Reform Committee's inquiry into access by donor-conceived people to information about donors'?

Donor-conceived people's right to information

2. In your view, should donor-conceived people have a legal right to have access to information about their donor?
 - As you are aware, the laws in Victoria relating to whether a donor-conceived person can access information about their donor have changed over time. Under the current law, donors have to agree to be identified but before 1988 donors were anonymous and between 1988 and 1999 their consent was required before information about them could be released. What are your views about these legal changes?

LRC recommendations

3. We'd like to know your views about the Law Reform Committee's recommendations. I'll ask you about each main point. The LRC recommended that the Victorian Government should introduce a new law that: *[invite a response to each item]*
 - a. allows all donor-conceived people access to identifying information about their donor, including donors who expected to remain anonymous;
 - b. the donor should be able to sign a contact veto, which would mean that their offspring would not be allowed to contact them;

- c. the donor would be able to lodge a contact preference form, where he or she could state how they would prefer to be contacted; for example, via e-mail, letter, or telephone;
- d. a donor-conceived person who is at risk of hereditary disease should be given medical information about their donor;
- e. the voluntary register could use DNA matching where medical records are unreliable or incomplete.
- f. Do you have any alternative options to the recommendations you would like to suggest?

Intermediary services

- 4. We are interested in your views about how donors' needs can best be met if the law changes so that donor-conceived people can access information about their donor.
 - a. If a donor-conceived person you helped create wanted more information about you, how would you like to see this managed?
 - b. What information or services do you think you and those close to you might need?

Implications of LRC recommendations

- 5. How would the Law Reform Committee's recommendations affect you personally?

Communicating changes to legislation

- 6. If the law allowing donor-conceived people access to identifying information about their donor was introduced, what would be the best way to communicate this to donors and the general public?
- 7. What support could be provided to those who donated prior to 1998 if legislation to allow donor-conceived people access to identifying information about their donor is introduced?
- 8. Would you be willing to join the Voluntary register if you are not on it already?

Conclusion

Is there anything else you want to say that we haven't talked about so far?

[Thank warmly for participation.

Would the participant like to receive a summary of the findings? If so, by what means? (Email, post.)]



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