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Proposed legislative change mandating retrospective release of identifying information: consultation with donors and Government response

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STUDY QUESTION: How do gamete donors who presumed they could remain anonymous respond to proposed legislation to retrospectively remove anonymity?

SUMMARY ANSWER: A little more than half of the donors opposed the recommendation to introduce legislation to remove donor anonymity with retrospective effect.

WHAT IS KNOWN ALREADY: An increasing proportion of parents disclose their origins to their donor-conceived children and growing numbers of donor-conceived adults are aware of how they were conceived. Research indicates that access to information about the donor is important to donor-conceived people. However, worldwide most donor-conceived people are unable to find any identifying information about the donor because of the practice of anonymous gamete donation.

STUDY DESIGN, SIZE, DURATION: This study adopted a qualitative research model using semi-structured interviews with gamete donors that included open questions. Interviews with 42 volunteers were conducted between December 2012 and February 2013.

PARTICIPANTS/MATERIALS, SETTING, METHODS: Before 1998 gamete donors in Victoria, Australia, were able to remain anonymous. Pre-1998 donors were invited through an advertising campaign to be interviewed about their views on a recommendation that legislation mandating retrospective release of identifying information be introduced.

MAIN RESULTS AND THE ROLE OF CHANCE: Donors were almost evenly split between those who supported and those who rejected the recommendation to introduce legislation to remove donor anonymity with retrospective effect. 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. The findings of this study informed the Victorian Government's response to the proposed legislative change. While acknowledging donor-conceived people's right of access to information about their donors, the Government decided that identifying information should be released only with the consent of donors and that donors should be encouraged to allow themselves to be identifiable to their donor offspring.

LIMITATIONS, REASONS FOR CAUTION: There is no way of knowing whether participants were representative of all pre-1998 donors.

WIDER IMPLICATIONS OF THE FINDINGS: The balancing of donors' and donor-conceived people's rights requires utmost sensitivity. All over the world, increasing numbers of donor-conceived people are reaching adulthood; of those who are aware of their mode of conception, some are likely to have a strong wish to know the identity of their donors. Legislators and policy-makers in jurisdictions permitting anonymous gamete donations will need to respond when these desires are expressed, and may choose to be guided by the model of consultation described in this paper.

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© The Author 2013. Published by Oxford University Press on behalf of the European Society of Human Reproduction and Embryology. This is an Open Access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (http://creativecommons.org/licenses/by-nc/3.0/), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited. For commercial re-use, please contact journals.permissions@oup.com Key words: donor conception / anonymity / disclosure / legislation / intermediary services

Introduction

The use of donor gametes (sperm and eggs) and embryos to conceive is an integral part of assisted reproduction technology (ART) treatment practices. Donor sperm has been used in medical settings to treat couples with male infertility since at least the 1940s (Hill, 1970); egg and embryo donation became possible some 30 years ago (Trounson et al., 1983; Wood et al., 1984). There is debate around the world about whether or not donor conception should be anonymous; legislative responses range from mandating donor anonymity in some jurisdictions to prohibition of anonymous gamete donation in others. In some countries, such as the USA where donor practices are unregulated, recipient parents can choose between using an anonymous donor or a donor who is willing to be identified (Allan 2012b). A parallel contemporary debate concerns whether donor-conceived people should have a legal right to access identifying information about their donor.

Historically, and mirroring adoption practices, secrecy surrounded the use of donor gametes, children born as a result were not informed about their mode of conception, and donor anonymity was expected (Brewaeys, 1996). The 1980s saw a shift in attitudes towards more openness in the field of adoption as the view that adopted children have a right to know their biological origins began to gain acceptance (Chisholm, 2012). Subsequently, the idea that donor-conceived people should be told about the way they were conceived and have access to information about the gamete donor was increasingly supported; counselling practice thus moved from advocating secrecy to promoting openness (Daniels and Taylor, 1993). The Ethics Committee of the American Society for Reproductive Medicine (ASRM) notes that professional opinion has moved towards acceptance of identity disclosure to children, evident, for example, in ASRM guidelines which changed from recommending anonymous donation in 1993 to accepting known donation in 2002 (Ethics Committee of the American Society for Reproductive Medicine, 2013). An increasing proportion of parents now disclose their origins to their donor-conceived children and growing numbers of donor-conceived adults are aware of how they were conceived (Söderström-Anttila et al., 2010; Isaksson et al., 2011). However, most of these people are unable to find any identifying information about the donor because of the practice of anonymous gamete donation (Blyth et al., 2012). Those who do identify their donor are vulnerable to rejection, hurt feelings and distress should the donor decide not to exchange information (Turner and Coyle, 2000).

Research demonstrates that people involved in donor conception and in the general public support disclosure of the donor origin to donor-conceived children (Kirkman, 2003, 2004a; Kirkman *et al.*, 2007; Hammarberg *et al.*, 2008) and donor-conceived people's right to access information about their donor (Allan 2012b). Evidence of attitudinal changes towards openness in relation to donor conception includes the increasing likelihood that parents will disclose the use of a gamete donor to their children (Blake *et al.*, 2010; Söderström-Anttila *et al.*, 2010), that parents of donor-conceived children want to make contact with 'donor siblings' (Freeman et *al.*, 2009), that some anonymous donors welcome the removal of donor anonymity (Daniels *et al.*, 2012), that change in donor anonymity legislation has not necessarily resulted in a decline in the number of men willing to donate sperm (Shukla *et al.*, 2013), and the influence of counselling on donors' and recipients' willingness to disclose the use of donor gametes to children conceived as a result (Hammarberg *et al.*, 2008). Donor-conceived people's right to medical and genetic information about the donor is asserted (Lindheim *et al.*, 2011; Ravitsky, 2012). Contemporary evidence suggests that it is best for donor-conceived children to be informed by their parents at an early age about the means of their conception (Nuffield Council on Bioethics, 2013).

ART practices have a long tradition in Australia, particularly in the state of Victoria, where scientists and clinicians pioneered some of the ART techniques, including the use of donor gametes, in the 1970s and 1980s (Cohen et al., 2005; Hammarberg et al., 2011). There is increasing and broad public acceptance in Australia of the use of ART procedures for conception, including with donor gametes (Kovacs et al., 2003, 2012), and ART procedures are subsidized by a publically funded universal health insurance scheme. 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 managed by a state authority to allow donor-conceived people to apply for access to information about their donors when they reached adulthood. As a condition of donating, donors from 1988 to 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, the Infertility Treatment Act 1995 (Vic), enacted in 1998, removed the necessity for the donor's consent to release information to the donor-conceived person. Hence, those who donated gametes from 1998 have agreed that adults aged 18 years and older who were born as a result of their donation can have access to identifying information about their donors. This resulted in a situation whereby some donor-conceived people have access to information about their donor while others do not. Under both Acts, parents may apply through the donor registers for information about their donor on behalf of their donor-conceived children aged under 18 years. The donor's consent is required before the information is released to a parent under these circumstances.

The 1995 legislation also stipulated that a Voluntary Register for information exchange between the parties involved in donor conception be established. The Voluntary Register became operational in 2001. It allows pre-1998 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, exchange of information can be facilitated between them.

A legacy of donor anonymity is that many donor-conceived adults are unable to trace their donor through the Central or Voluntary Registers and express significant distress and frustration about their inability to do so (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).

While there is some evidence about the wishes and experiences of donor-conceived adults, to date little research has investigated the psychosocial needs and expectations of donors and there are few follow-up studies of donors (Van den Broeck et al., 2012). Recent studies suggest that some donors are willing to join a voluntary register in order to be potentially identified by their donor offspring (Crawshaw et al., 2013), and among donors who joined a US-based international registry that facilitates contact between donor-conceived offspring and donors, most are open to contact with their donor offspring (Daniels et al., 2012) and about half want to know the outcome of their donation, including identifying information about children conceived as a result (Jadva et al., 2011). Debate about the right of donors to gain access to information about their donor offspring (Raes et al., 2013).

In response to changing community attitudes, the Victorian Government asked the Parliamentary Law Reform Committee (LRC) to consider various matters related to donor-conceived persons, including whether they should have access to identifying information about their donor, irrespective of when they were born or the circumstances under which the donations were made. After considering submissions and views expressed during public hearings by service providers, donor-conceived people, donors and others, one of the LRC's recommendations was that the Victorian Government should introduce legislation to allow all donorconceived people to obtain identifying information about their donors (Law Reform Committee, 2012). The nine donors who provided submissions or appeared in public hearings during the LRC inquiry expressed diverse views about whether identifying information should be made available to donor-conceived people and under what circumstances.

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 and the implications for donors and their families of introducing a law that removes donor anonymity with retrospective effect are unknown. Reactions to the LRC's recommendation to do so ranged from labelling it 'unfair' and having the potential to undermine trust in government (Pennings, 2012) to welcoming it as a 'move towards openness and honesty' (Allan, 2012a,b).

While acknowledging the value of the contributions of the nine donors who made submissions to the LRC or attended its public hearings, the Government decided to canvass views from a broader donor community before reaching a conclusion on the LRC's recommendations. The Government sought assistance in balancing the rights of gamete donors who assumed they could remain anonymous and of donor-conceived people who want to learn about their donors, and asked the Victorian Assisted Reproductive Treatment Authority (VARTA) to consult with donors who donated before the introduction of legislation in 1988 or under the conditions of legislation introduced in 1988. VARTA, a statutory authority responsible for ART-related public education and community consultation and administration of aspects of the Assisted Reproductive Treatment Act 2008 (Vic), contracted researchers from Monash University to conduct interviews with donors who agreed to take part in the consultation.

Method

People who donated sperm or eggs in Victoria, Australia, before 1998 (the sole inclusion criterion for the study) were sought to give their opinions of the LRC's recommendations and to provide insight into how they believed that these might affect their lives, should they be introduced into legislation. Qualitative methods are the appropriate choice when insight into personal experience and reflections is being sought. Interviews permit rich, nuanced discussion and enable participants to raise matters that might not be considered by those constructing standardized questions with fixed-choice responses. To allow in-depth discussion as well as ensuring that all aspects of the proposed legislative change were discussed, a semi-structured interview guide that included open questions was developed.

Ethics committee approval

The research was approved by the Victorian Department of Health Human Research Ethics Committee.

Recruitment

Community awareness of the research was raised through the announcement in the media that the Government wanted to consult with donors before responding to the LRC's recommendations and through a comprehensive advertising campaign that ran in January and February 2013. An advertising company crafted sensitive print and radio advertisements to convey the scope of the research and assure potential participants of confidentiality.

Potential participants were requested to contact VARTA for information about the research. Those who chose to proceed after reading the information material and Participant Information and Consent Form were asked for permission to give their contact details to the Monash University researchers who then sought an appointment for an interview in person, by telephone, or via Skype, or to arrange a written response to the interview questions. The mode of interview was chosen by each participant.

Interview guide

The interview guide was devised from the LRC's report and consultation with VARTA and Department of Health staff. 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 recommendations that:

- The Victorian Government introduce legislation to allow all donorconceived people to obtain identifying information about their donor, 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;
- If legislation were changed to enable all donor-conceived people to have access to their donor's identifying details, donors who did not want to be contacted by their donor offspring could institute a renewable 5-year contact veto;
- Donors be offered the opportunity to lodge a contact preference form for presentation to a donor-conceived person;
- A mechanism should be introduced for providing medical information from a donor to a donor-conceived person who is at risk of hereditary disease;
- The Voluntary Register should include provision for DNA matching where records are unreliable or incomplete.

Donors' opinions were also sought on:

 How potential changes to legislation should be communicated to donors and the general public;

- What support could be provided to pre-1998 donors should legislation to remove anonymity be introduced; and
- Ways in which agencies given responsibility for providing intermediary services could assist donors.

Procedure

All interviews were conducted by one of two researchers (M.K. and K.H.) and, with the donors' consent, audio-recorded and transcribed. Donors who elected to respond in writing were sent the questions by email. Identifying information was removed from or disguised in the transcripts before analysis.

Analysis

Thematic analysis of transcripts and written responses was conducted by one of the researchers (MK), in consultation with the research team. A summary of donors' opinions and experiences is reported in this paper. Detailed illustrative quotations are available in the report provided to the Victorian Government (Victorian Assisted Reproductive Treatment Authority, 2013).

Results

Participant characteristics

VARTA received 55 enquiries about the consultation of which six donors were deemed ineligible to participate: two had donated after 1998; one was a parent, not a donor; one was an IVF patient who was concerned that some of her eggs had been donated without her knowledge; one was a man who had provided a sperm sample but not become a donor; and one had donated outside Victoria. Of the remaining 49, two people who made enquiries did not receive written information: one declined to leave contact details, the other decided not to proceed because of concern about privacy. The remaining 47 people who contacted VARTA elected to receive information about the consultation. Two participants created non-identifying email accounts for participation in the consultation.

After reading the information, 45 donors agreed to have their contact details forwarded to the researchers and 42 of them were interviewed. Of the remaining three, one could not be found at the given telephone number, one responded 2 weeks after the closing date for interviews and one did not return his written responses to the interview questions. The characteristics of those who were interviewed are presented in Table I.

Views on the recommendation to introduce legislation allowing all donor-conceived people access to identifying information about their donor

Just under half of the donors supported the recommendation. These donors emphasized the needs of donor-conceived people to understand their genetic heritage (expressed as 'genetic parentage', 'genetic history', 'genetic origins' or 'who their biological parents are') and the responsibility of donors to do all they can to assist their donor offspring. Some 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.
 Table I Characteristics of the 42 gamete donors in

 Victoria, Australia, who were interviewed in the study.

	(n)
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 1988–1997	13
Declined to answer	L
Place of donation	
Royal Women's Hospital	11
Prince Henry's Hospital	9
Queen Victoria Hospital	9
Epworth	6
Monash IVF	5
Melbourne IVF	I.
Declined to answer	I.
Present family aware of donation	
Yes	26
Partner but not children	6
No	9
Declined to answer	I.
Did births result from donation	
Yes	32
No	I.
Unsure	9
Number of births from donation (range)	0-36
Joined the Voluntary Register	
Yes	25
No but considering	6
No	H
Contacted by donor offspring	
No	32
Yes	10
Made submission to LRC	
No	34
Yes	7
Declined to answer	L
Type of interview	
Telephone	30
In person	6
Written (email, post)	6

LRC, the Parliamentary Law Reform Committee.

Current legislation against (for example) financial claims on donors was not seen as protective if a precedent were to be set of change with retrospective effect.

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. A model of voluntary engagement derived from donors' suggestions encompassed publicity about the Voluntary Register to urge donors (and donor-conceived people) to join it, and that an intermediary organization should contact a donor personally to seek permission to release identifying or non-identifying information to a donor-conceived person who had made an enquiry. Some donors suggested that such an approach would be appropriate whether or not they had already joined the Voluntary Register.

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

Despite contrasts in the meaning of sperm donation and egg donation (e.g. Kirkman, 2004b), the only identifiable difference between egg donors and sperm donors in this consultation was that none of the former were categorized as rejecting the central recommendation outright: egg donors either supported the recommended mandatory loss of anonymity with retrospective effect, or rejected it and proposed a compromise position. This distribution is consistent with the practice of egg donation having developed after the era in which donor anonymity was taken for granted in Victoria. In their explanations for reaching their conclusions and their thoughts about donor-conceived people, the same range of views was found among egg donors as among sperm donors. Distinctions have therefore not been drawn between egg donors and sperm donors in the reporting of results.

Views on other recommendations

On related LRC recommendations, donors' opinions were diverse and not consistently aligned with their attitudes to removal of anonymity.

A donor contact veto, in which donors could refuse contact 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 being unfair to donor-conceived people (on the one hand) and both as putting donors in a difficult position (having to reject contact with a possibly distressed donor offspring) and as unenforceable and therefore providing 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 removal of anonymity rejected the preference form, as arising from donors' wishes to remain distant from their donor offspring, and some donors who opposed removal of anonymity rejected the preference form as part of an unwelcome set of changes 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.

Donors' suggestions for managing proposed legislative changes

Suggested 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 donorconceived 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 organization with staff who can provide expert counselling on donor conception and are experienced in helping people to manage the complexities of these new relationships. The provision of accurate information to donors about legal and psychosocial aspects of gamete donation was identified as part of the intermediary organization'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 the recommendation to remove anonymity advocated the provision of counselling and support as an essential accompaniment to any contact between donors and donor-conceived people. Counselling was also seen as important to the families of both parties. Some donors who rejected removal of anonymity, however, also rejected counselling and support services as inadequate compensation for any compulsory release of information about donors to donor-conceived people, or even as patronizing.

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.

Discussion

To our knowledge, this is the first study of the views of anonymous donors about the potential for mandated release of information that will identify them to their donor offspring who request it. 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. There is thus no way of knowing whether participants were representative of all pre-1998 donors. However, the diversity of the sample in age, year and place of donation, disclosure patterns in terms of whether or not and to whom they had disclosed being a donor, 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.

The LRC's recommendations were based on extensive community consultation, including with donors. However, it is possible that donors who are willing to appear before a committee and make their views known are more likely to be open to disclosure than those who do not ordinarily make themselves available to government inquiries or researchers because they prefer to maintain anonymity. Extensive publicity was given to the LRC's recommendations, especially the core recommendation for the mandatory identification of donors with retrospective effect. This, combined with the Victorian Government's call for further contributions from donors, created an unusual historical moment when there was widely-distributed knowledge about a real, legislated threat to their anonymity that may have encouraged donors who had not previously made their opinions known to participate in this research.

In August 2013 the Victorian Government made known its response to the donor consultation, stating that the findings of the consultation had informed the Government's understanding of donors' views and its response to the LRC's recommendations. While acknowledging donorconceived people's right of access to information about their donors, the Government decided that identifying information should be released only with the consent of donors. As a result, the Government stated its intent to introduce legislation extending the 1988–1997 legislative arrangements to people who were conceived with gametes donated before 1988.

The Government presented its reasons for this position, including that this consultation and other emerging evidence indicate that many donors are willing to be identified. Among donors who do not wish to be identified, some are likely to agree to the release of non-identifying contemporaneous information which may help donor-conceived people searching for information about their donor. A consent model respects the privacy and choice of the donor and acknowledges the circumstances under which the donor originally consented to donation. The Government's response also acknowledged that there is no guarantee that records relating to pre-1988 donor conception procedures will be available, complete or accurate. Furthermore, even if the information is complete, there is no guarantee that donors can be traced to provide information, because they may no longer be at the recorded address or may even have died.

In part informed by donors' views about the necessity for an intermediary organization with expert staff to manage donors' and donorconceived people's need for support and information, the Government stated its intention to extend the role of VARTA. In addition to public education and promotion of the Voluntary Register to encourage parties to join and enable them to connect, the intent is that VARTA provide counselling services and intermediary support for donor-linking, including a letter-box service to help parties who are contemplating contact to exchange information without revealing their identity to each other.

The investigation reported here arose from acknowledgement that donor-conceived people did not have equal access to information about their donors: people born from donations made when anonymity was accepted are at a disadvantage. The wide range of views and experiences elicited by this study led the Government to propose a position designed to maximize the chance of donor-conceived people finding their donor or, at least, non-identifying information about their donor, while allowing donors who wanted to retain their anonymity to do so.

It would be naïve of us to assert that evidence from the consultation was solely responsible for this governmental decision; it has been established that historical, political and social forces must create a window to enable policy change and action (e.g. Nutbeam and Boxall, 2008; Baum et al., 2013). In Victoria, through successive legislative changes, donorconceived people have gained the legal right to receive identifying information about their donors. This most recent government decision strengthens the commitment to assisting each donor-conceived person to identify her or his donor no matter when the donation took place. It does not, however, radically change the policy direction.

Discussion of donor anonymity usually incorporates discussion of the competing rights of donors and donor-conceived people (e.g. Blyth, 2002; Chisholm, 2012). The Government's responses to the LRC's recommendations and to the results of the consultation indicate its sensitivity to this difficult exercise. However, this consultation found that the goals and wishes of donors may coincide with those of donor-conceived people when they reflect on sharing identifying information. This suggests that an assumption of binary rights may be an inappropriate simplification when policy decisions are being made about how best to serve the needs of donor-conceived people while respecting the position of donors. Nevertheless, arguments have been made that it is appropriate to emphasize the rights of donor-conceived people (whose interests were, by definition, engaged after others have exercised theirs) and the responsibilities of those instrumental in their conception, including donors (e.g. Blyth, 2002). A human rights argument has also been used to justify an intermediary position very similar to that adopted by the Victorian government (Tobin, 2012).

All over the world, increasing numbers of donor-conceived people are reaching adulthood; of those who are aware of their mode of conception, some are likely to have a strong wish to know or know about their donors. Legislators and policy-makers in jurisdictions permitting anonymous gamete donations will need to respond when these desires are expressed, and may choose to be guided by the model of consultation described in this paper.

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Authors' roles

K.H. contributed to the design of the study, interviews with participants, and data analysis and interpretation. She also drafted the manuscript. L.J. and K.B. contributed to the design of the study, recruitment of participants, interpretation of the data and revisions of the manuscript. J.F. contributed to the design of the study, interpretation of the data and revisions of the manuscript. M.K. contributed to the design of the study, interviews with participants, and led the work on data analysis and interpretation. She also contributed to the first draft of the manuscript and revised the manuscript critically.

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Conflict of interest

None declared.

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