

**This response was submitted to the evidence call held by the Nuffield Council on Bioethics on Donor conception: ethical aspects of information sharing between 21 March 2012 and 15 May 2012. The views expressed are solely those of the respondent(s) and not those of the Council.**

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I am glad to have this opportunity to put my evidence and opinions before the Nuffield Council on Bioethics. I write primarily as a scholar who has conducted psychosocial research on donor-assisted conception but also as the mother of a child (now aged 23) conceived using donated sperm and gestational surrogacy.

I have chosen to answer all questions. Some of the later questions depend on assertions made in earlier questions, which I have not repeated; most draw on evidence in my research publications. I have listed at the end my relevant publications, both research-based and autobiographical.

**1. What ethical concerns arise in the disclosure, or not, of information in connection with donor conception?**

I identify the donor-conceived person as central to any ethical consideration of disclosure or non-disclosure. The primary concern in not disclosing is the potential harm done to a person who may remain ignorant of significant medical history and who may experience psychological harm through discovery in adult life under adverse circumstances. Until relatively recently, this was the way most people learnt that they had been conceived using donated sperm: for example, told by an angry relative during a family dispute, or by a widowed mother at the social father's funeral, or discovering that their social father could not be a genetic relation after learning at school about inherited physical characteristics or blood groups. Although some parents say that they have not disclosed in order to protect their child, modern technology and the fact that most parents tell at least one other person about their "secret" means that disclosure at some time is becoming increasingly likely.

The conditions under which donors contributed sperm, eggs, or embryos, including whether or not they agreed to be identified or to be contacted by the donor-conceived person, are relevant to ethical considerations of disclosure. The interests of their partners and children, even of their parents, are also relevant.

The authority of parents to make decisions about their children's welfare is also a matter for consideration. Parents without a genetic connection to their children may need to have attention paid to their own concerns about their legitimacy as parents and whether their donor-conceived children will acknowledge them as parents after disclosure.

Given the primacy of the welfare of the donor-conceived child, I argue that, rather than allowing non-disclosure in order to protect donors and parents, public education should be undertaken to raise public awareness of donor-assisted conception and the diverse ways in which families are created. Secrecy and non-disclosure thrive when the subject is taboo and when the long history and widespread practice of donor-assisted conception is misunderstood.

**2. Is the disclosure of a child's donor conception essentially a matter for each individual family to decide? What if there is disagreement within the family? Who else should have a role in making this decision?**

Public policy and legislation should be developed on the assumption that all donor conceived children have the right to know, from an early age, that they were donor-

conceived and, from an appropriate age, the identity of the donor. If this right is accepted, the decision cannot be left to individual families. Parents should have access to guidance on how best to manage sharing this information with their children. The legislation developed in my home State of Victoria is a good model, as is the work done by the Victorian Assisted Reproduction Treatment Authority (VARTA) in implementing the necessary education and support.

**2. What information, if any, do parents need about a donor in order to enable them to carry out their parenting role? Please explain.**

I am not sure how to answer this question. If there is to be no provision for anonymous donors, parents will choose donors on the (often idiosyncratic and non-heritable) characteristics that matter to them. However, how these characteristics influence or enable their parenting is a matter for investigation.

If the question refers to parents' desire to raise their children in accordance with the donor's characteristics, such as ethnicity or religion, this is another matter. I suggest that parents be advised to choose donors who seem compatible with them in important ways such that, should the donor-conceived person choose to associate with the donor later, there is no distressing disjunction between the two families. However, what can be identified as an "important way" is likely to vary from one family to another.

**3. What information might a donor-conceived person need about the donor, either during childhood or once they become adult? Please explain.**

I think all donor-conceived people should have access to full identifying information about their donors. The information needed will vary from one person to another, so full disclosure should be available.

**4. How significant is information about the medical history of the donor and the donor's family for the health and wellbeing of donor-conceived offspring? Do you know of any examples or evidence in this area?**

Information about medical history can be of very great relevance, whether to ascertain details of a specific health condition or because a donor-conceived person feels distressed at being unable to have access to such information should she or he need it. Submissions to various inquiries in Victoria include personal statements about both specific and general need for medical information about donors. One young woman who has been very active in lobbying for reform and has gained wide publicity, Narelle Grech, first described her general need for medical history as part of her desire to identify her donor. (Narelle was conceived before anonymous donors were outlawed in Victoria.) After she was diagnosed with bowel cancer, she redoubled her efforts to find her sperm donor in case there is a genetic cause that would put at risk her donor and his other children. The need for information about medical history is not unidirectional but extends to all first-degree relatives.

**5. Where information about inherited medical risk becomes apparent after donation has taken place, who should be told, and by whom?**

Where information is managed through a dedicated organisation that also acts as a clearing house and provides counselling and support to all parties involved in donor conception, distribution of new information would best be provided through this intermediary. A useful model is the Infertility Treatment Authority in Victoria. The organisation is no longer able to provide such comprehensive service; in its current form as VARTA it carries out some of this work.

**7. What is the impact on donor-conceived offspring of finding out about their donor conception at different ages: for example medically, psychologically and socially? Do you know of any examples or evidence in this area?**

Research is not yet comprehensive enough to be definitive, although the evidence (including from my own research) suggests that children are best served when they grow up knowing that they are donor-conceived. In this way, they do not have to reassess their identity or beliefs about family, as they do when they learn of their origins at a later age. Information-sharing from infancy requires parents to be confident in their own identity as parents and in the decisions they have made about forming their family. Parental confidence can be encouraged and supported through public education as well as personal support. Parents may benefit from guidance on how to begin talking about conception. Many parents find it difficult to discuss sexual conception with their children, which can mean that they have a double hurdle to leap when they need to describe alternative means.

Learning from infancy but certainly before puberty appears to be ideal. When they find out later than this, donor-conceived people can feel that they lose trust in their parents (“If they have lied to me about this, how do I know they are telling the truth about anything?”) and lose the sense of identity that they have constructed all their lives (“Who am I if I am not the person I thought I was?”). They may be overcome by anger and grief and embark upon a consuming quest to find their donor, with possibly unrealistic expectations of how this will bring personal insights and peace. Apart from research such as my own, the various donor-conception websites provide evidence of the distress occasioned by discovery in later years. If parents have not told their children when they are young, they should still be encouraged and helped to tell their children as soon as possible on the understanding that this information comes best from them and not from other sources. There is a range of useful parent guides from several countries that can assist in this endeavour.

**8. What is the impact on donor-conceived offspring of making contact with either the donor or any previously unknown half siblings? Do you know of any examples or evidence in this area?**

In Victoria, good evidence is held by VARTA.

My own unsystematic inquiries, in addition to my limited research evidence on this topic, suggest that contact made with donors at a young age with full family support can be beneficial. It can mean that the child grows up knowing the donor as a family friend or acquaintance and a person secondary to the parents in her or his life.

However, there appear to be differences according to the type of donation. In Victoria, egg donation and surrogacy are likely to be within existing relationships. Embryo donation can be between families who come to know each other when children are very young. It is the more common sperm donation in which contact may be made later in life. There are also differences depending on whether the donation is to a heterosexual couple, a same-sex couple, or a single person. Single people and same-sex couples are far more likely to have disclosed to a young child than heterosexual couples, and the father in a heterosexual couple is most likely to be concerned about the role of a sperm donor in his child’s life, which can influence the possibility for and success of a meeting between the donor and the adult donor-conceived person.

I know of examples covering the full range of possible outcomes, from extremely happy continuing friendships to disappointing single encounters. The evidence from adoption has

taught us that contact is best made through a dedicated intermediary organisation and with professional support.

### **9. What interests do donors and donors' families have in receiving any form of information about a child born as a result of the donation?**

The donor should know that a child or children has been born as a result of the donation, if only to ensure that the donor does not contribute to the creation of more than the mandated number of genetically-related children. Apart from that, the donor-conceived person should be given (by the mediating body) a chance to consent to a request for the release of information and to the kind and amount of information released. If the donor-conceived person is taken as the pivotal figure in the arrangement, her or his needs should be the first priority.

Although a case can be made for the need of the donor and her or his family to learn about the person conceived as a result of the donation, the fulfilment of their need is dependent on the welfare and decisions of the donor-conceived adult (or child's parents in consultation with the child).

### **10. What responsibilities arise in connection with the disclosure of information? Where do these responsibilities lie? (for example with government, fertility clinics, professionals or families?)**

My preference is for an appropriate authority to be set up under legislation that outlines rights and responsibilities. These responsibilities should emphasise support and education rather than sanctions. The Victorian model is a good start, although it is not ideal.

### **11. What support is required in connection with these responsibilities?**

The authority requires legislative support. It also needs to be adequately funded to provide the necessary professional staff and to support counselling and community education activities as well as provide record-keeping and mediation services. Support for individual donor-conceived people, families, and donors can be provided by the authority.

### **12. Do you have any other comments? Please highlight any relevant areas you think we have omitted, or any other views you would like to express about information disclosure in the context of donor conception.**

The secrecy enveloping donor-assisted conception has arisen because of the historical stigma of infertility and childlessness and the conflation of masculine fertility with virility. Punishment of those who do not share with their children the story of their family formation is likely to be counter-productive, encouraging even greater shame and secrecy. Openness in donor-assisted conception requires public education and attitude change.

#### **Kirkman publications that include pertinent evidence**

Kirkman M, Rosenthal D, Johnson L. (2007). *Telling it Your Way: A Guide for Parents of Donor-Conceived Adolescents*. Melbourne: Infertility Treatment Authority. ISBN 978 0 646 47772 5

Kirkman M, Kirkman L. (1988). *My sister's child*. Ringwood, Australia: Penguin Books. ISBN 0 14 011437 8

Jones HG, Kirkman M. (Eds). (2005). *Sperm wars: The rights and wrongs of reproduction*. ABC Books, Sydney. ISBN 0 7333 1542 9

Kirkman M. (2005). Going home and forgetting about it: Donor insemination and the secrecy debate. In HG Jones & M Kirkman (Eds). *Sperm wars: The rights and wrongs of reproduction* (pp. 153-169). ABC Books, Sydney.

Kirkman M. (2008). Being a „real“ mum: Motherhood through donated eggs and embryos. *Women's Studies International Forum*, 31(4), 241-248.

- Kirkman M, Rosenthal D, Johnson L. (2007). Families working it out: Adolescents' views on communicating about donor-assisted conception. *Human Reproduction*, 22(8): 2318-2324. doi: 10.1093/humrep/dem138.
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- Kirkman M, Kirkman A. (2002). Sister-to-sister gestational "surrogacy" thirteen years on: A narrative of parenthood. *Journal of Reproductive and Infant Psychology*, 20(3), 135-147.
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