

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.

Progress Educational Trust

Donor conception: ethical aspects of information disclosure

Response by the Progress Educational Trust to the Nuffield Council on Bioethics Call for Evidence

15 May 2012

The Nuffield Council's Call for Evidence asks for 'responses...in the form of a single Word document, with numbered paragraphs throughout'. Because we have structured our response around the 12 Consultation Questions, we thought it most practical to give one-paragraph responses to each question, so that the paragraph numbers and the question numbers are aligned.

Please note that our response concerns only gamete and embryo donation. Although the remit of the Nuffield Council's Call for Evidence extends to surrogacy, addressing surrogacy arrangements would have made our response prohibitively long and complex, given the limited time and resources available to us.

As a supplement to our response, we have appended links to News, Comment and Review articles from the archive of our BioNews website that address some of the issues raised in the Nuffield Council's Call for Evidence. These articles do not always reflect our views, but may nonetheless be a useful resource for the Working Party of this Nuffield Council project.

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

The principal ethical concern connected with donor conception and the disclosure of information – at least in the present social and political climate – arises from the fact that donors, donor-conceived people and their families may ascribe emotional importance to information about one another. This prompts the ethical questions of whether, when, how, by whom and to whom such information should be made available.

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?

In our view, disclosing the fact that a child is donor-conceived should indeed be a matter for each individual family to decide. If there is disagreement about disclosure within the family, then it is incumbent upon family members to negotiate the matter themselves. It is the prerogative of any family member who knows that a child is donor-conceived to disclose that information to, or withhold that information from, the child in question and/or any other person. If a non-family third party reveals that a person is donor-conceived, or reveals information about a donor, then this should be a consequence either of the donor-conceived person

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seeking out the information on their own initiative, or of a family member having previously been indiscreet. This should never be a direct consequence of the third party's initiative.

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

It is not axiomatic that the parents of donor-conceived children need any information about the relevant donor(s), in order to carry out their parenting role. It is possible for the parents of donor-conceived children to ascribe emotional importance to any type of information about donors, in which case access to such information may be a necessity in the opinion of those parents. While parents of donor-conceived children should have access to information (to which they are legally entitled) that the donor has provided, it does not necessarily follow from this that donors should be encouraged to give more than the rudimentary information that has been legally required of them since the entitlement to donor anonymity was removed in the UK. It is not the place of the UK fertility regulator, or any other authority, to make or encourage any pejorative assumptions about the amount of information that a gamete donor provides.

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

It is not axiomatic that donor-conceived people, during childhood or adulthood, need any information about the donor(s) from whose donation they were conceived. It is possible for donor-conceived people to ascribe emotional importance to any type of information about donors, in which case access to such information may be a necessity in the opinion of those donor-conceived people. While donor-conceived people should be able to obtain, on request, information (to which they are legally entitled) that the donor has provided, it does not necessarily follow from this that donors should be encouraged to give more than the rudimentary information that has been legally required of them since the entitlement to donor anonymity was removed in the UK. It is not the place of the UK fertility regulator, or any other authority, to make or encourage any pejorative assumptions about the amount of information that a gamete donor provides.

5. 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?

It is always a remote possibility that medical information about the donor and their family will be significant for the health and wellbeing of donor-conceived people, but it is far from likely. Donors in the UK are screened for medical problems in accordance with standard guidelines. While these guidelines, and the parameters of the fertility clinic's professional duty of care to the donor, are not perfect and should be kept under regular review, the fact remains that a level of assurance as to the health of donors is standard, when this is not true of people who conceive without donation. It is also worth noting that medical information about the donor and their family can have a negative impact on the health and wellbeing of donor-conceived offspring by creating unnecessary anxiety, especially if this information is not properly contextualised. (If UK fertility patients receive treatment in other countries and jurisdictions, then the answer to the question above may vary, depending on what donor screening

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procedures are in place and what information about the donor is available in the location where treatment is received.)

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

It would be an exceptional scenario in which it were discovered, after donor conception had already taken place, that a donor might have transmitted to donor-conceived offspring a condition so serious that notification of the donor, the donor-conceived offspring or the family of either party was warranted. 'Medical risk' is not a clear-cut concept in such situations, because such risk has two components – the chance or probability of a medical problem occurring, and the extent of damage or burden to the patient. The former is largely a matter of scientific knowledge, empirical recurrence data and clinical diagnostic skills (although even here there is the subjective element of what constitutes too high a chance in light of the burden), while the latter has a considerable subjective element. Given these subtleties, and given the unlikelihood of the scenario implied by the question above, we would be reluctant to suggest any generic provision for such a scenario. Anecdotally, we know of one relevant instance in the UK, in which a donor-conceived child was born with a condition that meant that clinicians felt duty-bound to notify the relevant sperm donor of possible risk to himself and/or his existing or prospective offspring. The sperm donor was successfully notified without undue impediment, and all of this occurred *prior* to the removal of entitlement to donor anonymity. We conclude from this that the flexibility of the system, and the parameters of clinicians' duty of care, are sufficient to address such scenarios as and when they occur.

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?

It has been well established that there are few, if any, adverse consequences for donor-conceived children of their parents telling them at a young age that they are donor-conceived. Some evidence suggests that disclosure can become more difficult over the course of donor-conceived people's childhood and even more difficult after donor-conceived people reach adulthood (see, for example, Jadva *et al*, 'The experiences of adolescents and adults conceived by sperm donation: comparisons by age of disclosure and family type', *Human Reproduction* vol 24 no 8, 2009). Such evidence notwithstanding, we believe that whether, when, how and by whom disclosure takes place are decisions that should remain in the hands of the parents of donor-conceived children.

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?

The impact on donor-conceived offspring of making contact with the donor, or with any previously unknown half-siblings, is socially and culturally mediated. Whether or not such contact has a significant impact, and whether this impact is positive or negative, is at least partially contingent upon the significance that society as a whole tends to ascribe to biological relationships. Such perceived significance may also be magnified by secrecy, inasmuch as the

longer one knows of the existence of genetic relatives without knowing their identity, the greater the scope to be curious about and to speculate about them, and the more acute the potential positive or negative impact of eventually making contact. For examples in this area, we would recommend examining the work of the Donor Sibling Registry in the USA.

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?

Donors and their families may be interested in any number of things about children conceived from their donation, but the only information to which they are legally entitled in the UK is the number of children born as a result of their donation, and the sex and year of birth of those children. There is therefore an asymmetry, whereby there is more information about donors to which donor-conceived people and their parents are entitled, than there is information about donor-conceived people and their parents to which donors are entitled. We believe that this asymmetry is entirely appropriate and fair, inasmuch as donation should be made in a spirit of generic good faith, without there being a concomitant expectation of specific information about any resulting offspring. If donor-conceived people and their families prefer not to make information available to donors and donors' families, then this is entirely within their prerogative. (Some have argued that if donors express an interest in children conceived from their donation then this is a good indication of their moral character, but in our view donors should be screened only on medical grounds and not on moral grounds.)

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?)

The principal responsibility that arises in connection with the disclosure of information is the responsibility of an authoritative body to maintain a central and secure register of information pertaining to donor conception, and to administer this register competently. For the past 20 years, such a register has been maintained in the UK by the Human Fertilisation and Embryology Authority (HFEA) – a body which currently faces abolition, with the consequence that responsibility for the register is due to be transferred elsewhere. Clinicians are responsible for collecting donor and patient details and submitting them for inclusion on the register, but responsibility for the register itself lies ultimately with the Government, which empowers the HFEA and will empower the latter's successor(s). If responsibility for the register is indeed transferred away from the HFEA, then it is of the utmost importance that the centrality, security and integrity of the register is maintained.

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

Counselling should be available, but not mandatory, for donors and for the parents of donor-conceived children before and after donor conception. Such counselling should be provided by clinics, as a condition of their license to perform fertility treatment. There is also scope for various types of organisations to provide support, advice and counselling to the parents of donor-conceived children, regarding matters such as whether, when and how to disclose the fact that a child is donor-conceived to the child in question. However, it should remain the

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prerogative of parents whether or not they avail themselves of, or act in accordance with, such support, advice or counselling.

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 significance ascribed to biological relationships is, to an underappreciated extent, determined by prevailing cultural trends. Donor conception policy contributes to the prevailing culture, inasmuch as it not only seeks to meet the needs and desires of people involved in donor conception, but also shapes these same needs and desires going forward. There is potentially no limit to the types of information to which donors, donor-conceived people and their families will ascribe emotional importance. Following the removal of entitlement to donor anonymity in the UK, there is qualified – and, in our view, adequate – scope for those involved in donor conception to seek out information about one another. Incorporating further openness into the system would risk promulgating the idea that biological relationships deserve to be invested with emotional significance, when this is something that people should have the latitude to decide for themselves.

Appendix A: News from the BioNews archive

- **Scientist allegedly fathered 600 children at own sperm clinic**
By Cait McDonagh, 16 April 2012
http://www.bionews.org.uk/page_138707.asp
- **All donor-conceived people should have access to donor information, Australian committee recommends**
By Rosemary Paxman, 2 April 2012
http://www.bionews.org.uk/page_137284.asp
- **Sperm donor anonymity in question in British Columbia court case**
By Julianna Photopoulos, 20 February 2012
http://www.bionews.org.uk/page_127681.asp
- **Known donation on trial**
By Natalie Gamble, 20 February 2012
http://www.bionews.org.uk/page_128449.asp
- **Australian sperm donors' details could be linked to birth certificates**
By Dr Rebecca Robey, 20 February 2012
http://www.bionews.org.uk/page_127654.asp
- **Sperm donor fathers 17 families and breaks UK limits**
By Jessica Ware, 26 September 2011
http://www.bionews.org.uk/page_106823.asp

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- **UK DonorLink closes its doors to new registrants**
By Dr Vivienne Raper, 22 August 2011
http://www.bionews.org.uk/page_104993.asp
- **Lesbian couple have sperm donor removed from birth certificate**
By Oliver Timmis, 22 August 2011
http://www.bionews.org.uk/page_104979.asp
- **Dead father granted parenthood in surrogacy case**
By Antony Blackburn-Starza, 8 August 2011
http://www.bionews.org.uk/page_102726.asp
- **Sperm donor had 24 kids and a fatal genetic mutation**
By Rose Palmer, 1 August 2011
http://www.bionews.org.uk/page_102689.asp
- **Canadian woman wins legal case to end donor anonymity in BC**
By Sarah Guy, 23 May 2011
http://www.bionews.org.uk/page_95012.asp
- **Canadian court allows woman to seek information on sperm-donor father**
By Antony Blackburn-Starza, 25 October 2010
http://www.bionews.org.uk/page_73638.asp
- **Lesbian ruled not child's legal 'parent'**
By Dr Vivienne Raper, 21 June 2010
http://www.bionews.org.uk/page_64893.asp
- **First US study of attitudes towards donor conception published**
By Antony Blackburn-Starza, 10 June 2010
http://www.bionews.org.uk/page_64254.asp
- **Fertility watchdog aims to put donor siblings in touch**
By Nisha Satkunarajah, 12 April 2010
http://www.bionews.org.uk/page_57961.asp
- **Sperm donor wins right to see child**
By Ben Jones, 12 December 2009
http://www.bionews.org.uk/page_52127.asp
- **Fatal heart condition passed on by sperm donor**
By Ben Jones, 25 October 2009
http://www.bionews.org.uk/page_50173.asp
- **UK's Department of Health consults on disclosure of identifying information for research**
By MacKenna Roberts, 12 October 2009
http://www.bionews.org.uk/page_49595.asp

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- **UK registry will allow donor children to trace biological siblings**
By MacKenna Roberts, 5 October 2009
http://www.bionews.org.uk/page_49270.asp
- **Donor-conceived children should be told at an early age**
By Dr Kirsty Horsey, 7 July 2008
http://www.bionews.org.uk/page_13432.asp
- **Parent status of sperm donors in the spotlight**
By Antony Blackburn-Starza, 7 January 2008
http://www.bionews.org.uk/page_13263.asp
- **Parliament supports children's right to know of donor conception**
By MacKenna Roberts, 6 August 2007
http://www.bionews.org.uk/page_13145.asp
- **Sperm donor seeks custody of his biological son**
By Danielle Hamm, 23 July 2007
http://www.bionews.org.uk/page_13130.asp
- **US teenagers trace their sperm donor father**
By Antony Blackburn-Starza, 19 February 2007
http://www.bionews.org.uk/page_12992.asp
- **New donor identification laws in Victoria**
By Dr Kirsty Horsey, 3 July 2006
http://www.bionews.org.uk/page_12780.asp
- **Unknown US sperm donor passes genetic disorder to five children**
By Dr Kirsty Horsey, 25 May 2006
http://www.bionews.org.uk/page_12729.asp
- **Victoria's fertility authority advises parents to tell children about donors**
By Dr Kirsty Horsey, 22 May 2006
http://www.bionews.org.uk/page_12728.asp
- **Teenager tracks down sperm donor using internet**
3 November 2005
http://www.bionews.org.uk/page_12558.asp
- **Removal of anonymity potentially reduces donors by half**
22 October 2005
http://www.bionews.org.uk/page_12548.asp
- **Sperm donation studies show move towards openness?**
26 January 2005
http://www.bionews.org.uk/page_12233.asp
- **Donor anonymity to be removed in UK**



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21 January 2004

http://www.bionews.org.uk/page_11833.asp

- **UK to rule on donor anonymity**
27 January 2003
http://www.bionews.org.uk/page_11539.asp
 - **High court allows review of donor information policy**
19 November 2001
http://www.bionews.org.uk/page_11251.asp
 - **Genetic disorder passed on by sperm donor**
24 September 2001
http://www.bionews.org.uk/page_11211.asp
 - **Review of egg and sperm donor anonymity announced**
8 January 2001
http://www.bionews.org.uk/page_10981.asp
 - **Legal bid to identify sperm donors**
18 September 2000
http://www.bionews.org.uk/page_10874.asp
 - **UK government to consider removing sperm donor anonymity**
25 April 2000
http://www.bionews.org.uk/page_10727.asp
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Appendix B: Comment from the BioNews archive

- **Victoria's secret (or 'V' for victory)**
By Dr Ruth Shidlo, 2 April 2012
http://www.bionews.org.uk/page_137523.asp
- **Donor information – time for a debate**
By Dr Marilyn Crawshaw and Walter Merricks, 27 February 2012
http://www.bionews.org.uk/page_130217.asp
- **Marquardt's off the mark**
By Susan Kane, 14 November 2011
http://www.bionews.org.uk/page_112120.asp
- **A private sperm donor writes...**
By Andrew Proven Donor, 31 October 2011
http://www.bionews.org.uk/page_110900.asp
- **Let's retrospectively release information to Australia's donor-conceived**
By Dr Sonia Allan, 5 September 2011

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http://www.bionews.org.uk/page_104517.asp

- **BBC documentary shows why we need UK DonorLink**
By Dr Marilyn Crawshaw, 30 August 2011
http://www.bionews.org.uk/page_105512.asp
- **What the kids really want**
By Professor Naomi Cahn and Wendy Kramer, 8 August 2011
http://www.bionews.org.uk/page_103648.asp
- **Is it a harm to be born with different skin colour to your parents?**
By Professor Sally Sheldon, 18 July 2011
http://www.bionews.org.uk/page_102222.asp
- **The birth of donor offspring rights in the USA?**
By Professor Naomi Cahn and Wendy Kramer, 27 June 2011
http://www.bionews.org.uk/page_97446.asp
- **Countdown begins for ending donor anonymity in British Columbia: lessons for us all?**
By Professor Eric Blyth and Dr Marilyn Crawshaw, 6 June 2011
http://www.bionews.org.uk/page_96105.asp
- **My daddy's name is adoption**
By Vince Londini, 16 May 2011
http://www.bionews.org.uk/page_93262.asp
- **Rising from the Ashes: two countries, two reviews of donor conception services – Australia leads the way**
By Damian Adams and Dr Marilyn Crawshaw, 21 February 2011
http://www.bionews.org.uk/page_89766.asp
- **Donor anonymity to bite the dust in South Australia**
By Professor Eric Blyth, 6 December 2010
http://www.bionews.org.uk/page_81599.asp
- **The 'donated' generation: action now not formal apology later**
By Damian Adams and Dr Marilyn Crawshaw, 29 November 2010
http://www.bionews.org.uk/page_82853.asp
- **Lesbian mums in dispute: fertility law, child maintenance and what makes a parent**
By Natalie Gamble, 8 November 2010
http://www.bionews.org.uk/page_71986.asp
- **Is the glass half full or half empty? Debating the research on donor offspring: a reply to Blyth and Kramer's critique of 'My Daddy's Name is Donor'**
By Elizabeth Marquardt, 9 August 2010
http://www.bionews.org.uk/page_68162.asp
- **Birth certificates: a new era?**

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By Louisa Ghevaert, 30 April 2010

http://www.bionews.org.uk/page_59481.asp

- **Gamete Donation in the UK: time to think again**
By the London Bridge Fertility, Gynaecology and Genetics Centre, 12 April 2010
http://www.bionews.org.uk/page_58241.asp
- **Telling is more important than ever: rights and donor conception**
By Dr Lucy Frith, 19 January 2010
http://www.bionews.org.uk/page_53094.asp
- **Sperm donor screening needs to be overhauled**
By Wendy Kramer, 16 November 2009
http://www.bionews.org.uk/page_51359.asp
- **Not your child's biological parent? You may still have an influence on their genes**
By Olivia Montuschi, 3 August 2009
http://www.bionews.org.uk/page_46274.asp
- **Registering concern: should anonymous gamete donors be encouraged to reregister and if so how?**
By Antony Blackburn-Starza, 15 June 2009
http://www.bionews.org.uk/page_46250.asp
- **The case for comprehensive medical testing of gamete donors**
By Wendy Kramer, 26 May 2009
http://www.bionews.org.uk/page_38070.asp
- **Disclosing donor information: a new code of silence?**
By Professor Eric Blyth, 9 March 2009
http://www.bionews.org.uk/page_38058.asp
- **Fathers or donors? The legal position of friends who act as informal sperm donors**
By Natalie Gamble, 8 December 2008
http://www.bionews.org.uk/page_38037.asp
- **Child development and parent-child relationships in assisted reproduction families**
By Jennifer Readings, 1 August 2008
http://www.bionews.org.uk/page_38007.asp
- **The real impact of the removal of donor anonymity**
By Peter Wardle, 18 February 2008
http://www.bionews.org.uk/page_37975.asp
- **Donor insemination in the post-anonymity world: one clinic's experiences**
By Dr Kamal Ahuja, 13 January 2008
http://www.bionews.org.uk/page_37968.asp

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- **Restrictions on the disclosure of information about patients receiving fertility treatment should be removed**
By Michael Litos and John Parsons, 3 December 2007
http://www.bionews.org.uk/page_37964.asp
- **Parents want to tell children about donor conception...and children want to know**
By Louise Johnson, 16 September 2007
http://www.bionews.org.uk/page_37952.asp
- **Is there a right not to be a parent?**
By Dr Anna Smajdor, 30 April 2007
http://www.bionews.org.uk/page_37931.asp
- **Telling donor conceived children about their origins**
By Olivia Montuschi, 7 November 2005
http://www.bionews.org.uk/page_37833.asp
- **How might we best undertake research on donor-conceived persons' views about their conception?**
By Professor Eric Blyth, 31 May 2005
http://www.bionews.org.uk/page_37802.asp
- **Donor anonymity and rights**
By Professor Emily Jackson, 23 January 2004
http://www.bionews.org.uk/page_37724.asp
- **Defending 'secrecy': why removing donor anonymity is not a good idea**
By Dr Ainsley Newson, 28 April 2003
http://www.bionews.org.uk/page_37685.asp
- **Will donor anonymity be a thing of the past?**
By Juliet Tizzard, 29 July 2002
http://www.bionews.org.uk/page_37634.asp
- **Should egg and sperm donors remain anonymous?**
By Dr Jess Buxton, 20 May 2002
http://www.bionews.org.uk/page_37624.asp
- **What rights do people born of donor conception have?**
By Juliet Tizzard, 8 January 2001
http://www.bionews.org.uk/page_37557.asp
- **Do we have a right to know our genetic parents?**
By Juliet Tizzard, 26 July 1999
http://www.bionews.org.uk/page_37487.asp

Appendix C: Reviews from the BioNews archive



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- **Film Review: Anonymous Father's Day**
By Dr Rachael Panizzo, 27 February 2012
http://www.bionews.org.uk/page_130191.asp
- **TV Review: Donor Mum – The Children I've Never Met**
By Jenny Dunlop, 5 September 2011
http://www.bionews.org.uk/page_105930.asp
- **Film Review: Donor Unknown – Adventures in the Sperm Trade**
By Rachel Pepa, 31 May 2011
http://www.bionews.org.uk/page_95078.asp
- **Film Review: The Kids Are All Right**
By Ruth Saunders, 18 October 2010
http://www.bionews.org.uk/page_72995.asp