

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.

PROGAR (Project Group on Assisted Reproduction, British Association of Social Workers

Consultation questions

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

- 1.1 The primary ethical concern is that the welfare of those who are most likely to be affected, donor conceived offspring, is not afforded paramountcy within the 'groups' affected, i.e. parents, donors and donor conceived people except where surrogacy arrangements have been involved (paramountcy was brought in for children born through surrogacy through the 2010 Regulations). As an area of family life donor conception needs to be brought into line with UK children's legislation.
- 1.2 Donor offspring are the only people who did not have a say about the use of donor conception to bring them into being yet information about their donor is of more concern to them than to any other party. Where other parties claim that their rights are being infringed with respect to any aspect of information disclosure, the absence of paramountcy means that fruitless debates are opened time after time into whose rights should prevail.
- 1.3 This rights argument is frequently invoked by commentators who speak as if on behalf of donors and parents, and who tell donor-conceived people what they should think and do. It is also an ethical issue that a number of commentators were semen donors in the past but have not revealed this publicly, thus concealing a conflict of interest.
- 1.4 The UK parliament has legislated to allow a range of donor conception treatments but has failed to mandate the provision of support services for people with a personal involvement. Research, practice experience and the views of donor conceived people, their parents and donors all make clear that some of them are affected adversely at some stage during their lifetime and that there are others who would benefit from professional support during information disclosure or contact with genetic relatives, but there are no dedicated professional support services available for them. In addition, it is clear from these same sources that some parents struggle to disclose to their child that they are donor conceived, even if they believe this to be the right course of action, and need support to do it including advice about techniques for telling. DC Network has been running highly effective 'Telling and Talking' workshops for parents with young children and has produced several relevant publications (which urgently need extending) but UK Department of Health funding for their work has now ceased.
- 1.5 Progar members believe that there needs to be a debate about whether there should be:

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- retrospective disclosure of donors' identity, with safeguards similar to those recommended by the Victoria Law Reform Committee in Australia.
- a system within the Birth Registration system that ensures that donor conceived adults are alerted to their status, *and* informed about how to retrieve 'their' information. This is not the same as saying that 'donor conceived' or some such term should be displayed on birth certificates themselves.

1.6 The variation in clinic practice that allows recipients and donors to decide whether or not to meet with a counsellor prior to undertaking treatment is not in the best interests of the children that might be born nor the families that may be formed, and is therefore not ethical practice. Preparation for this form of family creation through referral to an appropriately qualified and accredited infertility counsellor should be a mandatory requirement.

1.7 Whether parents tell their children or not about their conception status raises the issue of trust between parents and children. Not telling their children suggests that children are not being trusted with the information by their parents, as though the matter must be kept a secret. It is significant that heterosexual couples are less likely to tell their children than single parents and same sex couples. The belief in the need for secrecy often derives from the shame of male infertility. It is also an ethical issue that people who are involuntarily childless feel that they are treated with disrespect and are stigmatised.

1.8 The disclosure or repression of information about origins give different and important messages about relationships, openness, and truth-telling in a society. Donor conceived people are sometimes accused of being genetic essentialists, that is, of attaching more importance to their genetic parents and genetic inheritance than to the parents who nurture them. In our view, this unfounded and simplistic accusation deliberately ignores the complex feelings which donor conceived people have about their social and genetic parentage, and is based on a narrow concept of what it means to be a parent.

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?

2.1 The wording of this question is unclear. If you are asking whether it should be a *family* decision (i.e *including* the child) to decide whether to disclose the information to others then we suggest that as with any sensitive and complex family decision-making which includes children, it should start as being primarily the responsibility of parents to decide while the child is an infant, taking account of the likely impact on their child of others probably being aware of their child's status. As the child gets older, then children should become more fully involved

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in decision making so that by the time they reach their teenage years, they should be afforded a primary say except in extreme circumstances where non-disclosure could be damaging to their health (for example if the teenager said 'No' to informing medics). As adults of course (and arguably from age 16 where many services and institutions accept that young people are old enough to make decisions for themselves) then the decision should rest with them exclusively.

2.2 However if the question means should it be up to the *parents*¹ to decide whether to disclose to either the child or others then our answer is:

- No. The principle that children have the right to know of their origins and that this is important for their emotional, mental and physical well-being means that information-giving or withholding is not a 'life-style choice' for parents.
- In the practice experience of Progar members, recipients usually fall into 3 categories:
 - a) Very clear that they will be open and want to discuss the timing and process of telling (and these are now the majority)
 - b) Not sure and want to explore the issues including how and when to tell
 - c) Do not intend to be open (a minority and most frequently their attitude is linked to cultural issues such as fear of stigma of infertility and childlessness and consequent rejection in their families and communities)
- Given an opportunity to receive good information and to explore their personal beliefs the majority of group 2 and some of group 3 recipients conclude that they will be open with their children. This underlines the essential role of counselling for ALL recipients, not just those who decide to attend counselling, at an early stage and of access to support during the process of talking to their children as they grow up.

2.3 It is essential that clinics do not give the impression to prospective parents that suppressing information is easy, risk-free and has no impact on family relationships.

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

3.1 Parents will require different kinds of information at different times, but they should be able to access medical and social history, including family history, for the donor and the donor's parents, as would be considered good practice in adoption. Parents of donor-conceived children should not be forced into a position of being evasive or feeling inadequate if they are asked to provide their own (irrelevant) medical history by health visitors, paediatricians and family doctors.

¹ We are aware that it is not unusual for writers to mean 'parents' when they say 'family'

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- 3.2 According to a number of research studies, biographical information is important to some recipients because they want to know about their donors as people, their likes and dislikes, their interests, temperament, name and looks (perhaps through receiving a photograph).
- 3.3 Progar members' practice experience is that recipients express a strong desire for full biographical information about the donor in order to feel confident of making a choice about a specific donor. One counsellor member finds that many prospective parents who are considering travelling overseas for treatment, due to the shortage of egg donors, view the policy of mainland European clinics which provide no information as unacceptable, not only because they are not prepared to trust the clinic to choose their donor, but also because they cannot contemplate a future in which they would be unable to answer their child's questions about their origins. There is evidence that the majority of children are eager for a full description of the donor and to know about the existence of siblings. Prospective recipients want to be able to meet these needs and may go to the extra expense and inconvenience of travelling to America so that they can choose their own donor on the basis of full information, including photographs, of the donor.
- 3.4 Prospective parents find the articles, books, leaflets and DVDs from Donor Conception Network extremely helpful and empowering in relation to future parenting tasks including talking about donor conception with their children.
- 3.5 Parents need to have this information if they are able to meet their child's needs for information, for reassurance, and for emotional well-being at whatever age and stage that they ask for it (or that parents consider it appropriate to share with them). None of us know how our children will turn out and what their needs will be. Parents need to have this information provided right from the start so that they do not have to face the problem of searching for it should their child desire it at any stage.

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

See our answer to Question 3

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?*

- 5.1 Very important. We know from the work of UK DonorLink that people 'linked' to genetic relatives on its register have learned that there has been early sudden

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death from heart disease in the ‘other’ family, prompting the need for tests. Conversely there have been registrants who previously thought that they were at risk from such diseases as cancers with genetic risk, or Huntington’s, from their social father and made significant life decisions on the basis of that belief (for example not to have children). Some registrants have undergone invasive tests only to discover later that they were not biologically related to their [social] father.

- 5.2 Some donor offspring find it very difficult indeed to deal with the uncertainty of not knowing anything about the medical history of the donor. In other words, people do not assume that no news is good news.
- 5.3 It is also very important for recipients who nearly always want a good deal of reassurance that the medical history of the donor does not increase the risk of their child having medical problems.
- 5.4 The context of the significance of medical information is the increasing importance of genetics in diagnosis and treatment. Without access to information or possible ways of obtaining information, then donor-conceived offspring will be at a disadvantage.

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

- 6.1 Transparency about such information is a matter of good practice based on sound ethical principles therefore parents of any children conceived if the children are minors; and donor-conceived adults if adults.
- 6.2 Donors should be told and their partners and children may also have the right and need to know. This would need careful management if the donors have not disclosed the fact of their donation to them.
- 6.3 Health authorities should have protocols and guidance in place. We assume that the personnel involved might include geneticists, genetic counsellors, family doctors and psycho-social professionals such as counsellors and social workers with training in disability and medical health.

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?*

- 7.1 Progar’s view is that it is risky to delay telling a child beyond infancy and that a child-centred view of family creation with donated gamete assistance allows no other conclusion. There is no evidence of which we are aware that children suffer from knowing from infancy, but plenty to suggest that risks increase

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beyond that stage, and there are many accounts from donor-conceived people of the significant psychological distress which they have experienced as a result of learning about their donor-conceived origins at a later in life.

7.2 This does not mean that not ever being informed would have been better, partly because there is never any guarantee that the information will remain secret forever.

7.3 As with adoption, children should be given information before they necessarily understand what it means.

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?*

8.1 This is also a complex question. We know that UK DonorLink registrants and staff will be presenting oral evidence on this to the Working Group. We know of research data gathered from on-line surveys from the Cambridge Centre for Family Research which suggests that outcomes are good, but no long term studies are available. We also know that some people with a personal involvement with donor-assisted conception who make contact go on to form relationships which are valued by all parties, whilst others struggle with the impact and are either not interested in forming relationships or find them difficult to deal with if established.

8.2 However we also know of research amongst people living in other jurisdictions or who went there for treatment which show positive experiences of contact. These variations of experience are understandable given that as in adoption, making and deciding on contact is a process, not a once-off event, and is influenced by existing experiences and beliefs about what it means to be related.

8.3 This highlights the importance of access to professional support. This should include therapeutic counselling but more urgently, access to intermediary services with staff who are experienced in helping people with the process of making contact with those with whom they have not been brought up. This is a complex and demanding role requiring particular skills and experience but it is well worth accessing for people affected by the issues of donor-assisted conception.

8.4 It should be borne in mind that 'contact' is not only with donors and siblings but also often with all the family members/networks for these individuals, including children and grandchildren of donors and donor offspring. This highlights the fact that contact between those involved may be complex but also offers social

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enrichment, which is surely a ‘good’ ethical outcome, rather than the alarming and transgressive one insisted upon by some commentators.

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?*

9.1 Our research and practice experience indicates that some donors have not disclosed their involvement to partners and offspring, others have told their partners but not their children, or have told partners and children, and yet others have told many of their social circle.

9.2 As with adoption contact registers, we suggest that there should not be a narrow view of who is important and that adult children and close biological relatives of donors should be allowed to join the two HFEA Registers.

9.3 Apart from the difficulty of carrying out research, one of the reasons why we know so little about the interests is that virtually no resources have been put into raising public awareness about the rights of donors to have information, and sperm donors in particular have been very poorly served in relation to the provision of counselling about the implications of their decision. There is evidence (from Australia) that public awareness campaigns can result in a significant increase in past donors opting to become identifiable which indicates that they do have an interest in the outcome of their donations.

9.4 The available research data suggests that donors and their families are interested in receiving information for a variety of reasons including concern about unwitting incest, reassurance that the offspring have turned out happy and healthy (i.e. that any altruism has not been invalidated), curiosity about what offspring look like, a sense of being connected, and a sense of wanting to meet a felt responsibility for providing genealogical information.

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?)*

10.1 Disclosure is not simply one action. It is a process and a succession of experiences for both parents and children, which will be affected by what there is to disclose. There is an absolute moral responsibility on clinics and the HFEA to ensure that full information is provided by the donor, and practice currently falls far short of what is needed. The HFEA does not require donors to complete all sections of the Donor Information form and does not require all donors to have counselling. Counsellors should be required to inform donors of the importance of full information and facilitate them in completing the forms in a manner that will be in the best interests of children in the future.

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10.2 We believe that there is a [moral] responsibility for professional support services to be provided to families with young children including recipient families and donors' families to assist them with disclosure/information sharing and to support them throughout what may be a long process.

10.3 These services should be accessible to all, regardless of economic circumstances.

10.4 The same applies to disclosure matters when this occurs at an older age, either in childhood or adulthood. In terms of family welfare and children's and adults' mental health, the UK government should acknowledge this responsibility as should fertility treatment services.

10.5 As we keep emphasising, family creation through the use of donor conception carries lifelong implications and treatment services should take account of that. Various models should be explored: in one Australian infertility clinic, the costs of treatment services include an additional amount that entitles those affected to return for professional support later on. Another model might be to place a levy on clinics to fund a national professional support service combined with some government funding.

10.6 Progar regrets the decisions made by the HFEA which resulted in it avoiding taking on responsibility for support services in connection with releasing information from its two Registers. We believe that only to provide contact details for the British Association of Counselling and Psychotherapy (BACP) is inappropriate and unethical. It is not right to lump all support services under the umbrella of counselling. Given that the HFEA supported the recommendations of the British Infertility Counselling Association's report 'Opening the Record' in 2003, Progar suggests that the HFEA should have taken robust steps to enable the implementation of the report.

10.7 From Progar's response so far it will be obvious that we are deeply concerned about the threat to the professionally supported voluntary register service UK DonorLink for those conceived/donating prior to 1991. In our view, closing this service or removing its professional underpinning would not be ethical.

11 What support is required in connection with these responsibilities?

11.1 As set out above:

- d) A UK-wide professional support service that employs staff with a range of skills and experiences including intermediary services and therapeutic individual and family work
- e) Funding for peer support organisations such as DC Network

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f) Funding for a professionally-led voluntary register for those conceived/donating prior to 1991

11.2 In addition we advocate funding to allow families with younger children to make contact with others that share a donor whilst their child(ren) are growing up. This is working successfully in other parts of the world such as Australia and New Zealand and the need is evident from the 30,000+ parents of younger children that are currently registered with the Donor Sibling Registry, some of whom are domiciled in the UK.

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.

12.1 If donor conception treatment services are to be provided and run responsibly, then they should not cut corners and should instead take account of lifetime issues. Donors (including known donors) should be assessed and prepared within a context and atmosphere that leaves them in no doubt that what they are considering is engagement in assisting family building. This is not the same as 'treating donors well' in customer care terms – essential though that is.

12.2 Although we know that a number of donors are aware of this and that it may be a motive for donating, donors need to be assisted to think through the implications for donor offspring in *their* life courses. Within such an approach, it would be compulsory, for example, for pen portraits to be completed to a high standard prior to their gametes being used; and for donors' immediate family members to be fully aware of what they are doing. This includes donors' parents, because informal evidence suggests that older people can be distressed about their children donating gametes.

12.3 Prospective parents should be similarly attended to and no-one should be accepted for treatment if they stated their intention to withhold information from children. Ongoing support services should be in place.

12.3 Such an approach does not and should not come cheap, but it is the only ethical way to provide services, to avoid exploiting people at their most vulnerable, especially those desperate to have a family and those donors in straightened financial circumstances and attracted by financial compensation, and to avoid risking the health and well-being of donor conceived offspring.

12.4 There needs to be a sustained public awareness campaign about the importance of donor information, encouraging former donors to update their files on the HFEA register and educating them about the need to re-register as identifiable if they donated prior to 2005.

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12.5 Infertility clinics should be inspected much more intensively in relation to the counselling of recipients and donors, and regulations should make counselling a default requirement when donation is being considered.

12.6 The HFEA should make the full completion of donor forms a condition of a clinic's licence, and clinic records should be inspected for compliance with this requirement.

12.7 The Government should review the birth registration system as a matter of some urgency and as was initially planned following the lifting of donor anonymity in 2005. It is important that there is a system in place that enables all donor-conceived people to have the opportunity to know of their donor conceived status, so that they can make informed decisions that may profoundly affect their lives. The review could explore the possibility of retrospective disclosure of donor identity.

12.8 Access to information needs to be tracked through all assisted conception procedures. For example when a donated egg is used in a surrogacy arrangement (that is, the egg is not from the surrogate nor the commissioning mother) then mechanisms need to ensure that the offspring can learn this, such as through the birth registration and Parental Order Register systems). At present, children might only know that they were born to a surrogate, as that is all that appears on the original birth certificate.