

Donor anonymity and secrecy versus openness concerning the genetic origins of the offspring: international perspectives

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Introduction

What is now known as donor insemination (DI) has been practiced for at least several hundred years (Novaes, 1998). Professor William Pancoast's insemination of a female patient in Philadelphia in 1884, using sperm from his 'best looking' medical student, is frequently cited as the first detailed account of its successful use as a 'medical' procedure. The woman, who had been anaesthetised prior to her insemination, did not know what had been done to her and, although her husband was aware of his wife's insemination, he was instructed never to tell her. It is likely their son did not know of the circumstances of his conception, although he may have met his donor. One of Pancoast's students, Addison Hard, claimed that, several years later, he had 'shake[n] the hand of the young man' who had been conceived following Pancoast's ministrations (thus inviting speculation that Hard himself had been the donor) (Gregoire and Mayer, 1965; Daniels, 1998).

I mention this story since, while we have stopped anaesthetising women prior to insemination and, as far as I know, women are no longer inseminated without their knowledge or permission, the principles of secrecy and anonymity in donor conception have survived for over a century.

For example, as recently as 1987, the UK's Royal College of Obstetricians and Gynaecologists was advising prospective DI recipients: 'unless you

reveal [DI conception] to your child, there is no reason for him or her ever to know that he or she was conceived by donor insemination' (Royal College of Obstetricians and Gynaecologists, 1987, p. 3).

Justifying secrecy and anonymity in donor conception

Various reasons have been advanced for the maintenance of secrecy and anonymity in donor conception, although different factors may operate to support – on the one hand secrecy - and on the other, donor anonymity. And, as technological development has enabled both embryos and eggs to be used in donor procedures, the orthodoxy of secrecy and anonymity was extended across the board to encompass all donor procedures.

Focusing first on the main arguments advanced in support of **secrecy in DI**, there is the argument that disclosure of the nature of the child's conception reveals the potentially stigmatising condition of male infertility, risks jeopardising the relationship between the child and his or her genetically unrelated father and also possibly distorting the balance of family relationships more generally. Within some religious communities, recourse to DI

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is tantamount to adultery – the view of Islam and the Roman Catholic Church (see Bielawska - Batorowicz, 2004), for example. Thus Shariah law prohibits DI and surrogacy, although egg donation may be accommodated within ‘temporary marriage’ (Fatemi and Akhondi, 2003), while the Italian government’s decision in March 2004 to prohibit all forms of donor conception and surrogacy probably owes much to the influence of the Catholic Church. Disclosure also risks subjecting the child to potentially prejudicial attitudes of others; while ambiguity about the child’s legal status – and even more the **certainty** that a donor-conceived child is illegitimate – provide a clear justification for non-disclosure. In cultures characterised by patrilineal family systems, recourse to donor conception – and especially DI - risks ostracism for both parents and child within the family and community, a risk evident in Hong Kong (Ng, Liu, Chan and Chan, 2004) and Singapore (Ow, 2004). For the donor, disclosure reveals the act of masturbation, still regarded varyingly as a topic for jokes,¹ an unsavoury pastime or even a mortal sin.

The practicalities of egg and embryo donation mean that female donors are less likely than sperm donors to be subjected to adverse social repercussions - indeed the efforts of egg donors are often portrayed as heroic - and egg and embryo donation are less likely to be perceived as adulterous. However, the other factors supporting secrecy in sperm donation are otherwise applicable to egg and embryo donation.

Specific arguments that have been used to support **donor anonymity** include the risk that an identifiable donor could intrude into the privacy and family life of donor-conceived children and their parents and that a donor-conceived person seeking the identity of their donor could intrude

into the donor’s privacy and family life. In addition, in the absence of legislation specifying the limits of responsibility that a donor - especially a sperm donor - might have towards any child conceived, anonymity offers some safeguard against any legal, financial or emotional claims that may be made on the donor – either by the child or (indeed) the child’s parents. Additionally, in the absence of any limit on the number of offspring that may be conceived from any one donor, anonymity may protect the donor from the unimaginable consequences of a personal relationship with a large number of genetic offspring (not to mention **their** social and kinship networks).

Professional bodies have also begun to endorse disclosure

To put this prospect into perspective, in 1999 a woman wrote in the newsletter of a UK support group, the DI Network (now renamed the Donor Conception Network), that she knew that over 100 offspring had been born following the use of her (now deceased) father’s sperm at a London clinic in the 1940s and ’50s. Since she believed that her father would have wanted to provide any background information for any of his offspring who wished to know about their genetic history, she indicated her willingness to be contacted (Festing, 1999/2000). Finally, a key underlying assumption – and apprehension - is that the abolition of anonymity would seriously jeopardise donor supply and thereby threaten the viability of donor conception services (see, for example, Craft and Thornhill, 2005).

Little wonder, then, that discretion was considered the best policy for so long.

The tide begins to turn

During the last quarter century, however, the notion that **secrecy** in donor conception is necessarily the best option has weakened – at least in official discourses. Several factors may account for such change. First, evidence that secrets in families may be damaging (see, for example, Triseliotis, 1973; Karpel, 1980; Sorosky *et al.*, 1984;

1. The British Parliament is not immune from jokes about sperm donation. On 21 March 1989, in a discussion of lesbians using donor insemination, Labour MP Tony Banks castigated Conservative MPs: ‘If they are in any way short of raw material, I am sure there are plenty of wankers opposite who would be happy to oblige’ (The Observer, 1989; Tony Banks MP, personal communication, 14 October 1989).

Department of Health *et al.*, 1993; Imber-Black, 1993, 1998) have been endorsed by influential government-appointed committees on assisted conception and reproductive technology in different countries (e.g. Australia's Waller Committee [Waller, 1983]; the UK's Warnock Committee [Department of Health and Social Security, 1984] and the Canadian Royal Commission on New Reproductive and Genetic Technologies [1993]). Professional bodies have also begun to endorse disclosure. For example, in March 2004, the Ethics Committee of the American Society for Reproductive Medicine concluded that parents of donor-conceived children should be encouraged to tell their children how they were conceived (Ethics Committee of the American Society for Reproductive Medicine, 2004).

A second key factor has been implementation in a number of countries of legislation protecting the donor from any financial or legal responsibility for any child conceived as a result of their donation and also enabling the husband or partner of an inseminated woman legally to register himself as the child's father, thus legitimating the child.² However, legitimating parent-child relationships in this way could facilitate efforts by the family to 'pass as normal,' thus encouraging concealment. Given potential ambiguities surrounding determination of the child's legal mother in a surrogacy arrangement, a number of countries that permit surrogacy have also clarified their legislation in this regard.³

A third influence has been the increasing number of personal accounts of people who have used donor conception to establish their families,

of donor-conceived people and - to a lesser extent - donors (see, for example, Donor Conception Support Group of Australia, 1997; Lorbach, 2003). In a number of countries support groups for donor-conceived families have been established, whose very existence challenges the essence of secrecy and non-disclosure (e.g. Infertility connection in Canada, the Donor Conception Support Group of Australia, and the Donor Conception Network and the Daisy Network in the UK). However, in the main, it has to be acknowledged that what limited empirical research exists indicates that many parents who have used donor conception have been - and many remain - unlikely to tell their children about their conception (see, for example, Snowden *et al.*, 1983; Cook *et al.*, 1995; Golombok *et al.*, 1995, 1996, 2002a, 2002b; Brewaeys, 1996; McWhinnie, 1996; Brewaeys *et al.*, 1997, 2005; Nachtigall *et al.*, 1997, 1998; Gottlieb *et al.*, 2000; Lindblad *et al.*, 2000; Kirkman, 2003).

Much of this research, though, is relatively recent so we know very little about longer-term trends, and some recent research suggests that in some countries at least there may be an increasing inclination on the part of parents to tell their donor-conceived children about their conception (Adair and Purdie, 1996; Rumball and Adair, 1999; Gottlieb *et al.*, 2000; Hunter *et al.*, 2000; Blood *et al.*, 2001; Scheib *et al.*, 2003; Lycett *et al.*, 2004, 2005; Brewaeys *et al.*, 2005).

The management of information in donor conception

While the notion of absolute **secrecy** in donor conception appears to have lost some of its force, maintenance of donor **anonymity** continues to command much support. Not only is anonymity generally advocated by professional medical bodies (in the UK for example, both the British Medical Association and the specialist interdisciplinary - but medically-dominated - British Fertility Society have advocated strongly for the maintenance of

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2. For example, the UK's Human Fertilisation and Embryology Act 1990 and the Infertility Treatment Act 1995 in Victoria (Australia).

3. The conventional rule of law is that the mother who gives birth to a child is that child's legal mother (Mater est quam gestation demonstrat) "by gestation the mother is demonstrated." This principle was judicially recognised in the UK in the *Amphill Peerage Case* [1977] AC 547.

donor anonymity) but is also afforded legislative support in many countries. At the present time, of jurisdictions that have introduced legislation regarding donor conception, only Austria, Germany, the Netherlands, New Zealand, Norway, Sweden, Switzerland, the United Kingdom and the Australian states of Victoria and Western Australia, have legislated to allow donor-conceived people to learn the identity of their donor – although this is under active consideration in some other jurisdictions.

A number of jurisdictions that promote donor anonymity have, nevertheless, established statutory donor conception registers, containing details of donors, recipients of donated gametes or embryos and children born as a result of donor procedures, and permit varying degrees of access to information held on the register.⁴

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In some countries a hybrid system, conventionally known as the ‘double track’ system (Pennings, 1997), may operate, whereby a donor may choose at the point of donation either to be identifiable to any offspring or to remain anonymous. Prospective recipients of donated gametes may then choose to receive the gametes of either an anonymous or identifiable donor. Thus, both donors and recipients may exercise choice, at the time of donation and receipt respectively, although the future options available to any donor-conceived person are restricted by the choice made by their parent(s). Within Europe, the Czech Republic and Iceland operate such a scheme. In the USA, in the absence of federal or state legislation, individual practitioners or agencies may determine their own practice. Several American sperm banks, which have pioneered donor identity-disclosure programmes, also employ the ‘double track’ system.⁵

So what are the pressures bringing about this change?

Increasingly, donor-conceived people have been articulating their interest in knowing about their donor, frequently asserting a ‘right to know’ the donor’s identity. Although empirical evidence about donor-conceived individuals’ experiences is limited, with studies drawing on relatively small populations to date, what exists – together with individual accounts - suggests that they would prefer to be told the truth about their conception and want information about their donor, including knowledge of his or her identity (see, for example,

5. See, for example, Raboy (1993); Scheib *et al.* (2000) and (2003); Xytex Corporation (2000). California Cryobank operates an ‘openness policy’ which is effectively a modified ‘twin track’ system that is based on a presumption that neither a donor nor a recipient of donor sperm should be asked to commit to a decision about disclosure to take effect at least 18 years later. Rather, ‘when a child is age 18 or older, if he or she request additional information about the genetic father, we will make all reasonable efforts to supply that information’ (California Cryobank Inc undated: 6).

4. For example, the register set up in the UK in 1991 under provisions of the Human Fertilisation and Embryology Act 1990, and which is maintained by the statutory regulatory body, the Human Fertilisation and Embryology Authority. Donor information that is provided for the register is subject to wide variations and may, in many cases, be extremely limited (Maclean and Maclean 1996; Abdalla *et al.* 1998; Blyth and Hunt 1998). A person intending to marry may enquire if the register contains any information indicating a possible genetic relationship to their intended spouse. Additionally, at age 18, anyone can enquire if the register indicates whether or not they may have been conceived following an assisted conception procedure performed by a licensed treatment centre (including all donor procedures). In January 2004 (Department of Health, 2004), the government specified the following non-identifying donor information would be made available to a donor-conceived person:

- Sex
- Date of birth
- Height
- Weight
- Ethnic group
- Eye colour
- Hair colour
- Skin colour
- Whether the donor had any children when he or she donated.

Further donor information may be provided, if it is included on the register:

- Religion
- Occupation
- Interests
- Pen picture

Donor Conception Support Group of Australia, 1997; Cordray, 1999/2000; Franz and Allen, 2000; Spencer, 2000; Turner and Coyle, 2000; Gollancz, 2001; Rose, 2001; Stevens, 2001; Anonymous, 2002; Hamilton, 2002; Hewitt, 2002; Scheib *et al.*, 2005).⁶

Second, human rights arguments have been advanced in support of disclosure of donor identity, and interpretation of human rights conventions has clearly been influential (e.g. Freeman, 1996; Blyth, 1998, 2002; Blyth and Farrand, 2004). For example, the introduction of the Reproductive Medicine Act (**Fortpflanzungsmedizingesetz** - S 20 FMedG 1992) in Austria affording a donor-conceived person reaching the age of 14 the right to learn the donor's identity⁷ was predicated on the Austrian government's interpretation of Article 7 of the United Nations Convention on the Rights of the Child (the right of a child '... as far as possible... to know... his [*sic*] parents') and Article 8 of the European Convention on Human Rights and Fundamental Freedoms (the right to 'respect for ... private life') (personal communication, Dr Michael Stormann, Austrian Justice Ministry, 26 November 1997).

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However, consensus is lacking on the intrinsic human rights arguments. Former Norwegian Ombudsman for Children, Målfrid Flekkøy, has explicitly questioned whether a donor-conceived person has a 'right' to information about their 'biological heritage' (Flekkøy and Kaufman, 1997). On the other hand, Steve Ramsey, Director of

South Australia's Office of Families and Children, has stated: 'principles from the domain of human rights can provide an important framework for responding to one of the most pressing challenges confronting reproductive technology... and that is **access by donor offspring to information about their origins** .. Put at its most succinct, from a human rights perspective, one might ask the question – **how can one argue against the basic human right to know one's own genetic identity**' (Ramsey, 1998, p. 4 – emphasis original).

Ramsey's stance is supported by the United Nations Committee on the Rights of the Child, which has explicitly criticised endorsement of donor anonymity in Denmark, France, Norway and the UK (before Norway and the UK lifted donor anonymity) as potentially conflicting with Article 3 ('the best interests of the child') and Article 7 of the UN Convention. However, given that so few states that have ratified the Convention promote disclosure of the donor's identity, the selection of these states alone for censure suggests that the UN Committee on the Rights of the Child has yet to adopt a systematic approach to this issue (Blyth and Farrand, 2004).

A third element has been the emergence of egg donation since the 1980s, which challenges the dominance of the inherently male discourse associated with sperm donation. Several empirical studies indicate that egg donors appear less likely than sperm donors to demand anonymity.⁸ Crucially, providers of assisted conception services

6. Such views were acknowledged by Melanie Johnson MP, Minister for Public Health, announcing the British government's decision to remove donor anonymity: 'It has not been an easy decision to make. We have concluded that the interests of the child are paramount..... We believe it is right that people conceived by future donations should be able to obtain identifying information about their donor' (Johnson, 2004).

7. In Austria egg and embryo donation are illegal; only sperm donation is permitted.

8. See, for example, Braverman (1993); Schover *et al.* (1992). Söderström-Anttila (1995) reported that one third of Finnish egg donors considered that a donor-conceived child should be able to learn the donor's identity. Additionally, research suggests that a high proportion of egg donors would continue to donate if their identity became known to the recipient. Power *et al.* (1990) found that 87% would do so, while Kirkland *et al.* (1992) found that 63% would do so. Craft and Thornhill (2005) found that just over half of women recruited as anonymous egg donors would donate again as an identifiable donor. Blyth (2004) found that 83% of women participating in a British egg sharing programme would continue to donate if their identity were to be disclosed to any offspring. In a study of embryo donation, Söderström-Anttila *et al.* (1998) found that while half of the female donors were willing to provide identifying information about themselves, only one third of donor couples did so, because of a reluctance on the part of the male partner to provide identifying information.

and their professional bodies, who remain committed to the principle of donor anonymity in respect of sperm donation, are willing to countenance the recruitment of known or identifiable egg donors in order to address the significant shortage of donated eggs (International Federation of Fertility Societies, 2001; Murdoch, 2001).

Voluntary contact registers

A particularly recent development has been the 'Voluntary Contact Register' (Blyth and Speirs, 2004). The first state-sanctioned voluntary register was established in Victoria in 2001. Its full title is the 'Donor Treatment Procedure Information Register,' but is colloquially known as the 'Voluntary Register,' thus providing the generic description of such registers.⁹ Western Australia set up a similar register in November 2002,¹⁰ a UK voluntary register was formally launched in April 2004.¹¹ In New Zealand, the Human Assisted

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Reproductive Technology (HART) Register, was set up in 2005, which operates both a voluntary contact register for births resulting from donor conception prior to August 2005 and a compulsory register for subsequent donor-conceived births.¹²

The idea behind such registers is that where donation has been made anonymously, information - including identifying information - can be disclosed with the mutual consent of the parties involved.

In addition to state-established registers, a number of sperm banks, individuals and self-help groups have established their own registries although, as yet, the development of these has inevitably tended to be somewhat piecemeal.¹³

The voluntary contact registers that have been established so far are accessible to a greater range of individuals than most statutory registers which tend to limit access to donor-conceived individuals only. Typically, voluntary contact registers allow enquiries from donors, recipients of donated gametes and embryos, descendants of donors and descendants of donor-conceived people. This principle is not exclusive to voluntary contact registers, though. New Zealand's Human-Assisted-Reproductive-Technology Register - known as the HART Register¹⁴ - and Victoria's Central Register¹⁵ also provide rights of access to information to donors and to the recipients of donated gametes - identifying information being available where consent to its disclosure has been given - while the Victoria Register further extends these rights to the descendants of donor-conceived people.

Where donor conception is permitted, with the exception of recent Canadian legislation,¹⁶ the trend in new legislation and an emerging emphasis on 'children's rights' appears to favour the disclosure of donor identity.

Some key future issues internationally

First, I anticipate there will be increasing legislation removing donor anonymity, at least in industrialized countries. This will be accompanied, preceded, or followed by changing arrangements regarding donor recruitment. The lesson from countries that have had some experience of this suggests the inadequacy of traditional recruitment

9. www.ita.org.au/_documents/donors/The_Voluntary_Register.PDF.

10. www.voluntaryregister.health.wa.gov.au

11. UK DonorLink, www.ukdonorlink.org.uk. Uniquely, the UK register will use DNA profiling to establish a genetic match.

12. [http://www.dia.govt.nz/diawebsite.nsf/wpg_URL/Services-Births-Deaths-and-Marriages-Human-Assisted-Reproductive-Technology-\(HART\)-Register?OpenDocument](http://www.dia.govt.nz/diawebsite.nsf/wpg_URL/Services-Births-Deaths-and-Marriages-Human-Assisted-Reproductive-Technology-(HART)-Register?OpenDocument)

13. See, for example, California Cryobank Inc undated; the 'Sibling Registry' (Single Mothers By Choice - www.singlemothersbychoice.com); the 'Donor Sibling Registry' (www.donorsiblingregistry.com).

14. Established under the Human Assisted Reproductive Technology Act 2004

15. Established under the Infertility Treatment Act 1995

16. Assisted Human Reproduction Act 2004

practices and the need to develop new ones; if sperm donor services are to remain viable older men with children with children will need to be targeted rather than students.¹⁷ The culture of donation will also have to change, so that the contribution made by gamete and embryo donation to helping others to have families is more openly and properly recognized by the wider public. This will need to include education and awareness-raising supported by government (Johnson, 2004).

Second, there will be increasing evidence available about the experiences of people personally affected by donor procedures finding out about – and maybe even making contact with – each other. We have yet to see the impact of setting up both statutory and voluntary contact registers, but over the next decade or so information about how these are working in practice will begin to emerge. A key feature of the new spirit of openness and transparency will be its impact on any limits that may be placed on the maximum number of children who may be conceived from the sperm, eggs or embryos of a single donor (which in practice is likely to affect sperm donation only). While higher limits may have been appropriate where donor anonymity meant that the extensive ‘kinship networks’ created by donor-conception could not be established in practice, the ability of donor-conceived people to identify and trace genetic relatives exposes all the parties directly involved to their uncharted risks and rewards. It is not evident that the implications of policy changes have been taken into account by

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regulators; in the UK, for example, the Human Fertilisation and Embryology Authority has redefined its maximum limit of 10 ‘birth events’ per donor (when donors remained anonymous) to ‘children in 10 families’ (following the abolition of donor anonymity) (HFEA, 2005b).

Third, while the rights of donor-conceived people to information about their conception and genetic history (and counter arguments) have been comprehensively articulated, who else should be able to find out what and when, will feature significantly in future debates. Over time we will doubtless learn more about the experience of ‘donor conception sibling unions’ and the establishment of contact between other people connected through donor conception.

Finally, I am mindful that much of this debate is currently couched in terms of ‘Western’ values and assumptions. Yet, issues around donor anonymity touch on the interface between western medicine – in this case assisted conception – and non-western cultural traditions, assumptions and practices. As I indicated earlier, in societies where breach of family bloodlines – or at least acknowledgement of such breaches – may result in extreme social sanctions, it may be argued that concealment of the nature of the child’s conception may be the least-worst option available and therefore consistent with the child’s **best** interests. So one of the key challenges in pursuing this debate internationally and cross-culturally is to what extent change can be promoted or accommodated while addressing concerns about the imposition of a Eurocentric homogeneity and the erosion of time-honoured cultural values.

17. In the UK, the statutory regulator, the Human Fertilisation and Embryology, has reported just such a changing profile of donors during 2004-2005 (HFEA, 2005a). See also the experience of Fertility Associates, Auckland, which has employed a sperm donor co-ordinator to focus on recruitment, advertising and caring for donors. The donor coordinator runs group meetings for donors and keeps in touch with them each year with a letter. Donors are informed about the outcomes of their donation (number and gender of children born but not date(s) of birth). Donors are invited to be identifiable at their initial contact with the clinic and this is considered to engender a feeling in donors of increased involvement and responsibility about the process and outcomes (Blyth 2003).

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