In this paper we consider the recording of information in donor conception and access to this information by donor-conceived people. While our preference is for a formalised record (register) that mandates disclosure of donor identity, where the necessary political support for such a system does not exist then we suggest that a voluntary contact register could help to meet the needs and rights of donor-conceived people and to respect the dignity of others directly involved in donor conception and that counselling values and principles should underpin the operation of these registers.

*Key words:* donor conception, donor anonymity, voluntary contact registers
Introduction

Thousands of children are born annually worldwide following assisted conception procedures using donor sperm, eggs or embryos. Their exact number is unknown because few countries maintain a register of donor-conceived births, and birth registration documentation does not record whether the child was conceived as a result of assisted conception. Historically, providers of donor conception services have kept minimal records and, in the past, any records were often destroyed to preserve the donor’s anonymity (Shapiro et al. 1990). In the UK it was claimed that, at birth registration, parents of donor-conceived children often illegally registered the details of the child’s social father and not those of the child’s biological father (Department of Health and Social Security 1984). UK law was subsequently changed in order to legitimate such practices and under the Human Fertilisation and Embryology Act 1990, which regulates the provision of assisted conception services, a sperm donor whose informed consent has been properly obtained is not regarded as the child’s legal father and incurs no parental responsibilities in respect of the child.

An early international review of more than 100 government, and government-initiated, reports on the regulation of assisted conception (Knoppers and LeBris 1991) recorded a lack of consensus regarding the maintenance of donor conception registers and access by a donor-conceived person to information about their conception, including details of the donor’s identity. A more recent review of policy and practice in a number of European countries, Australia, Canada, New Zealand and the USA (Council of Europe 1998) noted continuing differences regarding donor-conceived people’s access to information about their genetic origins and differing circumstances under which any information might be made available; for example, when the donor-conceived person reaches a specified age or where the donor-conceived person has a genetic condition that they might have inherited from the donor.

A few countries (Austria, Germany, the Netherlands, Sweden, Switzerland, and the state of Victoria in Australia) have prohibited donor anonymity. Norway has introduced legislation to abolish donor anonymity with effect from January 2005, and the UK will do so from April 2005. At the time of writing, legislation in New Zealand which will prohibit donor anonymity, is currently completing its parliamentary passage, and several Australian states are currently reviewing their position regarding the disclosure of donor identity. However, most countries that have introduced legislation or regulation protect donor anonymity; where statutory registers containing details of donors, recipients of donated eggs, sperm or embryos and children born as a result of donor procedures have been established, the identity of the parties cannot be disclosed to each other unless they are already known to each other. In the absence of legislation, professional medical codes generally endorse anonymity (International Federation of Fertility Societies 2001). Consequently, most donor-conceived people have no right to learn the identity of their donor or indeed to know anything about their donor at all.
Policy in the Nordic nations

Sweden was the first nation in the world to afford a donor-conceived person a legal right to learn the identity of their donor. Only sperm donation was permitted when the Insemination Law came into operation in 1985 establishing a register containing donor information maintained by the National Board of Health and Welfare which may be accessed by a donor-conceived person once they reach ‘maturity’. (Uniquely, Sweden does not mandate a minimum age at which such information may be requested). It is left to parents to decide not only when their child has attained sufficient maturity but also if it is in the child’s best interests to be told about their conception. In practice, despite the law, few Swedish parents of donor-conceived children plan to tell their child about their conception (Gottlieb et al. 2000) – a practice that appears commonplace in other countries (for an overview of recent research see Blyth and Landau 2004), although ‘at hospitals where insemination takes place, the attention of parents should be drawn to the importance of frankness with the child as a principle’ (United Nations Committee on the Rights of the Child 1998).

In Denmark the donor’s right to anonymity is legally protected.

Norway’s current policy protecting donor anonymity will be changed under provisions of the Act on Biotechnology with effect from 1 January 2005. After this, any donor-conceived person reaching the age of 18 will be able to learn the identity of the donor. As part of this process a donor register will be established.1

Iceland operates a ‘twin track policy’ (Pennings 1997); under the Artificial Fertilisation Act 1996 no 55, 29 May, a donor’s request for anonymity must be respected. However, if the donor does not request anonymity, the centre providing treatment must keep a record of the donor and if a child is conceived using the donor’s egg(s) or sperm, the donor-conceived child may request access to these records when they reach 18.1

Finland has no legislation and current clinical practice supports preservation of the donor’s anonymity. However, there have been proposals for legislation for nearly 20 years, some of which have advocated the abolition of donor anonymity (Malin and Burrell 2004).

A right to know one’s genetic heritage?

Donor-conceived people have argued that they are marginalized by the denial of information about their origins or ‘genetic heritage’, and that their need for information is subordinated to their parents’ and donors’ presumed right for privacy (see, for example, Donor Conception Support Group of Australia Inc 1997; Hamilton 2000; Franz and Allen 2001). The United Nations Committee on the Rights of the Child has criticised some countries’ endorsement of donor anonymity, including Norway

(United Nations Committee on the Rights of the Child 1994), Denmark (United Nations Committee on the Rights of the Child 1995) and the United Kingdom (United Nations Committee on the Rights of the Child 2002) as potentially conflicting with Article 7 of the United Nations Convention on the Rights of the Child which provides the child with the right ‘... as far as possible... to know... his [sic] parents’. A claim by two donor-conceived people alleging that the UK’s statutory enforcement of donor anonymity contravenes their right to ‘respect for private and family life’ guaranteed by Article 8 of the 1950 European Convention for the Protection of Human Rights and Fundamental Freedoms is currently before the English High Court (Rose and Another versus Secretary of State for Health and Human Fertilisation and Embryology Authority 2002). However, even human rights authorities disagree over the rights of donor-conceived people to information about their donor. Former Norwegian Ombudsman for Children, Målfrid Flekkøy, has questioned whether they have a right to information about their ‘biological heritage’ (Flekkøy and Kaufman 1997), while Steve Ramsey (1998), Director of the South Australian 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’ (p. 4 – emphasis original). The Norwegian government appears to have been influenced by the latter arguments, citing Article 7 of the UN Convention as a factor behind its decision to remove donor anonymity (Ministry of Foreign Affairs 2002).

In principle, we support those who argue that a donor-conceived person should have a legal right to full information about their conception and that only donors who are willing for their identity to be disclosed should be recruited (see, for example, Speirs 1998; Blyth 2002. However, we recognise the potential conflict of interest between a donor-conceived individual wishing to learn the identity of their donor and a donor who has already been recruited on the basis that their anonymity will be protected.

**Donor conception registers**

Formal donor conception registers, often with statutory backing, containing details of donors, recipients of donated eggs, sperm or embryos and children born as a result of donor procedures, have been established in several countries. While these contain information that could reveal the identity of the donor, most restrict the disclosure of information. Three general types of register exist at present: registers that allow a donor-conceived person to obtain non-identifying information about the donor; registers that allow a donor-conceived person to learn the identity of the donor (where the donor consented to such disclosure at the time of donation), and registers that allow
a donor-conceived person to learn the identity of the donor with the donor’s consent (where the donor originally consented to donate under conditions of anonymity). It should be noted that such registers do not extend to the recipients of donated egg[s], embryo or sperm any right to learn the donor’s identity and space precludes further discussion of the potential implications of such an extension.

Registers that allow a donor-conceived person to obtain non-identifying information about the donor

The UK provides an example of this type of register, which was set up 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. It contains information about basic physical characteristics of donors, and details of recipients of donated eggs, sperm or embryos and children born following donor procedures. The HFEA specifies minimal conditions for the collection of donor information; what is provided is subject to wide variations depending on the policies adopted by the clinics that recruit donors and may, in many cases, be extremely limited (Blyth and Hunt 1998). It should also be noted that while DI was available in the UK prior to 1991, no protection is afforded to the preservation of any records that may have been kept prior to the implementation of the Human Fertilisation and Embryology Act 1990. A person intending to marry may enquire if the register contains any information indicating a possible genetic relationship to their intended spouse [the earliest age that anyone could seek this information is 16, the minimum age for marriage in the UK]. Additionally, a person aged 18 may enquire whether 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).

The government has proposed that anyone donating eggs, sperm or embryos after 1 April 2005 must be willing to disclose his or her identity to any offspring (Department of Health 2004). Additionally, under new regulations, the Human Fertilisation and Embryology Authority (Disclosure of Donor Information Regulations) 2004, the government has prescribed more extensive donor information to be held on the HFEA Register and made available to an applicant for information, which includes:

- the sex, height, weight, ethnic group, eye colour, hair colour, skin colour, year of birth, country of birth and marital status of the donor;
- whether the donor was adopted;
- the ethnic group or groups of the donor’s parents;
- the screening tests carried out on the donor and information on his [sic] personal and family medical history;
- where the donor has a child, the sex of that child and where the donor has children, the number of those children and the sex of each of them;
- the donor’s religion, occupation, interest and skills and the donor’s reasons for donating;
- matters contained in any description of himself [sic] as a person which the donor has provided;
- any additional matter which the donor has provided with the intention that it be made available to an applicant.

Registers that allow a donor-conceived person to learn the identity of the donor (where the donor consented to such disclosure at the time of donation)

Under this system a donor is recruited subject to their agreement that their identity may be disclosed to any child born using their egg[s], embryo or sperm. As indicated above, Sweden was the first country to establish such a register. This requires the donor’s medical records to be kept for at least 70 years.

In January 1998 Victoria [Australia] established a central register of information allowing a donor-conceived person to learn the identity of their donor. This register, known as the 1995 Central Register, supplemented an existing register (the 1984 Central Register) that had been set up in July 1988. Both registers are maintained by the statutory regulatory body, the Infertility Treatment Authority (ITA). The 1984 Central Register contains a permanent record of donors, recipients and children born as a result of donor procedures. Non-identifying information on the register may be disclosed to any of these parties. Identifying information may only be released with the express consent of the person to whom that information relates. The ITA is required to make ‘reasonable efforts’ to locate any donor whose consent to the release of information is required. The amount of non-identifying donor information held by the ITA is less extensive than that kept by the clinic or doctor providing treatment. Where a donor-conceived individual requests non-identifying information held by a clinic or doctor, this information must be provided in accordance with section 71 of the Infertility Treatment Act 1995.

The 1995 Central Register permits disclosure of the donor’s identity to a donor-conceived individual reaching the age of 18. This right is unconditional and donors consenting to the use of their egg[s], embryo or sperm for the treatment of another person after 1 January 1998 do so on the basis that their identity will be disclosed if requested by someone entitled to receive this information.

Where a request is made for the release of identifying information from either of the 1984 and 1995 Central Registers, the ITA is required to arrange the necessary search for the individual about whom information is requested. Before providing identifying information from the 1995 Register, the ITA must advise the donor that such information is to be released and provide them with information about the availability of counselling.
The Sperm Bank of California (Raboy 1993; Scheib et al. 2000, 2003) was the first assisted conception centre in the world (in the absence of legislation requiring such action) to set up such a system in 1984, in effect operating a ‘twin track’ policy of recruiting both donors who wished to remain anonymous and donors agreeing to be identified to any offspring reaching the age of 18. Subsequently, other American sperm banks have recruited donors whose identity can be made available to their offspring at age 18 (e.g. Xytex Corporation 2000).

Registers that allow a donor-conceived person to learn the identity of the donor with the donor’s consent (where the donor originally consented to donate under conditions of anonymity)

These registers are of recent origin. The first such register, the 'Donor Treatment Procedure Information Register' (colloquially known as the 'Post-1988 Voluntary Register') was established in Victoria in 2001 under Section 82 of the Infertility Treatment Act 1995.2

This register establishes a means of providing or receiving information or to link people who are either:
- donor-conceived individuals
- descendants of donor-conceived individuals
- couples who have had a child through donor procedures
- egg, embryo or sperm donors
- relatives of any of the above
- people wishing to establish whether they were born as a result of a donor procedure
- genetic siblings of donor-conceived individuals

This Register allows any of the above involved with a donor procedure since 1 July 1988 (i.e. since the 1995 Central Register has been operational) voluntarily to provide any information about themselves for inclusion on the register that may be released to other people to whom they may be biologically linked. This could include a photograph or any other information that may be of interest to a potential enquirer and may include identity and contact details. This register does not only allow for the possibility of a donor-conceived person obtaining information about their donor and vice versa, but could also allow contact to be made between donor-conceived half-siblings. The ITA is expected to take a proactive role, ‘ensur[ing] that every attempt is made to find the donor code relevant to that person’ and ‘us[ing] every opportunity to promote [the register’s] existence’ (Infertility Treatment Authority 2001a). As of May 2004, 22 ap-

applications by donors and 29 by recipient parents had been recorded on the Post-1988 Voluntary Register (Infertility Treatment Authority 2004).

There is a second Voluntary Register in Victoria, the 'Pre-1988 Donor Treatment Procedure Information Register', which was established under the provisions of Part 7A of the Infertility Treatment (Amendment) Act 2001 for people who were involved with a donor procedure before 1 July 1988, i.e. the date of proclamation of the Infertility (Medical Procedures) Act 1984. As no central records existed before 1 July 1988, the mechanics of obtaining information are more complex than for the 'Donor Treatment Procedure Information Register'. Any requests for information concerning pre-1988 donor procedures received by the ITA are referred to the clinic providing the treatment. However, in its Annual Report for 2001 the ITA notes that, following media publicity concerning donor information, it had received 38 unsolicited applications relating to pre-1998 donor procedures – predominantly from sperm donors who had donated during the 1970s and early 1980s who wanted to ‘ensure that should their offspring wish to contact them, that information could be lodged somewhere’ (Infertility Treatment Authority 2001a, p. 15). As of May 2004, 30 applications by donors and 9 by donor-conceived people and 7 by relatives had been recorded on the Pre-1988 Voluntary Register (Infertility Treatment Authority 2004).

In Western Australia, a central register of donor procedures was established in 1993 under legislation that protects the donor’s identity. While donor anonymity is currently under review, it remains protected by legislation. The Health Department established a Voluntary Register that was launched in November 2002. The operation of this register will be similar to that in Victoria and will cover both pre- and post-1993 donor procedures.3

Since November 2002, completed applications forms had been submitted by 21 parents, 17 donors and 3 donor-conceived people. In addition application forms had been requested (but not yet returned) by 18 parents, eight donors and one donor-conceived person (Western Australia Department of Health, personal communication, 19 July 2004).

In the UK the government has funded a pilot voluntary contact register, UK DonorLink,4 that will exchange information and facilitate contact by mutual consent between anyone over the age of 18 who:
- was conceived using donated sperm or eggs,
- donated in the UK, or
- thinks that they may be biologically related to a donor-conceived person

Uniquely, this register, which was formally launched in April 2004 will use DNA profiling to establish a genetic match. It is initially restricted to those who were involved in

3 www.voluntaryregister.health.wa.gov.au
4 www.ukdonorlink.org.uk
donor procedures prior to implementation of the Human Fertilisation and Embryology Act 1990. It has not been determined whether the remit of UK DonorLink could be extended to include all anonymous donations made under the provisions of the 1990 Act.

In addition to state-established registers, a number of sperm banks, individuals and self-help groups have begun to establish their own registries. As yet, the development of these has inevitably tended to be somewhat piecemeal. For example, California Cryobank (California Cryobank Inc undated: 6) operates an ‘openness policy’ based on a presumption that neither a donor nor a recipient of donor sperm should be asked at the point of donation or insemination whether to commit to a decision about disclosure to any child. 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’.

Two internet-based registries of which we are aware are based in the USA. The ‘Sibling Registry’ set up by Single Mothers By Choice, an American organisation, but with an international membership, enables members to register their donor-conceived children for the purpose of locating children who were conceived with the same donor sperm.\(^5\) As of July 2004, details of 235 donor-conceived children had been registered and 46 matches had been made (Single Mothers by Choice, personal communication, 21 July 2004).

The more recent ‘Donor Sibling Registry’ was established in September 2000 by Wendy Kramer and her donor-conceived son, to help individuals seeking to make contact by mutual consent with their biological relatives (their own or their child’s half-siblings; their own or their child’s donor; or their biological offspring) conceived as a result of either sperm or egg donation. Contact may be made by anyone aged 18 or over on their own behalf and parents may make contact on behalf of their children aged under 18. By July 2004, membership of the Registry had grown to 3018 and over 500 matches between half-siblings had been facilitated (http://www.DonorSiblingRegistry.com/ - accessed 24 July 2004).

‘Donor-linking’ counselling

A request by a donor-conceived person for information about their donor should be seen as a normal expression of interest in personal genetic history and should not engender any presumption of psychopathological abnormality. However, we consider that it is insufficient merely to make information available; while counselling should not be imposed we believe that it should be routinely offered when a request for information is made, and provided by an appropriately skilled and experienced individual. Before any information is provided, the person seeking information should be encour-

\(^5\) http://www.singlemothersbychoice.com
aged to consider their motivations, expectations, needs, hopes and the implications of receiving the information - including the possibility that it might differ from their expectations or hopes (British Infertility Counselling Association 2003).

Drawing on the principles for so-called ‘donor-linking’ counselling that have been established in Victoria (cited in British Infertility Counselling Association 2003) the ‘initial implications discussion’ with the donor-conceived person should include:

- their motivation for seeking information;
- the background to their decision to seek information. As we have noted, many parents of donor-conceived children do not intend to tell their child about their origins. It may be, therefore, that the donor-conceived person has discovered their status ‘accidentally’ or from a source other than their parents, or may simply suspect that there may be information about their conception that has been withheld from them;
- their awareness of legal and formal requirements in relation to the disclosure of information, and the process of such disclosure;
- the options available to them and the implications and potential consequences of proceeding with the application for information. This may include the potential for - and possible implications of - a future relationship with the person about whom the information relates. If so, the potential impact on the person about whom the information relates and members of their social and kinship networks should also be considered;
- the possible impact of the disclosure of information on themselves and on any immediate and extended family (in particular their parent[s] and any spouse/partner, siblings or children);
- how they will deal with potentially varying emotional reactions arising from the disclosure of information - or discovery of the lack of information.

It will also be important to assess whether there are additional issues that the donor-conceived person may need to address or with which they may need assistance, including any longer–term support, which may require the involvement of another service (Infertility Treatment Authority 2001b; British Infertility Counselling Association 2003).

While professional information, advice and support are essential, formal services are not necessarily the only sources of help. Adoption Contact Registers that exist in some countries and provide a system for information exchange where the adoption took place under a system of anonymity, may provide a template model for the operation of voluntary contact registers in donor conception. The successful operation of such schemes relies on the availability of support provided both by professionally qualified counsellors and people with direct experience of adoption and an explicit commitment to the ‘right’ to information and contact, and an ethos of empower-
ing people who hitherto may have lacked control over significant aspects of their life (Blyth et al. 2001). In donor conception it is important to recognise the expertise and contribution of dedicated support groups, such as the UK’s DC Network\(^6\) and Daisy Network,\(^7\) Canada’s Infertility Network,\(^8\) and the Donor Conception Support Group of Australia.\(^9\) These and other groups have successfully utilised the internet, and we anticipate that future expansion of information technology and telecommunications will increase service users’ control over their lives by providing information and support involving variable levels of interaction and disclosure of personal details.

**Conclusion**

Our preferred policy for donor conception is that recruitment of donors should be restricted to those who are willing to reveal their identity to any offspring who wish this information and so we welcome the abolition of anonymity. However, since most countries that permit donor conception still protect donor anonymity and past donors will have been anonymous in countries moving to a more open system, Voluntary Contact Registers offer a practical means by which at least some donor-conceived people may learn more information about their genetic origins without compromising past assurances given to donors. We would encourage their extension to countries where they do not currently exist.

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\(^6\)www.dcnetwork.org
\(^7\)www.daisynetwork.org
\(^8\)www.groups.yahoo.com/group/InfertilityNetwork

**Endnotes**

1 Following a 1989 a German Federal Court ruling that a child has a right to know their heritage.
2 http://www.lovdata.no/all/hl-20031205-100.html#2-7.
3 The date of each Register derives from the date of the substantive legislation under which they were established (the Infertility [Medical Procedures] Act 1984 and the Infertility Treatment Act 1995) rather than the year of their implementation.
4 In Victoria, access to donor procedures has been restricted to heterosexual couples, although this has been subject to legal challenge.
References

California Cryobank Inc. (undated) When you Succeed, we Succeed. Los Angeles: California Cryobank Inc.
Rose and Another versus Secretary of State for Health and Human Fertilisation and Embryology Authority (2002) EWHC 1593.
Scheib, J. E., Riordan, M. and Shaver, P. R. (2000)


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Summaries

Keinollisesti hedelmöitettyjen lasten oikeuksiin ja tarpeisiin vastaaminen: vapaaehtoisen yhteystietorekisterin merkitys


Að koma á móts við réttindi og þarfir líffæraþega – stofnað sér til frjálsrar/sjálfboðaliða skráningarskríftstofu

Höfundar greinarinnar fjalla um skráningu á upplýsingum um tilurð líffærarjafa og aðgang að upplýsingum fyrir líffærarjafa um gjaðan. Þau aðhyllast formlega skráningu á eiginleikum gjaðan. Par sem að ekki er nauðsynlegur politískur stuðningur fyrir hendi fyrir slikri starfsemi telja höfundar að það sé mikilvegt að þessari þorf sé mætt með frjálsrí skráningu sjálfboðaliða. Þau leggja áherslu á að vandað sé til skráningarinnar í anda ræðgjafar þannig að þegnir fái þórfum sinnum og réttindum fullnægt og að gjaðan haldi sinni virðingu.