



www.sciencedirect.com
www.rbmsociety.com



ORIGINAL RESEARCH

Emerging models for facilitating contact between people genetically related through donor conception: a preliminary analysis and discussion

Marilyn Crawshaw^{a,*}, Ken Daniels^b, Damian Adams^c, Kate Bourne^d,
J.A.P. van Hooff^e, Wendy Kramer^f, Lauri Pasch^g, Petra Thorn^h

^a Department of Social Policy and Social Work, University of York, UK; ^b School of Social Work and Human Services, University of Canterbury, Christchurch, New Zealand; ^c School of Nursing and Midwifery, Flinders University, SA 5042, Australia; ^d Victorian Assisted Reproductive Treatment Authority, Melbourne, Australia; ^e Fiom/ISS Netherlands, 's-Hertogenbosch, The Netherlands; ^f Donor Sibling Registry, Nederland, CO 80466, USA; ^g Departments of Psychiatry and Obstetrics, Gynecology and Reproductive Science, University of California San Francisco, USA; ^h Private Practice, Moerfelden, Germany
* Corresponding author. E-mail address: marilyn.crawshaw@york.ac.uk (M. Crawshaw).



Marilyn Crawshaw

An Independent Researcher and Practitioner and Honorary Fellow, University of York, Marilyn Crawshaw has long standing professional and academic psychosocial interests in donor conception, surrogacy, cancer-related fertility and adoption. Marilyn has been a Social and Ethical Inspector and External Adviser to the HFEA; was the National Adviser to the UK DonorLink voluntary register for adults affected by donor conception pre-1991 from 2003 to 2013; is a founder member of the British Infertility Counselling Association and editor of its Practice Guide series; and chairs UK PROGAR the multi-agency group concerned with child and family welfare following assisted reproduction.

Abstract Previous research indicates interest among some donor-conceived people, donors and recipient parents in having contact. Outcomes of such contact appear largely, but not universally, positive. This paper seeks to understand better the characteristics of associated support services. Information gathered using the authors' direct experiences and professional and personal networks in different parts of the world indicates the emergence of four main groupings: (i) publically funded services outside of treatment centers; (ii) services provided by fertility treatment or gamete bank services; (iii) services provided privately by independent psychosocial or legal practitioners; and (4) services organized by offspring and/or recipient parents. Key operational features examined were: (i) who can access such services and when; (ii) what professional standards and funding are in place to provide them; and (iii) how 'matching' and contact processes are managed. Differences appear influenced variously by the needs of those directly affected, local policies, national legislation and the interests of the fertility services which recruit gamete donors and/or deliver donor conception treatments. The paper is intended to inform fuller debate about how best to meet the needs of those seeking information and contact, the implications for the way that fertility treatment and gametes donation services are currently provided and future research needs.

© 2016 The Authors. Published by Elsevier Ltd. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

KEYWORDS: donor-conceived people, donor conception, donors, information exchange/contact, intermediary services

<http://dx.doi.org/10.1016/j.rbms.2015.10.001>

2405-6618/© 2016 The Authors. Published by Elsevier Ltd. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Introduction

There is growing recognition of donor-conceived peoples' interest in learning more about their donor(s) on medical grounds, prompted by the need for more complete genetic information and medical history – not least to aid early diagnosis of disease and inform lifestyle choices to help prevent onset of adult diseases with a known hereditary component – and/or to pass on medical information to the donor and other offspring (Centres for Disease Control and Prevention, 2004; Oberlandesgericht Hamm, 2013; Parliament of Victoria Law Reform Committee, 2012; Ravitsky, 2012) and by documented cases of genetically inherited health conditions (see Tomazin, 2013; www.donorsiblingregistry.com/resource-library/medical-issues) including where legal action was undertaken to uncover the donor's medical history (Johnson v Superior Ct, 2000). The documented need to have curiosity satisfied or psychological and social needs met is more long standing (see Blyth et al., 2012; Hertz et al., 2013). Some past donors also have an interest in and curiosity about those conceived with their donation (Daniels and Kramer, 2013; Kirkman et al., 2014; Riggs and Scholz, 2011; Speirs, 2012). There are also reports of donors' parents (Beeson et al., 2013) and offspring (Daniels et al., 2012) having an interest in contact with donor-conceived offspring.

While some donor-conceived people search for their donor(s) only, others also search for what we are here calling 'donor-related siblings' (i.e. those conceived through the same donor or non-donor conceived offspring of their donor(s)) (Jadva et al., 2010; Nelson et al., 2013; Scheib et al., 2005). Recipient parents have also been found to have an interest in learning more about their child's genetic relatives (Rodino et al., 2011). Such interest can extend to families with children conceived with the same donor having contact while the children are still young, with largely positive outcomes (Freeman et al., 2009; Goldberg and Scheib, 2015; Scheib and Ruby, 2008). We are aware of growing numbers of support groups in our own countries, both of donor-conceived people and of recipient parents, pressing for greater opportunities for contact.

The ease with which information about biological and biographical connections can be accessed is often severely limited. This may be through a lack of, or destruction of, records (New South Wales Parliamentary Committee on Law and Safety, 2013; Ravitsky, 2012; Yuen, 2007), guarantees or contracts of anonymity and privacy that may be seen to override the offsprings' desire to know (Pennings, 2001; Sauer, 2009), legislation or regulation preventing access to information (for example see: Belgium, 1996; Spain, 2006) or a clinic's reticence to assist in linkage (Adams and Lorbach, 2012; Oberlandesgericht Hamm, 2013). Even in jurisdictions where information release is mandated (usually age specific), there is no standardization in its management (Allan, 2012).

Some professional organizations have produced ethics statements or guidelines which, although not carrying statutory authority, can influence policy change. The British Fertility Society's recent Policy and Practice recommendations for good practice in information collection at the time of donation and in later information release to donor-conceived people, recipient parents and donors (Wilde et al., 2014) contributed to the decision by the UK regulator, the Human Fertilization and

Embryology Authority (HFEA) to fund a 3-year pilot specialist intermediary and support service for those approaching its statutory register (HFEA, 2014). The non-mandatory ethics statement of the American Society for Reproductive Medicine (Ethics Committee of the American Society for Reproductive Medicine, 2014) recommending the indefinite retention of records regarding gamete donation and the need for every US clinic to have an information-sharing policy also carries some influence. However, clashes with state regulations (where they exist) can lead to such regulations taking precedence, and state variations continue. For example, egg (not sperm) donor records in New York are stored until the offspring reach 21, while those in Washington are kept indefinitely (though this requirement is new so it is still subject to interpretation in practice), and there is a wide variation in clinic policies on donor anonymity. On the latter, some legal commentators have speculated that 'contracts' between donors and clinics designed to ensure anonymity will, regardless of state regulations, increasingly be subject to legal challenge (for a discussion see Rees, 2012).

For donors donating under conditions of anonymity who wish to stay anonymous, and indeed other affected parties who do not welcome contact that is not mutually agreed, the growth of genetic genealogy services (i.e. developed for purposes other than donor linking) is creating concerns. With little government or international debate on these services, they are set to continue to grow and the anonymity of those who wish to retain it following donor conception, adoption, infidelity or the like can no longer be guaranteed.

Little is known currently about routes open to those seeking and/or providing information or how best to meet such needs. Although research has been conducted into the outcomes for searchers and what information may be available to them (Adams and Lorbach, 2012), this has included little analysis of which attributes of services such as skills mix, cost and infrastructure were found to be helpful. The small amount of practice-based literature documenting work with searchers (Crawshaw and Marshall, 2008; Crawshaw et al., 2013; Daniels and Meadows, 2006; Johnson et al., 2012; Kramer and Cahn, 2013) suggests the potential importance of psychosocial (known as mental health in some countries) professional input. This is further supported by research findings that donor-conceived people learning of their origins later in life and/or in unplanned ways may be at risk of acute and lasting emotional distress and may embark on searching soon after disclosure; that some donor-conceived people have dysfunctional family experiences, whether donor-conception related or not; that some contact arrangements can prove difficult to manage; and that family relationships (including those of donors) can be affected by late disclosure and/or searching (Baran and Pannor, 1989; Beeson et al., 2013; Crawshaw and Marshall, 2008; Crawshaw et al., 2013; Cushing, 2010; McWhinnie, 2000; Turner and Coyle, 2000). Past donors have said that they would welcome access to support services in the event of searching and/or being contacted (Crawshaw et al., 2007; Hammarberg et al., 2014; Kirkman et al., 2014; Speirs, 2012).

This paper provides illustrative rather than exhaustive examples of initiatives in different parts of the world that use voluntary routes – i.e. those without legal requirements that mandate information provision or release – to respond to the growing phenomenon of people genetically related

through donor conception seeking information and/or contact. We chose to limit our inquiry in this way both for reasons of space and in order to examine how services develop when they are not governed by mandatory rights. It needs to be acknowledged, however, that the country-specific legislative and policy context in relation to donor conception may nevertheless have *affected* their development both nationally and internationally. By developing a categorization of the services and then comparing their key operational features, the aims are to: (i) stimulate further discussion of the implications of such developments both generally and for contemporary donor conception fertility treatment services; and (ii) provide a possible framework for their future comparative evaluation.

Materials and methods

A group of experienced practitioners and academics (including some with personal experience of donor conception), known to have extensive professional and personal links across the USA, Europe and Australasia, were brought together by MC and KD. Each author used a common set of questions (available on request) to gather and collate information about voluntary searching services available to those genetically related through donor conception but with no legal right to access such information. While unusual, such an approach enabled us to put together information about the emerging phenomenon of such services from those with relevant experience from different parts of the world. This range would have been difficult to capture through other routes at this early stage in their development.

After several readings to determine a framework for organizing the material, four discrete categories of service providers were identified by two members of the team (MC and KD) and finalized after discussion with the whole team. Using the same process, the data were analyzed manually and three key emerging operational themes were identified, and then considered comparatively across the four categories. At each stage the appropriateness of the initial categorization was kept under review. The analysis process thus mirrored that which is used in qualitative research methods when studying a newly emerging field (Mason, 2003). Finally, the implications for current services were discussed across the team.

Results

Categories of voluntary information exchange services

The four key groupings were: (i) services funded by central government or state (i.e. public funding) and outside of treatment centers; (ii) services provided through fertility treatment or gamete bank services; (iii) services provided privately by independent practitioners; and (iv) services provided through offspring- and/or recipient parent-led initiatives.

Services funded by central government or state (i.e. public funding) and outside of treatment centers

These services appear only to be available in countries with legislation lifting donor anonymity. In some cases, services are funded for both those exercising statutory rights

to information retrieval and those without. The latter are typically available only within proscribed dates and for those without records who therefore need the help of a DNA-based register (such as the Donor Conceived Register, formerly UK DonorLink, in the UK available only to adults affected prior to August 1991; and Fiom in The Netherlands, open only to those aged 16 and above – or aged 12 to 15 years with written permission from legal parents or guardians – conceived under an anonymous regime) and/or only for those for whom records exist (such as the Victorian Assisted Treatment Authority (VARTA) and previously the Infertility Treatment Authority (ITA) in Victoria, Australia, and the Reproductive Technology Council in Western Australia).

The origins of such services may differ but they all operate from within an organizational infrastructure. ITA, now VARTA, was established by legislation with a small team to manage both a statutory and a voluntary register as well as a public education role. After a brief spell during which responsibility for the two registers was transferred to the Registry of Births, Deaths and Marriages and that for counseling to the adoption service, the counseling and professional support aspects are to transfer back to VARTA in 2015 after the [Parliament of Victoria Law Reform Committee \(2012\)](#) reported that standards had fallen (Victoria, 2014).

In contrast, when Fiom took on The Netherlands's voluntary register from its inception in 2010, it was already a long-established national social work organization. Its domestic focus was primarily providing help with searching for birth and biographical origins (including with donor-conceived people) and decision-making about unplanned pregnancies and its international partnership with International Social Service focused on inter-country casework, mainly adoption, surrogacy and donor conception. Fiom already had ongoing contact with *Stichting Donorkind* (translated as 'Donor Child Foundation', an organization of donor-conceived people and sperm donors). Given that 'matching' using physical characteristics and/or incomplete or missing written documentation alone is impossible, Fiom works in collaboration with Canisius-Wilhelmina Hospital (CWZ), Nijmegen, who established a dedicated DNA database for those conceived or donating prior to 2004 (note: since 2004, donor-conceived people in The Netherlands aged 16 and over have the legal right prospectively to access the identity of their donors through a government-funded national register—www.donorgegevens.nl to which Fiom also provides a professional support service).

Services provided through fertility treatment or gamete bank services

Such provision does not follow standard patterns, either within or across the countries of the authors. This is despite the fact that the majority of donor-conceived adults using these routes were conceived through anonymous sperm donation at a time when no records were kept routinely, in clinics, gamete banks or centralized databases.

Where records do exist, responses to enquiries can range from blank refusals to release any information or to contact the genetic 'relative(s)' through to more open services. This is often dependent on the goodwill, skill and time commitment of staff (often the counselor) and/or the support of senior managers or owners. Where information is released, this can be anything from basic factual information only to the provision as well of counseling, support and perhaps

intermediary work. In New Zealand and some clinics in Australia, for example, clinics have been active in facilitating offspring contact with previously anonymous donors mostly using the clinic counselor working to guidelines developed by the [Australia and New Zealand Infertility Counsellors Association \(ANZICA\) \(2011\)](#).

Over time many US sperm banks in particular have developed a range of 'contact' options not only for donor-conceived people when searching but also for prospective parents. The first was The Sperm Bank of California (TSBC), which pioneered the concept of 'identity-release' donors willing to have contact with their offspring at age 18. Today most US banks have an option for offspring-donor and/or offspring information exchange and contact, with varying terms including 'open donor' and 'willing to be known donor', and the rate of 'open' donation is on the rise ([Scheib and Cushing, 2007](#)).

Some clinics and banks outside the USA also offer the exchange (via them) of non-identifying or identifying information and 'in person' meetings, delivered variously at the time of the donation (if both parties consent) or while the child is growing up or once the offspring has reached age 18, though the extent to which donors are facilitated to provide updated contact information varies. Some clinics and banks provide online methods for parents and offspring to make contact with other offspring born from the same donor and some are now including reference to the US Donor Sibling Registry (DSR) in their contracts so that contact can be made between recipient families and donors right from the start. Most recently, a sperm bank in Georgia, Xytex, announced a new service called xyConnect, which allows for anonymous exchanges between donors and offspring and gives the option for exchange of identifying information, regardless of the age of the offspring. This may reflect a changing commercial view of the attractiveness of such services to prospective service users and/or an attempt to minimize the risk of future litigation.

Services provided privately by independent practitioners

These independent practitioners include psychosocial professionals such as social workers, psychologists and counselors, but also lawyers. Referrals may come from fertility treatment services, gamete banks or direct from recipient parents, donor-conceived people or donors. Requests include assistance in agreeing a process for later contact, in making contact, and/or (for psychosocial professionals) help for dealing with emotions associated with the lack of contact. In Germany, one of the authors (PT) reports that there are few psychosocial practitioners with experience in this area. Attempts to mediate between offspring and clinics are often met with doctors' reluctance to provide information about donors or to contact them. However, contacts between intended parents and donors as well as between adult offspring and donors are starting to take place, with professional support. In New Zealand, one of the authors (KD) reports working with all three parties, including where recipient parents or donors wish to disclose the facts of the conception/donation to their family members, including adult offspring, and wish for access to information ahead of such a move.

We found involvement of attorneys in this field to be available mainly in the US. There, some donor arrangements include legal contracts describing the process for the

provision of identifying information at the time of the donation or later. Some attorneys have developed services in which they act as a protective source of such information, accessible by any of the parties in the future with the attorney playing the role of balancing the needs and possibly rights of all parties. Where psychosocial support is needed, this has to be contracted separately, sometimes through the attorney.

Services provided through offspring and/or recipient parent-led initiatives

These initiatives include the largest registry in the world, the US based Donor Sibling Registry (DSR) (www.donorsiblingregistry.com), established in 2000 by a mother and her then 10-year-old donor-conceived son, Wendy and Ryan Kramer, and now a charity organization hosting a global forum for mutual consent contact. Most DSR members have either used, donated or been conceived at large US sperm banks (who ship globally), as well as smaller clinics and facilities in cities and towns worldwide. There are currently 45,000 members registered from around the world and many previous members who choose to not be publicly listed on the website ([Kramer and Cahn, 2013](#)).

More recent initiatives have been established by donor-conceived adults without input from parents, clinics, donors or legislators. Instead they have come together through online communities as a result of frustration not only with the roadblocks to their search for information but also with some of the linkage models that already exist. One of the first networks to attempt linking donor-conceived people together was the international People Conceived Via Artificial Insemination (PCVAI) Yahoo group created in 2000 (recently renamed People Conceived Via Donor Insemination) ([PCVAI, 2000](#)). The group is primarily used for email communication between members of the community, including discussion about how to find information on the donor. Another Yahoo group is the Australian Donor Conception Registry, which both shares information via email and runs its own database ([Australian Donor Conception Registry, 2006](#)).

A network that combines an information and educational website with an email mailing list is [Spenderkinder \(2006\)](#) Germany. Also in Europe there is [Procreation Medicalement Anonyme \(2004\)](#) (France), [Spenderkinder Schweiz \(2009\)](#) (Switzerland), [Donorkinderen België \(2014\)](#) (Netherlands and Belgium), [Stichting Donorkind \(2014\)](#) (Netherlands) and [VZW Donorkind \(2014\)](#) (Belgium). The aforementioned groups along with individual members from Denmark, Austria and the UK collectively form a larger organization called [Donor Offspring Europe \(2014\)](#) (DOE), interacting and communicating with each other, owing to the fact that donor gametes may be shipped to other countries, recipient parents utilize reproductive tourism and donors donate in more than one country. The DOE and the individual groups allow for information sharing with the aim of also trying to help linkage. On the other side of the world, Japan has the [Donor Offspring Group \(2014\)](#), which runs an email list to share information among members and tries to assist linkage. However, the lack of information available to offspring in Japan makes their task extremely difficult.

In the current trend of social media, offspring are also creating groups in a more contemporary format. Groups such as Worldwide Donor Conceived People Network, Sperm/Egg/

Embryo Donor Children Finding Family, Australian Donor Conceived People Network, American Donor Conceived People Network, Donor Children from Danish Cryobanks, Donorbarn-sæddonor-ægdonor, and Donorbørn uden nummer, have been created on Facebook.¹ They all serve a similar purpose: allowing for the sharing of information and to ascertain matches based on donor codes, where these are available.

From 2007 some offspring have begun posting their stories and photos on a website called '[Searching for my sperm donor father](#)' (2007), specifically designed to highlight such stories. Offspring and donors upload photos of themselves and any information they deem pertinent to their search, including looks, traits and interests, as well as clinic and donor code information.

The online linkage tools that are providing the most hope for success, particularly for those with no information about their donor or donor-related siblings, are genetic genealogy tests and websites. These direct-to-consumer (DTC) services have already resulted in donor-conceived people discovering and meeting not only their donors but also other donor-related siblings conceived in other families using the same donor (Adams and Allan, 2013; Lehmann-Haupt, 2010; Motluk, 2005). Offspring themselves have had no input into the starting or running of these companies. However, on the FamilyTreeDNA website a group called Donor Conceived (Donor Conceived FamilyTreeDNA group, 2011) has been created by offspring. While offspring, donors and next of kin will be matched automatically irrespective of their membership of this group, the group's purpose is to highlight the clinics and locations of members to encourage other donor-conceived people still undecided about whether to take the test, and to also highlight their need to the wider community for finding their genetic relatives.

The most recent appearance of a linkage group is the Donor Children (2013), which aims to link donor-conceived people with their donor-related siblings, donors and donor relatives. It facilitates social networking and information sharing through a registry, which includes not only donor codes, clinic names, treating Doctor's names and dates of donation, but also those university names that were often associated with donor recruitment in the early years (Levine, 2010; New South Wales Law Reform Commission, 1986; Turney, 2010).

Perhaps more so than in the other models, services in this category are likely to have two primary functions: firstly to provide support through shared experiences to those who join their group; and secondly to act as advocates for changes in legal, policy and practice matters related to donor conception.

What this overview indicates is that a variety of models are emerging in response to the growth in the desire and need to facilitate contact between people genetically related through donor conception. While some of those seeking information exchange or contact may be successful relatively easily, others face major obstacles. Those who are able to access the growing number of avenues open to them may find that beneficial in itself, while others may find it

confusing. It is also possible that some genetic relatives will not locate each other because they have not accessed the same site(s) as each other.

Having described the models, we now discuss three key operational themes arising from the models that have implications for those providing treatment services currently and for the wider lifelong policy dimensions of donor conception provision. They are: (i) eligibility criteria; (ii) service and staffing needs, including funding; and (iii) managing 'matching' and contact processes.

Key operational themes

Eligibility criteria

A dominant issue for all services is who they are for. Historically the focus in research and statutory service provision has been on the two parties most impacted by donor conception, namely the offspring and the donor, with the primary emphasis being on the offspring. However eligibility for voluntary, non-statutory services can differ and appears to be influenced by 'consumer' views, professionals' views and commercial interests.

Some services run by those directly affected restrict membership to offspring alone, with decisions made by the membership or controlling group. These include PCVAI, Worldwide Donor Conceived People Network and Japanese Donor Offspring Group. PCVAI, for example, explains this as being in order for offspring to feel they are in a safe environment: "We want our members to feel comfortable expressing strong opinions and feelings that may be unacceptable to their parents, friends or the general public...". At the same time, similar groups, such as Donorbarm-Saeddonor-Aegdonor, Australian Donor Conception Registry and Donor Children, embrace offspring, donors and recipient parents, presumably considering the benefit of this to outweigh the costs. The DSR has perhaps the most comprehensive eligibility criteria of any service, developed in response to the perceived interests of those seeking information. It is open to donor-conceived offspring of any age (with some caveats), sperm, egg and embryo donors, recipient parents and family members of all parties directly affected. Fiom, on the other hand, has eligibility determined by government policy and restricts membership to donor-conceived offspring above a minimum age and donors conceived or donating prior to 2004. VARTA, which also receives public funding, also operates to state policy, which means in their case that it is open to offspring above a minimum age, donors, parents and descendants and relatives of these groups. Where services are provided by fertility treatment providers or gamete donor banks, eligibility decisions appear to be made primarily by senior managers or owners and hence may reflect commercial interests as well as professionally informed ones. Finally, independent providers are free to respond to whoever seeks their assistance, as long as this meets their financial ability to provide the service and their interpretation of their professional values base.

As awareness grows that donor conception can impact on a wide network of parties, the determining of who should be entitled to access information and/or instigate contact raises questions for debate about the complexity of whose information it is and how to reconcile competing rights.

¹ Some of the European organizations also have Facebook pages, which have not been listed because they are organizational pages rather than group pages populated by posts by individual members with information on donor codes and clinics.

Even in jurisdictions that have statutory regulations in place, the growing use of informal, voluntary routes for searching evidenced here means that adherence to such regulations is restricted to statutory services alone.

Service and staffing needs, including funding

Where services use paid staff, these appear in the main to be professionally qualified in the psychosocial disciplines of social work, psychology and counseling. As such, their training in understanding human functioning centrally informs their approach, and hence their focus is on communication, individual and family functioning, relationships, boundary setting and managing expectations. In some jurisdictions, such as Western Australia, it is a requirement that such professionals are registered with the regulatory authority for both the statutory and voluntary registers, but that is not the norm. ANZICA, the professional body for infertility counselors, has developed relevant guidelines that all members are expected to adhere to. However, we have not identified any other such professional guidelines, leaving the development of good practice to be an unregulated, emerging area aided currently by peer discussion at study days and conferences alongside the small number of written papers.

Funding sources for services using paid staff vary. Public funds for services such as VARTA and Fiom may be limited and, in some cases, uncertain but nevertheless mean that professional and associated support is either free or subsidized. Where the service involves DNA testing by an outside body, such as with Fiom and the DSR (and also the DCR in the UK), the cost has to be met in full by the service user, and this in itself can prove a barrier to proceeding further.

Where services are provided by fertility treatment centers or gamete banks, costs have traditionally been absorbed. However, as demand grows, some services have been withdrawn, curtailed or charged for on the grounds of resource constraints, except where the service provider considers them to make the service more commercially or otherwise attractive and/or because of their values base, as with TSBC and Xytex.

Services provided by independent practitioners typically involve a fee. The likelihood of costs being met under health or other types of insurance is variable and may be restricted to certain disciplines such as psychologists.

As with DNA testing fees, charging for support services can prove a barrier to access.

Where psychosocial practitioners are not included as part of a service response, it is less clear how psychosocial needs are met. For example, services provided through offspring- or recipient parent-led initiatives are usually run by volunteers and free to access but rely heavily on the use of peer support. This can leave anyone needing professional psychosocial support to seek this locally, often without guidance about whom to approach and having to meet associated costs themselves. However, the DSR, which now charges a registration fee, uses a predominantly peer-led service with access to a cost-limited psychosocial professional service. Peer support is provided through: (i) telephone and email contact from office staff who have gained experience and knowledge 'on the job'; and (ii) two listserv forums, on Facebook and Yahoo Groups, where people share stories, look for advice and discuss issues significant to them. Where deemed appropriate and/or on

request, the names of professional counselors whom the DSR considers competent in this field are also provided to members with the DSR meeting the cost of the first counseling session but with costs thereafter met by the service user.

What this overview highlights is that services are being provided by a variety of persons, ranging from peers to highly qualified professionals – sometimes operating co-operatively; sometimes wholly separately – and from a variety of contexts, ranging from a one-person operation to an organization with its own infrastructure and that is either dedicated to donor conception alone or embedded within a wider service. Expectations may be higher in publicly funded and clinic/bank-led services that professionally qualified staff are utilized, and this may also reflect expectations about the tasks involved. What appears to be a shared feature is the need for support during this process and the need for attention to the meaning and implications of donor conception for those seeking contact.

Managing 'matching' and contact processes

Facilitating contact between parties starts with 'matching'. The process whereby this takes place and is then acted on can vary a great deal. As this lies at the heart of this paper, we describe in some detail what is emerging internationally.

There are variations in the point at which information can be sought or released and to whom it can be provided. For example, there are examples in three of the service categories (publicly funded services, fertility treatment clinics/ gamete banks and independent practitioners) of facilitating contact either directly or setting it up for later in life right at the point of treatment itself or while children are growing up as well as when all the parties are adults. Some arrangements are made without the knowledge of the clinic where recipient parents are being treated. Services vary, however, in the extent to which they allow parties to amend or update their information and/or proactively encourage this.

The nature of information exchange or contact can either be open to negotiation or restricted by the service provider or legal requirements. It can include: (i) private email addresses available at any time to the parties involved or through a third party; (ii) contact information only available to recipient parents for use when they decide it to be appropriate; and (iii) direct face-to-face contact from the start. On the DSR, for example, registrants can share photos and email messages anonymously with those to whom they are 'matched', if desired. Donors can fill out a private questionnaire with 25 'frequently asked questions of donors by donor-conceived people' which is only viewable by those to whom they are matched. VARTA's letterbox service allows 'matched' parties to write letters, which are forwarded on confidentially on their behalf, thus enabling parties to exchange information and get to know each other privately. In time the parties may choose to include identifying information if they wish and then communicate independently. Similar experiences have been reported by independent practitioners.

In addition to approaches from those wishing for information exchange and contact, some services are approached by those whose motivation is to access medical information about or from their genetic relative or to seek assistance with, say, bone marrow donation. In other cases, the motivation is to transmit medical information, for example of a health condition that they have developed

and know to have a genetically transmissible component. Some (but not all) fertility treatment clinics and gamete donor banks who refuse to release information for non-medical uses are willing to do so for exchange of important medical information only, as defined by staff at the time. Such contacts require careful handling, but it is not always clear which staff become involved, how the information is conveyed and what follow-up, if any, is available.

There is also a distinction to be made between searchers with some prior form of potentially identifiable information – for example a donor profile, donor code, accurate information about where and when the conception and/or donation took place – and those without.

For those seeking information who already have some details about the conception, access will depend primarily on the willingness of the service holding the information to release it and/or to trace the other party to obtain consent (if required). The extent to which the service holding the information (i.e. usually the clinic or gamete bank) offers tracing varies. Some will not do it at all, leaving it entirely to the person who has approached them. Some, often through their counselor, will attempt contact with the donor (requests usually come from donor-conceived people or recipient parents, rather than donors) using their last known contact information and then facilitate the sharing of information and meeting if parties consent. Some may suggest the searcher pays a private detective agency or similar. The process leading up to any information exchange or contact can last quite some time and can require careful, skilled handling, especially when the donor has donated under an anonymous regime. Some services insist that the identity of each party is not disclosed until each is sufficiently comfortable with this, unless the law dictates otherwise.

In Victoria, parties on the voluntary register are only contacted if there is a corresponding application that links them to each other (different rules apply to the statutory register, which is not covered here). The link might be between (i) recipient parents who have used the same donor; (ii) donor-conceived people who have a common donor; (iii) people who have been until now 'waiting in the wings', i.e. open to contact but not wanting to actively seek the other party (typically donors); (iv) people not covered by the current legislation; or (v) descendants or relatives. Applicants are supported by the same professional staff member from their initial enquiry right through making an application (if appropriate) to the initial stages of information release/contact and beyond if there are any issues. People close to the applicant or the party being sought may also be seen if, for example, the donor has not informed his children of the donation, or if his wife or partner has concerns, or if the donor-conceived person's parents need support. Approaches to practice in VARTA have, however, been more strongly affected by changes in Victorian legislation than the wishes and needs of service users, as outlined earlier.

The DSR, as with other peer-led initiatives, has been an important vehicle for bypassing statutory registers, clinics and gamete banks and appealing directly to other donor-conceived individuals, parents or donors by posting their details online. Sometimes 'matches' are considered

sufficiently robust by those involved to move straight to contact. Sometimes they decide to have independent DNA testing before taking the 'next steps'. DSR members can most easily connect if they know their facility name and donor number.

In the PCVAI group, members submit an introductory piece detailing information about their conception, thus facilitating 'matching' between those conceived at the same clinic using a donor with the same donor code. Some other groups such as the Worldwide Donor Conceived People Network and Australian Donor Conception Registry require that registrants verify their donor conception or donor status by writing to the group's administrators specifying the details of what they know about their conception or donation (a brief story) before they will be admitted to the group and allowed to share information. This information may involve dates of donation/conception, location (clinic/hospital), treating doctor's name and donor code if known. Such information is typically taken as factual and truthful and no documentation is required to support these details. Others such as Donor Children have online submission of details by filling out specific fields. The Australian Donor Conception Registry runs its own database that allows members to upload their information, including donor codes, clinic and dates of treatment or donation, to facilitate linkage between members. Information exchange is left to the discretion of the registrants, with guidance and support provided by other registrants and the administrators if requested.

In all cases, attention needs to be paid to the possibility that the levels of information exchange or contact desired by each party do not match expectations. If that proves to be the case, the parties may each need further support from professionals or others. For several groups/services, the number of 'matches' may thus far be relatively small and may lead to frustration now or in the future, sometimes also warranting professional help.

For those without information, the matching process is likely to be dependent on DNA testing, as those involved will either not know which clinic, gamete bank or register to approach or may have had their requests for information turned down or met with the news that relevant information has been destroyed.

If DNA testing is integral to the service, as with Fiom, this involves a partnership with a DNA laboratory and the use of a dedicated DNA database. At Fiom, staff complete the registration process with applicants, usually via the internet, and applicants then take a form containing their unique code to one of 19 Dutch hospitals, who then send the blood sample to their partner lab, CWZ. CWZ prepares the DNA profile, which is stored in the DNA database after being compared against existing profiles. Once a sufficiently strong probability of a match is found (at least 99.9%, i.e. still with a degree of uncertainty) between donor-conceived person and donor or between donor-related siblings (this sometimes requires the biological parent of the donor-conceived person to also supply their DNA if they are willing or able), CWZ notifies Fiom (for a fuller discussion of DNA testing see: [Adams and Lorbach, 2012](#)). Once Fiom identifies those concerned, a social worker invites each of them for individual meetings (attendance is a requirement) until all are ready to take the next step of information exchange and, perhaps, a

direct meeting with the social worker on hand if the parties want this. Aftercare is available to all parties from the same social worker, according to their wishes.

Where DNA testing is not an integral part of the service, then an independent DNA testing service is sometimes used, as discussed earlier. This could be either for those who have reasons to believe they may be genetically related with each other already or for those who wish to register with a site such as the FamilyTreeDNA service to find previously unknown genetic relatives. The DSR provides information and advice, verbal and written, as to how best to utilize DNA testing and the internet to locate their donor and donor-related siblings (see <https://www.donorsiblingregistry.com/dsr-support-and-info/dna-testing>). Some online support forums are available to assist with the technical understanding of test results.

Discussion and conclusion

This paper has set out information that we have collated about the emerging voluntary routes, i.e. those without legal requirements that mandate information provision or release, being used to enable donor-conceived individuals and donors to access information about and contact with those to whom they are genetically related through donor conception. We are conscious that there will be some services that have not been identified in our searches and that new groups and initiatives are developing regularly. Their proliferation is an emerging phenomenon that has not yet been discussed. There has, of course, been extensive discussion of the wishes and needs of donor-conceived persons and their families for information and the implications of this for the donor and his/her family and networks. The focus of this paper has been on the responses at an organizational, service delivery level. It seems clear that these initiatives have emerged in response to different cultural, social, legal, professional and commercial climates, but further research is essential to evaluate the extent of such influences. As those climates have changed and continue to change there will also be a flow on effect with widespread implications, particularly for treatment service providers, in relation to their donor recruitment and retention approaches, their attractiveness to prospective parents and their assessment of any long-term risks of litigation.

In this paper, we have deliberately not sought to evaluate the relative merits of each type of initiative, but rather to provide a descriptive account of what they observe to be happening and to highlight some of the issues that require discussion and debate. The latter include: Who is and should be eligible for receiving assistance with searching and making contact and who should decide? How can potential users without financial means or access to the internet be assisted to access services? How should relevant services/organizations be run in relation to professional and support staffing structures, funding, peer support and service user involvement? Which tasks are more appropriately dealt with by professionals and which by peers? How should 'matching' and contact processes be managed and which practice approaches might better promote positive outcomes? How far do legislative and policy contexts affect the development

of searching support services? How do, and will, such services respond to the increasingly transglobal nature of treatment services? What impact does the use of social media have on these developments and what are the risks and rewards? The issue has moved from one focused on access to information and the impact of receiving information alone to the ways this is being managed and responded to by those directly affected, professionals and legislators within and across borders. We are raising this issue in a professional forum – this journal – to inform, and more importantly to begin a discussion of, the implications for professionals in the field along with treatment service providers, legislators and, of course, those directly affected. We also hope that this preliminary attempt to analyze developing services carries the potential to inform future research that might start to address questions of 'what works, when and why?'

Declaration

The authors report no financial or commercial conflicts of interest.

References

- Adams, D., Allan, S., 2013. Building a family tree: donor-conceived people, DNA tracing and donor 'anonymity'. *Aust. J. Adopt.* 7, 1–16.
- Adams, D., Lorbach, C., 2012. Accessing donor conception information in Australia: a call for retrospective access. *J. Law Med.* 19, 707–721.
- Allan, S., 2012. A Cross-jurisdictional Study of Regulatory Requirements and Practice Regarding the Recording of Donor Information and its Release to Donor Conceived People. Winston Churchill Memorial Trust of Australia, Australia.
- ANZICA, 2011. ANZICA Guidelines for professional standards of practice: donor linking counselling. <http://www.fertilitysociety.com.au/wp-content/uploads/20120504-anzica-guidelines-donor-linking-final-version.pdf> (06.01.2015).
- Baran, A., Pannor, R., 1989. *Lethal secrets: the shocking consequences and unsolved problems of artificial insemination*. Warner, New York.
- Beeson, D., Jennings, P., Kramer, W., 2013. A new path to grandparenthood: parents of sperm and egg donors. *J. Fam. Issues* 34 (10), 1295–1316.
- Belgium, 1996. Criminal Code of the Kingdom of Belgium—Article 458.
- Blyth, E., Crawshaw, M., Frith, L., Jones, C., 2012. Donor-conceived people's views and experiences of their genetic origins: a critical analysis of the research evidence. *J. Law Med.* 19, 769–789.
- Centers for Disease Control and Prevention, 2004. Awareness of family health history as a risk factor for disease—United States, 2004. *Morb. Mortal. Wkly Rep.* 53 (44), 1044–1047.
- Crawshaw, M., Marshall, L., 2008. Practice experiences of running UK DonorLink, a voluntary information exchange register for adults related through donor conception. *Hum. Fertil. (Camb.)* 11, 231–237.
- Crawshaw, M.A., Blyth, E.D., Daniels, K.D., 2007. Past semen donors' views about the use of a voluntary contact register. *Reprod. Biomed. Online* 14, 411–417.
- Crawshaw, M., Gunter, C., Tidy, C., Atherton, F., 2013. Working with previously anonymous gamete donors and donor-conceived adults: recent practice experiences of running the DNA-based

- voluntary information exchange and contact register, UK DonorLink. *Hum. Fertil. (Camb.)* 16, 26–30.
- Cushing, A., 2010. I just want more information about who I am—the search experience of sperm-donor offspring, searching for information about their donors and genetic heritage. *Inf. Res.* 15 (Paper 428 (available from: <http://InformationR.net/ir/415-422/paper428.html>)).
- Daniels, K., Kramer, W., 2013. Genetic and health issues emerging from sperm donation — the experiences and views of donors. *Adv. Reprod. Sci.* 1, 1–6.
- Daniels, K., Meadows, L., 2006. Sharing information with adults conceived as a result of donor insemination. *Hum. Fertil. (Camb.)* 9, 93–99.
- Daniels, K.R., Kramer, W., Perez-y-Perez, M.V., 2012. Semen donors who are open to contact with their offspring: issues and implications for them and their families. *Reprod. Biomed. Online* 25, 670–677.
- Donor Children, 2013. <http://donorchildren.com> (06.01.2015).
- Donor Conceived FamilyTreeDNA group, 2011. http://www.familytreedna.com/public/donor_conceived/default.aspx (05.01.2015).
- Donor Conception Registry, 2006. <http://groups.yahoo.com/neo/groups/AustralianDonorConceptionRegistry/info> (06.01.2015).
- Donor Offspring Europe, 2014. <http://donoroffspring.eu> (06.01.2015).
- Donor Offspring Group, 2014. <http://blog.canpan.info/dog> (06.01.2015).
- Stichting Donorkind, 2014. <http://www.donorkind.nl/default.html> (06.01.2015).
- VZW Donorkind, 2014. <http://www.donorkind.be/> (05.01.2015).
- Donorkinderen België, 2014. <http://www.donorkinderen.com> (05.01.2015).
- Ethics Committee of the American Society for Reproductive Medicine, 2014. Interests, obligations, and rights in gamete donation: a committee report. *Fertil. Steril.* 102, 675–681 (updated from 2009).
- Freeman, T., Jadva, V., Kramer, W., Golombok, S., 2009. Gamete donation: parents' experiences of searching for their child's donor siblings and donor. *Hum. Reprod.* 24, 505–516.
- Goldberg, A.E., Scheib, J.E., 2015. Female-partnered and single women's contact motivations and experiences with donor-linked families. *Hum. Reprod.* 30, 1375–1385.
- Hammarberg, K., Johnson, L., Bourne, K., Fisher, J., Kirkman, M., 2014. Proposed legislative change mandating retrospective release of identifying information: consultation with donors and government response. *Hum. Reprod.* 29, 286–292.
- Hertz, R., Nelson, M.K., Kramer, W., 2013. Donor conceived offspring conceive of the donor: the relevance of age, awareness, and family form. *Soc. Sci. Med.* 86, 52–65.
- HFEA, 2014. Human Fertilisation and Embryology Authority meeting—Marh 2014. <http://www.hfea.gov.uk/8782.html> (08.01.2015).
- Jadva, V., Freeman, T., Kramer, W., Golombok, S., 2010. Experiences of offspring searching for and contacting their donor siblings and donor. *Reprod. Biomed. Online* 20, 523–532.
- Johnson v. Superior Ct., 2000. 80 Cal. App. 4th 1050. pp. 1056–1057 (Ct. App. 2000).
- Johnson, L., Bourne, K., Hammarberg, K., 2012. Donor conception legislation in Victoria, Australia: the 'Time to Tell' campaign, donor-linking and implications for clinical practice. *J. Law Med.* 19, 803–819.
- Kirkman, M., Bourne, K., Fisher, J., Johnson, L., Hammarberg, K., 2014. Gamete donors' expectations and experiences of contact with their donor offspring. *Hum. Reprod.* 29, 731–738.
- Kramer, W., Cahn, N., 2013. *Finding our Families: A First-of-its-kind Book for Donor Conceived People and Their Families*. Penguin, New York.
- Lehmann-Haupt, R., 2010. Are Sperm Donors Really Anonymous? DNA Testing Makes Them Easy to Trace. (<http://www.slate.com/id/2243743>). 25.01.2013).
- Levine, A.D., 2010. Self-regulation, compensation, and the ethical recruitment of oocyte donors. *Hastings Cent. Rep.* 40, 25.
- Mason, J., 2003. *Qualitative Researching*. Sage, London.
- McWhinnie, A., 2000. Families from assisted conception: ethical and psychological issues. *Hum. Fertil. (Camb.)* 3, 13–19.
- Motluk, A., 2005. Anonymous sperm donor traced on internet. *New Sci.* 2524, 6.
- Nelson, M.K., Hertz, R., Kramer, W., 2013. Making sense of donors and donor siblings: a comparison of the perceptions of donor-conceived offspring in lesbian-parent and heterosexual-parent families. *Contemp. Perspect. Family Res.* 7, 1–42.
- New South Wales Law Reform Commission AC, 1986. Human artificial insemination. Report 49 at (5.4).
- New South Wales Parliamentary Committee on Law and Safety, 2013. *Managing Donor Conception Information*. New South Wales Parliament, New South Wales.
- Oberlandesgericht Hamm, 2013. I-14 U 7/12 (Superior Court Decision in Germany).
- Parliament of Victoria. Law Reform Committee, 2012. Inquiry into access by donor-conceived people to information about donors. Report of the Law Reform Committee for the Inquiry into Access by Donor-Conceived People to Information about Donors (http://www.parliament.vic.gov.au/images/stories/committees/lawreform/iadcpiad/DCP_Final_Report.pdf). 05.01.2015).
- PCVAI, 2000. People Conceived Via Artificial Insemination. <http://groups.yahoo.com/group/PCVAI>. 06.01.2015.
- Pennings, G., 2001. The right to privacy and access to information about one's genetic origins. *Med. Law* 20, 1–15.
- Procréation Médicalement Anonyme. <http://www.pmanonyme.asso.fr>. 05.01.2015.
- Ravitsky, V., 2012. Conceived and deceived: the medical interests of donor-conceived individuals. *Hastings Cent. Rep.* 42, 17–22 (Jan-Feb).
- Rees, A., 2012. Keeping mum about dad: 'contracts' to protect gamete donor anonymity. *J. Law Med.* 19, 758–768.
- Riggs, D.W., Scholz, B., 2011. The value and meaning attached to genetic relatedness among Australian sperm donors. *New Genet. Soc.* 30, 41–58.
- Rodino, I.S., Burton, P.J., Sanders, K.A., 2011. Donor information considered important to donors, recipients and offspring: an Australian perspective. *Reprod. Biomed. Online* 22, 303–311.
- Sauer, J.L., 2009. Competing interests and gamete donation: the case for anonymity. *Seton Hall Law Rev.* 39, 919–954.
- Scheib, J.E., Cushing, R.A., 2007. Open-identity donor insemination in the United States: is it on the rise? *Fertil. Steril.* 88, 231–232.
- Scheib, J.E., Ruby, A., 2008. Contact among families who share the same sperm donor. *Fertil. Steril.* 90, 33–43.
- Scheib, J., Riordan, M., Rubin, S., 2005. Adolescents with open-identity sperm donors: reports from 12–17 year olds. *Hum. Reprod.* 20, 239–252.
- Schweiz, Spenderkinder, 2009. <http://www.spenderkinder.ch/Spenderkinder/Home.html> (05.01.2015).
- Searching for my sperm donor father. <http://www.searchingformyspermdonorfather.org> (05.01.2015).
- Spain, 2006. Law 14/2006: 27th May 2006. BOE no. 126.
- Speirs, J.M., 2012. Semen donors' curiosity about donor offspring and the barriers to their knowing. *Hum. Fertil. (Camb.)* 15, 89–93.
- Spenderkinder, 2006. <http://www.spenderkinder.de> (06.01.2015).
- Tomazin, F., 2013. Sperm donor daughter dies after reunion. *The Age* (April 7, 2013). http://newsstore.theage.com.au/apps/viewDocument.ac?page=1&sy=age&kw=SPERM+DONOR+DAUGHTER+DIES&pb=all_ffx&dt=selectRange&dr=5years&so=relevance&sf=text&sf=headline&rc=10&rm=200&sp=nrm&cclsPage=1&docID=SAG1304079F3L67HIPKB.
- Turner, A., Coyle, A., 2000. What does it mean to be a donor offspring? The identity experiences of adults conceived by donor insemination and the implications for counselling and therapy. *Hum. Reprod.* 15, 2041–2051.

- Turney, L., 2010. The making and breaking of paternity secrets in donor insemination. *J. Med. Ethics* 36, 401–406.
- Victoria, 2014. Assisted Reproductive Treatment Further Amendment Act 2014 (Amendment Act) (No. 58 of 2014).
- Wilde, R., McTavish, A., Crawshaw, M., 2014. Family building using donated gametes and embryos in the UK: recommendations for policy and practice on behalf of the British Infertility Counselling Association and the British Fertility Society in collaboration with the Association of Clinical Embryologists and the Royal College of Nurses Fertility Nurses Forum. *Hum. Fertil. (Camb.)* 17, 1–10.
- Yuen, S., 2007. Information privacy approach to regulating the middlemen in the Lucrative Gametes Market. *Univ. Pa. J. Int. Law* 29, 527–562.