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ORIGINAL ARTICLE

## 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

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### Abstract

This article describes recent practice experiences with donor conceived adults, donors, non-donor-conceived adult children of donors using the voluntary DNA-based register, UK DonorLink. It highlights additional complexities faced when using DNA rather than paper records for searching, in particular from the risk of false positives, low chances of success and potential inclusion of biological parents' DNA. Professionals' experiences in supporting those being "linked" suggest challenges as well as rewards. Registration carries the potential to be therapeutic for donor-conceived adults and donors and to enhance their political awareness regardless of links being made. Registrants value both peer and professional support, providing the latter can respond flexibly and be delivered by staff experienced in intermediary work. Given that the majority of those affected by donor conception internationally come from anonymous donation systems, these findings are highly pertinent and argue the need for political and moral debate about such service provision.

**Keywords:** *Voluntary register, donor-conceived adults, donors, donor linking, searching*

### Background

This article describes recent practices at UK DonorLink (UKDL), the world's first DNA-based voluntary register service for donor-conceived adults (DCAs), donors and their offspring (for earlier experiences, see Crawshaw & Marshall, 2008). UKDL opened in 2004 for those affected prior to the launch of the Human Fertilisation and Embryology Authority's statutory register in August 1991. Registrants have no legal right to access relevant paper records or information, mirroring the experience of most DCAs and donors internationally (Allan, 2012).

The government's decision to pilot and fund the service was intended to test the need for a voluntary register and explore how best to provide it (for an account of the openness campaign, see Wincott & Crawshaw, 2006). In 2010, the Public Health Minister declared the pilot successful and that its future should be secured. Despite confirmation by subsequent Ministers, this has not yet been achieved, nor have evidence-based decisions been made about features of an ongoing service despite government assurances of being "very happy with the service

that has been provided" and of being "... very keen to ensure the valuable lessons from the pilot ... will be taken forward..." (personal correspondence March 2010).

Recent developments elsewhere include a professionally-led service in The Netherlands (Fiom-KID Register [http://www.fiom.nl/KID-register\\_en\\_DNA-data\\_bnk/f4029003/0/KID-register\\_en\\_DNA\\_databank.aspx](http://www.fiom.nl/KID-register_en_DNA-data_bnk/f4029003/0/KID-register_en_DNA_databank.aspx)) and recommendations by the Legal and Constitutional Affairs References Committee (2011) and the Victorian Law Reform Committee (2012) to establish a DNA-based service in Australia. Non-DNA-based voluntary registers appear to be used primarily by parents of younger children desiring knowledge of, and/or contact with, the donor and other families thus formed (Freeman et al., 2009; Crawshaw, 2011; Hertz & Mattes, 2011).

### Profile of current registrants

By the end of June 2012, 558 people were registered or in the process of registering (i.e. had started but were still deciding whether or not to proceed or had not yet

fully completed the registration process): 357 donor-conceived adults (174 fully registered); 167 donors (82 fully registered); 34 “other” including 11 non-donor-conceived children of donors (4 fully registered) and the remainder of as yet unknown categorisation. Some remain “in the process” for a considerable time.

There are currently considerably more female (127) than male (47) DCA registrants, with a mean age for females of 34.0 years (range 20–66 years) and for males of 35.7 years (range 21–67 years). Of the fully registered donors, 74 were sperm donors (mean age 53.4 years, range 41–77 years) and 8 were egg donors (mean age 56.4 years, range 50–62 years).

After a gradual start which saw annual increases of around 30 in the early years of operation as might be expected in such a new service – but perhaps also reflecting difficulties of targeting promotion, and potential caution about DNA among would-be registrants – recent years have seen increasing rates of take-up with the 3 most recent annual rises being 87, 72 and 172. This profile may also reflect the increased mainstream media coverage of the service itself and of the issues involved in “search and contact” following donor conception.

Take-up thus remained surprisingly robust despite uncertainty over the Register’s future in the wake of the Government’s announcement of the success of the pilot in Spring 2010 and subsequent failure to provide/achieve permanent funding. However, new registrations in recent months have dropped considerably, perhaps because of the publicity surrounding the ongoing funding difficulties, the recently stated government intention to combine the service with the promotion of donor conception and donor recruitment and fund the National Gamete Donation Trust, who currently provide the latter service, to provide both (Pepa, 2012) or for some unrelated reason. The Department of Health have now indicated that this is now likely to go out to open tender, as a combined service.

### Challenges of using DNA

Using DNA rather than paper records to search brings additional complexity. DNA testing cannot provide absolute certainty of the presence of genetic relationships, especially “sibling” relationships. In addition, those seeking information through this route are reliant solely on their genetic relatives also registering rather than being able to retrieve information from existing paper records. Professional support can be important for managing expectations and disappointments.

Comparison of DNA profiles cannot provide certainty, especially without supporting data such as donation and conception taking place at the same clinic and/or “siblings” born within reasonable timescales. Some donors have poor recall about when, where and for how long they donated. Although inclusion of DCAs’ biological parent’s DNA increases test accuracy, parents may have died, be unaware of the search or refuse to help.

Professional support is offered for mediating or coping with absence of parental involvement.

Where initial results suggest possible “links” between females or males, further DNA tests (“x” and “y” chromosome) are offered but some move straight into information exchange and/or contact. UKDL only considers a link significant where the likelihood ratio concerned is 100 or above – i.e. 100 times more likely than not to be genetically related to each other – and preferably where the DCA biological parent’s DNA and/or supporting data are available. The use of this linkage probability is informed by laboratory advice and reflects our ethical concerns about raising “false hopes” and practical concerns about absorbing staff resources when probabilities are very low. Some DCAs recently challenged this approach as inappropriately gate-keeping [their] information and resonating with denied access elsewhere to donor information. We therefore conducted a pilot with 13 DCAs, releasing results in full and, on request, contacting registrants with whom they had a “link” regardless of probability levels. This proved resource-intensive, dissatisfying to those who found resulting uncertainty too great (especially where it involved opposite gender registrants and hence no recourse to “x” or “y” tests) but satisfying for those who found it more open and hopeful. Discussions about future practice are ongoing.

Some registrants prefer UKDL staff (predominantly post adoption social workers, counselling trained and aware of DC matters) to GPs to witness their DNA test (usually for privacy, sometimes to avoid GP charges) and in the process, discuss issues and feelings. Its therapeutic value, together with ongoing contact with headquarters-based staff, may contribute to the low take up of formal therapeutic counselling at any stage.

Paying for DNA tests poses financial and/or emotional barriers for some. Additionally, the introduction into the market of new types of DNA tests which some believe to be more accurate but about which there is scientific debate (Adams & Lorbach, 2012) present practical and other challenges of whether and how to change the tests used (and perhaps the laboratories), potentially involving re-testing and prompting anxiety and financial costs for those already registered.

### Experience with donor-conceived adults

While some registrants had traumatic experiences and poor family relationships, others appear emotionally stable with a strong sense of self, and robust family relationships suggesting the desire to search is not pathologically driven. Such patterns match those of adults adopted in infancy (Howe & Feast, 2000).

We find similarities to the existing [limited] research evidence (for a review see Blyth et al., 2012 [This review searched from 1990–2011 and found that only 19 papers from 13 studies were published, all since 2000. Readers are directed to the review paper for specific details of studies and their findings.]) – including that

specific to UKDL registrants (Blyth, 2012) – and some unreported reactions. Those distressed or disturbed by disclosure or by being donor conceived (separating root causes can be difficult) can report feelings of betrayal, anger, relief, shame, identity confusion and genealogical bewilderment. Some feel disturbed by the thought of being “conceived in a Petri dish,” “mass produced” or akin to “animal husbandry.” Some have concerns about accidental incest. A few have health-related needs driving their search – for example the need for a bone marrow donor or desire to pass on crucial health information. Many feel angry, frustrated and powerless at having no access to records. Some have changed their views about DC over time, more often towards being critical than supportive.

Despite the absence of a pre-conception relationship between donor and biological-social parent, we find more similarities than differences in the information needs of DCAs and adopted adults. All are curious for information they feel necessary to that part of their biographical identity attached to biological/genetic connections. Thus, as well as basic demographic and health details, they are often interested in their “absent biological parent’s” physical appearance, personality traits, hobbies, occupation, family and whether they are still alive. Both groups appear keen to know their reasons/motivation for involvement in their conception and apparent disinterest (or, in the case of some adoptions, inability) in parenting them.

Unlike our experience with most adopted adults coming forward to search, large numbers of DCA registrants learn of their origins as adults and in adverse circumstances (family arguments; following a death) and quickly turn to searching. Some parents only disclosed when the DCA was offered (or undergoing) invasive tests for congenital disease for which they were not at risk. Others, like Rachel, worked it out for themselves:

My parents never told me they had used a donor to conceive me, but when I was 25 I worked out that I could not be related to the father who brought me up and they had to tell me the truth. I felt shattered and isolated ...

<http://www.ukdonorlink.org.uk/stories.asp>

Relationships with key “others” can be strained or estranged, especially when disclosure is late or accidental: as above, apportioning relative cause (to disclosure or the decision to search) is difficult. However, some have strong relationships with parents *and* appear able to cope with late disclosure if they can understand parents’ reasons. Cognitive and affective processing of disclosure and its implications, including for relationships previously assumed biological, is needed and this takes time (see also Daniels & Meadows, 2006). New situations, including registration, can also prompt reappraisal of previously processed thoughts and feelings. Some – registrants and family members alike – welcome professional support at other times as well as in the early stages of contact,

making it inappropriate to be limited to the registration process alone. Others take a more hands off approach, drawing instead on their own resources.

Some report that registration makes them feel more in control of their lives (what is called “personal agency”) and reduces isolation, even without a link. As many have not previously met other DCAs or have been raised with DC siblings little interested in searching, some find relief in knowing their reactions are normal.

Although DCAs are most interested initially in tracing their donor, the possibility of tracing half siblings is typically welcomed. Some struggle with terminology about existing or potential new “relatives” (Hertz, 2009; Blyth, 2012; Johnson et al., 2012).

### Experience with donors

Despite fears to the contrary, large numbers of donors have registered (ratio 1:2 of donors to donor conceived adults) though some, worryingly, reject our advice to inform partners or children of this. Their reasons for registering resonate with research findings that (sperm) donors may think about offspring periodically regardless of their original motivation to donate (Daniels et al., 2005; Thorn et al., 2008; Riggs & Scholz, 2011); may feel apprehensive about contact and welcome intermediary services on hand (Crawshaw et al., 2007; Johnson et al., 2012); and can gain satisfaction from contact with offspring (Jadva et al., 2011). Some are curious to meet biological offspring and/or feel a responsibility to meet their information needs; a few appear hopeful of a relationship. Some are distressed by awareness that their donation may have led to negative outcomes. Many consider with hindsight that they had too little understanding of its implications (as in Speirs, 2012). Some seek help with informing family members of their past donation. A small number of donors report troubling memories of the physical and emotional context of their donation, though the majority do not. As with DCAs, donors appear to welcome professional support at various stages while others manage with their own resources.

John illustrates how his awareness changed over time:

At the time, I gave knowing it was totally anonymous, there was no comeback and the outcome was nothing to do with me. But, as the years have passed I feel ..... I don’t want to be anonymous. It is like giving a pair of shoes to a child but keeping the laces, or giving a picture without the name of the artist.

<http://www.ukdonorlink.org.uk/story2.asp>

### Role of peer support

Peer support has developed not only between DCAs but also between donors and DCAs. Putting a face to the

other “side” appears therapeutic, and ensuing relationships have proved beneficial. For example one donor recently supported a DCA to their mutual benefit in her moves to approach the clinic where she was conceived and where he had donated. Having access to both peer and professional support meets different but complementary needs, as Bev illustrates:

... I have through the service received great support and advice from the staff and been put in touch with many other DCAs and donors. We are a very close community who regularly chat on the internet and arrange meetings between ourselves ..... I no longer feel alone. All the thoughts and feelings I have had over the years have been normalized as I discovered others share in these feelings, it is not just me.

<http://www.ukdonorlink.org.uk/stories.asp>

The UKDL Registrants Panel contributes significantly to UKDL’s development, drawing on their wide range of views about DC. Members have also increasingly engaged in external lobbying for the continuation of their service, with politicians, civil servants, HFEA, media and others. Mahlstedt et al. (2010) have argued that the coming together of DCAs on the basis of their shared oppression to challenge existing orthodoxies is a new “social movement.” Our Panel’s ability to provide contextual analysis that moves beyond “only” being personal (Pepa, 2012) supports that.

### Experiences of linking

To date, UKDL has established or confirmed 6 donor to DCA links and 35 probable “sibling” links: a surprisingly high rate:

- 1 group of 11 “siblings”;
- 1 group of 5 “siblings”;
- 1 of 3 “siblings”;
- 8 of 2 “siblings.”

Some groups have gained members over time. This has required professional support to the new member whilst ensuring existing members are notified and offered support simultaneously. New members of the two largest groups (which both know the donor’s identity) learn the identity of their donor as well as “siblings,” suggesting the importance of professional support at this time:

The feelings that surround the discovery of the identity of one’s [donor] father or half siblings are complex and cannot be dealt with in a quick chat with a friend. A new sibling is not necessarily the best person to explore such feelings with ..... This is not a job for DIY but needs experienced and qualified staff.

Letter from Shirley Brailey to HFEA, August 2010, reprinted with permission.

Reactions to possible links have varied. Some move straight into contact, regardless of the risk of a false positive and without further DNA tests – usually because of the strength of the probability and/or supporting information, but not always. Others, even at very high levels of possible linkage are cautious and can take months before deciding to take the next steps.

The limited research suggests the outcomes of contacts are largely positive (Jadva et al., 2010; Blyth, 2012). Our experience is that realigning relationships and “kin” networks after linking can nevertheless be demanding. While many have established satisfying and sustained relationships – in some cases involving family and friends, children and grandchildren – a few have found the aftermath more difficult, bringing new pain to that previously there. Others choose to retain an emotional distance, perhaps satisfied with information alone.

For most, professional support is accessed intensively in the run up to contact (*anticipation*) with fewer needing intensive support afterwards (*reality*). Registrants tell us they value having well-informed professionals, experienced in intermediary work, “walking alongside” them: weighing the risks (and rewards) of information exchange/contact without absolute certainty of genetic connection; considering its impact on themselves and existing relationships; managing the contact process both immediately and over time. As with registration-related needs, the flexible responsiveness of the service appears to be welcomed – sometimes “little and often,” sometimes bursts of intensity, often by telephone or email rather than face-to-face and rarely requiring more formal counselling.

An additional professional challenge arises from there ‘being no “primary” client. Linkages involve at least two individuals (sometimes many more) and resolution of any conflicting needs cannot therefore be informed by affording priority to any one party. This can include, for example, when one party asks for confidentiality about issues with which they are seeking help and this leads to the other(s) believing UKDL itself is blocking progress.

### Conclusion

Our experience, added to the growing research evidence, suggests the need for DNA-based register services for those without access to relevant paper records. The growth of our register – especially as it has become more widely known – together with the very small numbers (3) who have withdrawn, further indicate that donor-conceived adults, donors and their non-donor-conceived children consider its value sufficient to outweigh the uncertainties that attach to the use of DNA for “linking” and the low likelihood of achieving a “link.”

There is a political and moral debate to be had about who should carry responsibility, including financial, for providing such services. This article indicates that wherever responsibility lies, services should include both professional and peer support, meeting as they

do different but complementary needs. Our view is that professionals should be trained and experienced in the dynamics of searching for genetic relatives and in intermediary work, with a good understanding of the unique context of donor conception and able to respond flexibly. In addition, there is a need, albeit small, for a formal therapeutic counselling service. Wherever future responsibility for providing this service rests (an issue currently under debate in the UK), these are, in our view, the minimum requirements for a safe, robust and user-centred service.

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