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# **GAMETE DONORS' REASONS FOR, AND EXPECTATIONS AND EXPERIENCES OF, REGISTRATION WITH A VOLUNTARY DONOR LINKING REGISTER**

## ***HUMAN FERTILITY***

**E. BLYTH, M. CRAWSHAW, L. FRITH, & O. VAN DEN AKKER**

*When I was at medical school, we had a lecture from a fertility expert, who encouraged the male students to donate to the hospital sperm bank. Moved by the stories of childless couples, I donated and thought little of it. Yet as I've grown older, I've sometimes caught myself wondering whether I am, indeed, a father. It's profoundly strange to think there may be children who, biologically, are mine – and yet I know nothing of them, nor they of me. (Pemberton, 2015)*

### **ABSTRACT**

This paper reports on a study of the views and experiences of 21 sperm donors and five egg donors registered with UK DonorLink (UKDL), a voluntary DNA-based contact register. Specifically, the paper examines donors' reasons for searching for, or making information about themselves available to donor-conceived offspring. Their expectations of registration with UKDL, experiences of being registered and finally, the experiences of those who had made contact with donor-conceived offspring and other genetic relatives are investigated. While most respondents reported largely positive experiences of registration, the study found significant issues relating to concerns about donation, about DNA testing, possible linking with offspring and expectations of any relationship that might be established with offspring that have implications for support, mediation and counselling. Research that puts the experiences, perceptions and interests of gamete donors as the central focus of study is a relatively recent phenomenon. This study contributes to this research and highlights directions for future research in this area.

### **INTRODUCTION**

From its earliest beginnings as a medical procedure, donor conception was considered to require secrecy (including from the offspring) and anonymity between donor and recipient (Barton et al., 1945; Royal College of Obstetricians & Gynaecologists, 1987; Novaes, 1998). Furthermore, any “unusual” interest (in practice any interest at all) shown by a potential

donor in the outcome (Johnston, 1980; Speirs, 2007) or plans to tell anyone about their donation (Finegold, 1964) was deemed a contraindication for recruitment.

However, from the 1980s, some sperm banks and national/state governments initiated systems to facilitate the disclosure of information between donors and offspring (Scheib, 2003; Johnson, 2013; Blyth & Frith, 2015). Although primarily motivated by a desire to enable donor-conceived people to learn more about their biogenetic<sup>1</sup> and biographical heritage, provisions in some jurisdictions explicitly acknowledged and legitimated donors' interests in the outcomes of their donation (Raes et al., 2013; Blyth & Frith, 2015), and social scientists began to explore such interests (Jadva et al., 2011; Riggs & Scholz, 2011; Daniels et al., 2012; Speirs, 2012; Daniels & Kramer, 2013; Kirkman et al., 2014). The UK was one of the first jurisdictions to implement legislation requiring details of donors, and the outcomes of donations to be registered by a state regulator, the Human Fertilisation and Embryology Authority (HFEA) (Blyth & Frith, 2015). Implemented in 1991, this legislation gave a donor-conceived individual the right to request non-identifying donor information from the HFEA from age 18, although it did not apply retroactively. A 2004 legislative amendment required all prospective donors to agree to disclosure of their identity as well. Since these provisions affected only donor procedures taking place *after* 1991, a voluntary register, UK DonorLink (UKDL), was established in 2004 with government funding to help donor-conceived adults and donors (and their non-donor-conceived offspring) involved in a pre-1991 donor procedure to identify each other voluntarily and, if mutually agreed, to share information and contact. In the absence or inaccessibility of formal records relating to pre-1991 donations, UKDL's linking services relied on DNA testing. In 2013 UKDL's functions were transferred to the Donor Conceived Register (DCR) (Crawshaw et al. 2013).

Previous research investigating the sharing of personal information following donor conception has tended to focus on the perspectives of donor offspring, with relatively limited attention paid to that of donors (Van den Broeck et al., 2013). Most of the available research has involved sperm donors, and some egg donors, who donated anonymously, a very small number of whom subsequently took active steps to make available personal information to any offspring. Rather less research has investigated the attitudes and experiences of women who donated eggs to a known recipient (Purewal & van den Akker, 2009). More recently, Swedish research has investigated attitudes and experiences of egg and sperm donors

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<sup>1</sup> the term 'biogenetic' is adapted from Strathern (2005), to include genetic/biological information

voluntarily enrolled in an identity-release donor programme (Lampic et al., 2014) and research from the Netherlands has reported on counselling needs of identifiable sperm donors (Visser et al., 2016).

Given the specific focus of the study reported here, the literature summarised below focusses only on those recruited as anonymous donors and indicates a range of views regarding the outcomes of their donation. Five key themes emerge from this research. First some donors are curious about offspring - including health, education and physical characteristics.

(Handelsman et al., 1985; Daniels, 1987, 1989; Mahlstedt & Probasco, 1991; Kalfoglou & Geller, 2000a ,b; Daniels et al., 2005; Scheib et al., 2005; Jadva et al., 2011; Daniels et al., 2012). Second, some wonder about the wellbeing of offspring and feel some responsibility for them (Söderström-Anttila, 1995; Jordan et al., 2004; Kirkman, 2004; Ernst et al., 2007; Hertz et al., 2015). Third, some are willing to release non-identifying genealogical and medical information to offspring (Daniels, 1987; Mahlstedt & Probasco, 1991; Pedersen et al., 1994; Daniels et al., 1996a, b; Speirs, 2012). Fourth, some are willing to disclose their identity to offspring (Robinson et al., 1991; Cook and Golombok, 1995; Thorn et al., 2008; Kirkman et al., 2014). Finally, some are willing to establish varying levels of contact with offspring, from one-off meetings to close and longer-term personal relationships, using a range of media, ranging from internet communications to face-to-face contact (Daniels, 1989; Mahlstedt & Probasco, 1991; Kirkland et al., 1992; Kalfoglou & Geller, 2000a, b; Braverman & Corson, 2002; Klock et al., 2003; Daniels et al., 2005; Godman et al., 2006; Crawshaw et al., 2007; Ernst et al., 2007; Jadva et al., 2011; Daniels et al., 2012; Speirs, 2012; Kirkman et al., 2014; Hertz et al., 2015).

Of special relevance to the present study are three recent studies involving donors registered with the US-based Donor Sibling Registry (DSR). These investigated attitudes and experiences of donors initially recruited anonymously and who subsequently took active steps to share information about themselves and possibly make contact with offspring (Jadva et al., 2011 [63 sperm donors and 11 oocyte donors]; Daniels et al., 2012 [164 previous sperm donors]; Hertz et al., 2015 [57 sperm donors]). Reinforcing previous research findings, most DSR respondents demonstrated particularly high levels of commitment to providing information for, and willingness to make contact with, offspring if desired. These studies also advanced an understanding of the dynamics of actual contact and its impact on donors and their families. While donors who made contact with offspring (or with parents in the case of offspring too young to engage in direct contact) generally recounted this as a positive

experience, some reported challenges. These included: having less contact than they desired and tensions in relationships with members of their own family (mostly partners and to a lesser extent their children); where some level of secrecy was being maintained in the offspring's family; where the offspring's mother was a single woman; and where contact was terminated by an offspring's mother.

The aim of the current study was to provide information about the views and experiences of donor-conceived adults (van den Akker et al., 2015) and gamete donors registered with UKDL, a voluntary DNA-based register for adults wishing to identify and locate other people to whom they were genetically related following donor conception. In addition to basic demographic data the study sought information about registrants' reasons for registering with UKDL, their experiences of registration, their views about the operation of the register, and services provided by UKDL and its funding and, where this had occurred, their experiences of contact with donors and/or donor offspring or any other people with whom they had a genetic relationship as a result of gamete donation. This paper specifically reports on information provided by gamete donors regarding their reasons for searching for genetic relatives and specific triggers for registration with UKDL, their expectations and experiences of registration, the experiences of those who had contacted one or more donor genetic relatives and finally, experiences of distress and retrospective unease regarding gamete donation.

## **METHODS**

Drawing on prior research and their previous practice experience, the authors devised a questionnaire comprising 96 questions (including specific sections for donors and donor-conceived adults) that also incorporated a modified version of Cheek's Aspects of Identity Questionnaire [AIQ]) (Cheek, 1989; van den Akker et al., 2015). The questionnaire comprised both open questions inviting free-text responses and closed questions requiring forced choice replies as well as the opportunity to include additional replies (using the formula "Other (please specify)" and to expand on pre-determined responses. In addition, in order to provide respondents with as much scope as possible to inform us of their thoughts and experiences of registration, a final question provided opportunity for any free-text comments that respondents considered relevant to our inquiry. The survey was administered online through Bristol Online Surveys - with hard copies available to participants on request. Completion of the online version required respondents to click on the relevant response

option(s) for responses to closed questions and to type their own words for free-text responses. In the hard copy version, respondents were required to tick the relevant response option(s) for responses to closed questions and to type or hand-write their free-text responses.

### **Data analysis**

Study data comprise both quantitative and qualitative data. Descriptive statistics are used to analyse quantitative data and qualitative data were analysed thematically (Braun & Clark, 2006), using *Atlas.ti* software. The emergent analysis of qualitative data was discussed within the team to reach agreement and explore different interpretations and linkages. All quotations in this paper are taken from the survey responses; incorrect spellings have been corrected but language and grammar have been left in their original form. Respondents are identified by gender (F/M) and number.

### **ETHICAL APPROVAL**

UKDL gave permission to undertake the study and ethical approval was given initially by Middlesex University (ref 57/1201/2/PS), subsequently ratified by Huddersfield and Liverpool Universities.

### **RESULTS**

#### **Study respondents**

At the start of this study in October 2012, 65 sperm and 7 egg donors were registered with UKDL, of whom 21 sperm donors (32.3% of all registered sperm donors) and five egg donors (71.4% of all registered egg donors) participated in the study. The actual response rate is likely to be higher than this however, since UKDL advised the research team that not all registrants had informed UKDL of contact changes, and so would not have received information about the study. All respondents had donated prior to 1991 under conditions of anonymity. At the time of the study, the age of egg donors ranged from 51 to 61 years, and that of sperm donors from 42 to 78 years. Most donors had no or limited information about the outcome of their donation. Two egg donors and three sperm donors knew that donor-conceived offspring had been born from their donation and three of these had established contact with their donor-conceived offspring; one sperm donor had established contact with a grandchild via donor conception. Two egg donors stated that they had adult donor-conceived children themselves who had also registered with UKDL. All topics on which this paper

reports elicited a high level of response from participants, with virtually no non-responses to specific questions, as indicated in the Tables below.

### **Donors' reasons for searching for genetic relatives and for registration with UKDL**

Respondents indicated that their search for genetic relatives was prompted not only to make contact so that they could provide any offspring with information about them, but also to provide information for their own family, especially children of egg donors, and to satisfy their own interests (as indicated in Table 1 below):

Table 1 here

Twelve respondents (one egg donor and eleven sperm donors) elaborated on these themes as the following quotations illustrate:

*So that any offspring can contact their biological parent, if that's what they want to do (M71).*

*Not wanting a child to know they were donor conceived but be unable to trace their biological father if they wished to do so (M81).*

*I just felt a strong need to meet my donor offspring and to offer them the chance to ask questions etc. .... [I]t was very important to me that my son got the chance to meet his half sister and brother as he is donor conceived and I hoped it would give him an extra sense of family/identity (F10).*

*I would dearly love to make contact with my offspring. However, were none of my offspring ever to foster a desire to contact me, then I would take a view that it meant my children were sufficiently comfortable in their own identity and basically happy without my presence in their lives, and I would be content with that too (M70).*

The majority of respondents indicated a long-standing interest in information about donor conceived offspring, which for some dated back to the time of donation. One sperm donor reported an interest extending for over 30 years, while twelve more indicated length of interest between 10 and 20 years:

*A lot of years but only recently found out that it may be possible (F31).*

*I was always curious, more so as I reached middle age, curious to see how they turned out (M68).*

Respondents were also asked “what, if anything, provided a particular trigger to register with UK DonorLink when you did?” The two most frequently reported triggers for both sperm and egg donors were starting to feel that they should register in case someone was looking for them and learning about UKDL for the first time. The death of a key family member and starting their own family were also cited as trigger events (as indicated Table 2 below):

Table 2 here

Nine respondents (two egg donors and seven sperm donors) elaborated on their responses; two sperm donors reporting being prompted by watching TV documentaries on donor conception:

*Saw BBC Documentary in early 2000s about a DC offspring searching for their donor father (M70).*

*Saw a documentary film on the subject (M81).*

### **Donors’ expectations of registration**

Although those registering with UKDL do so in the hope that this will result in a link of some kind being made with one or more genetic relatives, donor respondents were generally unsure about the likelihood of any link actually being made. This was the case even for sperm donors who estimated that they could have many offspring. For example, M70 calculated he may have between 75-110 offspring “out there”. However, he thought that “maybe 5% will make contact eventually”, and while he would “dearly love” to make contact with any offspring, to date, none had done so.

Of the 19 sperm donors who expressed a view (i.e. excluding the two sperm donors who had already made contact with offspring), more than half (11) were unsure that a link would be made, seven expected a link to be made, and only one did not expect a link to be made. Excluding the egg donor who was in contact with the recipient of her eggs and the resultant children, three egg donors were not sure if a link would be made and one had no expectation that a link would be made.

Most respondents were positive about being on the register, although five sperm donors appeared to anticipate possible difficulties regarding contact, five sperm donors worried that they might ‘find out more than they anticipated’, six sperm donors and three egg donors feared they might never being linked, five sperm donors and three egg donors were concerned about coping with the fact that DNA results are not 100% accurate and twelve sperm donors, but only one egg donor, considered that ‘getting ‘false positive’ results would be ‘possibly difficult’.

### **Donors’ experiences of registration**

The study enquired about respondents’ experiences of registration with UKDL. First, we were interested in learning to whom in their family and close social networks they had confided their decision to register, both at the time of registration itself and at the time of the study (Table 3). Levels of disclosure to family members, i.e. parents, partners and children, may be higher than these figures suggest since non responses may also include those who had no parents, partner or children at the relevant time. What the data indicated, not surprisingly, is that among family members, partners tend to be the best informed about respondents’ decision to register with UKDL and that all donors, especially sperm donors, are more likely to disclose to friends over time. However, a good proportion of parents and children were not informed of donors’ registration.

TABLE 3 here

Respondents were also asked what impact, if any, knowledge of their registration with UKDL had had on their relationships with their parents, partner, children, friends and others. Of those reporting some impact, one egg donor and three sperm donors providing additional comments:

*My son who is donor conceived registered himself at 18 years old and this was as a result of my being registered as an egg donor, he was aware of the service offered and was supported by them in his search to find more info. about his biological father ... [He]was aware that he had 2 half siblings as a result of my donation. He was interested to know about them and meet them if it were possible which it was last year. (F10 - reporting the only impact concerned her donor-conceived son).*

*Most disapproved (M32 - reporting that his relationship with parents, partner and friends had been affected “a little”).*



*It feels uncomfortable to talk about, I would like to resolve it but at the same time I would rather not have to* (M66 who reported “a little” impact on relationships with his partner and friends).

*Some concerns from partner and mother* (M70 reporting “a little” impact on relationships with his parents and partner).

Three other respondents, whilst reporting no actual impact on relationships, offered further comments:

*My wife would be very happy and interested if donor children were discovered* (M53).

*They [friends and others] were interested to hear about it. No more* (M2).

*It gave us a little hope of "having" a link to a child of ours* (F80 - who had no children of her “own”).

### **Donors’ experiences of contact with donor offspring and others**

As reported above, few donors had expectations that registration with UKDL would result in a link being made with any offspring. However, three respondents had established contact with their donor-conceived offspring and one reported being in contact with the grandparent of his donor-conceived offspring.

It is noticeable that all three donors reported that linking with offspring had changed both their sense of family and sense of self and that, unlike donors who had not yet been linked, none anticipated difficulties regarding types and levels of contact. However, the prospect of ‘false positive’ results was considered a possible difficulty by all three, thus echoing one of the principal concerns expressed by not-yet-linked donors, and two reported that contact had resulted in some negative consequences for them. Interestingly, all three linked donors expressed uncertainty about the emotional demands of linking.

Two respondents elaborated on their responses.

M54 who, as shown in Tables 4 and 5, indicated the highest levels of uncertainty and potential problems related to contact, further expressed his doubts in the context of his perception of himself as a father to someone about whom he has previously known nothing and has never seen:

*It has confused me. How do I behave as a dad? What am I expected to do or say? Do they want to see me or hear from me after my initial letter...*

F10 wrote at length about her thoughts and experience related to linking:

*This is a complex area and there is no rule book or guidance, I just felt a strong need to meet my donor offspring and to offer them the chance to ask questions etc. My story was somewhat unique ....[a]s I was aware of the recipient's identity albeit through chance I knew that twins were conceived from my egg donation 5 weeks after donating, hence I always hoped to meet them and be in contact with them, which I now am, it was very important to me that my son got the chance to meet his half-sister and brother as he is donor conceived and I hoped it would give him an extra sense of family/identity..... Having met my donor offspring ..... my son now knows his half siblings and is in contact, this is a modern family and it is the future. The most startling thing for me was how similar my son was to my biological donor son, they really do look alike and this was gratifying.*

TABLE 4 here

TABLE 5 here

### **Donors' experiences of distress and retrospective unease regarding gamete donation**

Although most responses to our inquiry were largely positive, analysis of free-text comments indicted that at least some, albeit a minority, had experienced distress and retrospective unease regarding gamete donation (four sperm donors and two egg donors). This was evident in free text responses to questions about reasons and specific triggers for registration, as well as in response to the invitation to provide any further free-text comments that they thought relevant:

*The absence of access to knowledge of their donor parents in my opinion constitutes a possible 'harm' to my offspring. It is a personal life principle 'to do no harm' and this is the best way I could act in accordance (M70)*

*Not wanting a child to know they were donor conceived but be unable to trace their biological father if they wished to do so (M81)*

*I am worried that any child/children who were born have not had a good life and may be in need. .... I have bad feelings about the private gynaecologists who were earning great sums*

*of money in my particular case. I was approached when I worked at X hospital purely because of my looks – blonde, blue eyed, tall, good physique and good intelligence. So sick now I think about it. Nazi Germany comes to mind (M87).*

He also referred to feelings of “guilt” and a desire to help ... If they are in need of support or help and added that “any help to trace any dependants would be appreciated”.

*I am aware that many adopted late teens turn out extremely troubled and would have thought that some DC persons would be of a similar mind-set, particularly males (M86).*

*I ache for it [making contact] to happen, but am also realistic in realising how unlikely it is (F80 - our emphasis).*

F78 wrote that a major concern of donating for her had been “the not knowing”.

## **DISCUSSION**

This paper reports on the first study to be undertaken of the views and experiences of gamete donors who have registered with the UK’s voluntary donor contact register, UK DonorLink (UKDL). As has been found in previous studies, conducted in various countries, respondents in this study indicated that their reasons for linking with donor offspring was multifaceted. Primarily the reasons reported included a wish to assist any individual born from gamete donation seeking information about their biogenetic and biographical heritage and a desire to inform their “own” children about any genetic half-siblings they may have.

More than has been observed in earlier studies, respondents in this study highlighted a wish to satisfy their own needs for information and contact and to assuage any apprehensions, and responsibility for this, as to how their lives had turned out (Daniels, 1989; Mahlstedt and Probasco, 1991; Kirkland et al., 1992; Kalfoglou & Geller, 2000a, b; Braverman and Corson, 2002; Klock et al., 2003; Daniels et al., 2005; Godman et al., 2006; Crawshaw et al., 2007; Ernst et al., 2007; Jadva et al., 2011; Daniels et al., 2012; Speirs, 2012; Kirkman et al., 2014; Hertz et al., 2015).

In contrast to prevailing orthodoxy at the time these men and women donated, when donors “were not supposed to be revealed as donors, and not to give a second thought to having donated” (Speirs, 2012:89), most respondents indicated that their interest in discovering the outcome of their donation and in any offspring had long-standing roots. The establishment of UKDL offered a possibility of taking active steps to further that interest.

Other researchers have noted that, even if a donor does not have a partner or children at the time of donation, donors do not live in a social vacuum and the decision to donate and to register with a donor register has implications for members of the donor's social network (Daniels et al., 2012). This was recognised by most respondents in this study, and only two (both sperm donors) claimed to have not told anyone about their registration with UKDL. In the main, disclosure of registration was reported to have limited impact, either negative or positive, on the donor's relationship with partners, parents, children, friends or others.

However, respondents appeared to be selective about those in whom they confided their decision to register. While partners tended to be informed of registration, parents and children were less likely to be informed. We found similar results in a previous study of UK pre-1991 sperm donors (Daniels et al., 2005), and this finding is also consistent with a report of UKDL's practice experience that some donors rejected advice from UKDL staff to tell family members that they were registering (Crawshaw et al., 2013). This could be problematic and have implications for the need for information, support and counselling services, especially if a link is made and contact between the donor and any offspring is established or if the donor's own children were to later and in an unplanned way discover their parent's involvement.

Respondents generally expressed few problems resulting from registration, although a minority worried about some aspects regarding linking with offspring. The first reported concern was agreeing on type and levels of contact with offspring. As one of the three respondents who had made contact with his offspring reported, such concerns may persist when contact is actually established. This finding is consistent with previous research investigating contact between donors and offspring which has also reported that donors may not always be satisfied with the contact they have managed to establish or may be disappointed with their contact (Freeman et al., 2009; Jadva et al., 2011; Daniels et al., 2012; Hertz et al., 2015). Indeed, two of the three respondents in the current study who had linked with offspring reported that contact had brought some negative consequences for them.

A key aspect of quality of relationships with donor-conceived offspring is the nature of relationship that is desired. Sperm donor R54 reported concerns about possible expectation of him as a "father" to any donor-conceived offspring. Egg donor R80, who reported having no children of her "own" and had not yet linked with any donor-conceived offspring, referred to possible offspring as "a child of ours", presumably meaning a child of her and her partner.

Previous studies of gamete donors have also found that a minority of donors regard their relationship to offspring to be that of parent-child (Daniels et al., 2012; Kirkman et al., 2014; Hertz et al., 2015). Studies of the views of donor-conceived adults reveal that few donor conceived adults regard this relationship in such a way (Blyth et al., 2012), so there is no guarantee of reciprocity of perceptions between donors and offspring in the event of a link being established.

Some respondents were also concerned about the fallibility of DNA testing and the risk of receiving ‘false positive’ results. Whilst rare, the personal impact of such erroneous linking can be devastating (Pryer, 2010). Despite these concerns, DNA testing has become increasingly accessible to members of the public independent of any intermediary agency such as UKDL. Indeed, a recently-published paper, provocatively entitled “The end of donor anonymity: how genetic testing is likely to drive anonymous gamete donation out of business” (Harper et al., 2016), highlights the potential contribution of DNA testing to ending donor anonymity regardless of legislative change in individual jurisdictions.

Three donors reported having made contact with donor offspring, each of them indicating that linking had changed both their sense of self-identity and family. As a corollary to the findings of Jadvá et al. (2011) who found that offspring contact with donors sometimes extended to the donor’s wider family, our study revealed that donors’ contact with offspring can also extend to members of the offspring’s family, such as grandparents. Registration thus poses a dilemma for registrants. Whilst it may lead to nothing at all, it could open up a whole range of extended family networks, possibly multiple family networks if several offspring are linked. Changes to donors’ sense of family following linking were previously noted by Hertz et al. (2015), and may become a forced reality (Harper, et al., 2016).

## **STUDY LIMITATIONS**

This study has some limitations. First, in common with similar studies in this field (Riggs & Russell, 2011; Visser et al., 2016) all our respondents were Caucasian; therefore, this study’s findings might not apply to donors from other ethnicities and backgrounds. Second, among UKDL registrants, compared to egg donors, relatively few sperm donors participated in the study, and the overall sample size was relatively small. Again, this is a not uncommon characteristic of research in this field (Jadvá et al., 2011). There is no way to ascertain whether the views and experiences of our respondents are shared by other donor registrants who were unaware of the survey, including those UKDL registrants who were ‘lost-to-

contact', or who were aware of it but chose not to participate. Furthermore, even though nearly three-quarters of UKDL's egg donor registrants took part in the study, the low number of egg donors registered with UKDL serves to emphasise the limitations of both the size and representativeness of our sample. That said, close scrutiny of participants' age and gender profile reflected the overall profile of UKDL donor registrants (Crawshaw et al., 2013) and it is important to recall the relatively low prevalence of egg donation before 1991. Third, our participants were self-selecting and had taken action to enable any offspring to find out about them and/or to seek out offspring to satisfy their own interests. They are, therefore, not representative of the wider body of gamete donors who have not initiated such steps. Nevertheless, the data are by design specific to this understudied population and the range of responses from even this relatively small sample of gamete donors highlights the diversity of their perspectives and experiences. Fourth, some data reported here are responses to specific questions in the survey; others are themes that emerged from analysis of the data. The collection of qualitative data via a survey such as used in this study is subject to specific limitations: it is not possible to probe responses and clarify understanding of the issues and questions, and contextual data (voice tone, emotion and body language) are not captured. However, invitations for respondents to provide free-text comments, which they used extensively, facilitated clarification and expansion of responses, as well as enabling respondents to comment on other issues related to the topic that they considered relevant.

## **IMPLICATIONS FOR PRACTICE AND FUTURE RESEARCH**

This study has highlighted a number of issues that have implications for practice and future research. The need for information, support, mediation and counselling is indicated in two key areas. First the comparatively low levels of disclosure by sperm donors of their registration to their own children; in the event of a link with offspring being made, this lack of disclosure is potentially problematic. Second, donors reported a number of negative considerations, including concerns about DNA testing and its accuracy, the management of linking and guilt about having donated in the first place. A potential mismatch between donors' and offspring perceptions and expectations of any relationship in the event of linking was also revealed. This study contributes to the relatively new research area that explores gamete donors' experiences as individuals in their own right and key stakeholders and the novel phenomenon of extended family networks unexpectedly discovering new 'grand children', 'cousins' etc. (Burke et al., 2015a, b; Nordqvist & Smart, 2014). Public education may provide a way forward to assist in 'normalising' these new processes which are set to

increase in the future. The study also points to the need for longer-term research with larger participant numbers and with donors in different situations (for example comparing and contrasting the experiences of initially-anonymous donors who later agree to be identifiable, donors who agree to the disclosure of their identity from the outset, and donors known to recipients from the outset) so as to gain a more comprehensive understanding of what it means to be a gamete donor.

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## **DISCLOSURE STATEMENT**

The authors have no conflict of interests to declare except for MC who was national adviser to UKDL from 2003-2013. The authors alone are responsible for the content and writing of the paper.

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**Table 1: What were the main reasons for your interest in searching for genetic relatives?**

Reason*	Sperm donors	Egg donors
To be able to pass on information about them to my own children/ family	8 (38%)	4 (80%)
To find out what has happened in their lives since the time of donation/conception	9 (43%)	2 (40%)
To make me feel more 'complete' in my identity	3 (14%)	1 (20%)
To satisfy my curiosity about these 'relatives'	11 (52%)	1 (20%)

\*forced choice responses

**Table 2: What, if anything, provided a particular trigger to register with UK DonorLink when you did?**

Particular trigger*	Sperm donors	Egg donors
Had started to feel that I should register in case anyone was looking for me	13 (62%)	4 (80%)
Read/heard about the service for the first time	11 (52%)	3 (60%)
Key family member died	2 (10%)	1 (20%)
Was starting my own family.	2 (10%)	0

\* forced choice responses

**TABLE 3: When you registered with UKDL, whom did you tell that you were registering and who knows now?**

	Told				Did not tell				Not applicable				No reply			
	Sperm donors		Egg donors		Sperm donors		Egg donors		Sperm donors		Egg donors		Sperm donors		Egg donors	
	At time of registration	No w	At time of registration	No w	At time of registration	No w	At time of registration	No w	At time of registration	No w	At time of registration	No w	At time of registration	No w	At time of registration	No w
<b>Parents</b>	3 (14%)	4 (19%)	1 (20%)	3 (60%)	14 (67%)	10 (48%)	0	0	2 (10%)	3 (14%)	1 (20%)	0	2 (10%)	4 (19%)	3 (60%)	1 (20%)
<b>Partner</b>	14 (67%)	16 (75%)	3 (60%)	3 (60%)	5 (24%)	3 (14%)	0	0	1 (5%)	1 (5%)	1 (20%)	0	1 (5%)	1 (5%)	1 (20%)	1 (20%)
<b>Children</b>	2 (10%)	5 (24%)	4 (80%)	4 (80%)	13 (62%)	10 (48%)	0	0	3 (14%)	3 (14%)	0	1 (20%)	3 (14%)	3 (14%)	1 (20%)	0
<b>Friends</b>	8 (38%)	13 (62%)	3 (60%)	5 (100%)	9 (43%)	7 (33%)	1 (20%)	0	1 (5%)	0	0	0	3 (14%)	1 (5%)	1 (20%)	0
<b>Others</b>	1 (5%) <sup>i</sup>	3 (14%)	0	2 (50%)	19 (90%)	8 (38%)	1 (20%)	0	3 (14%)	3 (14%)	0	0	7 (33%)	7 (33%)	4 (80%)	3 (60%)

<sup>i</sup> identified as family GP

**TABLE 4: Expectations and Experiences of linking – donors who have been linked**

<b>Expectations/experiences*</b>	<b>F10</b>	<b>M2</b>	<b>M54</b>
Do you believe that you will find more links through being on the register?	Not sure	Yes	Not sure
Did your sense of family change when you were linked?	Yes	Yes	Yes
Did your sense of self change when you were linked?	Yes	Yes	Yes
When you were linked, did you and the other person/people have direct contact?	Yes	Yes	No
Did this contact affect you positively?	Yes	Not sure	Yes
Did it affect your linked relative(s) positively?	Yes	Not sure	Not sure
Did it affect your existing relative(s)/personal relationships positively?	Not sure	Yes	Not sure
Do you now have regular contact with the linked relative(s)?	Yes	No	Not sure
Does the contact bring some negative consequences for you?	Yes	Not sure	Yes
Does the contact bring some negative consequences for your linked relative(s)?	Not sure	Not sure	Not sure
Do you expect to maintain regular contact with those with whom you are linked?	Yes	Not sure	Not sure

\*forced choice responses

**TABLE 5: Thoughts of donors who have been linked about being on the register in terms of .....**

<b>Thoughts*</b>	<b>F10</b>	<b>M2</b>	<b>M54</b>
Agreeing on type and levels of contact	No problem	No problem	No problem
Getting along with anyone you get linked with	No problem	No problem	Not sure
Regretting starting the process	No problem	No problem	Not sure
Finding out more than you anticipate	No problem	Not sure	Not sure
Finding out less than you anticipate	No problem	No problem	Possibly difficult
Coping with the fact that DNA results are not 100% accurate	No problem	No problem	Possibly difficult
Never being linked	Possibly difficult	No problem	Possibly difficult
Getting 'false positive' results	Possibly difficult	Possibly difficult	Possibly difficult
Not being able to cope emotionally	Not sure	Not sure	Not sure

\*forced choice responses