Expectations and experiences of gamete donors and donor-conceived adults searching for genetic relatives using DNA linking through a voluntary register

Running title: Searching for a genetic link

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Abstract

Study question: What are the experiences of donor-conceived adults and donors who are searching for a genetic link through the use of a DNA-based voluntary register service?

Summary answer: Donor-conceived adults and donors held positive beliefs about their search and although some concerns in relation to finding a genetically linked relative were reported, these were not a barrier to searching.

What is known already: Research with donor-conceived people has consistently identified their interest in learning about – and in some cases making contact with – their donor and other genetic relatives. However, donor-conceived individuals or donors rarely have the opportunity to act on these desires.

Study design, size, and duration: A questionnaire was administered for online completion using Bristol Online Surveys. The survey was live for three months and responses were collected anonymously.

Participants/materials, setting, and methods: The survey was completed by 65donor-conceived adults, 21 sperm donors and five oocyte donors who had registered with a DNA-based voluntary contact register in the UK. The questionnaire included socio-demographic questions, questions specifically developed for the purposes of this study and the standardized Aspects of Identity Questionnaire (AIQ).

Main results and the role of chance: Motivations for searching for genetic relatives were varied, with the most common reasons being curiosity and passing on information. Overall, participants who were already linked and those awaiting a link were positive about being linked and valued access to a DNA-based register. Collective Identity, as assessed by the AIQ, was significantly lower for donor-conceived adults than the donor groups ($P<.05$), but not significantly different between linked/not linked or length of time since disclosure of donor conception (all Ps $>.05$) for donor-conceived adults.

Limitations, reasons for caution: Participants were members of a UK DNA-based registry which is unique. It was therefore not possible to determine how representative participants were of those who did not register for the service, those in other countries or of those who do not seek information exchange or contact.

Wider implications of the findings: This is the first survey exploring the experiences of donor-conceived adults and donors using a DNA-based voluntary register to seek information about and contact with genetic relatives and the first to measure aspects of identity using standardised measures. Findings provide valuable information about patterns of expectations and experiences of searching through DNA linking, identity, and of having contact in the context of donor conception that will inform future research, practice and policy development.

Trial registration number: Not applicable.

Key words: Gamete donation, Donor searching, , UK Donor Link, Identity, Donor register

Introduction

This paper examines the extent to which the personal, social and collective components of identity (Cheek, 1989) are affected by the experiences of being a donor or donor-conceived adult, and (for donor-conceived adults) the role of age at the time of disclosure of donor conception, drawing on a survey of registrants of UK DonorLink (UKDL). UKDL, launched in 2004, was the first register in the world to use DNA as the primary basis for enabling donor-conceived adults, donor-conceived and non donor-conceived siblings and donors to identify each other voluntarily and, if mutually agreed, to share information and have direct contact (Crawshaw *et al.*, 2013). UKDL became the UK Donor Conceived Register in April 2013 (www.donorconceivedregister.org.uk). There is one further DNA-based register service, FIOM, in The Netherlands which is also government funded. The study also examines the shared and comparative experiences of donor-conceived adults and donors of searching for a genetic link through a DNA register.

The ability of gamete and embryo donors, donor-conceived people and others who are genetically connected by virtue of gamete or embryo donation to find out about, and make contact with, each other has been a recent phenomenon. While there has been some research on both donors' and donor-conceived people's attitudes and views about such information and contact, little is currently known about those who take positive action either through a voluntary contact register or using their own resources. Existing research is limited because of the inclusion of small numbers of participants, having been conducted in few geographical locations, in different time periods, under different disclosure regimes, focussing largely on sperm donation and examining intentions rather than actual behaviour. These studies have also been restricted to providing merely a snapshot of participants' experiences at a single point in their lives (Van den Broeck *et al*., 2013).

Background to research on donors and donor-conceived people

The majority of studies with sperm and oocyte donors have indicated donors' desire to learn the outcome of their donation, although fewer have expressed interest in knowing the identity of, or disclosing their identity to, or making contact with, their donor offspring (Purewal and van den Akker, 2009; Van den Broeck *et al*., 2013). Findings from these studies are likely to be influenced by the regimes under which donors were recruited (i.e. mostly anonymous) and the unlimited and largely unknown number of offspring who may have been born using the gametes from the same donor.

Two recent online surveys have reported on gamete donors, primarily in the USA, who were recruited as anonymous donors but subsequently took active steps to share information about themselves with their offspring, by registering with the Donor Sibling Registry (DSR) (Jadva *et al*., 2011; Daniels *et al*., 2012). An unspecified number of sperm donors appear to have participated in both studies. Half (37) of the 63 sperm donors and eleven oocyte donors surveyed by Jadva *et al.* (2011) wanted identifying information about their donor offspring and almost one third (24) reported that they viewed their relationship with their donor offspring as 'special […], like a good friend', while a comparable number (20) viewed it as a 'genetic relationship only'. Some expressed concerns about the impact of any contact on their own families or those of the offspring. Twenty-two sperm donors (35%) and one oocyte donor had made contact with at least one donor offspring - or with their parents where the offspring were too young for direct contact - and all reported this to be a positive experience. The majority of sperm donors noticing similarities in appearance (21), personal interests (17), personality (16) and behaviour/mannerisms (11).In Daniels *et al*'s (2012) survey of 164 sperm donors, 147 (97%) reported thinking about their offspring and 150 (94%) were

agreeable to some form of contact, including in a smaller number of cases (46; 28%) a parent-child relationship if that was desired. Among those who had established contact with offspring (33), reports were positive although some indicated it had prompted challenges within their existing relationships, especially with spouses. Studies in Australia (Kirkman *et al*., 2014) and the UK (Daniels *et al*., 2004) of men recruited initially as anonymous sperm donors indicate that they continue to think about potential offspring and some would be interested in or willing to meet them.

Previous research has shown negative outcomes for adjustment in donor-conceived adults told of their donor origins beyond early childhood (Blyth *et al*., 2012). Findings from research regarding donor-conceived individuals also show that they are often interested in knowing about their donor and any other genetic relatives, especially donor siblings, they may have a result of the donation. Those who do not have the option of identifying their donor generally want more information than they possess or are likely to acquire (Blyth *et al*., 2012). Few studies have explicitly investigated the experiences of actual exchange of information or communication. Although some negative experiences of donor-conceived individuals' contact – or attempted contact – with donors has been reported (e.g. Cushing, 2010; Turner and Coyle, 2000), most of the limited number of studies where this has been investigated have reported largely positive outcomes (Cushing, 2010; Jadva *et al*., 2010; Beeson *et al.*, 2011; Daniels *et al.*, 2012). Positive outcomes have also been reported in the few studies that have investigated contact between donor-conceived half-siblings (Kirkman, 2004; Scheib and Ruby, 2008; Jadva *et al*., 2010; Blyth, 2012a, b) However, unsuccessful efforts to locate donor-siblings are accompanied by frustration and disappointment (Cushing, 2010).

A number of studies have highlighted the contribution of support networks in facilitating and providing assistance for searches (Turner and Coyle, 2000; Paul and Berger, 2007; Berger and Paul, 2008; Cushing, 2010; Jadva *et al.*, 2010; Mahlstedt *et al*., 2010) and for mediating contact with donors and/or other genetic relatives (Scheib *et al*., 2005; Rodino *et al.*, 2011; Blyth, 2012a, b). For the most part, even when the search had not been successful, such support was reported favourably. Cushing (2010), Jadva *et al*. (2010) and Beeson *et al.* (2011) also considered the impact of searching for donors and/or donor-siblings on participants' relationships with their parents. While for the most part, participants' searches appear not to have adversely impacted these relationships, some donor-conceived individuals have reported negative experiences and strained relationships. Two participants in Cushing's (2010) study thought that their mothers "felt hurt and unloved" because of their daughters' search for "another parent". A small number of participants in the study conducted by Beeson *et al.* (2011) reported parents feeling "angry" and/or "fearful" about the participant's "curiosity about the[ir] donor". Few "negative" (not further elaborated) responses were reported by participants who searched for their donor and/or donor-siblings in Jadva *et al's* (2010) study. One father was reported as "not especially comfortable" and one mother as feeling "excluded" in Blyth's (2012 a, b) study of participants' search for and discovery of donor-siblings. In the same study, reported responses of adoptive or donor siblings with whom participants had been raised as children, but who were not themselves donor-conceived, ranged from indifference to feelings of exclusion.

Previous research has conceptualised negative aspects of donor-conceived individuals' identity that result from lack of adequate information about their genetic parenthood and inheritance (Stevens-Botsford, 2000; Turner and Coyle, 2000; Stock, 2002). In research and theory on identity orientations, reference is made to the relative importance of various

identity attributes in the construction of self-definitions. Cheek and Briggs (1982) developed a questionnaire to assess personal, collective and social aspects of identity orientations, making the fundamental theoretical distinction between (1) inner or 'personal identity', one's private conception of self, (2) 'collective identity', subjective feelings of continuity and uniqueness , and (3) outer or 'social identity', which refers to one's public image as presented through social roles and relationships (Hogan and Cheek, 1983). According to this theoretical framework, collective identity is an identity shared with others who are believed to have some characteristics in common and give the individual 'a place in the social world' (Simon and Klandermans, 2001, p. 320). This shared position does not require direct contact with others who share category membership (Sedikides and Brewer, 2001). Instead, it is psychological. Collective identity is therefore explicitly connected to a group of people outside the self, Personal identity, on the other hand, typically refers to characteristics of the self that one believes, in isolation or combination, to be unique to the self (Sedikides and Brewer, 2001). Social identity includes the in-group versus out-group comparison process which is fundamental to Social Identity Theory (SIT) (Tajfel, 1978), involving external perceptions of image attributed through social roles. The standardised Aspects of Identity Questionnaire (AIQ) (Cheek, 1989) was developed to obtain information on personal (reflecting one's emotions and feelings), collective (reflecting self-defining issues such as pride in being a citizen or belonging to a family) and social (reflecting reputational issues, such as 'what others think of me') aspects of identity, which are important to the development of a sense of who one is. The AIQ items reflect these differences in Personal (My personal values and moral standards; My dreams and imagination), Social (My popularity with other people; The ways in which other people react to what I say and do) and Collective identity orientations (Being a part of the many generations of my family; my race or ethnic background) confirming these theoretical distinctions. Alpha coefficients of .84

(personal) .86 (social) and .68 (collective) have been reported (Cheek, 1989; Cheek and Briggs, 1982).

Method

Design

An online questionnaire-based study design was used to obtain qualitative and quantitative responses from donor-conceived adults and donors. Where appropriate, statistical analysis comparing the needs, experiences and identity scores between the donor-conceived adults and donors were undertaken.

Participants

All registrants of the UK Donor Link (n=244) were approached to participate in the study, excluding four non-donor conceived offspring of donors. Registrants included n=172 donor conceived adults; n= 65 sperm donors; and n=7 oocyte donors. A total of 91 participants responded to the questionnaire survey, representing 37.3% of those sent the request for participation (n=65 (37.8% of all registered) donor conceived adults; n=21 (32.3% of all registered) sperm donors and n=5 (71.4% of all registered) egg donors. Fifty donor-conceived adults were women and fourteen were men (one did not provide details). Most questionnaire surveys (81) were completed online and ten via paper copies. However, the research team subsequently learnt from UKDL that during transfer of the register to a new provider in early 2013, UKDL had become aware that a number of registrants had changed their contact details without notifying the registry. Consequently, some registrants would not have received the survey, although the research team was not provided with the actual number of such registrants. Hence the actual response rate of requests *received* will have been higher than the 37% response rate reported.

Materials

The questionnaire was developed specifically for this study by the researchers in consultation with UKDL and combined both open and closed questions with some dedicated sections for completion either by donor-conceived adults or donors as well as sections common to both groups. In addition, the 35 item standardised Aspects of Identity Questionnaire (AIQ-IIIx; Cheek, 1989) was modified to obtain information on identity in our population. Specifically, ten questions were classified by Cheek (1989) as 'Special items' and were not relevant to our study and thus were omitted. An example of a non-relevant, omitted item from the original questionnaire is "My role of being a student in college". Thus, the final version of the AIQ in our study was comprised of 25 items. The three AIQ subscales used contained questions on Personal Identity Orientation (PIO; reflecting internal, individualistic identity), Social Identity Orientation (SIO; reflecting social aspects of identity – e.g. reputational, physical attractiveness, impressions created on others -), and Collective Identity Orientation (CIO; an outgrowth of social identity personally acknowledged as self-defining in some respect such as one's ethnicity or gender or family membership). Questions were rated on a 5 point scale ranging from 1 = 'Not important to my sense of who I am' to 5 = 'Extremely important to my sense of who I am'. The SIO subscale consisted of seven items (e.g. 'My popularity with other people'), the CIO subscale consisted of eight questions (e.g. ' Being a part of the many generations of my family') and the PIO consisted of ten items (e.g. My personal values and moral standards'). The personal, social, and collective orientation scales have been shown to have distinct patterns of correlations with other measures of identity and self-concept in subsequent research (Cheek *et al*., 2013).

Procedures

An on-line survey was administered using the Bristol Online Surveys (BOS) with hard copy questionnaires sent to those without email contact or who otherwise requested one. Participants were provided with an information sheet and informed that their consent was implied from completion of the questionnaire. A debrief sheet was provided for participants at the end of the on-line questionnaire or on a separate page of the hard copy. The invitation to participate and the link to the survey (or hard copy) were sent out via the UKDL Head Office (with two reminders) to all those who were registered; the survey was open from mid October 2012 to mid January 2013.

Statistical analysis

Data were converted from BOS into SPSS and descriptive analyses were carried out on all variables. Open ended responses were listed separately by group. Analysis of categorical data was carried out using Chi square statistics and the AIQ was analysed using Anova (3 groups) and t-tests (2 groups).

Ethics

Ethical approval was obtained from Middlesex and Huddersfield Universities and approval for the study was given by UKDL.

Results

Demographic variables

Ages were significantly different between the groups ($F(2,87)=25.22$, $P<.000$) with donor-conceived adults significantly younger (mean=35.68, SD= 12.64) than either the sperm donors (mean=55.0, SD=8.95) or oocyte donors (mean=55.8, SD=4.14). There were no significant differences on any other socio-demographic variables between groups (see Table

1). All donor-conceived adults and donors were white except for one Asian male donor-conceived adult.

INSERT TABLE 1 HERE

There were significant differences in current family makeup, possibly reflecting the differing age profiles of the donor-conceived adults and the donors. The donor group reported children living with them more often than did the donor-conceived adults group (χ^2=4.22, df=1, P<.05), and the donor-conceived adults were more likely than the donors to report that their mother and father (χ^2=6.37, df=1, P<.01) were still alive, though the latter did not reach significance levels. There was no significant difference between groups as to whether their parents (if alive) were still living together.

Group differences on the AIQ

Analysis of variance comparing the donor-conceived adults, sperm and oocyte donors on the three AIQ-IIIx subscales (Personal Identity Orientation (PIO); Social Identity Orientation (SIO); Collective Identity Orientation (CIO); showed the three groups differed significantly on CIO ($F(2, 82)=3.60$, P<.03), with donor-conceived adults scoring significantly lower (mean=20.49, SD=5.58) than either donor (sperm donors mean=23.90, SD=5.59; oocyte donors mean=24.75, SD=3.30) group. The groups did not differ significantly on either the PIO (donor conceived adults mean=38.98, SD=6.50; sperm donors mean=38.05, SD=6.46; oocyte donors mean=37.80, SD=4.65) or SIO (donor conceived adults mean=22.80, SD=5.41; sperm donors mean=23.80, SD=456; oocyte donors mean=24.00, SD=5.22) subscales. Since the few oocyte donors were similar in age to sperm donors and did not differ from them on the AIQ IIIx subscales, a Combined Donor group (26) was created for further

analysis. The same CIO subscale for the combined group differed significantly from the donor-conceived adults group ($F(1,83)=7.20$, $P<.01$; see Figure 1).

INSERT FIGURE 1 HERE

The donor-conceived adults' Collective Identity Orientation (CIO) subscale was rated significantly lower (mean=20.49; SD=5.58) than the donor groups (sperm donors mean = 23.90; SD=5.59 and oocyte donors mean = 24.75; SD=3.30). The donor-conceived adults's CIO subscale was also lower compared to normative values based on a sample of European Americans (means CIO=22.94; SD=5.55; SIO=23.81, SD=4.67; PIO=42.22, SD=5.62) – Cheek *et al*., 2013), indicating they may have less emotional connection to a particular community or institution, such as their family.

Characteristics of donor-conceived adults

Four donor-conceived adults were raised within families with siblings from the same donor, twenty-three with siblings from a different donor and nine with non-donor siblings; the remainder did not report being raised with siblings. Eleven donor-conceived adults had siblings who were also registered with UKDL. Knowledge of the nature of their conception began at different ages, ranging from 'as long as I can remember' through to older adulthood. Some found out in an unplanned way, such as following parental death or separation, discovery of blood group incompatibility or of paperwork relating to gamete donation and during a row. Ages at which donor-conceived adults were informed were re-categorised into four age groups for further analysis: 0-10 years (10, 15%); 11-20years (24, 37%); 21-30years (22, 34%) and 31+years (9, 14%).There were no significant differences between donor-

conceived adults who found out about their status at different ages on the identity subscales; PIO ($F(3,54)=.834$, $p>.05$); SIO ($F(3, 58)=.705$, $P>.05$), or CIO ($F(3,57)=.470$, $P>.05$).

Reasons for searching

All participants were asked about their reasons for searching, so participants will have been answering according, where relevant, to whoever they perceive to be their children and family. Participants were invited to endorse reasons from a list arts well as provide additional reasons. Reasons for searching varied between groups (Table 2). For donor-conceived adults, the most frequently-cited reasons were 'to satisfy my curiosity' (84.6%), 'to see whether we have anything in common' (75.4%), 'to access medical information' (70.8%) and 'to make me feel more complete in my identity' (69.2%). For sperm donors they were 'to satisfy my curiosity' (66.7%), 'to find out what happened in their lives since conception' (66.7%), 'to be able to pass on information to my children/family'(47.6%) and 'to make me feel more complete in my identity' (28.6%) whereas for oocyte donors, they were 'to be able to pass on information to my children/family' (100%), 'to find out what has happened in their lives since conception' (80%) and then evenly spread among the remaining reasons.

INSERT TABLE 2 HERE

There were also open comments (that are classified as 'other' in table 2). For sperm donors, these related primarily to meeting the needs of donor-conceived adults: 'to provide context for them about me, if they wished to know more'; 'to help resolve the issue for any donor conceived offspring' and 'I think any children should know about me so they can understand themselves better'. This was summed up by one participant who said: 'the absence of access to knowledge of their donor parents in my opinion constitutes a possible 'harm' to my

offspring.' And another said, 'it is a personal life principle 'to do no harm' and this is the best way I could act in accordance.' Others talked about meeting their own needs by searching: 'to find out if any people exist'; 'if they are in need of support or help, Guilt.' One oocyte donor commented; 'As 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'.

Donor-conceived adults also made open comments, many of which expressed deep sentiments related to their own needs such as: 'Curiosity' doesn't go anywhere near the HUNGER (*emphasis original*) to find someone I was connected to'. 'To see whether we have anything in common" sounds so casual. It's a case of looking for CONNECTION (*emphasis original*). For me, that was not anything in the zone of curiosity or idle research; it was visceral.' Another donor-conceived adult stated; 'It is a fundamental quest to find family and get to know them and feel a part of a new family and be accepted by them', and; 'This is my only chance to find blood relatives'.

Expectations and experiences of using a DNA-based primary route to locate genetic relatives

Most donor-conceived adults (62; 95.3%), and all sperm and oocyte donors valued access to a DNA-based register to identify possible genetic relationships even though DNA often cannot provide absolute certainty of a relationship. Decision time from first thoughts to actually registering took a few days (five); weeks (thirty-three); months (twelve); a year or more (twelve) for donor-conceived adults (three participants either said they 'could not

remember' or did not answer the question). Two sperm donors made the decision in days; six in weeks; six in months and five over a year or longer (two could not remember). Four oocyte donors took weeks and one a few months to register.

Donor-conceived adults' estimations as to how many [more] siblings they thought they might find ranged from zero to 1000 and included statements such as 'hopefully not more than one', 'absolutely no idea'; 'Only God knows'. The maximum number of siblings with whom they would feel comfortable about being linked ranged from fewer than five (eight); 5-10 (ten); 10-20 (four); 20 or more (two) to 'No limit' (thirty-nine) (two donor-conceived adults did not answer the question).The number of offspring that donors believed they might find ranged from zero to 110 (sperm donors) and from zero to three (oocyte donors). The maximum number of adult offspring with whom oocyte donors would feel comfortable having future contact was four (one did not answer this question), whereas among sperm donors, most (thirteen) imposed no limit, one would feel comfortable with '20+', four with between 5 and 10, and one with fewer than 5 (two sperm donors did not answer the question).

Experiences of being linked to a genetic relative through the UK DonorLink register

Twenty-six participants (23 donor-conceived adults, two sperm donors and one oocyte donor) had been linked. Of the donor-conceived adults with a link, six were linked to their donor and eighteen had been linked with between one and fourteen 'siblings'. A series of t-tests were carried out between those already linked (twenty-six) and those not linked (65) and the identity subscales. No significant differences on any of the three identity scales were found (all Ps >.05), suggesting identity orientation is not different between individuals linked or those still searching for a link.

For the donor-conceived adults, questions about the consequences of being linked, and positive or negative effects upon themselves and their existing relatives and links are reported in Table 3. Since few donors were linked, their responses are not reported. Most donor-conceived adults reported direct, regular and continuing contact and perceived this to be mutually positive; however just over one fifth (five, 22%) did not have regular contact and around one quarter (six, 26%) reported some negative consequences for themselves. Almost two thirds (fifteen, 65%) of donor-conceived adults who were linked believed their sense of family and self had changed, but there was little evidence of the contact adversely affecting their existing relationships. Almost half (eleven, 48%) believed that more links would be found for them with the remainder (twelve, 52%) being not sure.

INSERT TABLE 3 HERE

Feelings/Beliefs about being linked among those 'not yet linked'

Questions were asked of those not yet linked about their expectations should a link be made and the consequences they anticipated for themselves and their relatives/ links (Tables 4 and 5). Although the majority of participants wanted to make contact as well as exchange information, they were not sure whether these would become regular occurrences. They were positive about contact for themselves and any relatives to whom they might be linked through donor conception but were less certain than those already linked about the impact this might have on their existing family and uncertain about any possible negative consequences for themselves, their linked and their existing relatives.

INSERT TABLE 4 HERE

Although most not-yet-linked participants were realistically uncertain whether they would ever be linked through the register, about half of donor-conceived adults and sperm donors and all oocyte donors believed their sense of 'family' would change if a genetic link was found (Table 5).

INSERT TABLE 5 HERE

Anticipated and actual difficulties of being on a voluntary register among linked and not-yet-linked donor-conceived adults and donors

All participants were asked about their experiences and thoughts about being on the UKDL register with responses grouped according to whether they had been linked or not (Table 6). Participants either experienced or anticipated few difficulties, confirming the positive beliefs among those not yet linked and actual experiences among those already linked, as reported above. Although there was consistency in responses between the two groups, levels of uncertainty were expressed more frequently by the 'not-yet-linked' group, as might be expected. The only aspect where the majority of participants (in both groups) anticipated possible difficulties was in the event of 'getting false positive results' (76% linked; 61% not linked).

INSERT TABLE 6 HERE

Discussion

Our online study provides the first research evidence of the experiences of donor-conceived adults and donors using a DNA-based service to search for genetic relatives. It suggests that this group of searchers have similar motivations and experiences to those using other

searching routes (e.g. Jadva *et al*., 2010, 2013; Daniels *et al*., 2012). Curiosity was a key driver, as was, variously, the desire to see if they had anything in common with linked relatives, to access medical information, to be able to pass on information to their children/family, and to find out what had happened in their lives since conception. In addition, while understandably apprehensive about the uncertainty attached to the fact that DNA testing provides less stringent evidence of a genetic link than a robust paper-trail based on accurate documented records, the use of DNA did not appear to dampen positive beliefs about the value of being linked for themselves and, albeit less so, for their existing relationships. This held true for those already linked and not yet linked, and across all three groups of donor-conceived adults, sperm and oocyte donors, there was strong support for the value of a DNA-based register. Contrary to popular representations, DNA testing to identify genetic relationships can produce complex results that require scientific and statistical interpretation (Crawshaw *et al*., 2008; Adams and Lorbach, 2012). More robust results may be secured where the DNA from the biological parent of a donor-conceived person is available and any supporting evidence such as date and place of donation. For laboratories such as that used by UKDL which use CODIS markers that are considered more reliable for identifying putative links, results for half sibling relationships are even more complex to interpret and generally carry a higher risk of false positives or negatives. As DNA science has advanced, new supplementary tests have been developed for same sex pairs (the X and Y tests) but there are as yet no such tests available for opposite sex pairs. All results are expressed as a numerical probability of a genetic relationship existing with the proviso that this may alter with the addition of new DNA into the database. The current state of DNA science leaves services such as UKDL with the decision as to whether to release all results to all registrants, regardless of the risk of false positives and false negatives, and has implications for the availability of comprehensive information and support services to enable

458 registrants to cope with associated uncertainty and decision-making about progressing with
459 information exchange or contact. Given that DNA testing will be the only route through
460 which the majority of those affected by donor conception internationally will be able to
461 identify genetic relatives, these are important findings.
462
463 This study is also the first to measure aspects of identity for searchers, using standardised
464 measures. More than two thirds of donor-conceived adults were motivated to search by a
465 desire to feel more complete in their identity, as were six sperm donors and two oocyte
466 donors. While qualitative studies have previously reported such a motivation in relation to
467 donor-conceived adults, this has not been asked previously of donors, nor has it been assessed
468 using a specifically designed standardised questionnaire. The age of donor-conceived adults
469 at disclosure of their donor-conceived status varied, similar to that reported in previous
470 research (Blyth *et al*., 2012). However, the data did not show a significant relationship
471 between AIQ and age of disclosure; this was a surprising finding given data on negative
472 outcomes for adjustment in donor-conceived adults told of their donor origins beyond early
473 childhood, and is a phenomenon worthy of further study. .
474
475 Collective identity is a multidimensional concept referring to a belief that one shares
476 characteristics with a group of others and includes a set of cognitive beliefs associated with
477 that category (stereotypic traits thought to be shared by category members or ideological
478 positions that define the group's goals). Collective identity also involves 'value and
479 emotional significance'. This affective aspect of collective identification can include how we
480 evaluate a category and the perceived value placed on the category by others (Tajfel, 1981).
481 Collective identity is therefore described as referring to the individual rather than to a group
482 (Social Identity) because it is a psychological concept and only becomes a collective identity

when it is personally acknowledged as self-defining in some way. Collective Identity can include people one has not yet met but with whom common attributes, such as gender, nationality, occupation, (or DNA) is shared. Furthermore, CIO is connected to a group of people outside the self. , (Sedikides and Brewer, 2001).

The significantly lower COI scores of donor-conceived adults as compared to donors therefore suggests their perceived collective (or family) identity, as distinct from their personal or social identity, was low. This is somewhat further supported by the findings that donor-conceived adults also rated 'to feel more complete in my identity' as one of the prominent reasons for searching for genetic relatives. They also believed their 'sense of family' would change if they were to find a link, and those who were already linked reported their 'sense of self' had changed as a result. Since Aspects of Identity subscales were also analysed by whether participants had been 'linked' or 'not yet linked' to genetic 'relatives' and these analyses were not significant, the data indicate this low collective identity is important to donor-conceived adults regardless of their linked status, and warrants further qualitative research to improve understanding.

Interestingly, although participants in all three groups considered that their sense of self and of family might or did change, negative impacts on themselves or on existing relationships that might or did arise from being linked were generally rated to be low. Those who were linked reported, on the whole, direct, regular and continuing contact which was mutually positive. This is not to say that contacts were wholly positive but that the risk of adverse or troubling reactions appeared to be low. This extends previous research findings (Turner and Coyle, 2000; Cushing, 2010; Beeson *et al*., 2011; Jadva *et al*., 2010; Blyth, 2012a,b; Daniels *et al*., 2012). However a sizeable minority (six, 26%) of linked donor-conceived adults (26%)

reported some negative consequences for themselves and 'not yet linked' registrants across all three groups were somewhat more likely than those already linked to express uncertainty about potential impact on themselves and their existing relationships. Here again, quantitative research does not allow us to look beyond the figures, suggesting the need for qualitative research to provide better indications of what helps and what hinders such experiences – including any service-related needs (such as the in-depth qualitative study of a small group of donor-conceived registrants with UKDL undertaken by Blyth (2012a,b)).

The actual and anticipated effect of being linked on existing relationships, whether donor-conceived adult or donor, also marks an interesting shift in terms of whose needs are being met through donor conception. Previously, the perceived needs of donors and their families for privacy through anonymity (Meirow and Schenker, 1997; Novaes, 1998) were prioritised over those of donor-conceived adults (RCOG, 1987). Our findings suggest that a DNA register may prioritise the needs of both donor-conceived adults and donors who appear willing to seek information and contact even if they are uncertain as to whether any links may have negative consequences for their family members and existing relationships. In fact the only areas where more than a third of participants anticipated or experienced difficulties in coping as a result of being on the register were focussed on personal coping in the event of 'finding out less than anticipated', with 'the fact that DNA results are not 100% positive' and that they may 'get false positive results'. In other words, although historically concern has been about parties sharing too much information, our data suggest there may be negative impacts of having too little information.

We are not aware of any research that looks at the length of time taken by donor-conceived adults and donors from first contemplation of joining a register to moving ahead with

registration. Our study suggests that this might range from a few days to more than a year. When reviewing details of the 64 people who had started but not completed registration with UKDL during 2012, one of the authors (MC) found that twelve donor-conceived adults (29%) and two donors (14%) had also started and stopped the process *at least* once prior to the start of 2012, with a few having made several approaches over many years. This hitherto unreported aspect of searching carries implications for service delivery and for the support needs of potential registrants and warrants further investigation.

Limitations

This study recruited approximately 37% of the sample contacted for participation, which is a relatively low response rate. However, it is likely to be a conservative estimate as it is known that contact details for a number of those sent the survey were out of date and hence would not have received it. Looking more closely at the profile of participants, their age and gender profile reflected the profile of the three groups of registrants on UKDL – donor-conceived people, sperm donors and oocyte donors - (Crawshaw *et al*., 2013) and further reflects the gendered participation rates in research involving donor-conceived people more generally (Blyth *et al*., 2012). No socio-demographic differences existed across the three groups beyond the donor group being older, more likely to have children living with them and less likely to still have living parents.

Conclusion

This study has shown that donor-conceived adults and gamete donors registering on a voluntary DNA-based Register appeared to have thought carefully about searching and were undeterred by the uncertainties attached to DNA as a basis for linking. The experiences of those linked and expectations of those not yet linked were similar and generally positive, and

in the case of donor-conceived adults, potentially a necessity in relation to their low subjective feelings of continuity and uniqueness (collective identity orientation). Further research, policy and practice should focus on preparation of donor conception parents for meeting the needs of their donor conceived children to seek information about their genetic relatives with potential altered sense of self and sense of family. Preparation of donors for their own future information and contact needs, impact on their family members, improved understanding of the services required to assist those searching for genetic relatives, and making contact when those affected do not have access to a records-based Register and instead use DNA testing needs more research.

Declaration of author's roles

OA was responsible for the data analysis and all authors contributed equally to the study design and writing of the paper.

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