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Voluntary DNA-based information exchange and contact services following donor conception: an analysis of service users' needs

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### **Voluntary DNA-based information exchange and contact services following donor conception: an analysis of service users' needs**

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## **Abstract**

Medical science has enabled the creation of families through the use of donor conception but some lifelong policy and practice implications are only recently being recognised. Research and practice have shown that donor conception can, for some, carry substantial long term consequences. In this paper we present findings from a questionnaire-based study that sought to shed light on donor-conceived adults' and gamete donors' views on service and support needs when searching for genetic relatives with the aid of DNA testing. The findings demonstrate the complexity and sensitivity of providing services in this newly emerging area of need. Such provision requires collaboration between very different disciplines and agencies (scientific and psycho-social), introduces the potential for blurring of lines of accountability and responsibility and highlights the challenges of identifying appropriate

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<sup>1</sup> During the course of the study, MC retired from her permanent academic post and became an Honorary Fellow at the University of York

funding streams. In addition, the findings demonstrate the opportunities and limitations afforded by the use of DNA in identifying unknown genetic relatives.

### **Key words**

DNA testing; donor-conceived adults; gamete donors; donor register; intermediary services; counselling.

### **Introduction**

There is growing demand from donor-conceived people for access to information about those to whom they are genetically related through donor conception. While a small number of jurisdictions have legislated to allow the release of information about donors and/or donor-related siblings to donor-conceived people (Blyth and Frith, 2015), there has also been a growth in the use of voluntary registers such as the Donor Sibling Registry (Kramer and Cahn, 2013) and informal searching routes (Crawshaw et al, 2015). Currently only two national register services, each funded by their respective governments and including some professional support services, offer DNA testing combined with a dedicated DNA database as a route to identifying genetic ‘relatives’ – FIOM<sup>2</sup> in the Netherlands and the Donor Conceived Register in the UK (formerly UK DonorLink). Stand-alone DNA testing services can be used independently by two or more individuals interested in finding out if they may be genetically related. In the latter situation, the individuals would have to find each other first through their own means whereas the register services offer the potential for individuals previously unknown to each other to be ‘linked’. Given that few of those affected will have access to written records, DNA testing could be the only searching route available.

The interest among donor-conceived individuals in seeking information about donor conception and/or contact with those genetically related through donor conception seems driven by curiosity, a need for identity completion or related psychological and social matters, or a belief in the right to information (van den Akker 2015; Blyth et al., 2012; Blyth, 2012a; Hertz et al., 2013; Jadvá et al., 2010; Nelson et al., 2013; Scheib et al., 2005) and/or a desire for medical information (Centers for Disease Control and Prevention, 2004; Donor Sibling Registry, 2015; Parliament of Victoria Law Reform Committee, 2012; Ravitsky, 2012; Tomazin, 2013). There is also growing evidence that donors may wish to know more about the outcome of their donations and about any offspring (Daniels and Kramer, 2013; Goedeke et al., 2015; Kirkman et al., 2014; Riggs and Scholz, 2011; Speirs, 2012). However, this literature focuses predominantly on those affected by sperm donation, reflecting its greater incidence and longer history and more studies are needed into information seeking and contact patterns among those affected by egg, embryo or double donation.

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<sup>2</sup> There is as yet no published research about the work of Fiom though further detail about its operation can be found in Crawshaw et al 2015. There is also no published research about the work of the Donor Conceived Register.

Little is known about how best to meet the needs of these different groups, donors and donor-conceived adults, and how to provide associated support services. Even jurisdictions that have mandated the release of biogenetic information following donor conception apply varying standards in their approach to its management and any reference to what kind of professional support might be needed, when and how, is generally absent (Allan, 2012). The small amount of practice-based literature regarding work with searchers (Crawshaw et al., 2013; Daniels and Meadows, 2006; Johnson, et al., 2012; Kramer and Cahn, 2013) suggests that having psycho-social professional support available may be warranted. This is supported by research indicating that some donor-conceived people, especially those learning of their genetic origins later in life and/or in unplanned ways and/or who have had dysfunctional family experiences, may experience acute and lasting emotional distress (Baran and Pannor, 1989; Cushing, 2010; Mahlstedt et al, 2010; McWhinnie, 2000; Turner and Coyle, 2000). In addition, contact arrangements have occasionally proved difficult to manage (Crawshaw et al., 2013; Goldberg and Scheib, 2015) and their nature can unfold and change over time and carry different meanings to the different parties involved (Blyth 2012b). Some donors have expressed an interest in using support services in the event of being contacted and/or searching themselves (Crawshaw et al., 2007; Hammarberg et al., 2014; Kirkman et al., 2014; Speirs, 2012). One sperm donor who recently spoke publicly about his experience of being traced on two separate occasions – once with professional support and once without - made clear his preference for the former (Whitehead 2016).

This paper seeks to contribute to the sparse information on what donor-conceived adults and donors might look for in services designed to help them locate and make contact with those to whom they are genetically related through donor conception and considers the implications of these findings.

## **Materials and Methods**

The findings reported here are part of a larger questionnaire-based study of the views and experiences of donor-conceived adults and donors registered with UK DonorLink (UKDL), a voluntary DNA-based UK register for adults seeking those to whom they were genetically related through donor conception (see also van den Akker, 2015). It was open to adults who had been conceived or had donated in the UK prior to August 1991 when a central register of all treatments and births was established through the Human Fertilisation and Embryology Act 1990. The HFEA Register provides rights of access to information for donor-conceived adults (which have evolved over the years and now include identifying information for certain groups) and donors (for the current situation see [www.hfea.gov.uk](http://www.hfea.gov.uk)). UKDL was funded by the Department of Health from its launch in 2004. At the time of the survey its financial future had been uncertain for some time but this was later resolved and the service was transferred to a new provider, the Donor Conceived Register, in April 2013<sup>3</sup>.

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<sup>3</sup>The Donor Conceived Register allows registrants direct access to the staff at the DNA laboratory that they use. They do not routinely provide professional support at each stage of the process but formal therapeutic counselling is available on request and is compulsory at the point of information exchange following DNA ‘matching’.

UKDL kept a Register and provided support through four main types of services:

- i. DNA testing and the maintenance of a DNA database of registrants for identifying probability of linkages, provided under contract by an independent, government-approved laboratory;
- ii. professional support for registrants or potential registrants considering the implications of proposed actions when undertaking DNA tests or when requiring information, advice or support outside a formal therapeutic counselling service;
- iii. intermediary services to anyone identified through DNA testing with a high probability of being genetically related to one or more other registrants wanting support during the process of exchanging information and/or making contact; and
- iv. therapeutic counselling for those wanting in-depth help with psychological, emotional or relationship issues arising from their involvement in donor conception.

Registrants paid for DNA testing at a price determined by the laboratory (as required by the Department of Health, although UKDL was allowed to subsidise those in financial hardship from its grant). UKDL support and intermediary services were free of charge and without time limits. Therapeutic counselling was free for a limited number of sessions and then became available for a fee. UKDL staff were predominantly qualified in both social work and counselling with prior experience of providing post-adoption support.

The questionnaire (available on request) was developed specifically for this study by drawing on prior research evidence and practice experience and in consultation with UKDL. It comprised 96 questions (both open and closed) with some specific sections for donors or donor-conceived adults and some common sections for all. Free-text responses were invited through open questions. Closed questions provided a range of multiple choice answers together with the opportunity for responses through an 'other' box. A final question invited all respondents to provide additional free-text comments if they wished.

The survey was administered using the Bristol Online Survey with hard copies sent to those without email contact. Respondents were provided with an information sheet and consent was implied from completion of the questionnaire. The invitation to participate was sent out via the UKDL Head Office (with two reminders) to all registrants; the survey was open from mid October 2012 to mid January 2013.

#### *Data analysis*

All responses to the 28 questions that covered any aspect of service provision were analysed, together with the free-text responses to the final open question. As the number of respondents was too small for statistical comparisons to be made, descriptive statistics are reported for the quantitative data by the following groups: donor-conceived adults, sperm donors and egg donors and all donors (hereafter called combined donors).

A thematic analysis was undertaken of the open responses and those provided under the 'other' box for closed questions. The transcripts were coded for concepts. From these concepts, core themes were generated that illustrated how the respondents thought about service provision. Transcripts were read by members of the team and the coding, themes and analytic milestones discussed. The validity of the range of interpretations and suggested relationships between these core themes was explored and tested against the data using the constant comparative method (Silverman, 2006).

The final stage comprised discussion within the team as to how the quantitative and qualitative data could be reported in order to appropriately reflect the range of respondents' views on key aspects of service provision.

All quotations used are from survey responses with incorrect spellings corrected but language and grammar left in their original form. Respondents (R) are identified by number, gender and category (donor-conceived adult, sperm or egg donor).

### **Ethical Approval**

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

### **Results**

#### *Participants*

Ninety one adults registered with UKDL responded to the questionnaire survey (eighty one on-line and ten through paper copies), representing just over a third (37.3%) of those approached. However an unspecified number of those sent the survey were later found to have changed their contact details without notifying UKDL so would not have received it.

All 65 donor-conceived adult respondents (50 females, 14 males and one who did not specify their sex) were conceived with the use of donor sperm. Of the 26 donors, 21 were sperm donors and five egg donors with the lower number of egg donors reflecting the more recent introduction of such services in the mid 1980s. The mean age of donor-conceived adults was 35.7 years (SD=12.64), of sperm donors was 55 years (SD=8.95) and of egg donors was 55.8 years (SD=4.14). No significant differences between groups were evident on any other socio-demographic variables. All respondents were White except for one Asian male donor-conceived adult (full demographic and study information is reported in van den Akker et al., 2015).

Twenty three donor-conceived adult respondents, two sperm donors and one egg donor had been linked to at least one other person at the time of the survey. UKDL staff used the term 'linked' rather than 'matched' given that DNA testing could only provide probability of genetic linkage rather than certainty. Reliability of the results also varied according to (i) whether the DNA of the biological parent of the donor-conceived registrant was provided for

the DNA database and (ii) whether testing was for ‘donor to offspring’ or for ‘sibling’ genetic relationships, with the latter being less reliable (see also Adams and Allan, 2013). Supplementary DNA testing to increase reliability was available but only if those concerned shared a gender (‘x’ chromosome testing for females, ‘y’ chromosome testing for males) and could afford the additional cost.

We report here on responses to the following four main groups of questions that we asked:

- (i) Which services, if any, affected their decision to register;
- (ii) Which services they considered important;
- (iii) How services were provided;
- (iv) How services should be funded and potential impact of funding on their usage.

It should be noted that given that, as reported above, UKDL staff could themselves provide all services other than those provided by the DNA laboratory, the difference between professional support, intermediary and counselling services was not necessarily fully understood by some registrants.

*(i) Services that affected the decision to register*

Respondents were asked whether they had used professional support to help them decide whether to register and whether the availability of intermediary services affected their decision. Bearing in mind that some may not have fully understood these distinctions, nineteen (21%) reported using professional support, with a slightly higher proportion of sperm donors than egg donors or donor-conceived adults. The potential availability of intermediary services influenced the decision to register for around a third of donor-conceived adults (23, 35%), just under half of sperm donors (10, 48%) and one egg donor (20%) (Table 1).

INSERT TABLE 1 ABOUT HERE

*(ii) Services considered to be important*

Respondents were asked which of the three non-DNA services they considered important. There was consistency among the three groups of respondents on the importance of all, i.e. professional support services (71, 78%), intermediary services (71, 78%) and formal therapeutic counselling (65, 71%) (Table 2).

INSERT TABLE 2 ABOUT HERE

Open comments suggested some of the reasons why they were considered important. One donor-conceived adult (RF77) remarked that “..... *So many seem to have had great difficulty with issues surrounding the uncertainty of their background*”. An egg donor (RF10) said that “.... *these are complex emotional issues and deeply personal, it is a massive thing to consider*

*meeting biological relatives and support through people/organisations specialised in this is key to a smooth supported link”.*

(iii) *How services were provided*

*Views about and experiences of receiving non DNA-based services*

Views were sought about the levels of professional support provided to those ‘not yet linked’. Around half said they were ‘about right’ (36, 55% donor-conceived adults, 12, 57% sperm donors, 3, 60% egg donors, 15, 58% combined donors) with considerably less saying they were ‘too little’ (16, 25% donor-conceived adults, 2, 10% sperm donors, 1, 20% egg donors, 3, 12% combined donors). None said they were ‘too much’ or responded ‘not sure’. Thirteen (20%) donor-conceived adults, seven (33%) sperm donors and one (20%) egg donor did not reply.

Among all respondents, whether linked or not, open comments indicated themes concerning reactions to, and usage of, the services provided. A small number, such as donor-conceived adult RF15, reported little contact and would have welcomed more: *“I haven’t heard much from UKDL apart from surveys and letters that are clearly sent to everyone!!!”*. Others, such as donor-conceived adult RF69, felt support was readily available if and when needed: *“They were so supportive, but not pushy in any way, just dealt with it how I wanted to”*. And sperm donor RM2 said they provided: *“Great moral support and advice from UKDL. They really have been marvellous”*. Some respondents, such as sperm donor RM62, found their needs met by one or two sessions: *“... just once when I registered. was ok, clarified a couple of things. Some, like donor-conceived adult RM64, needed far longer: “..... for a couple of years. Very helpful, perhaps essential to avoid suicide....”*. As these were open comments, the type of service was usually not specified.

In reply to a specific question about whether respondents had ever used counselling in relation to being donor conceived/a donor, whether from UKDL or elsewhere, twenty (31%) donor conceived adults and four (19%) sperm donors (but no egg donors) said they had. While some reported this beneficial regardless of source, others, such as donor-conceived adult RF28, found non-specialist counselling of little help: *“I spoke with my doctor and she referred me for CBT. I didn't like the therapist, nor the type of therapy (which was definitely wrong for my situation) and so didn't go back and haven't bothered asking my GP for help since”*. One donor-conceived adult, RF30, compared her positive experience of the specialist UKDL counselling with seeing a GP counsellor for 12 weeks and using RELATE sessions with her mother saying: *“... neither of the above 2 were very helpful as no-one has really encountered DCA's [donor-conceived adults] before”*. Another, RF29, who reported using a UKDL counsellor for four sessions, said: *“...it was exceptionally helpful. It made me talk to my Dad about DC for the first time, it strengthened our relationship and helped me to become comfortable with being DC [donor conception]”*.



### *Views about and experiences of receiving DNA-related services*

Some respondents reported being adversely affected by the length of time taken by the DNA laboratory to provide test results (a service delivery issue already reported to the research team by UKDL staff and apparently resistant to UKDL's own complaints). One donor-conceived adult, RF47, said: *"It took 8 months to get the autosomal results that should have taken 1 month, still waiting for the x test results that should take 10 days – it's now 6 weeks. Very slow and frustrating process that affects your whole life – waiting for results....."*

In response to asking for respondents' thoughts about specific aspects of being on the register, 17 (26%) donor-conceived adults, six (29%) sperm donors and three (60%) egg donors said that coping with the fact that DNA results are not 100% accurate was 'possibly difficult' and 41 (63%) donor-conceived adults, 14 (67%) sperm donors and one (20%) egg donors said that getting false positive results was 'possibly difficult'. In contrast, 36 (55%) donor-conceived adults, nine (43%) sperm donors and two (40%) egg donors reported 'no problem' with DNA results not being 100% accurate and 12 (18%) donor-conceived adults, three (14%) sperm donors and no egg donors reported the same in relation to getting false positive results. The remainder were 'not sure'.

One donor-conceived adult, RM45, would have liked: *"..... mutually voluntary access to DNA data via web, and web service similar to donorregistry.com"*. And an egg donor, RF78, would have liked access to a service providing *".... genetic history establishing relevance of possible connection to another country, i.e. donor not being of English origin"*.

A shortfall in the existing service identified only by donor-conceived adults - perhaps reflecting that 'sibling' testing was less reliable as explained above - was the lack of detailed DNA-related advice when results indicated an apparently high 'probability' of being genetically related to one or more other registrants. One donor-conceived adult, RF8, explained that having: *".... someone to explain the workings of the DNA and testing in a lot more detail would be helpful. My donor conceived brother hired a professor to advise us who made it all clear"*. Another, RM24, was looking for a way of simplifying the results, albeit unrealistic:

*"They [UKDL] have been great but very challenged to explain the statistical nature of the results – they are an "odd-on" rating, not a simple yes or no. There should be a hand-out/link explaining the results in very simple terms..... A simple explanation of what the numeric "score" actually is. I suggest that simple explanations such as, "it is as likely that you are related as it is that you will buy a lotto ticket this week and win", or be struck by lightning today, or roll double-six twelve times straight etc."*

About half of all respondents (38, 58% donor-conceived adults; 14, 46% combined donors) would have welcomed access to a DNA expert or similar to explain the tests and results in

greater depth – a service not available at the time of the survey – with the remainder more ‘unsure’ than against (see Table 3).

INSERT TABLE 3 ABOUT HERE

#### *Contact with other registrants*

Twenty one (32%) donor-conceived adults, two (10%) sperm donors and one egg donor (20%) (3, 12% combined donors) had met registrants other than those to whom they had been linked. This was through one of the regular UKDL Registrants’ Panel meetings (open to all registrants), the Annual Meeting of registrants, one-to-one contact arranged via the UKDL staff, or a combination of these. Such contact was far more often reported as ‘helpful’ than not, such as by egg donor RF10: “ ..... *the regular meetings are also a great way to network and share experiences, also registrants support one another which is vital*”.

A small number reported such contact as unhelpful. Although there was little to indicate the reasons for this, one donor-conceived adult, RF35, described hers thus: “*I found it very upsetting meeting other members as I took being donor conceived as a positive thing, knowing how much my parents wanted me, and most other people were very unsure of themselves and blamed their parents for making them incomplete. I think it would be useful to have some good examples discussed at future meetings*”.

#### *(iv) How the services should be funded and potential impact on usage*

As outlined earlier, all UKDL services were free except for DNA testing and therapeutic counselling after a limited number of sessions. Respondents were invited to give their views on charging for DNA tests, joining the register, ongoing registration and whether charging would have inhibited take-up.

While views about charging for DNA testing were fairly evenly spread (29, 32% were against; 18, 20% were not sure; 41, 45% agreed with charging), high levels of opposition to charging for joining (69 [76%]) and ongoing registration (71 [78%]) were reported. The potential negative impact of introducing higher charges for DNA testing (23, 25% said they would not have registered) or a registration fee (20,22%) was less clear cut than for charging for ongoing registration (31, 34%), but across all groups, and especially donor-conceived adults, sizeable numbers reported a deterrent effect (see Table 4).

INSERT TABLE 4 ABOUT HERE

Views about whether professional services should attract a charge, i.e. professional support services, intermediary services and therapeutic counselling, were also sought. The majority of donor-conceived adults (40, 62%) and sperm donors (11, 52%) were opposed to charges for professional support services for those ‘not yet linked’ and for intermediary services (49,

75% donor-conceived adults; 12, 57% sperm donors). There was less strong opposition to charging for therapeutic counselling (35, 54% donor-conceived adults; 9, 43% sperm donors). Egg donors were more likely throughout to be unsure (see Table 5).

INSERT TABLE 5 ABOUT HERE

Finally, respondents were asked in an open question how they thought the service should be funded and the 79 responses (54 from donor-conceived adults, 20 from sperm donors and five from egg donors) were categorised (see Table 6).

INSERT TABLE 6 ABOUT HERE

The most common suggestion across all groups was that the service should be funded by central government directly or through an existing government-funded service such as the National Health Service (NHS) (26, 48% donor-conceived adults, nine, 45% sperm donors and two, 40% egg donors). This was followed by mixed sources of funding in various combinations drawn from public sources, charities, private fertility clinics and so on (16, 30% donor-conceived adults, 7, 35% sperm donors and 1, 20% egg donors).

Donor-conceived adults were more likely than donors to offer accompanying explanations. Some took a moral view as to why services should be free, namely that they had no choice about the manner of their conception but experienced the disadvantages resulting from the lack of regulation at the time and poor practices. Hence, those bodies that should have acted more responsibly at the time should now fund the service. Donor-conceived adult RM64 said: *“The government decided, completely inappropriately, that it would allow anonymous donors and it is up to the government to put right this mistake. It is not the responsibility of the donor-conceived to pay for this”*. Another, RF52, saw the responsibility arising from the government’s failure to regulate the fertility industry: *“... they [government] allowed an unregulated industry to make decisions about people's [lives] and ... there are adults who can have no chance of knowing who one of their parents is. They should fund any service that attempts to compensate for this”*.

Some respondents, such as donor-conceived adult RF23, extended moral responsibility to clinics that provided treatment services: *“I have absolutely no doubt in my mind that it should be funded by a levy on the fertility industry who (a) got us into this situation and (b) have profited from it. I think there are plenty of parallels/ precedents from other walks of life”*. For others, such as donor-conceived adult RM65, this was linked to the fact that they were profit-making: *“If clinics charge for AI [artificial insemination] services they should contribute”*.

Others employed a ‘rights’ approach, arguing the service should be free on the grounds of parity with comparable sections of the population, such as adopted people<sup>4</sup> :

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<sup>4</sup> Post adoption services in England and Wales are not automatically free, though they may be provided without charge in certain circumstances.

*There would be outrage if it was suggested that adopted people should pay for support services. We have no such rights. It was considered quite acceptable that we were conceived through anonymous donations with no identifying information recorded in any way that we could ever access. .... The government should fund this service - no one thought of the needs of donor conceived people or indeed donors when we were conceived. It would be unconscionable if we were again ignored and in effect told that if we cannot afford to arrange do it yourself testing too bad. There needs to be access to a similar service as adopted people have, with adequate funding to advertise that the service exists. Donor-conceived adult, RF1*

Or those conceived using donor conception since 1991 (when legislation was implemented)<sup>5</sup>:

*“... We should not have to pay for the right that everyone since 1991 has access to for free let alone the rest of the population who have it automatically”. Donor-conceived adult, RF37*

Donor-conceived adult RF67 believed the NHS should become involved given the lack of medical family history for many donor-conceived adults: *“The National Health Service has a responsibility to all sections of society especially those with a ? over their medical family history..... The NHS and social care framework should pool funds and expertise for the department of Donorlink”*. Another donor-conceived adult, RM45, approached it from the perspective of a public interest in reducing the risks of consanguinity: *“.....it is in the public interest for 'donor'-conceived persons to know their close genetic ties, due to the danger of consanguinity”*.

Although only one respondent, an egg donor, thought the service could be funded by registrants alone, several others suggested that registrants should contribute towards the running costs providing that there was support for those in hardship:

*“... I think no charge should be made to start with, to encourage people to join, but I would be happy to make a small donation monthly to stay in the register and support the fantastic work that is provided. Say £5 per month” Donor-conceived adult RM69*

*“If charging for all-any of these services is the only way to ensure they are available then definitely charge and provide hardship funds for those unable to pay. ....if the only way to keep it running is for it to be a stand alone services and for users to pay what it costs to run I would still choose to do so” Donor-conceived adult, RF14*

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<sup>5</sup> Since June 2015, donor-conceived adults who were conceived after 1<sup>st</sup> August 1991 and donors who donated after that time are, in certain circumstances, eligible to access time-limited professional support and intermediary services free of charge.

## DISCUSSION

This study's findings contribute to the limited existing research (Allan, 2012; Crawshaw et al., 2015) about what types of services might be appropriate for adults seeking contact with those to whom they are genetically related as a result of donor conception. All 91 respondents (donor-conceived adults, sperm and egg donors) were registrants with UK DonorLink (now Donor Conceived Register), a government-funded voluntary register using a dedicated DNA database of registrants' DNA profiles (held by a sub-contracted service) to identify those with high probabilities of being genetically related alongside directly provided psycho-social support and register services.

Having psycho-social professionals on hand at each stage of the process was clearly important to some (but not all) respondents regardless of whether actually used or not (take-up and frequency of usage figures were not collected). This has also been reported by practitioners with experience in this field (Daniels and Meadows, 2006; Johnson et al., 2012) including UKDL's own staff (Crawshaw et al., 2013). UKDL employed professional support staff in front-line services as well as offering second tier therapeutic counselling services; in other words employing a partnership, support-focussed model rather than a problem-focussed one (Trevithick, 2000). Other sources indicate such approaches can be effective and may reduce the need for therapeutic counselling (Kohli and Mather, 2003; McCluskey, 2005). Additionally, typically, fewer people take up therapeutic counselling than want it to be on offer, perhaps because it carries the stigma of mental ill-health or is perceived as indicating weakness, especially among males (Cousineau and Domar, 2007; Crawshaw, 2013), whereas professional support may be more acceptable. Where therapeutic counselling *was* used by respondents in this study, there was some indication that it might be more effective if informed by a specialist understanding of donor conception issues, although the small numbers warrant caution in this interpretation. However, making services available for reassurance alone, whether professional support or counselling, can be problematic for service commissioners/providers given that impact on well-being is difficult to measure and services might be underutilised. At the same time, their absence can drive need underground, especially when potential service users lack confidence in expressing their needs and/or do not have others to advocate for them.

Contact with peers was reported more helpful than not for the majority of those who accessed it, although it could prove unexpectedly distressing when peers' experiences differed markedly. This is a challenge for peer support, perhaps especially in a field such as donor conception where experiences of being donor conceived (or donating) may be wide ranging, with the most negative often coming from those who learn of their genetic origins outside of childhood or in adverse circumstances (for a review see Blyth et al., 2012).

The unique aspects of using DNA to identify probable genetic links are also better understood through this study. These will be of wide interest given that (i) the majority of donor-

conceived people internationally do not have access to records of their genetic origins so can rarely trace through non-DNA routes, (ii) UKDL was one of only two services internationally using a dedicated DNA database as the primary searching vehicle and providing associated psychosocial support services and (iii) using stand-alone DNA testing through DNA banks without a dedicated database requires the parties involved to identify each other beforehand (though note that instances are now arising where identification has occurred inadvertently (Harper et al., 2016)) and rarely includes psycho-social support.

Given that UKDL staff found the use of DNA to be one of the most complex aspects of the service, practically and ethically (Crawshaw et al., 2013), it was therefore surprising that access to DNA experts was seen by respondents as less important than access to psychosocial services. This may be for a number of reasons. Although registrants were told that DNA testing is not 100% accurate – especially for identifying donor-related siblings – and that additional supporting non-DNA information is important (see also Adams and Allan, 2013) the drive (or hope) to find those to whom they are genetically related through donor conception may explain why around half of registrants in each category reported ‘no problem’ in being on the register when there was such lack of accuracy. In other words, acceptance of associated risk may be influenced by the individual meaning attached to finding such links. However it may also be influenced by media representation of DNA results as being clear cut, overriding information provided in this particular context. At the same time, around two thirds of donor-conceived adults and sperm donors reported that getting false positive results was ‘possibly difficult’. This suggests that engaging with the implications of uncertainty may be more likely to come to the fore once a ‘probable’ link – which may still be a ‘false positive’ - is identified. However, even then hope may still override caution for those who reported this as causing them ‘no problem’. The service response may thus need to include access to both DNA experts and to psycho-social professionals.

Using DNA services as an integral part of a post donor conception ‘contact’ service also brings organisational challenges. The study found the desire for both a speedier DNA results service and improved comprehensibility in the language used by UKDL staff when conveying results. In a newly emerging, highly specialist service such as this where the lifelong consequences of fertility treatments have only started being recognised recently (van den Akker, 2013), the organisational complexity becomes clearer. The service was provided by a small voluntary sector organisation (seen by the Department of Health as the appropriate primary provider) adapting its professional experience of ‘search and contact’ services in the post-adoption field. This organisation then had to commission a service from a wholly different discipline (and organisation) about which it had no specialist knowledge, i.e. DNA scientists, while at the same time being accountable to its funder, the Department of Health. The increasing challenges of such arrangements in the health and social care field are being recognised (Moriarty and Manthorpe, 2014). These include operational challenges of managing contracted services which are failing (Hudson, 2014) and financial challenges resulting from inadequate budgets and/or uncertain futures that can result in the side-lining of

advocacy services for those already socially marginalised and/or driving needs underground by cutting back higher cost professional services, as discussed above (Ishkanian, 2014). For example, UKDL informed us of their limited ability to address the shortfalls in the DNA service given the contracted service provider's resistance to complaints and the potentially high cost of transferring the contract elsewhere given their fixed budget and the potential disruption to the overall service. UKDL carried accountability but had little real power to ensure the standards of the contracted service. This was all within an overall context of funding uncertainty that made long term planning difficult. It was also clear that some respondents were aware of the pressure on the service and feared it may disappear.

In addition to the concerns about service standards, there is the thorny question of how services should be funded. All groups indicated strong opposition to charging for services: partly on moral (to right a wrong) 'rights' grounds (for parity with comparable groups) or for health reasons (risks from consanguinity or from having an incomplete medical history); and partly to avoid take-up being inhibited. The opposition may have been influenced by the UK context whereby public, including health-related, services have traditionally been provided free, although this has been changing rapidly following the economic downturn and introduction of 'austerity' measures (Speed and Gabie, 2013; Sturgeon, 2014). This context may also have contributed to the slightly higher support for paying for therapeutic counselling as many such services - which have expanded rapidly in recent times in the UK - are more readily available in the private sector. Once respondents were asked to hypothesise about their reactions should charges be introduced, there was more variation in views with some making clear that their expressed *need* to have the service led them to be prepared to pay even if they believed it should be free.

There were limitations to the study. Respondents were self-selecting *and* had chosen to try and find people to whom they were genetically related through donor conception so are not representative of all donor-conceived adults and donors; all the donor-conceived respondents were conceived following sperm donation; given the methodology used, there was no opportunity to drill deeper into responses and uncover more nuanced views; the views of those who have chosen to use other searching routes or who have not yet discovered this particular route were not included. Finally, the relatively small numbers of donors, especially egg donors, meant it was inappropriate to test for statistically significant differences across different groups.

## **Conclusion**

This questionnaire-based study into the views and experiences of donor-conceived adults and gamete donors using a DNA-based voluntary register to seek those to whom they were genetically related through donor conception adds important information to the sparse literature on the use of DNA in this context and on what support services might be appropriate. It demonstrates the complexity of marrying disciplines and services, and identifying funding streams in this post-treatment field. The case for tailored responses to the

range of identified needs is clear but the organisational complexity of ensuring accountability alongside responsibility in such a specialist and newly emerging field is also evident. Medical science has enabled the creation of families through the use of donor conception but the lifelong social policy and practice implications are only more recently being recognised.

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The authors have no competing interests to declare except for MC who was national adviser to UKDL from 2003-2013.

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**Table 1: Use of UKDL professional support and influence of availability of intermediary services when deciding whether to register**

<b>Use of professional support when deciding whether to register</b>	<b>No answer</b>	<b>No</b>	<b>Not sure</b>	<b>Yes</b>	<b>Total</b>
Donor-conceived adults	1 (2%)	51 (78%)	-	13 (20%)	65
Sperm donors	1 (5%)	15 (71%)	-	5 (24%)	21
Egg donors	-	4 (80%)	-	1 (20%)	5
Combined donors	1 (4%)	19 (73%)	-	6 (23%)	26
<b>Total</b>	<b>2 (2%)</b>	<b>70 (77%)</b>	<b>-</b>	<b>19 (21%)</b>	<b>91</b>
<b>Influence on registration decision of availability of intermediary services</b>	<b>No answer</b>	<b>No</b>	<b>Not sure</b>	<b>Yes</b>	<b>Total</b>
Donor-conceived adults	1 (15%)	27 (42%)	14 (22%)	23 (35%)	65
Sperm donors	-	8 (38%)	3 (14%)	10 (48%)	21
Egg donors	1 (20%)	2 (40%)	1 (20%)	1 (20%)	5
Combined donors	1 (4%)	10 (38%)	4 (15%)	11 (42%)	26
<b>Total</b>	<b>2 (2%)</b>	<b>37 (41%)</b>	<b>18 (20%)</b>	<b>34 (37%)</b>	<b>91</b>

**Table 2: Importance of availability of services**

<b>Professional support</b>	<b>No answer</b>	<b>Important</b>	<b>Not important</b>	<b>Not sure</b>	<b>Total</b>
Donor-conceived adults	6 (9%)	50 (77%)	0	9 (14%)	65
Sperm donors	2 (10%)	16 (76%)	1 (5%)	2 (10%)	21
Egg donors	-	5 (100%)	-	-	5
Combined donors	2 (8%)	21 (81%)	1 (4%)	2 (8%)	26
<b>Total</b>	<b>8 (9%)</b>	<b>71 (78%)</b>	<b>1 (1%)</b>	<b>11 (12%)</b>	<b>91</b>
<b>Intermediary services</b>	<b>No answer</b>	<b>Important</b>	<b>Not important</b>	<b>Not sure</b>	<b>Total</b>
Donor-conceived adults	6 (9%)	50 (77%)	0	9 (14%)	65
Sperm donors	1 (5%)	16 (76%)	0	4 (19%)	21
Egg donors	-	5 (100%)	-	-	5
Combined Donors	1 (4%)	21 (81%)	0	4 (15%)	26
<b>Total</b>	<b>7 (8%)</b>	<b>71 (78%)</b>	<b>0</b>	<b>13 (14%)</b>	<b>91</b>
<b>Therapeutic counselling</b>	<b>No answer</b>	<b>Important</b>	<b>Not important</b>	<b>Not sure</b>	<b>Total</b>
Donor-conceived adults	7 (11%)	46 (71%)	2 (3%)	10 (15%)	65
Sperm donors	2 (10%)	14 (67%)	2 (10%)	3 (14%)	21
Egg donors	-	5 (100%)	-	-	5
Combined Donors	2 (8%)	19 (73%)	2 (8%)	3 (12%)	26
<b>Total</b>	<b>9 (10%)</b>	<b>65 (71%)</b>	<b>4 (4%)</b>	<b>13 (14%)</b>	<b>91</b>

**Table 3: Would you value access to a DNA expert or similar?**

	<b>No answer</b>	<b>No</b>	<b>Not sure</b>	<b>Yes</b>	<b>Total</b>
Donor-conceived adults	2 (3%)	6 (9%)	19 (29%)	38 (58%)	65
Sperm donors	1 (5%)	4 (19%)	8 (38%)	8 (38%)	21
Egg donors	-	-	1 (20%)	4 (80%)	5
Combined Donors	1 (4%)	4 (15%)	9 (35%)	12 (46%)	26
<b>Total</b>	<b>3 (3%)</b>	<b>10 (11%)</b>	<b>28 (31%)</b>	<b>50 (55%)</b>	<b>91</b>

**Table 4: Views on paying for DNA testing and registration and the anticipated impact should fees be levied**

<b>Whether DNA testing should be charged for</b>	<b>No answer</b>	<b>No</b>	<b>Not sure</b>	<b>Yes</b>	<b>Total</b>
Donor-conceived adults	3 (5%)	22 (34%)	14 (22%)	<b>26 (40%)</b>	65
Sperm donors	-	7 (33%)	2 (10%)	<b>12 (57%)</b>	21
Egg donors	-	-	2 (40%)	<b>3 (60%)</b>	5
Combined donors	0	7 (27%)	4 (15%)	<b>15 (58%)</b>	26
Total	3 (3%)	29 (32%)	18 (20%)	<b>41 (45%)</b>	91
<b>Whether respondent would still have registered if DNA costs were higher</b>	<b>No answer</b>	<b>No</b>	<b>Not sure</b>	<b>Yes</b>	<b>Total</b>
Donor-conceived adults	4 (6%)	19 (29%)	<b>21 (32%)</b>	<b>21 (32%)</b>	65
Sperm donors	1 (5%)	4 (19%)	<b>9 (43%)</b>	7 (33%)	21
Egg donors	-	-	<b>4 (80%)</b>	1 (20%)	5
Combined donors	1 (4%)	4 (15%)	<b>13 (50%)</b>	8 (31%)	26
Total	5 (5%)	23 (25%)	<b>34 (37%)</b>	<b>29 (32%)</b>	91
<b>Whether there should be a fee for joining the Register</b>	<b>No answer</b>	<b>No</b>	<b>Not sure</b>	<b>Yes</b>	<b>Total</b>
Donor-conceived adults	3 (5%)	<b>49 (75%)</b>	6 (9%)	7 (11%)	65
Sperm donors	-	<b>16 (76%)</b>	-	5 (24%)	26
Egg donors	-	<b>4 (80%)</b>	1 (20%)	-	5
Combined donors	0	<b>20 (77%)</b>	1 (4%)	5 (19%)	26
Total	3 (3%)	<b>69 (76%)</b>	7 (8%)	12 (13%)	91
<b>Whether respondent would still have registered if joining fee were in place</b>	<b>No answer</b>	<b>No</b>	<b>Not sure</b>	<b>Yes</b>	<b>Total</b>
Donor offspring	4 (6%)	16 (25%)	<b>22 (34%)</b>	<b>23 (35%)</b>	65
Sperm donors	1 (5%)	4 (19%)	5 (24%)	<b>11 (52%)</b>	21
Egg donors	-	-	<b>3 (60%)</b>	2 (40%)	5
Combined donors	1 (4%)	4 (15%)	8 (31%)	<b>13 (50%)</b>	26
Total	5 (5%)	20 (22%)	30 (33%)	<b>36 (40%)</b>	91
<b>Whether there should be a fee for continuing registration</b>	<b>No answer</b>	<b>No</b>	<b>Not sure</b>	<b>Yes</b>	<b>Total</b>
Donor offspring	3 (5%)	<b>52 (80%)</b>	7 (11%)	3 (5%)	65
Sperm donors	-	<b>16 (76%)</b>	1 (5%)	4 (19%)	21
Egg donors	-	<b>3 (60%)</b>	1 (20%)	1 (20%)	5
Combined donors	0	<b>19 (73%)</b>	2 (8%)	5 (19%)	26
Total	3 (3%)	<b>71 (78%)</b>	9 (10%)	8 (9%)	91
<b>Whether respondent would have remained registered if ongoing fees were in place</b>	<b>No answer</b>	<b>No</b>	<b>Not sure</b>	<b>Yes</b>	<b>Total</b>
Donor-conceived adults	4 (6%)	<b>26 (40%)</b>	20 (31%)	15 (23%)	65
Sperm donors	1 (5%)	5 (24%)	6 (29%)	<b>9 (43%)</b>	21
Egg donors	-	-	<b>3 (60%)</b>	2 (40%)	5
Combined donors	1 (4%)	5 (19%)	9 (35%)	<b>11 (42%)</b>	26
Total	5 (5%)	<b>31 (34%)</b>	29 (32%)	26 (29%)	91

**Table 5: Views on charging for professional services**

<b>Professional support for those not yet linked</b>	<b>No answer</b>	<b>No</b>	<b>Not sure</b>	<b>Yes</b>	<b>Total</b>
Donor-conceived adults	3 (5%)	<b>40 (62%)</b>	17 (26%)	5 (8%)	65
Sperm donors	-	<b>11 (52%)</b>	7 (33%)	3 (14%)	21
Egg donors	-	1 (20%)	<b>4 (80%)</b>	-	5
Combined donors	-	<b>12 (46%)</b>	11 (42%)	3 (12%)	26
Total	3 (5%)	<b>52 (57%)</b>	28 (31%)	8 (9%)	91
<b>Intermediary services</b>					
Donor-conceived adults	3 (5%)	<b>49 (75%)</b>	11 (17%)	2 (3%)	65
Sperm donors	-	<b>12 (57%)</b>	5 (24%)	4 (19%)	21
Egg donors	-	-	<b>3 (60%)</b>	2 (40%)	5
Combined donors	-	<b>12 (46%)</b>	8 (31%)	6 (23%)	26
Total	3 (5%)	<b>61 (67%)</b>	19 (21%)	8 (9%)	91
<b>Therapeutic counselling</b>					
Donor-conceived adults	3 (5%)	<b>35 (54%)</b>	20 (31%)	7 (11%)	65
Sperm donors	-	<b>9 (43%)</b>	6 (29%)	6 (29%)	21
Egg donors	-	-	<b>5 (100%)</b>	-	5
Combined donors	-	9 (35%)	11 (42%)	6 (23%)	26
Total	-	<b>44 (48%)</b>	31 (34%)	13 (14%)	91

**Table 6: Views on how the service should be funded**

	<b>Donor-conceived adults</b>	<b>Sperm donors</b>	<b>Egg donors</b>	<b>Combined donors</b>	<b>TOTAL RESPONSES</b>
Public funding alone	<b>26 (48%)</b>	<b>9 (45%)</b>	<b>2 (40%)</b>	<b>11 (44%)</b>	<b>37 (47%)</b>
Fertility clinics/gametes donor banks alone	3 (6%)	1 (5%)	1 (20%)	2 (8%)	5 (6%)
Registrants alone	-	-	1 (20%)	1 (4%)	1 (1%)
Donors alone	1 (2%)	1 (5%)		1 (4%)	2 (3%)
Mixed – public and registrants' fees alone	6 (11%)	1 (5%)	-	1 (4%)	7 (9%)
Mixed (incl public, charitable, private fertility clinics, donations, commercial sponsorship)	16 (30%)	7 (35%)	1 (20%)	8 (32%)	24 (30%)
Other	2 (4%)	1 (5%)	-	1 (4%)	3 (4%)
<b>TOTAL</b>	<b>54 (100%)</b>	<b>20 (100%)</b>	<b>5 (100%)</b>	<b>(25)</b>	<b>79</b>