



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

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TITLE PAGE

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

Short title: Information and contact services after donor conception

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¹ During the course of the study, I retired from my permanent academic post and became an Honorary Fellow, a position I still hold

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 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’ – Fiom² 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; Jadva 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

² 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.

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3 greater incidence and longer history and more studies are needed into information seeking
4 and contact patterns among those affected by egg, embryo or double donation.
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8 Little is known about how best to meet the needs of these different groups, donors and
9 donor-conceived adults, and how to provide associated support services. Even jurisdictions
10 that have mandated the release of biogenetic information following donor conception apply
11 varying standards in their approach to its management and any reference to what kind of
12 professional support might be needed, when and how, is generally absent (Allan, 2012). The
13 small amount of practice-based literature regarding work with searchers (Crawshaw et al.,
14 2013; Daniels and Meadows, 2006; Johnson, et al., 2012; Kramer and Cahn, 2013) suggests
15 that having psycho-social professional support available may be warranted. This is
16 supported by research indicating that some donor-conceived people, especially those
17 learning of their genetic origins later in life and/or in unplanned ways and/or who have had
18 dysfunctional family experiences, may experience acute and lasting emotional distress
19 (Baran and Pannor, 1989; Cushing, 2010; Mahlstedt et al, 2010; McWhinnie, 2000; Turner
20 and Coyle, 2000). In addition, contact arrangements have occasionally proved difficult to
21 manage (Crawshaw et al., 2013; Goldberg and Scheib, 2015) and their nature can unfold and
22 change over time and carry different meanings to the different parties involved (Blyth
23 2012b). Some donors have expressed an interest in using support services in the event of
24 being contacted and/or searching themselves (Crawshaw et al., 2007; Hammarberg et al.,
25 2014; Kirkman et al., 2014; Speirs, 2012). One sperm donor who recently spoke publicly
26 about his experience of being traced on two separate occasions – once with professional
27 support and once without - made clear his preference for the former (Whitehead 2016).
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45 This paper seeks to contribute to the sparse information on what donor-conceived adults
46 and donors might look for in services designed to help them locate and make contact with
47 those to whom they are genetically related through donor conception and considers the
48 implications of these findings.
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53 54 **Materials and Methods**

55 The findings reported here are part of a larger questionnaire-based study of the views and
56 experiences of donor-conceived adults and donors registered with UK DonorLink (UKDL), a
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3 voluntary DNA-based UK register for adults seeking those to whom they were genetically
4 related through donor conception (see also van den Akker, 2015). It was open to adults who
5 had been conceived or had donated in the UK prior to August 1991 when a central register
6 of all treatments and births was established through the Human Fertilisation and
7 Embryology Act 1990. The HFEA Register provides rights of access to information for donor-
8 conceived adults (which have evolved over the years and now include identifying
9 information for certain groups) and donors (for the current situation see www.hfea.gov.uk).
10 UKDL was funded by the Department of Health from its launch in 2004. At the time of the
11 survey its financial future had been uncertain for some time but this was later resolved and
12 the service was transferred to a new provider, the Donor Conceived Register, in April 2013³.
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21 UKDL kept a Register and provided support through four main types of services:

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23 (i) DNA testing and the maintenance of a DNA database of registrants for
24 identifying probability of linkages, provided under contract by an independent,
25 government-approved laboratory;
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27 (ii) professional support for registrants or potential registrants considering the
28 implications of proposed actions when undertaking DNA tests or when requiring
29 information, advice or support outside a formal therapeutic counselling service;
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31 (iii) intermediary services to anyone identified through DNA testing with a high
32 probability of being genetically related to one or more other registrants wanting
33 support during the process of exchanging information and/or making contact;
34 and
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36 (iv) therapeutic counselling for those wanting in-depth help with psychological,
37 emotional or relationship issues arising from their involvement in donor
38 conception.
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51 ³ The Donor Conceived Register allows registrants direct access to the staff at the DNA
52 laboratory that they use. They do not routinely provide professional support at each
53 stage of the process but formal therapeutic counselling is available on request and is
54 compulsory at the point of information exchange following DNA 'matching'.
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3 Registrants paid for DNA testing at a price determined by the laboratory (as required by the
4 Department of Health, although UKDL was allowed to subsidise those in financial hardship
5 from its grant). UKDL support and intermediary services were free of charge and without
6 time limits. Therapeutic counselling was free for a limited number of sessions and then
7 became available for a fee. UKDL staff were predominantly qualified in both social work and
8 counselling with prior experience of providing post-adoption support.
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15 The questionnaire (available on request) was developed specifically for this study by
16 drawing on prior research evidence and practice experience and in consultation with UKDL.
17 It comprised 96 questions (both open and closed) with some specific sections for donors or
18 donor-conceived adults and some common sections for all. Free-text responses were invited
19 through open questions. Closed questions provided a range of multiple choice answers
20 together with the opportunity for responses through an 'other' box. A final question invited
21 all respondents to provide additional free-text comments if they wished.
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30 The survey was administered using the Bristol Online Survey with hard copies sent to those
31 without email contact. Respondents were provided with an information sheet and consent
32 was implied from completion of the questionnaire. The invitation to participate was sent
33 out via the UKDL Head Office (with two reminders) to all registrants; the survey was open
34 from mid October 2012 to mid January 2013.
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40 *Data analysis*

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42 All responses to the 28 questions that covered any aspect of service provision were
43 analysed, together with the free-text responses to the final open question. As the number of
44 respondents was too small for statistical comparisons to be made, descriptive statistics are
45 reported for the quantitative data by the following groups: donor-conceived adults, sperm
46 donors and egg donors and all donors (hereafter called combined donors).
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53 A thematic analysis was undertaken of the open responses and those provided under the
54 'other' box for closed questions. The transcripts were coded for concepts. From these
55 concepts, core themes were generated that illustrated how the respondents thought about
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3 service provision. Transcripts were read by members of the team and the coding, themes
4 and analytic milestones discussed. The validity of the range of interpretations and suggested
5 relationships between these core themes was explored and tested against the data using
6 the constant comparative method (Silverman, 2006).
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12 The final stage comprised discussion within the team as to how the quantitative and
13 qualitative data could be reported in order to appropriately reflect the range of
14 respondents' views on key aspects of service provision.
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19 All quotations used are from survey responses with incorrect spellings corrected but
20 language and grammar left in their original form. Respondents (R) are identified by number,
21 gender and category (donor-conceived adult, sperm or egg donor).
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27 **Ethical Approval**

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30 Ethical approvals were obtained from Middlesex and Huddersfield Universities and approval
31 for the study was given by UKDL.
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37 **Results**

38 *Participants*

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42 Ninety one adults registered with UKDL responded to the questionnaire survey (eighty one
43 on-line and ten through paper copies), representing just over a third (37.3%) of those
44 approached. However an unspecified number of those sent the survey were later found to
45 have changed their contact details without notifying UKDL so would not have received it.
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51 All 65 donor-conceived adult respondents (50 females, 14 males and one who did not
52 specify their sex) were conceived with the use of donor sperm. Of the 26 donors, 21 were
53 sperm donors and five egg donors with the lower number of egg donors reflecting the more
54 recent introduction of such services in the mid 1980s. The mean age of donor-conceived
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3 adults was 35.7 years (SD=12.64), of sperm donors was 55 years (SD=8.95) and of egg
4 donors was 55.8 years (SD=4.14). No significant differences between groups were evident
5 on any other socio-demographic variables. All respondents were White except for one Asian
6 male donor-conceived adult (full demographic and study information is reported in van den
7 Akker et al., 2015).
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14 Twenty three donor-conceived adult respondents, two sperm donors and one egg donor
15 had been linked to at least one other person at the time of the survey. UKDL staff used the
16 term 'linked' rather than 'matched' given that DNA testing could only provide probability of
17 genetic linkage rather than certainty. Reliability of the results also varied according to (i)
18 whether the DNA of the biological parent of the donor-conceived registrant was provided
19 for the DNA database and (ii) whether testing was for 'donor to offspring' or for 'sibling'
20 genetic relationships, with the latter being less reliable (see also Adams and Allan, 2013).
21 Supplementary DNA testing to increase reliability was available but only if those concerned
22 shared a gender ('x' chromosome testing for females, 'y' chromosome testing for males) and
23 could afford the additional cost.
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34 We report here on responses to the following four main groups of questions that we asked:

- 35 (i) Which services, if any, affected their decision to register;
36 (ii) Which services they considered important;
37 (iii) How services were provided;
38 (iv) How services should be funded and potential impact of funding on their usage.
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44 It should be noted that given that, as reported above, UKDL staff could themselves provide
45 all services other than those provided by the DNA laboratory, the difference between
46 professional support, intermediary and counselling services was not necessarily fully
47 understood by some registrants.
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53 (i) *Services that affected the decision to register*

54 Respondents were asked whether they had used professional support to help them decide
55 whether to register and whether the availability of intermediary services affected their
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3 decision. Bearing in mind that some may not have fully understood these distinctions,
4 nineteen (21%) reported using professional support, with a slightly higher proportion of
5 sperm donors than egg donors or donor-conceived adults. The potential availability of
6 intermediary services influenced the decision to register for around a third of donor-
7 conceived adults (23, 35%), just under half of sperm donors (10, 48%) and one egg donor
8 (20%) (Table 1).
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16 INSERT TABLE 1 ABOUT HERE
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21 *(ii) Services considered to be important*
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24 Respondents were asked which of the three non-DNA services they considered important.
25 There was consistency among the three groups of respondents on the importance of all, i.e.
26 professional support services (71, 78%), intermediary services (71, 78%) and formal
27 therapeutic counselling (65, 71%) (Table 2).
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40 Open comments suggested some of the reasons why they were considered important. One
41 donor-conceived adult (RF77) remarked that “ *So many seem to have had great*
42 *difficulty with issues surrounding the uncertainty of their background*”. An egg donor (RF10)
43 said that “.... *these are complex emotional issues and deeply personal, it is a massive thing to*
44 *consider meeting biological relatives and support through people/organisations specialised*
45 *in this is key to a smooth supported link*”.
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51 *(iii) How services were provided*
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53 *Views about and experiences of receiving non DNA-based services*
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55 Views were sought about the levels of professional support provided to those ‘not yet
56 linked’. Around half said they were ‘about right’ (36, 55% donor-conceived adults, 12, 57%
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3 sperm donors, 3, 60% egg donors, 15, 58% combined donors) with considerably less saying
4 they were 'too little' (16, 25% donor-conceived adults, 2, 10% sperm donors, 1, 20% egg
5 donors, 3, 12% combined donors). None said they were 'too much' or responded 'not sure'.
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7 Thirteen (20%) donor-conceived adults, seven (33%) sperm donors and one (20%) egg donor
8 did not reply.
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14 Among all respondents, whether linked or not, open comments indicated themes
15 concerning reactions to, and usage of, the services provided. A small number, such as
16 donor-conceived adult RF15, reported little contact and would have welcomed more: "*I*
17 *haven't heard much from UKDL apart from surveys and letters that are clearly sent to*
18 *everyone!!!*". Others, such as donor-conceived adult RF69, felt support was readily available
19 if and when needed: "*They were so supportive, but not pushy in any way, just dealt with it*
20 *how I wanted to*". And sperm donor RM2 said they provided: "*Great moral support and*
21 *advice from UKDL. They really have been marvellous*". Some respondents, such as sperm
22 donor RM62, found their needs met by one or two sessions: "*.... just once when I registered.*
23 *was ok, clarified a couple of things*". Some, like donor-conceived adult RM64, needed far
24 longer: "*..... for a couple of years. Very helpful, perhaps essential to avoid suicide....*". As
25 these were open comments, the type of service was usually not specified.
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37 In reply to a specific question about whether respondents had ever used counselling in
38 relation to being donor conceived/a donor, whether from UKDL or elsewhere, twenty (31%)
39 donor conceived adults and four (19%) sperm donors (but no egg donors) said they had.
40 While some reported this beneficial regardless of source, others, such as donor-conceived
41 adult RF28, found non-specialist counselling of little help: "*I spoke with my doctor and she*
42 *referred me for CBT. I didn't like the therapist, nor the type of therapy (which was definitely*
43 *wrong for my situation) and so didn't go back and haven't bothered asking my GP for help*
44 *since*". One donor-conceived adult, RF30, compared her positive experience of the
45 specialist UKDL counselling with seeing a GP counsellor for 12 weeks and using RELATE
46 sessions with her mother saying: "*... neither of the above 2 were very helpful as no-one has*
47 *really encountered DCA's [donor-conceived adults] before*". Another, RF29, who reported
48 using a UKDL counsellor for four sessions, said: "*...it was exceptionally helpful. It made me*
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3 *talk to my Dad about DC for the first time, it strengthened our relationship and helped me to*
4 *become comfortable with being DC [donor conception]”.*
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8 *Views about and experiences of receiving DNA-related services*

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10 Some respondents reported being adversely affected by the length of time taken by the
11 DNA laboratory to provide test results (a service delivery issue already reported to the
12 research team by UKDL staff and apparently resistant to UKDL’s own complaints). One
13 donor-conceived adult, RF47, said: *“It took 8 months to get the autosomal results that*
14 *should have taken 1 month, still waiting for the x test results that should take 10 days – it’s*
15 *now 6 weeks. Very slow and frustrating process that affects your whole life – waiting for*
16 *results.....”.*
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24 In response to asking for respondents’ thoughts about specific aspects of being on the
25 register, 17 (26%) donor-conceived adults, six (29%) sperm donors and three (60%) egg
26 donors said that coping with the fact that DNA results are not 100% accurate was ‘possibly
27 difficult’ and 41 (63%) donor-conceived adults, 14 (67%) sperm donors and one (20%) egg
28 donors said that getting false positive results was ‘possibly difficult’. In contrast, 36 (55%)
29 donor-conceived adults, nine (43%) sperm donors and two (40%) egg donors reported ‘no
30 problem’ with DNA results not being 100% accurate and 12 (18%) donor-conceived adults,
31 three (14%) sperm donors and no egg donors reported the same in relation to getting false
32 positive results. The remainder were ‘not sure’.
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42 One donor-conceived adult, RM45, would have liked: *“..... mutually voluntary access to DNA*
43 *data via web, and web service similar to donorregistry.com”.* And an egg donor, RF78, would
44 have liked access to a service providing *“.... genetic history establishing relevance of possible*
45 *connection to another country, i.e. donor not being of English origin”.*
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51 A shortfall in the existing service identified only by donor-conceived adults - perhaps
52 reflecting that ‘sibling’ testing was less reliable as explained above - was the lack of
53 detailed DNA-related advice when results indicated an apparently high ‘probability’ of
54 being genetically related to one or more other registrants. One donor-conceived adult,
55 RF8, explained that having: *“.... someone to explain the workings of the DNA and*
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3 testing in a lot more detail would be helpful. My donor conceived brother hired a
4 professor to advise us who made it all clear". Another, RM24, was looking for a way of
5 simplifying the results, albeit unrealistic:
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10 *"They [UKDL] have been great but very challenged to explain the statistical*
11 *nature of the results – they are an "odd-on" rating, not a simple yes or no.*
12 *There should be a hand-out/link explaining the results in very simple*
13 *terms..... A simple explanation of what the numeric "score" actually is. I*
14 *suggest that simple explanations such as, "it is as likely that you are related as*
15 *it is that you will buy a lotto ticket this week and win", or be struck by lightning*
16 *today, or roll double-six twelve times straight etc."*
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24 About half of all respondents (38, 58% donor-conceived adults; 14, 46% combined donors)
25 would have welcomed access to a DNA expert or similar to explain the tests and results in
26 greater depth – a service not available at the time of the survey – with the remainder more
27 'unsure' than against (see Table 3).
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33 INSERT TABLE 3 ABOUT HERE
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36 *Contact with other registrants*

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38 Twenty one (32%) donor-conceived adults, two (10%) sperm donors and one egg
39 donor (20%) (3, 12% combined donors) had met registrants other than those to whom
40 they had been linked. This was through one of the regular UKDL Registrants' Panel
41 meetings (open to all registrants), the Annual Meeting of registrants, one-to-one
42 contact arranged via the UKDL staff, or a combination of these. Such contact was far
43 more often reported as 'helpful' than not, such as by egg donor RF10: "..... *the regular*
44 *meetings are also a great way to network and share experiences, also registrants*
45 *support one another which is vital".*
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54 A small number reported such contact as unhelpful. Although there was little to
55 indicate the reasons for this, one donor-conceived adult, RF35, described hers thus: "*I*
56 *found it very upsetting meeting other members as I took being donor conceived as a*
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3 *positive thing, knowing how much my parents wanted me, and most other people*
4 *were very unsure of themselves and blamed their parents for making them incomplete.*
5 *I think it would be useful to have some good examples discussed at future meetings”.*
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10 (iv) *How the services should be funded and potential impact on usage*

11 As outlined earlier, all UKDL services were free except for DNA testing and therapeutic
12 counselling after a limited number of sessions. Respondents were invited to give their views
13 on charging for DNA tests, joining the register, ongoing registration and whether charging
14 would have inhibited take-up.
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20 While views about charging for DNA testing were fairly evenly spread (29, 32% were against;
21 18, 20% were not sure; 41, 45% agreed with charging), high levels of opposition to charging
22 for joining (69 [76%]) and ongoing registration (71 [78%]) were reported. The potential
23 negative impact of introducing higher charges for DNA testing (23, 25% said they would not
24 have registered) or a registration fee (20, 22%) was less clear cut than for charging for
25 ongoing registration (31, 34%), but across all groups, and especially donor-conceived adults,
26 sizeable numbers reported a deterrent effect (see Table 4).
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36 Views about whether professional services should attract a charge, i.e. professional support
37 services, intermediary services and therapeutic counselling, were also sought. The majority
38 of donor-conceived adults (40, 62%) and sperm donors (11, 52%) were opposed to charges
39 for professional support services for those ‘not yet linked’ and for intermediary services (49,
40 75% donor-conceived adults; 12, 57% sperm donors). There was less strong opposition to
41 charging for therapeutic counselling (35, 54% donor-conceived adults; 9, 43% sperm
42 donors). Egg donors were more likely throughout to be unsure (see Table 5).
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54 Finally, respondents were asked in an open question how they thought the service should
55 be funded and the 79 responses (54 from donor-conceived adults, 20 from sperm donors
56 and five from egg donors) were categorised (see Table 6).
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8 The most common suggestion across all groups was that the service should be funded by
9 central government directly or through an existing government-funded service such as the
10 National Health Service (NHS) (26, 48% donor-conceived adults, nine, 45% sperm donors
11 and two, 40% egg donors). This was followed by mixed sources of funding in various
12 combinations drawn from public sources, charities, private fertility clinics and so on (16,
13 30% donor-conceived adults, 7, 35% sperm donors and 1, 20% egg donors).
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20 Donor-conceived adults were more likely than donors to offer accompanying explanations.
21 Some took a moral view as to why services should be free, namely that they had no choice
22 about the manner of their conception but experienced the disadvantages resulting from the
23 lack of regulation at the time and poor practices. Hence, those bodies that should have
24 acted more responsibly at the time should now fund the service. Donor-conceived adult
25 RM64 said: *“The government decided, completely inappropriately, that it would allow*
26 *anonymous donors and it is up to the government to put right this mistake. It is not the*
27 *responsibility of the donor-conceived to pay for this”*. Another, RF52, saw the responsibility
28 arising from the government’s failure to regulate the fertility industry: *“... they*
29 *[government] allowed an unregulated industry to make decisions about people’s [lives] and*
30 *... there are adults who can have no chance of knowing who one of their parents is. They*
31 *should fund any service that attempts to compensate for this”*.
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43 Some respondents, such as donor-conceived adult RF23, extended moral responsibility to
44 clinics that provided treatment services: *“I have absolutely no doubt in my mind that it*
45 *should be funded by a levy on the fertility industry who (a) got us into this situation and (b)*
46 *have profited from it. I think there are plenty of parallels/ precedents from other walks of*
47 *life”*. For others, such as donor-conceived adult RM65, this was linked to the fact that they
48 were profit-making: *“If clinics charge for AI [artificial insemination] services they should*
49 *contribute”*.
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3 Others employed a 'rights' approach, arguing the service should be free on the grounds of
4 parity with comparable sections of the population, such as adopted people⁴ :
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8 *There would be outrage if it was suggested that adopted people should pay for*
9 *support services. We have no such rights. It was considered quite acceptable that we*
10 *were conceived through anonymous donations with no identifying information*
11 *recorded in any way that we could ever access. The government should fund*
12 *this service - no one thought of the needs of donor conceived people or indeed donors*
13 *when we were conceived. It would be unconscionable if we were again ignored and in*
14 *effect told that if we cannot afford to arrange do it yourself testing too bad. There*
15 *needs to be access to a similar service as adopted people have, with adequate*
16 *funding to advertise that the service exists. Donor-conceived adult, RF1*
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26 Or those conceived using donor conception since 1991 (when legislation was
27 implemented)⁵: *"... We should not have to pay for the right that everyone since 1991 has*
28 *access to for free let alone the rest of the population who have it automatically". Donor-*
29 *conceived adult, RF37*
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35 Donor-conceived adult RF67 believed the NHS should become involved given the lack of
36 medical family history for many donor-conceived adults: *"The National Health Service has a*
37 *responsibility to all sections of society especially those with a ? over their medical family*
38 *history..... The NHS and social care framework should pool funds and expertise for the*
39 *department of Donorlink".* Another donor-conceived adult, RM45, approached it from the
40 perspective of a public interest in reducing the risks of consanguinity: *".....it is in the public*
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48 ⁴ Post adoption services in England and Wales are not automatically free, though they may
49 be provided without charge in certain circumstances.
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52 ⁵ Since June 2015, donor-conceived adults who were conceived after 1st August 1991 and
53 donors who donated after that time are, in certain circumstances, eligible to access time-
54 limited professional support and intermediary services free of charge.
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3 *interest for 'donor'-conceived persons to know their close genetic ties, due to the danger of*
4 *consanguinity".*
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8 Although only one respondent, an egg donor, thought the service could be funded by
9 registrants alone, several others suggested that registrants should contribute towards the
10 running costs providing that there was support for those in hardship:
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15 *".... I think no charge should be made to start with, to encourage people to join, but I*
16 *would be happy to make a small donation monthly to stay in the register and support*
17 *the fantastic work that is provided. Say £5 per month" Donor-conceived adult RM69*
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22 *"If charging for all-any of these services is the only way to ensure they are available*
23 *then definitely charge and provide hardship funds for those unable to pay.if*
24 *the only way to keep it running is for it to be a stand alone services and for users to*
25 *pay what it costs to run I would still choose to do so" Donor-conceived adult, RF14*
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31 **DISCUSSION**

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34 This study's findings contribute to the limited **existing research** (Allan, 2012;
35 **Crawshaw et al., 2015**) about what types of services might be appropriate for adults
36 seeking contact with those to whom they are genetically related as a result of donor
37 conception. All 91 respondents (donor-conceived adults, sperm and egg donors) were
38 registrants with UK DonorLink (now Donor Conceived Register), a government-funded
39 voluntary register using a dedicated DNA database of registrants' DNA profiles (held
40 by a sub-contracted service) to identify those with high probabilities of being
41 genetically related alongside directly provided psycho-social support and register
42 services.
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51 Having psycho-social professionals on hand at each stage of the process was clearly
52 important to some (but not all) respondents regardless of whether actually used or
53 not (take-up and frequency of usage figures were not collected). **This has also been**
54 **reported by practitioners with experience in this field** (Daniels and Meadows, 2006;
55 **Johnson et al., 2012**) including UKDL's own staff (Crawshaw et al., 2013). UKDL
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3 employed professional support staff in front-line services as well as offering second
4 tier therapeutic counselling services; in other words employing a partnership, support-
5 focused model rather than a problem-focused one (Trevithick, 2000). Other sources
6 indicate such approaches can be effective and may reduce the need for therapeutic
7 counselling (Kohli and Mather, 2003; McCluskey, 2005). Additionally, typically, fewer
8 people take up therapeutic counselling than want it to be on offer, perhaps because it
9 carries the stigma of mental ill-health or is perceived as indicating weakness,
10 especially among males (Cousineau and Domar, 2007; Crawshaw, 2013), whereas
11 professional support may be more acceptable. Where therapeutic counselling *was*
12 used by respondents in this study, there was some indication that it might be more
13 effective if informed by a specialist understanding of donor conception issues,
14 although the small numbers warrant caution in this interpretation. However, making
15 services available for reassurance alone, whether professional support or counselling,
16 can be problematic for service commissioners/providers given that impact on well-
17 being is difficult to measure and services might be underutilised. At the same time,
18 their absence can drive need underground, especially when potential service users
19 lack confidence in expressing their needs and/or do not have others to advocate for
20 them.
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36 Contact with peers was reported more helpful than not for the majority of those who
37 accessed it, although it could prove unexpectedly distressing when peers' experiences
38 differed markedly. This is a challenge for peer support, perhaps especially in a field
39 such as donor conception where experiences of being donor conceived (or donating)
40 may be wide ranging, with the most negative **often** coming from those who learn of
41 their **genetic** origins outside of childhood or in adverse circumstances (for a review see
42 Blyth et al., 2012).
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49 The unique aspects of using DNA to identify probable genetic links are also better
50 understood through this study. These will be of wide interest given that (i) the majority of
51 donor-conceived people internationally do not have access to records of their **genetic**
52 origins so can rarely trace through non-DNA routes, (ii) UKDL was one of only two services
53 internationally using a dedicated DNA database as the primary searching vehicle and
54 providing associated psychosocial support services and (iii) using stand-alone DNA testing
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3 through DNA banks without a dedicated database requires the parties involved to identify
4 each other beforehand (though note that instances are now arising where identification has
5 occurred inadvertently (Harper et al., 2016)) and rarely includes psycho-social support.
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9 Given that UKDL staff found the use of DNA to be one of the most complex aspects of the
10 service, practically and ethically (Crawshaw et al., 2013), it was therefore surprising that
11 access to DNA experts was seen by respondents as less important than access to
12 psychosocial services. This may be for a number of reasons. Although registrants were told
13 that DNA testing is not 100% accurate – especially for identifying donor-related siblings –
14 and that additional supporting non-DNA information is important (see also Adams and Allan,
15 2013) the drive (or hope) to find **those to whom they are genetically related through donor**
16 **conception** may explain why around half of registrants in each category reported ‘no
17 problem’ in being on the register when there was such lack of accuracy. In other words,
18 acceptance of associated risk may be influenced by the individual meaning attached to
19 finding **such links**. However it may also be influenced by media representation of DNA
20 results as being clear cut, overriding information provided in this particular context. At the
21 same time, around two thirds of donor-conceived adults and sperm donors reported that
22 getting false positive results was ‘possibly difficult’. This suggests that engaging with the
23 implications of uncertainty may be more likely to come to the fore once a ‘probable’ link –
24 which may still be a ‘false positive’ - is identified. However, even then hope may still
25 override caution for those who reported this as causing them ‘no problem’. The service
26 response may thus need to include access to both DNA experts and to psycho-social
27 professionals.
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43 Using DNA services as an integral part of a post donor conception ‘contact’ service
44 also brings organisational challenges. The study found the desire for both a speedier
45 DNA results service and improved comprehensibility in the language used by UKDL
46 staff when conveying results. In a newly emerging, highly specialist service such as this
47 where the lifelong consequences of fertility treatments have only started being
48 recognised recently (van den Akker, 2013), the organisational complexity becomes
49 clearer. The service was provided by a small voluntary sector organisation (seen by the
50 Department of Health as the appropriate primary provider) adapting its professional
51 experience of ‘search and contact’ services in the post-adoption field. This
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3 organisation then had to commission a service from a wholly different discipline (and
4 organisation) about which it had no specialist knowledge, i.e. DNA scientists, while at
5 the same time being accountable to its funder, the Department of Health. The
6 increasing challenges of such arrangements in the health and social care field are
7 being recognised (Moriarty and Manthorpe, 2014). These include operational
8 challenges of managing contracted services which are failing (Hudson, 2014) and
9 financial challenges resulting from inadequate budgets and/or uncertain futures that
10 can result in the side-lining of advocacy services for those already socially marginalised
11 and/or driving needs underground by cutting back higher cost professional services, as
12 discussed above (Ishkanian, 2014). For example, UKDL informed us of their limited
13 ability to address the shortfalls in the DNA service given the contracted service
14 provider's resistance to complaints and the potentially high cost of transferring the
15 contract elsewhere given their fixed budget and the potential disruption to the overall
16 service. UKDL carried accountability but had little real power to ensure the standards
17 of the contracted service. This was all within an overall context of funding uncertainty
18 that made long term planning difficult. It was also clear that some respondents were
19 aware of the pressure on the service and feared it may disappear.

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34 **In addition to the concerns about service standards, there is** the thorny question of
35 how services should be funded. All groups indicated strong opposition to charging for
36 services: partly on moral (to right a wrong) 'rights' grounds (for parity with
37 comparable groups) or for health reasons (risks from consanguinity or from having an
38 incomplete medical history); and partly to avoid take-up being inhibited. The
39 opposition may have been influenced by the UK context whereby public, including
40 health-related, services have traditionally been provided free, although this has been
41 changing rapidly following the economic downturn and introduction of 'austerity'
42 measures (Speed and Gabie, 2013; Sturgeon, 2014). This context may also have
43 contributed to the slightly higher support for paying for therapeutic counselling as
44 many such services - which have expanded rapidly in recent times in the UK - are
45 more readily available in the private sector. Once respondents were asked to
46 hypothesise about their reactions should charges be introduced, there was more
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3 variation in views with some making clear that their expressed *need* to have the
4 service led them to be prepared to pay even if they believed it should be free.
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8 There were limitations to the study. Respondents were self-selecting *and* had chosen
9 to try and find **people to whom they were genetically related through donor**
10 **conception** so are not representative of all donor-conceived adults and donors; **all the**
11 **donor-conceived respondents were conceived following sperm donation**; given the
12 methodology **used**, there was no opportunity to drill deeper into responses and
13 uncover more nuanced views; the views of those who have chosen to use other
14 searching routes or who have not yet discovered this particular route were not
15 included. Finally, the relatively small numbers of donors, especially egg donors, meant
16 it was inappropriate to test for statistically significant differences across different
17 groups.
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25 26 **Conclusion**

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28 This questionnaire-based study into the views and experiences of donor-conceived adults
29 and gamete donors using a DNA-based voluntary register to seek **those to whom they were**
30 **genetically related through donor conception** adds important information to the sparse
31 literature on the use of DNA **in this context** and on what support services might be
32 appropriate. It demonstrates the complexity of marrying disciplines and services, and
33 identifying funding streams in this post-treatment field. The case for tailored responses to
34 the range of identified needs is clear but the organisational complexity of ensuring
35 accountability alongside responsibility in such a specialist and newly emerging field is also
36 evident. Medical science has enabled the creation of families through the use of donor
37 conception but the lifelong social policy **and practice** implications are only **more recently**
38 being recognised.
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48 49 **Acknowledgements**

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52 distributing the questionnaires.
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55 56 **Declaration of competing interests**

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3 The authors have no competing interests to declare except for MC who was national adviser
4 to UKDL from 2003-2013.
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10 No funding was obtained for this study.
11

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

Use of professional support when deciding whether to register	No answer	No	Not sure	Yes	Total
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
Total	2 (2%)	70 (77%)	-	19 (21%)	91
Influence on registration decision of availability of intermediary services	No answer	No	Not sure	Yes	Total
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
Total	2 (2%)	37 (41%)	18 (20%)	34 (37%)	91

Table 2: Importance of availability of services

Professional support	No answer	Important	Not important	Not sure	Total
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
Total	8 (9%)	71 (78%)	1 (1%)	11 (12%)	91
Intermediary services	No answer	Important	Not important	Not sure	Total
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
Total	7 (8%)	71 (78%)	0	13 (14%)	91
Therapeutic counselling	No answer	Important	Not important	Not sure	Total
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
Total	9 (10%)	65 (71%)	4 (4%)	13 (14%)	91

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

	No answer	No	Not sure	Yes	Total
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
Total	3 (3%)	10 (11%)	28 (31%)	50 (55%)	91

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

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

Sperm donors	-	16 (76%)	1 (5%)	4 (19%)	21
Egg donors	-	3 (60%)	1 (20%)	1 (20%)	5
Combined donors	0	19 (73%)	2 (8%)	5 (19%)	26
Total	3 (3%)	71 (78%)	9 (10%)	8 (9%)	91
Whether respondent would have remained registered if ongoing fees were in place	No answer	No	Not sure	Yes	Total
Donor-conceived adults	4 (6%)	26 (40%)	20 (31%)	15 (23%)	65
Sperm donors	1 (5%)	5 (24%)	6 (29%)	9 (43%)	21
Egg donors	-	-	3 (60%)	2 (40%)	5
Combined donors	1 (4%)	5 (19%)	9 (35%)	11 (42%)	26
Total	5 (5%)	31 (34%)	29 (32%)	26 (29%)	91

Table 5: Views on charging for professional services

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

Only

Table 6: Views on how the service should be funded

	Donor-conceived adults	Sperm donors	Egg donors	Combined donors	TOTAL RESPONSES
Public funding alone	26 (48%)	9 (45%)	2 (40%)	11 (44%)	37 (47%)
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%)
TOTAL	54 (100%)	20 (100%)	5 (100%)	(25)	79