

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

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4 **Running title: Searching for a genetic link**

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7 **O. van den Akker^{1*}, M.Crawshaw², E.Blyth³ and L. Frith⁴**

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11 ¹ Department of Psychology, Middlesex University, London, UK

12 ²Independent Researcher and Honorary Fellow, Dept of Social Policy & Social Work,

13 University of York

14 ³School of Human and Health Sciences, University of Huddersfield.

15 ⁴Dept of Health Services Research, University of Liverpool

16

17 ***Corresponding author, Department of Psychology, Middlesex University, The**

18 **Burroughs, London NW4 4BT, UK. Phone: +44 (0)208 411 6953; Email:**

19 **o.vandenakker@mdx.ac.uk.**

20

21 **Abstract**

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

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

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

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

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

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

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

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

57 **Trial registration number: Not applicable.**

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

59

60 **Introduction**

61 This paper examines the extent to which the personal, social and collective components of
62 identity (Cheek, 1989) are affected by the experiences of being a donor or donor-conceived
63 adult, and (for donor-conceived adults) the role of age at the time of disclosure of donor
64 conception, drawing on a survey of registrants of UK DonorLink (UKDL). UKDL, launched
65 in 2004, was the first register in the world to use DNA as the primary basis for enabling
66 donor-conceived adults, donor-conceived and non donor-conceived siblings and donors to
67 identify each other voluntarily and, if mutually agreed, to share information and have direct
68 contact (Crawshaw *et al.*, 2013). UKDL became the UK Donor Conceived Register in April
69 2013 (www.donorconceivedregister.org.uk). There is one further DNA-based register service,
70 FIOM, in The Netherlands which is also government funded. The study also examines the
71 shared and comparative experiences of donor-conceived adults and donors of searching for a
72 genetic link through a DNA register.

73

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

85

86 **Background to research on donors and donor-conceived people**

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

94

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

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

117
118 Previous research has shown negative outcomes for adjustment in donor-conceived adults
119 told of their donor origins beyond early childhood (Blyth *et al.*, 2012). Findings from
120 research regarding donor-conceived individuals also show that they are often interested in
121 knowing about their donor and any other genetic relatives, especially donor siblings, they
122 may have a result of the donation. Those who do not have the option of identifying their
123 donor generally want more information than they possess or are likely to acquire (Blyth *et al.*,
124 2012). Few studies have explicitly investigated the experiences of actual exchange of
125 information or communication. Although some negative experiences of donor-conceived
126 individuals' contact – or attempted contact – with donors has been reported (e.g. Cushing,
127 2010; Turner and Coyle, 2000), most of the limited number of studies where this has been
128 investigated have reported largely positive outcomes (Cushing, 2010; Jadva *et al.*, 2010;
129 Beeson *et al.*, 2011; Daniels *et al.*, 2012). Positive outcomes have also been reported in the
130 few studies that have investigated contact between donor-conceived half-siblings (Kirkman,
131 2004; Scheib and Ruby, 2008; Jadva *et al.*, 2010; Blyth, 2012a, b) However, unsuccessful
132 efforts to locate donor-siblings are accompanied by frustration and disappointment (Cushing,
133 2010).

134

135 A number of studies have highlighted the contribution of support networks in facilitating and
136 providing assistance for searches (Turner and Coyle, 2000; Paul and Berger, 2007; Berger
137 and Paul, 2008; Cushing, 2010; Jadvá *et al.*, 2010; Mahlstedt *et al.*, 2010) and for mediating
138 contact with donors and/or other genetic relatives (Scheib *et al.*, 2005; Rodino *et al.*, 2011;
139 Blyth, 2012a, b). For the most part, even when the search had not been successful, such
140 support was reported favourably. Cushing (2010), Jadvá *et al.* (2010) and Beeson *et al.*
141 (2011) also considered the impact of searching for donors and/or donor-siblings on
142 participants' relationships with their parents. While for the most part, participants' searches
143 appear not to have adversely impacted these relationships, some donor-conceived individuals
144 have reported negative experiences and strained relationships. Two participants in Cushing's
145 (2010) study thought that their mothers "felt hurt and unloved" because of their daughters'
146 search for "another parent". A small number of participants in the study conducted by Beeson
147 *et al.* (2011) reported parents feeling "angry" and/or "fearful" about the participant's
148 "curiosity about the[ir] donor". Few "negative" (not further elaborated) responses were
149 reported by participants who searched for their donor and/or donor-siblings in Jadvá *et al.*'s
150 (2010) study. One father was reported as "not especially comfortable" and one mother as
151 feeling "excluded" in Blyth's (2012 a, b) study of participants' search for and discovery of
152 donor-siblings. In the same study, reported responses of adoptive or donor siblings with
153 whom participants had been raised as children, but who were not themselves donor-
154 conceived, ranged from indifference to feelings of exclusion.

155

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

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

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

187 **Method**

188 **Design**

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

193

194 **Participants**

195 All registrants of the UK Donor Link (n=244) were approached to participate in the study,
196 excluding four non-donor conceived offspring of donors. Registrants included n=172 donor
197 conceived adults; n= 65 sperm donors; and n=7 oocyte donors. A total of 91 participants
198 responded to the questionnaire survey, representing 37.3% of those sent the request for
199 participation (n=65 (37.8% of all registered) donor conceived adults; n=21 (32.3% of all
200 registered) sperm donors and n=5 (71.4% of all registered) egg donors. Fifty donor-conceived
201 adults were women and fourteen were men (one did not provide details). Most questionnaire
202 surveys (81) were completed online and ten via paper copies. However, the research team
203 subsequently learnt from UKDL that during transfer of the register to a new provider in early
204 2013, UKDL had become aware that a number of registrants had changed their contact
205 details without notifying the registry. Consequently, some registrants would not have
206 received the survey, although the research team was not provided with the actual number of
207 such registrants. Hence the actual response rate of requests *received* will have been higher
208 than the 37% response rate reported.

209

210 **Materials**

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

232

233 **Procedures**

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

242

243 **Statistical analysis**

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

248

249 **Ethics**

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

252

253 **Results**

254 **Demographic variables**

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

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

261

262 INSERT TABLE 1 HERE

263

264 There were significant differences in current family makeup, possibly reflecting the differing
265 age profiles of the donor-conceived adults and the donors. The donor group reported children
266 living with them more often than did the donor-conceived adults group ($\chi^2=4.22$, $df=1$,
267 $P<.05$), and the donor-conceived adults were more likely than the donors to report that their
268 mother and father ($\chi^2=6.37$, $df=1$, $P<.01$) were still alive, though the latter did not reach
269 significance levels. There was no significant difference between groups as to whether their
270 parents (if alive) were still living together.

271

272 **Group differences on the AIQ**

273 Analysis of variance comparing the donor-conceived adults, sperm and oocyte donors on the
274 three AIQ-IIIx subscales (Personal Identity Orientation (PIO); Social Identity Orientation
275 (SIO); Collective Identity Orientation (CIO); showed the three groups differed significantly
276 on CIO ($F(2, 82)=3.60$, $P<.03$), with donor-conceived adults scoring significantly lower
277 (mean=20.49, $SD=5.58$) than either donor (sperm donors mean=23.90, $SD=5.59$; oocyte
278 donors mean=24.75, $SD=3.30$) group. The groups did not differ significantly on either the
279 PIO (donor conceived adults mean=38.98, $SD=6.50$; sperm donors mean=38.05, $SD=6.46$;
280 oocyte donors mean=37.80, $SD=4.65$) or SIO (donor conceived adults mean=22.80,
281 $SD=5.41$; sperm donors mean=23.80, $SD=4.56$; oocyte donors mean=24.00, $SD=5.22$)
282 subscales. Since the few oocyte donors were similar in age to sperm donors and did not differ
283 from them on the AIQ IIIx subscales, a Combined Donor group (26) was created for further

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

286

287

INSERT FIGURE 1 HERE

288

289 The donor-conceived adults' Collective Identity Orientation (CIO) subscale was rated
290 significantly lower (mean=20.49; SD=5.58) than the donor groups (sperm donors mean =
291 23.90; SD=5.59 and oocyte donors mean = 24.75; SD=3.30). The donor-conceived adults's
292 CIO subscale was also lower compared to normative values based on a sample of European
293 Americans (means CIO=22.94; SD=5.55; SIO=23.81, SD=4.67; PIO=42.22, SD=5.62) –
294 Cheek *et al.*, 2013), indicating they may have less emotional connection to a particular
295 community or institution, such as their family.

296

297 **Characteristics of donor-conceived adults**

298 Four donor-conceived adults were raised within families with siblings from the same donor,
299 twenty-three with siblings from a different donor and nine with non-donor siblings; the
300 remainder did not report being raised with siblings. Eleven donor-conceived adults had
301 siblings who were also registered with UKDL. Knowledge of the nature of their conception
302 began at different ages, ranging from 'as long as I can remember' through to older adulthood.
303 Some found out in an unplanned way, such as following parental death or separation,
304 discovery of blood group incompatibility or of paperwork relating to gamete donation and
305 during a row. Ages at which donor-conceived adults were informed were re-categorised into
306 four age groups for further analysis: 0-10 years (10, 15%); 11-20years (24, 37%); 21-30years
307 (22, 34%) and 31+years (9, 14%). There were no significant differences between donor-

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

310

311 **Reasons for searching**

312 All participants were asked about their reasons for searching, so participants will have been
313 answering according, where relevant, to whoever they perceive to be their children and
314 family. Participants were invited to endorse reasons from a list as well as provide additional
315 reasons. Reasons for searching varied between groups (Table 2). For donor-conceived
316 adults, the most frequently-cited reasons were ‘to satisfy my curiosity’ (84.6%), ‘to see
317 whether we have anything in common’ (75.4%), ‘to access medical information’ (70.8%)
318 and ‘to make me feel more complete in my identity’ (69.2%). For sperm donors they were
319 ‘to satisfy my curiosity’ (66.7%), ‘to find out what happened in their lives since conception’
320 (66.7%), ‘to be able to pass on information to my children/family’(47.6%) and ‘to make me
321 feel more complete in my identity’ (28.6%) whereas for oocyte donors, they were ‘to be able
322 to pass on information to my children/family’ (100%), ‘to find out what has happened in
323 their lives since conception’ (80%) and then evenly spread among the remaining reasons.

324

325 **INSERT TABLE 2 HERE**

326

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

333 offspring.’ And another said, ‘it is a personal life principle ‘to do no harm’ and this is the
334 best way I could act in accordance.’ Others talked about meeting their own needs by
335 searching: ‘to find out if any people exist’; ‘if they are in need of support or help, Guilt.’ One
336 oocyte donor commented; ‘As I was aware of the recipient’s identity albeit through chance I
337 knew that twins were conceived from my egg donation 5 weeks after donating, hence I
338 always hoped to meet them and be in contact with them, which I now am. It was very
339 important to me that my son got the chance to meet his half sister and brother as he is donor
340 conceived and I hoped it would give him an extra sense of family/identity’.

341

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

350

351 **Expectations and experiences of using a DNA-based primary route to locate genetic** 352 **relatives**

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

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

361

362 Donor-conceived adults' estimations as to how many [more] siblings they thought they might
363 find ranged from zero to 1000 and included statements such as 'hopefully not more than one',
364 'absolutely no idea'; 'Only God knows'. The maximum number of siblings with whom they
365 would feel comfortable about being linked ranged from fewer than five (eight); 5-10 (ten);
366 10-20 (four); 20 or more (two) to 'No limit' (thirty-nine) (two donor-conceived adults did not
367 answer the question). The number of offspring that donors believed they might find ranged
368 from zero to 110 (sperm donors) and from zero to three (oocyte donors). The maximum
369 number of adult offspring with whom oocyte donors would feel comfortable having future
370 contact was four (one did not answer this question), whereas among sperm donors, most
371 (thirteen) imposed no limit, one would feel comfortable with '20+', four with between 5 and
372 10, and one with fewer than 5 (two sperm donors did not answer the question).

373

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

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

382

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

393

394

INSERT TABLE 3 HERE

395

396 **Feelings/Beliefs about being linked among those ‘not yet linked’**

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

405

406

INSERT TABLE 4 HERE

407

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

412

413

INSERT TABLE 5 HERE

414

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

417 All participants were asked about their experiences and thoughts about being on the UKDL
418 register with responses grouped according to whether they had been linked or not (Table 6).

419 Participants either experienced or anticipated few difficulties, confirming the positive beliefs
420 among those not yet linked and actual experiences among those already linked, as reported
421 above. Although there was consistency in responses between the two groups, levels of
422 uncertainty were expressed more frequently by the ‘not-yet-linked’ group, as might be
423 expected. The only aspect where the majority of participants (in both groups) anticipated
424 possible difficulties was in the event of ‘getting false positive results’ (76% linked; 61% not
425 linked).

426

427

INSERT TABLE 6 HERE

428

429 **Discussion**

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

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

458 registrants to cope with associated uncertainty and decision-making about progressing with
459 information exchange or contact. Given that DNA testing will be the only route through
460 which the majority of those affected by donor conception internationally will be able to
461 identify genetic relatives, these are important findings.

462

463 This study is also the first to measure aspects of identity for searchers, using standardised
464 measures. More than two thirds of donor-conceived adults were motivated to search by a
465 desire to feel more complete in their identity, as were six sperm donors and two oocyte
466 donors. While qualitative studies have previously reported such a motivation in relation to
467 donor-conceived adults, this has not been asked previously of donors, nor has it been assessed
468 using a specifically designed standardised questionnaire. The age of donor-conceived adults
469 at disclosure of their donor-conceived status varied, similar to that reported in previous
470 research (Blyth *et al.*, 2012). However, the data did not show a significant relationship
471 between AIQ and age of disclosure; this was a surprising finding given data on negative
472 outcomes for adjustment in donor-conceived adults told of their donor origins beyond early
473 childhood, and is a phenomenon worthy of further study. .

474

475 Collective identity is a multidimensional concept referring to a belief that one shares
476 characteristics with a group of others and includes a set of cognitive beliefs associated with
477 that category (stereotypic traits thought to be shared by category members or ideological
478 positions that define the group's goals). Collective identity also involves 'value and
479 emotional significance'. This affective aspect of collective identification can include how we
480 evaluate a category and the perceived value placed on the category by others (Tajfel, 1981).
481 Collective identity is therefore described as referring to the individual rather than to a group
482 (Social Identity) because it is a psychological concept and only becomes a collective identity

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

487

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

499

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

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

515

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

530

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

533 registration. Our study suggests that this might range from a few days to more than a year.
534 When reviewing details of the 64 people who had started but not completed registration with
535 UKDL during 2012, one of the authors (MC) found that twelve donor-conceived adults
536 (29%) and two donors (14%) had also started and stopped the process *at least* once prior to
537 the start of 2012, with a few having made several approaches over many years. This hitherto
538 unreported aspect of searching carries implications for service delivery and for the support
539 needs of potential registrants and warrants further investigation.

540

541 **Limitations**

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

552

553 **Conclusion**

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

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

567

568 **Declaration of author's roles**

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

571 **Study funding:** No funding was obtained for this study.

572 **Competing interest(s):** The authors have no competing interests to declare except for MC
573 who was national adviser to UKDL from 2003-2013

574

575 **Acknowledgements**

576 The authors would like to thank UKDL for distributing the questionnaires to its membership,
577 and all those participating in the research.

578

579

580

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