

**TITLE:** Being an identity-release donor: a qualitative study exploring the motivations, experiences and future expectations of current UK egg donors.

**RUNNING HEAD:** Experiences of UK identity-release egg donors

**AUTHORS:** S. Graham<sup>1</sup>, V. Jadva<sup>1</sup>, T. Freeman<sup>\*1</sup>, K. Ahuja<sup>2</sup> and S. Golombok<sup>1</sup>

<sup>1</sup>Centre for Family Research, Department of Psychology, University of Cambridge, Free School Lane, Cambridge CB2 3RF, United Kingdom.

<sup>2</sup>The London Women's Clinic, 113 Harley Street, London W1G 6AW, United Kingdom.

1 **Abstract**

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3 The objective of this study was to examine the motivations, experiences and future  
4 expectations of identity-release egg donors in the UK following the removal of donor  
5 anonymity and the rise in financial compensation for egg donation. This exploratory, in-  
6 depth qualitative study comprised semi-structured interviews with eleven women who  
7 had attended an egg donation screening appointment at a UK clinic during a four-month  
8 period in 2014, conducted two to six weeks after the woman had donated or had  
9 withdrawn/been rejected from the donation process. Participants' primary motivation  
10 for donating was to help infertile women have their 'own child', and the recent increase  
11 in financial compensation did not seem to play a significant role. All were happy to be  
12 identifiable and contacted by children born as a result of their donation. However, some  
13 were hesitant about providing non-identifying information about themselves for these  
14 offspring and wished for further information about the recipient(s) of their eggs and the  
15 outcome of their donation. Whilst this study was limited due to the small sample size, it  
16 is the first study of UK egg donors following the rise in donor compensation and  
17 suggests that other strategies may be more effective in increasing donor numbers.

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19 **Key words:** egg donation; egg donor; identity-release donation; motivation;  
20 information provision; financial compensation.

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26 **Introduction**

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28 According to the Human Fertilisation and Embryo Authority's (HFEA) report on egg and  
29 sperm donation (HFEA, 2014), in 2013, 4% of the 48,477 fresh IVF cycles performed in  
30 the UK used donor eggs. The need for egg donation may arise for various reasons but for  
31 many women, it is poor egg quality associated with advanced maternal age that  
32 indicates the use of donor eggs. With childbearing in the UK now tending to occur at a  
33 later time in women's lives (ONS, 2013), it is likely that the demand for donor eggs will  
34 only increase.

35 In the UK, treatment with donor eggs can occur either through known donation,  
36 i.e., with the eggs of a woman who is known to the recipient at the time of donation, or  
37 through unknown donation. Known donors are usually friends or relatives of the egg  
38 recipient, but recently the growing trend for online connection sites enables those  
39 seeking donor eggs to meet women, previously unknown to them, who are willing to  
40 become a 'known' donor for them. Unknown egg donors may be patients, most  
41 commonly 'egg-sharers' (women who are themselves undergoing IVF treatment and  
42 choose to donate a portion of their eggs in exchange for reduced treatment costs) or  
43 non-patient donors. Since the removal of donor anonymity in 2005, the identity of the  
44 donor will be released upon request to any resulting offspring once they reach the age  
45 of eighteen.

46 In 2011, due to a perceived shortage of UK gamete donors, the HFEA launched a  
47 public consultation into gamete donation (HFEA, 2011). One of the goals of the  
48 consultation was to find ways to increase the numbers of new donors registering, and to  
49 maximise the use of their gametes. As a consequence of the consultation, in April 2012  
50 new limits for donor compensation were introduced, moving away from a system of

51 out-of-pocket expenses and a loss of earnings allowance capped at £250, to one where  
52 sperm donors are given a fixed sum of £35 per clinic visit and egg donors receive a fixed  
53 sum of £750 per donation cycle, including expenses.

54 Payment of egg donors has long been a controversial issue (Pennings et al., 2014;  
55 Pfeffer, 2011), raising concerns regarding exploitation of women in financial difficulty  
56 and commodification of the human body, as well as how a donor-conceived child may  
57 feel about being conceived with the aid of a monetary transaction. The HFEA's online  
58 survey exploring UK clinics' thoughts regarding how the new donation policies were  
59 working and their impact on practice (HFEA, 2014), found that the number of women  
60 expressing an interest in donating eggs had risen since the increase in compensation.  
61 The number of new non-patient egg donors actually registering with the HFEA (i.e.  
62 going through with egg donation) has also increased. In 2011 there were 815 new  
63 registrations, rising to 1103 in 2013. The rise in new donor registrations was attributed  
64 to the higher levels of compensation available to donors, as well as increased awareness  
65 and marketing (HFEA, 2014). However, the most common reason clinics gave for egg  
66 donors' motivation was the desire to help others.

67 Studies from contexts where women donate their eggs in a commercial setting  
68 indicate that motivations appear to comprise a mixture of altruism and financial  
69 compensation (Kenney and McGowen, 2010; Klock et al. 1998, 2003; Purewal and van  
70 den Akker, 2009). Patrick et al. (2001) found that US commercial<sup>1</sup> donors believed

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<sup>1</sup> Terminology within the field of gamete donation is complex and, at times, controversial. Purewal and van den Akker (2009), in their systemic review of egg donation describe 'non-patient donors' as including different subtypes: volunteer donors (donation without financial reward), known donors (donation to known recipients), commercial donors (donation with monetary compensation) and potential donors (whom report an intention to donate their oocytes). However, it is often not easy to so clearly define donors. A woman receiving \$5000 for donating her egg in the US may not see herself as a commercial donor but as someone helping another woman

71 financial compensation was necessary to recompense the hardship they endured and  
72 that most donors would not donate if payment was not provided. Similarly, Kenney and  
73 McGowen's (2010) survey of 80 women who had previously donated eggs in the US  
74 found that although their motivations to donate were complex and intertwined, the  
75 majority (73.8%) reported that financial compensation played a significant role in their  
76 decision to donate. By contrast, donors not receiving monetary compensation describe  
77 generally altruistic motivations, along with experiences of infertility, either personally  
78 or amongst family or friends (Fielding et al., 1998; Byrd et al., 2002). Other motivations  
79 reported in the literature include confirmation of one's own fertility (Jordan et al.,  
80 2004) and to pass on one's genes (Kalfoglou and Geller, 2000), as well as making up for  
81 a loss, such as a past abortion or miscarriage, or rape (Purewal and van den Akker,  
82 2009).

83 Pennings et al. (2014), in their survey of the socio-demographic and fertility-  
84 related characteristics and motivations of 1423 egg donors in eleven European  
85 countries with varying compensation schemes, found that 47.8% of egg donors  
86 reported being motivated by altruism alone, 33.9% were financially and altruistically  
87 motivated, 10.8% purely financially motivated, 5.9% motivated by altruism and their  
88 own treatment, and 2% motivated by their own treatment only. Motivation to donate  
89 was found to vary according to a donor's age, employment status and educational level  
90 (Pennings et al., 2014). In the subgroup of 116 UK donors, reported motivations were

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to have a baby (see, for example, Almeling, 2011). Moreover, due to the change in compensation system in the UK whereby egg donors now receive a set sum for their donation, it is unclear which subgroup these donors would be defined under: does their monetary compensation negate the 'volunteer' aspect of their donation and instead mean they are commercial donors? Daniels and Lewis (1996) go as far as disputing the term 'donor' when women are paid for their eggs and suggest it should instead be replaced with the term 'provider'.

91 30% altruism, 20% own treatment, 47.3% altruism and own treatment, and 2.7%  
92 altruism and financial. No egg donors reported financial motivation only. It is important  
93 to note that 78.4% of the UK donors taking part in the survey were egg-sharers and the  
94 authors did not break down their results into patient and non-patient egg donors. Egg-  
95 sharers who are themselves undergoing IVF in the pursuit of parenthood may well be  
96 differently motivated to women donating eggs who are not, at that time, undergoing  
97 fertility treatment.

98 Klock et al.'s (2003) survey of US commercial egg donors found that those  
99 donors who went on to become repeat donors rated financial compensation as more  
100 important to them than those women who only completed one cycle. However,  
101 regardless of motivation, studies have found that donors report high levels of  
102 satisfaction with the egg donor procedure and when questioned, most egg donors state  
103 that they would donate again (Purewal and van den Akker, 2009).

104 It is unclear how changes in legislation regarding donor anonymity may have  
105 impacted upon what it means for women to be an egg donor. Svanberg et al.'s (2012)  
106 questionnaire study of identity-release gamete donors in Sweden, the first country to  
107 remove donor anonymity, found that altruistic motives and awareness of the distress  
108 and sorrow of being childless were the most common reasons reported for becoming an  
109 egg donor. Sixty-nine percent of the 181 egg donors who participated in the study had  
110 biological children (Sydsjö et al., 2011) and this motivated them to want to help other  
111 couples experience parenthood. However, a study of UK gamete donors' views  
112 regarding the removal of donor anonymity found that half of the 75 egg donors who  
113 completed the survey would not continue to donate if their anonymity was removed  
114 (Frith et al., 2007). Interestingly, despite donating under identity-release legislation,  
115 15.5% of the UK egg donors completing Pennings et al.'s (2014) survey indicated that

116 they would be anonymous to the future child. The authors gave several possible  
117 explanations for this surprising finding: either counselling did not make this point clear  
118 to the donors or the respondents had misunderstood the question. A possible  
119 explanation that the authors did not note is that although at the time of donation egg  
120 donors agree to their identifying information being released to offspring at age  
121 eighteen, they have no intention of being available, or contactable, to these offspring at  
122 that time. Indeed, very little is known about how donors who have donated under an  
123 identity-release system think about their donation and future information exchange. A  
124 Swedish study (Isakkson et al., 2014) reported that 65% of identity-release egg donors  
125 surveyed 5-8 years after donating were positive towards being contacted by offspring  
126 once they reached the age of 18, with a further 17% being neutral towards this  
127 prospect, and only 2% stating that they did not want to meet a child conceived through  
128 their donation. It is not clear how UK donors think and feel about signing up to be an  
129 identifiable donor, how they interpret the legislation and how they envisage their future  
130 role.

131         The present study provides an in-depth insight into the perceptions, experiences  
132 and future expectations of current identity-release egg donors in the UK. It is the first  
133 study to explore UK egg donors' thoughts and feelings about being an identity-release  
134 donor and the impact of the increase in financial compensation on their willingness to  
135 donate.

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137

## 138 **Materials and Methods**

139

140 This paper reports findings from an in-depth, exploratory study of non-patient identity-  
141 release egg donors donating their eggs at a private clinic in London. The study was  
142 granted ethical approval from the University of Cambridge Psychology Research Ethics  
143 Committee (ref: Pre.2013.124). All women who attended a screening appointment at  
144 the Clinic between January and April 2014 were eligible to take part in the study and  
145 were given an information sheet and asked if they were happy to be contacted about  
146 taking part. Twenty-three of the 29 egg donors (79%) approached agreed to be  
147 contacted. Egg donors were contacted at the time they started hormonal stimulation or  
148 when they had withdrawn or been rejected from the egg donation programme. Of the  
149 23 egg donors who had agreed to be contacted, 11 were interviewed (of the others, 3  
150 were not contactable, 3 initially agreed to participate but were unable to be interviewed  
151 at a suitable time, and 6 were still waiting to be 'matched' with an egg recipient and  
152 begin the egg donation process at the end of the data collection period).

153         Semi-structured interviews were conducted with the egg donors between two  
154 and six weeks after egg collection, or after their withdrawal/rejection from the egg  
155 donor programme. As well as exploring the participants' own 'story' of their experience  
156 of becoming and being an egg donor, the interviews covered how they first heard about  
157 egg donation, their reasons for donating their eggs, their experiences of recruitment,  
158 counselling and the medical procedures they had undertaken, and whether they had  
159 discussed egg donation with others. The interview also explored the participants'  
160 thoughts and feelings about donating their eggs, including thoughts and feelings about  
161 the individual or couple who would receive their eggs, the child who may be conceived  
162 as a result of their donation and possibilities for future information exchange. The  
163 participants also completed the following questionnaires to assess their mental health:  
164 The Edinburgh Depression Scale (Cox et al., 1987), the Trait Anxiety Inventory



165 (Spielberger, 1983) and the Rosenberg Self Esteem Scale (Rosenberg 1989) to assess  
166 anxiety, depression and self-esteem respectively. They also filled out short  
167 questionnaires about their motivations and experiences of egg donation<sup>2</sup> and their  
168 demographic background.

169 All interviews were carried out by one researcher (Susanna Graham) and took  
170 place at a time and place convenient for the participant (in the Clinic, their own home or  
171 a public space such as a café). The interviews lasted approximately 90 minutes and  
172 were audio recorded with the participants' consent. The interviews were transcribed  
173 verbatim and inductive thematic analysis (Braun and Clark, 2006) performed. This  
174 analysis was an iterative process, consisting of familiarising oneself with the data,  
175 memo writing, initial coding of the data, subsequent combining, expanding and  
176 collapsing of codes in order to construct themes that were grounded in the data. The  
177 analysis was performed with the aid of the computer software, Atlas-ti. This paper  
178 provides an overview of the most salient themes that emerged from these women's  
179 accounts of becoming and being an egg donor.

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181

## 182 **Results**

183

### 184 *Egg Donor Characteristics*

185 Eleven participants, all living in the UK, took part in the study. Eight had completed an  
186 egg donation cycle. Three had to stop before egg collection: one was rejected due to low  
187 ovarian reserve, and two were awaiting rescheduling of their donation cycle due to

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<sup>2</sup> These questionnaires were completed to allow for comparisons with other studies. The results do not inform the analysis in this paper.

188 personal or medical reasons for being unable to get to egg collection. It was the first  
189 time each participant had donated her eggs. The participants ranged in age between 18  
190 and 30 years with a mean of 25 years. Five participants identified their ethnicity as  
191 White Other (Polish), four as White English/Welsh, one as Asian Indian and one as  
192 Asian Bangladeshi. Six participants stated that they had no religion, four were Christian  
193 and one was Muslim.

194 All participants identified as heterosexual. Six were single whilst five reported  
195 being in a relationship (two married, three cohabiting). Four participants had their own  
196 children. Of the seven women who did not have children, five were definite that they  
197 would like children in the future, one thought it most likely that she would have  
198 children and one was unsure.

199 Three participants were educated to GCSE level (or equivalent), two to A level  
200 (or equivalent) and six had a Bachelor's degree. Nine of the participants were employed  
201 (seven full-time, two part-time) in a range of occupations. One participant was a student  
202 and one a full-time mother. Eight participants reported no perceived financial  
203 difficulties whilst three said they were experiencing some/minor financial difficulties.

204 Individual scores on the Edinburgh Depression Scale (Cox et al., 1987), the Trait  
205 Anxiety Inventory (Spielberger, 1983) and the Rosenberg Self Esteem Scale (Rosenberg  
206 1989), revealed that ten out of the eleven participants were within the normal range for  
207 depression, anxiety and self-esteem. The one participant who scored above the cut-off  
208 point for clinical problems was experiencing unrelated stressful life events at the time.

209

### 210 *Becoming an egg donor*

211 Eight of the participants starting thinking about becoming an egg donor after they saw  
212 or heard an advert for egg donation online or on the radio. A further three began to

213 consider egg donation as a possibility after hearing about it through friends or  
214 colleagues. The majority (n=8) described having been previously unaware of egg  
215 donation. They were aware that men could donate sperm to help people have children,  
216 but had not realised this was scientifically possible for women.

217 The vast majority (n=10) of the participants discussed the possibility of donating  
218 their eggs with others before they made the decision to proceed. All of the women who  
219 were in a relationship (n=5) discussed the prospect of donating their eggs with their  
220 partner. Six participants discussed becoming an egg donor with family members and  
221 five with friends. However, all participants said that they were selective about who they  
222 told about becoming an egg donor, with the majority wanting to keep this information  
223 private between themselves and close family and friends. Reasons for not wanting to be  
224 open about being an egg donor stemmed from fear of misunderstanding and being  
225 judged, with ideas of relatedness, specifically that others may feel that they were “giving  
226 away their children”, often at the core of this concern:

227

228 *I just didn't know what their reactions would be. I thought my sister would be*  
229 *like, “Oh no, you shouldn't do that. It's your child. It's your egg”. And I guess*  
230 *being Asian it is sort of just a different sort of cultural thing. My family aren't*  
231 *like this but old fashioned Indians would be like, “That's part of my family. You*  
232 *can't do that. You can't get rid of our children”. (Priya,<sup>3</sup> 23 years old)*

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<sup>3</sup> Pseudonyms have been used throughout this paper and any potentially identifying information removed or altered.

234 Although this judgment was often attributed to religious or cultural differences, there  
235 was also a general feeling amongst all participants that the decision to become an egg  
236 donor should be a personal one.

237

238 *Motivations*

239 All participants described wanting to become an egg donor so they could help other  
240 women to have their 'own child'. They described the pain and sadness they believed  
241 childlessness would cause, and donating their eggs as something they could do to  
242 relieve this pain for others. Eight of the participants knew someone who had been  
243 personally affected by infertility and described this as a motivating factor, making them  
244 think about donating their own eggs:

245

246 *It's all down to having seen first-hand both my aunties' struggles to conceive.*  
247 *And being someone who has always wanted to have children, the thought of*  
248 *being told that you couldn't have children must be soul destroying. So knowing*  
249 *that that (egg donation), is out there, rather than just adopting or something,*  
250 *so you can actually carry a child, I think that is great. (Rebecca, 23 years old)*

251

252 The four participants who had their own children wanted to enable others to enjoy  
253 parenting as they themselves did. Six of the seven participants who did not have  
254 children did not want children at that time and thought they could give another woman  
255 who was struggling to conceive a chance to become a mother. Other reasons some  
256 childless participants gave for wanting to donate their eggs included a means to check  
257 one's own fertility (n=1), and as an alternative to having children oneself (n=1).

258           Although all participants described their main reason for donating eggs as helping  
259 others to have their own child, donating eggs was also seen as mutually beneficial:  
260 becoming an egg donor was seen as something that would also make them feel good  
261 about themselves:

262

263           *It just made me feel like I was a good person and so instead of just wasting*  
264           *them I could give them to someone else and it just made me feel good. (Rachel,*  
265           *23 years old)*

266

267           *Compensation*

268 Despite concerns that the increase in egg donor compensation would result in women  
269 donating eggs for financial gain, none of the participants mentioned payment when  
270 asked why they had wanted to become an egg donor. When asked specifically about  
271 compensation during the interview, ten of the participants said that they would have  
272 still donated their eggs even if they were not going to receive any money. In fact, when  
273 first investigating the prospect of donating their eggs, ten participants were unaware  
274 that they would receive money:

275

276           *When I first heard about it on the radio and started doing research about egg*  
277           *donation, I didn't know you received any money. So it was quite a shock but,*  
278           *yes, I guess it was nice to be paid for something that you were more than*  
279           *willing to do for free. (Rebecca, 23 years old)*

280

281 Although the majority of the egg donors taking part in the study did not seem to have  
282 been financially motivated, when asked why they thought others became egg donors,

283 five said that they thought receiving money may play a part. Unease was expressed at  
284 women donating for money rather than for the “right reasons”:

285

286 *I know there are people just doing it for the money and that is not good. If you*  
287 *want to do something then do it for free. (Emilia, 26 years old)*

288

289 *I think if you are making the choice to donate something then that should be*  
290 *your own choice and it shouldn't be about the money. (Claire, 30 years old)*

291

292

293 *Being an egg donor*

294 Despite initial concerns about the health implications of becoming an egg donor, all  
295 participants reported that physically, as well as emotionally, donating their eggs was  
296 much easier than expected. Only three participants described experiencing pain and  
297 bloating during hormone stimulation or after egg collection, and although all had been  
298 warned that the hormones might make them feel emotional, only three participants  
299 described feeling “slightly hormonal”. The other participants described how,  
300 emotionally, they felt no different to normal, or, in one case, even “happier and more  
301 stable than usual”. Five participants said that donating their eggs had made things  
302 difficult in their day-to-day life but put this down to juggling clinic appointments with  
303 the demands of childcare and work commitments, rather than any specific procedures  
304 involved in egg donation. The difficulty in juggling work, childcare and being an egg  
305 donor was found to be particularly problematic towards the end of the egg donation  
306 process due to the frequency and unpredictability of ultrasound appointments to

307 monitor ovarian response, as well as the uncertainty regarding the date on which egg  
308 collection would take place.

309

310 *Getting up there and back was pretty difficult. And obviously childcare and*  
311 *things. And then you'd go up there and they'd say, "Right, we'll see you again in*  
312 *three days' time." And then I'd be thinking, 'Argh, now I have to sort out*  
313 *something else for (her child)'. I could imagine if you worked it could be really*  
314 *difficult to do. And it's not like you can book it off in advance because you*  
315 *literally don't know. They just say, "Come back on this day". So for working*  
316 *people I imagine it would be really tricky. (Sophie 22 years old)*

317

318 With many of the participants only having told their partner, close family or friends,  
319 that they were donating eggs, trying to hide clinic appointments added a further  
320 burden:

321

322 *I had to attend the clinic for scans every two days and that was difficult to*  
323 *juggle with work. I'd be late for work all the time and I had to make excuses*  
324 *like, "I'm doing something" but I didn't want to say what it was I was really*  
325 *doing because not everyone will understand this. (Anna, 28 years old)*

326

327 *And also you feel like you are hiding something all the time. Your friends are*  
328 *asking you "What's going on? What is happening?" And I didn't want to tell*  
329 *them so that was why it was quite hard sometimes. I would say something and*  
330 *then I would forget what I had said. It's a shame but you are feeling like a liar.*  
331 *So that is tricky. (Julja, 26 years old)*

332

333 *Donor information*

334 One other aspect of being an egg donor that the study participants identified as difficult  
335 was providing non-identifying information about themselves in the form of a pen  
336 portrait and goodwill message to donor-conceived children. This information is  
337 included as part of the HFEA donor information form and can be accessed by a donor-  
338 conceived child at the age of sixteen or by parents from the time they begin choosing a  
339 donor. Only four of the participants completed the pen portrait and three of these  
340 women also completed the goodwill message. These participants all described finding  
341 these sections very hard to write, and five egg donors who did not complete them stated  
342 that difficulty in knowing what they should write was a reason for not providing this  
343 information:

344

345 *I wanted to but I couldn't really do it because I tried writing it but I kept on*  
346 *referring to me, or not referring to me, but I could see that I was giving*  
347 *something that was too personal. I found it hard to be objective about me*  
348 *without referring to me. So that was the difficulty. (Agnieska, 18 years old)*

349

350 *I filled it (pen portrait) in but I didn't do a goodwill message. Erm, I don't*  
351 *really know why. I think I just didn't know how to write it more than not*  
352 *wanting to write it. I just found it a bit... weird? I don't know whether that is*  
353 *the right word. I just didn't know what to write. (Claire, 30 years old)*

354

355 Reasons for not providing non-identifying information, or difficulty in knowing how to  
356 do so, were, in the most part, associated with ideas of relatedness: the participants were



357 contemplating their role as an egg donor and what connection, if any, they had with a  
358 child conceived with their donated egg. Ten out of the eleven participants  
359 conceptualised their donation as “just an egg”, the start of a very contingent process  
360 that *might* result in an ‘own’ child for the recipient of their egg.

361 In fact, it was concern and empathy for the recipient of their donated egg, rather  
362 than thoughts about the donor-conceived child, that were at the forefront of four of the  
363 participants’ minds when deciding not to fill in the goodwill message and pen portrait.  
364 They thought such information would make them, as an egg donor, into a ‘person’  
365 rather than the provider of “just an egg”. They believed such information would be  
366 painful for the woman who would receive their egg to read:

367

368 *I was just trying to put myself in their position. So being in the position of the*  
369 *mother that can't have a child in a normal way, natural way. So she's already*  
370 *stressed and probably frustrated about that. So what's the point giving her*  
371 *more things to worry about? I don't think it is necessary. Some donors maybe*  
372 *write things for the child. Is it important? I think it is most important if this is*  
373 *working out, yeah? If they are going to have the kids. So the woman can have*  
374 *her own child. That is why I have done it. That's what is important for me.*

375 (Julja, 26 years old)

376

377 Six of the participants were concerned that providing non-identifying information about  
378 themselves may place too much significance upon their role as an egg donor, specifically  
379 that it may cause a donor-conceived child to reconsider whether the egg recipient was  
380 their ‘real’ mother. Participants also asserted that a written description about  
381 themselves would not give a child an accurate representation of what they were *really*

382 like. However, four participants stated that a child's ability to access non-identifying  
383 information about their egg donor was somewhat important, describing how, if told that  
384 they were conceived with donor eggs, a child might like to have some information about  
385 their donor. The one participant who thought non-identifying information was very  
386 important believed that such information would be essential for a child's identity  
387 formation.

388

389 *Removal of anonymity*

390 Despite the majority of the participants downplaying the significance of non-identifying  
391 information about themselves, all were happy to be identifiable to any offspring  
392 conceived with their donated eggs and to be contacted by the donor-conceived child  
393 from the age of eighteen. In fact all the egg donors stated that it was their  
394 "responsibility" to make sure they were available to answer any questions a donor-  
395 conceived child may have. Even so, four of the participants stated that they had  
396 concerns about being an identity-release donor. Interestingly, for three of these  
397 participants, these stemmed from concern for the donor-conceived child's parents - the  
398 egg-recipient and her partner - rather than herself:

399

400 *I mean I think it might be quite hard for the parents because she has carried*  
401 *the child and brought it up and so yeah, I mean this could be quite hard if then*  
402 *their child wants to meet me. (Rachel, 20 years old)*

403

404 Other concerns included the impact that a donor-conceived child making contact would  
405 have on an egg donor's own family (n=1), what the donor-conceived child might want  
406 from them, specifically the extent to which they may wish to form a relationship with

407 them (n=2), and a donor-conceived child's reaction to their egg donor, specifically  
408 potential feelings of hurt and rejection (n=1).

409 Although all participants were happy to be contacted by a donor-conceived child,  
410 the majority believed that this would be very unlikely to happen. They thought that  
411 either the child would not be aware of their donor conception or that they would be  
412 comfortable with this information and so would not feel a need to try to find out more  
413 about their donor.

414

415 *Desire for further information*

416 All participants wanted to have more information about the outcome of their donation  
417 than they believed was currently possible. Although all gamete donors who have  
418 donated in the UK since 1991 are entitled to request information from the HFEA about  
419 the number, sex, and year of birth of any people born as a result of their donation  
420 (HFEA, 2014b), five of the egg donors did not know that they could receive information  
421 about the outcome of their donation. Although all participants wanted further  
422 information regarding the outcome of their donation, the egg donors varied in the type  
423 of information they desired. Nine of the eleven participants said that they would like to  
424 know whether the egg recipient had become pregnant and ten would like to know  
425 whether there had been a birth. Six participants wanted to be informed about the health  
426 and well-being of the baby, four wanted to know the baby's sex, three the child's  
427 physical appearance and three the child's personality. Ultimately, all participants  
428 wanted to know whether their donation had been "successful".

429

430 *And I would be interested to know how many births they got from it. I'd just be*  
431 *curious and I'd like to know how many people I have helped and how many*

432 *babies have come from it and how successful it was. Just knowing that I did*  
433 *actually make a difference and was it worth it to do it. (Sophie, 22 years old)*

434

435 It was not just the outcome of their donation where the participants desired further  
436 information. Seven of the participants described wanting to know more about the  
437 recipient(s) of their eggs and what these people were *like*. For two of the participants  
438 this desire related to concerns about whether they would make ‘good’ parents, wanting  
439 reassurance that any child conceived with their donated eggs would be brought up in a  
440 ‘good’ home. The other five participants were not concerned about the recipient’s  
441 parenting ability: they felt that anyone who was prepared to go through egg donation  
442 was someone who “really truly, truly wants a child”. For them the desire for more  
443 information was based on curiosity, so they could imagine the woman they had helped  
444 have a baby and the sort of family they had helped create:

445

446 *I just wanted to know what they were like, what they looked like, what they do,*  
447 *do they have any other kids? What are they like as people, how long have they*  
448 *been trying to have a kid? I wanted their personal statement I guess! That was*  
449 *all I needed was their one. It would be nice to know. Just out of curiosity. I don’t*  
450 *know where they (eggs) are at the moment. (Claire, 30 years old)*

451

452 Despite their concerns about the implications of identity release and their desire for  
453 more information about the recipients and the outcome of their donation, it should be  
454 noted that none of the participants had felt the need to take up the counselling they  
455 were offered in line with current UK regulations. Rather, the participants believed  
456 counselling was only necessary for people who were unsure about becoming donors, a

457 situation that they did not see as applying to themselves.

458

459

## 460 **Discussion**

461

462 Although reporting findings from a small-scale exploratory study, this paper has raised  
463 some important issues for further consideration in policy and practice, both within the  
464 UK, and internationally.

465 In line with existing literature on egg donors this study has shown motivation to  
466 donate to be multifaceted (Purewal and van den Akker, 2009; Kenney and McGowen,  
467 2010; Svanberg et al., 2012). Although the participants described wanting to “help  
468 people”, a motivation that in many studies has been classified as ‘altruistic’ (Pennings et  
469 al., 2014), this study has uncovered a nuanced view of what “helping” other women  
470 means: the participants placed value on their donation due to its ability to give egg  
471 recipients the *chance* of having their ‘own child’. This study has also shown the limits of  
472 asking about motivation and the value of exploring the meaning of being a gamete  
473 donor (Mohr, 2014). It was clear from the participants’ narratives that helping people  
474 was something that was mutually beneficial – being a donor made the women feel good  
475 about themselves, a finding also noted by Konrad (2005) in her ethnography of egg  
476 donation in the UK prior to the removal of anonymity. The rise in compensation for UK  
477 egg donors, brought into play by changes in HFEA policy in 2012, does not seem to have  
478 affected the current study participants’ decision to donate, with all but one of the egg  
479 donors stating that they would have donated “for free”. However, it is clear that the  
480 increase in public attention to egg donation that went hand in hand with the change in  
481 HFEA policies may have had an effect upon their decision to donate: the majority of the

482 participants were unaware of egg donation until hearing about the possibility through  
483 adverts. With many of the participants stating that most of their family and friends had  
484 limited knowledge of egg donation, it seems that awareness campaigns are still  
485 necessary.

486 Due to the arduous, “all consuming” nature of IVF described by infertile women  
487 (Franklin, 1997; Becker, 2000; Thompson, 2005), it is perhaps surprising that this study  
488 has shown how “easy”, both medically and emotionally, the participants found the  
489 processes and procedures involved in donating their eggs. Egg donors describing IVF as  
490 quick, easy and relatively painless has also been reported in other studies (Konrad,  
491 2005; Kenney and McGowen, 2010; Almeling, 2011). Konrad concluded that the  
492 anonymous UK egg donors she interviewed were “refusing to acknowledge the pain,  
493 discomfort and risk” involved in their egg donation. However, Almeling (2011), who  
494 noted a similar phenomenon in her study of commercial egg donors in the US, suggested  
495 that the reason for utilising a medical technology may affect a person’s embodied  
496 experience of that technology. Being paid to undergo hormonal stimulation and egg  
497 collection, for example, may cause women to experience this process very differently  
498 from women paying thousands of pounds for the procedure in the hope of conceiving a  
499 child after years of infertility. Although not receiving the sums of money available to  
500 donors in the US, UK donors may still experience the medical and emotional process of  
501 hormonal stimulation and egg collection differently due to their motivation to undergo  
502 the process: helping others have an ‘own’ child, rather than trying to conceive this ‘own’  
503 child themselves. If concerns regarding the medical and emotional effects of the  
504 procedures involved in egg donation were to be allayed by making the actual  
505 experiences of egg donors more widely known, perhaps more women would consider  
506 donating their eggs.

507 Problems in juggling appointments, especially not being able to be open with  
508 others about donating, were, however, a difficulty the study participants experienced in  
509 the process of donation. Increasing awareness and discussion about egg donation would  
510 again perhaps alleviate some of this difficulty through enabling egg donors to be open  
511 with friends and colleagues about their participation in an egg donation programme. In  
512 addition, clinics could run extended hours for egg donors, helping them combine egg  
513 donation with work commitments.

514 The majority of the participants did not complete the pen portrait and goodwill  
515 message included as part of the HFEA donor information form, and this paper has  
516 highlighted the difficulty that some egg donors experience in providing this non-  
517 identifying information. Abdalla et al. (1998) also found that the vast majority (93.5%)  
518 of the 585 women who had donated their eggs at a London clinic during a six year  
519 period prior to the removal of donor anonymity, did not write a brief personal  
520 description about themselves to be passed on to prospective children. In a more recent  
521 study, Crawshaw et al. (2012) interviewed twelve key informants (three donor-  
522 conceived adults, three egg donors, three sperm donors and three professionals) about  
523 the provision of donor information, and conducted a postal survey of HFEA licensed  
524 clinics' current practices and factors influencing completion of donor information. All  
525 six gamete donors interviewed supported the idea of providing non-identifying  
526 information but considered professional assistance to be inadequate, feeling they were  
527 not given any structure, prompts, or guidance about the information needs of the child.  
528 The findings reported in this paper have shed further light upon the anxieties some  
529 donors experience in providing donor information. The egg donors' uncertainty  
530 regarding their role and what connection, if any, they have with a child conceived with  
531 their donated egg, was central to the difficulty they experienced in writing the pen

532 portrait and goodwill message. For example, if they wrote about themselves as a  
533 'person' would this be placing too much importance on their role in the process and  
534 would this be painful for a recipient of their egg to read?<sup>4</sup>

535           Interestingly all the donor conceived offspring in Crawshaw et al.'s (2012) study  
536 considered information about their donor to be more important than the possibility of a  
537 relationship with them. This finding is supported by a growing body of research  
538 indicating why donor offspring want information about their donor - for identity  
539 formation, satisfaction of curiosity, anxiety about possible genetic inheritance (health or  
540 personality) and fears about consanguinity - and what information they would, ideally,  
541 like to have about their donor - as much up-to-date social, medical and family history as  
542 possible, and a description of what the donor looks like, their personality, temperament  
543 and interests (Turner and Coyle, 2000; Scheib et al, 2005; Jadva et al., 2010; Rodino et  
544 al., 2011).

545           Crawshaw et al (2012) concluded that dedicated staff time, alongside written  
546 guidance for professionals and donors, is needed to help donors understand the importance of  
547 donor information for recipients and donor-conceived offspring, and to help them with their  
548 anxiety/reluctance in completing it. The HFEA's National Donation Strategy Group has  
549 recently addressed the issue of donor information provision through strategies such as  
550 publishing leaflets to help donors think about how to write the pen portrait and goodwill

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<sup>4</sup> The American egg donors Almeling (2011) interviewed also downplayed the significance of their role as an egg donor, maintaining they were donating "just an egg". They also expressed concern for the feelings of egg recipients. However, the US egg donors in Almeling's study provided reams of donor information. At the egg banks at which these US donors were donating, donor information was not just seen as potential information for a donor conceived child: egg donor profiles, with details about the donor's physical characteristics, family health history, educational attainment, as well as open ended questions about hobbies, likes and dislikes, and motivation to donate and photographs of the donor, are used by the egg banks to recruit potential egg recipients. As such, Almeling describes how egg donors are coached regarding the sort of information they should provide and helped to construct gender appropriate profiles.



551 message.<sup>5</sup> However, results from the current study suggest that the provision of counselling  
552 for donors should also be addressed. Although all the egg donors had been offered  
553 implications counselling, in line with current HFEA guidelines, none of the study participants  
554 had taken up the opportunity of this session. This may, in part, be due to the terminology  
555 used to describe the session: they did not feel they needed to be ‘counselled’ regarding their  
556 decision to be an egg donor. If a counselling session was advertised as an ‘information  
557 session’ the participants may have been more inclined to attend and therefore would have had  
558 the opportunity to discuss and explore their thoughts and feelings about being a donor,  
559 including the provision of donor information.

560         Alongside difficulty in providing non-identifying information about themselves,  
561 the study participants expressed desire for further information about the outcome of  
562 their donation. Other studies have also pointed to egg donors’ desire for more  
563 information regarding their donation (Fielding, 1998; Klock et al 1998; Kalfoglou and  
564 Gittelsohn, 2000; Kalfoglou and Geller 2000; Patrick et al., 2001; Klock et al., 2003;  
565 Jordan et al., 2004; Kenney and McGowen, 2010). Of the 20% of US egg donors in  
566 Kenney and McGowan’s (2010) study who reported lasting psychological effects that  
567 they attributed to having donated, most said this was due to curiosity about the  
568 outcome of, and any children resulting from, their egg donation cycle.

569         In known donation, the donor is likely to not only be informed about the  
570 outcome of their donation but, in some cases, maintain a relationship with both the  
571 recipient of, and the child conceived with, their egg. Yee et al. (2011) reported that  
572 Canadian known egg donors whose donation had been successful described their  
573 experience as rewarding and life changing, extremely pleased to have helped their  
574 recipient realise her parental aspirations. Despite not *knowing* the recipient of their

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<sup>5</sup> The leaflet can be found here: [http://www.hfea.gov.uk/docs/Lifecycle\\_-\\_Info\\_for\\_current\\_egg\\_and\\_sperm\\_donors\\_v1.pdf](http://www.hfea.gov.uk/docs/Lifecycle_-_Info_for_current_egg_and_sperm_donors_v1.pdf)

575 eggs, the participants in the current study still had an empathy for this imagined  
576 recipient. They were donating their eggs to help another woman have an 'own child' and  
577 they wanted to know if they had been successful in this pursuit.

578         Indeed, in the UK donors are faced with somewhat conflicting messages  
579 regarding their role as an egg donor. They are anonymous at the time of donation,  
580 donating genetic material to an unknown recipient whom they are told nothing about.  
581 However, they are also encouraged to see themselves as an important player in a  
582 potential child's conception, with their identifying information often framed in terms of  
583 a child's 'right' to know their genetic origins (Freeman et al., 2014). Within this context,  
584 the current study has shown how egg donors experience uncertainty regarding the  
585 identity-release nature of their donation: although donating within a particular legal  
586 framework they are unsure what the repercussions of their donation will be. Will the  
587 parents disclose their use of donated gametes? Will the child be interested in them as  
588 their donor? Will they seek their identity? Will they try to make contact? The egg donors  
589 are donating "just an egg" to an unknown recipient yet are signing up to responsibilities  
590 through this action: in eighteen years' time they may be faced with the complex  
591 situation whereby an individual conceived with their donated egg wants to make  
592 contact with them; an individual whom they know very little about, nor the family  
593 context in which they have been raised. Indeed, inequality in information exchange was  
594 an issue raised in this study: recipients can receive information about their egg donor,  
595 in some cases *choosing* a particular donor, but egg donors do not receive any  
596 information about the recipient of their egg.

597         Pennings (1995) has suggested that the removal of donor anonymity increases a  
598 donor's involvement and responsibility in the donation process, arguing that being  
599 identifiable could reinforce donors' requests to allocate their gametes. Likewise, Raes et

600 al. (2013) suggested that the shift towards identity-release donation focuses on the  
601 rights and interests of donor-conceived children and that 'policy-makers seem to  
602 overlook whether information exchange could also be of interest to the other parties  
603 involved, in particular the gamete donors. Indeed, the Nuffield Council on Bioethics has  
604 highlighted information exchange between donors and donor-conceived offspring as an  
605 area requiring further investigation (Nuffield Council on Bioethics, 2013). The findings  
606 from the present study suggest that the possibility for donors to receive some non-  
607 identifying information about the recipient of their eggs at the time of their donation  
608 may make them feel more satisfied and comfortable with their role as an identity-  
609 release egg donor.

610

611

## 612 **Conclusions**

613 This qualitative study exploring the motivations, experiences and future expectations of  
614 UK identity-release egg donors has shown that the participants' primary motivation for  
615 donating was to help infertile women have their 'own child', and the recent increase in  
616 financial compensation did not seem to play a significant role. All participants were  
617 happy to be identifiable and contacted by children born as a result of their donation.  
618 However, some were hesitant about providing non-identifying information about  
619 themselves for these offspring and wished for further information about the  
620 recipient(s) of their eggs and the outcome of their donation.

621 Although providing important insights for both policy and practice, the limitations  
622 of this study require its findings to be interpreted with caution. This is an in-depth,  
623 exploratory study with a small sample size that may not be representative of other UK  
624 egg donors. Factors such as age, nationality and ethnicity, and whether a donor has her

625 own children or not, may all affect the perceptions and experiences of being an identity-  
626 release egg donor. When compared with the characteristics of all women registering as  
627 egg donors with the HFEA in 2013 (HFEA, 2014), a roughly similar proportion of the  
628 study participants had their own children. However, the study participants were  
629 younger than the HFEA donors and had a higher proportion of non-British participants,  
630 probably because the clinic was based in London. Given the study's small sample size  
631 we have not been able to examine sub groups within the sample, for example exploring  
632 how an egg donor's age, ethnicity or whether she has children may affect her  
633 perceptions and experiences of being an identity-release donor. Larger scale studies are  
634 required to investigate these issues further.

635 Further limitations of the study include a potential selective bias in egg donors  
636 taking part, with those willing to be interviewed perhaps having a more positive  
637 experience of donation. There is also the possibility of social desirability affecting the  
638 narratives of the egg donors, e.g. in terms of financial compensation and motivation to  
639 donate. Almeling (2011) found that the US commercial egg donors she interviewed  
640 conformed to gendered norms expressed in the clinic where they were expected to be  
641 selfless and express empathy for another woman's plight to have children. The current  
642 study participants may also be expressing ideals of what they think an egg donor *should*  
643 be motivated by, and what it *should* mean to be an identity-release donor.

644 Further research with both identity-release egg and sperm donors is needed. A  
645 research approach that takes gender into account is important in order to enable a  
646 discussion of whether egg and sperm donation should be regulated in the same manner  
647 (Richards, 2014). Many of the concerns raised regarding identity-release donation, and  
648 the provision of donor information, expressed by the egg donors in the current study  
649 related to their desire to help another woman have an 'own' child. Almeling (2006,

650 2011, 2014) found that US egg donors described themselves as ‘not-mothers’ to donor-  
651 conceived offspring, whereas sperm donors described themselves as ‘fathers’ to  
652 children conceived with their sperm. Gender is thus one factor that may affect a gamete  
653 donor’s thoughts and feelings about their role as a donor and their connection, or lack  
654 thereof, with the recipient of their gamete(s) and any offspring conceived. Other factors  
655 such as age, ethnicity, sexual orientation and whether a donor has their own children or  
656 not, may also affect perceptions and experiences of being a gamete donor (see, for  
657 example, Daniels et al., 1996; Riggs and Russell, 2010). In-depth, longitudinal studies  
658 with both egg and sperm donors need to explore such themes in order to help prepare  
659 for the time when donor-conceived offspring are able to request the identity of their  
660 donor and possibly make contact with them .

661

662

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664

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668

### 669 **Role of authors**

670 All authors were involved in the design of the study. KA assisted with the recruitment of  
671 participants. All other authors were involved in the analysis and interpretation of data.  
672 This manuscript was drafted by SG and has been approved by all authors.

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