UK gamete donors’ reflections on the removal of anonymity: implications for recruitment

Lucy Frith1,3, Eric Blyth2 and Abigail Farrand2

1University of Liverpool—Primary Care, The Whelan Building, Brownlow Hill, Liverpool; 2The University of Huddersfield
3Correspondence address. University of Liverpool—Primary Care, The Whelan Building, Brownlow Hill, Liverpool L69 3GP, UK.
E-mail: l.j.frith@liv.ac.uk

BACKGROUND: In 2005, UK legislation was changed requiring any donor of gametes or embryos used in the treatment of others to agree to the disclosure of their identity to any offspring reaching the age of 18. METHODS AND RESULTS: This paper analyses responses of a survey of existing donors’ views on the removal of donor anonymity that was undertaken by the Department of Health (UK) as part of its review that preceded changes to the law on donor anonymity. The survey provides an insight into what it is about the loss of anonymity that some donors find problematic, indicating that although some donors will be reluctant to donate under conditions of non-anonymity, others have concerns about the removal of anonymity that can be addressed. CONCLUSIONS: This paper identifies factors, in particular counselling, support and better information that could maintain gamete donor recruitment in the context of the UK’s policy of non-anonymous and non-remunerated donation.

Keywords: counselling; Gamete donation; non-anonymity; recruitment

Introduction

This paper analyses the results of a survey of existing gamete donors’ views on anonymity undertaken by the UK’s Department of Health (DH) that formed part of the government’s consultations over whether to remove gamete donor anonymity (Johnson, 2004). This study provides data on the specific concerns expressed by donors about donating non-anonymously and indicates strategies for recruiting donors within the context of non-anonymous and ‘cost neutral’ donation that now characterizes gamete donation in the UK. The data suggest that although some donors recruited as anonymous donors will be reluctant to donate non-anonymously, others have concerns that can be addressed by better information, counselling and support. It will be argued that implementing such a strategy could facilitate donor recruitment and go some way to ameliorating any negative impact on donor recruitment of the legislative change.

Background

In April 2005, UK legislation was changed requiring any donor of gametes or embryos used in the treatment of other people to agree to the disclosure of their identity to any offspring reaching the age of 18 (The Human Fertilization and Embryology Authority (Disclosure of Donor Information) Regulations 2004 enable a donor-conceived person aged 18 or older conceived following gamete or embryo donation taking place after April 2005 to request the identity of their donor from the Human Fertilization and Embryology Authority. The regulations provide no rights to donors or recipients to learn the identity of each other, either at the time of donation or subsequently). This was a controversial move, because it was thought that the abolition of anonymity in the context of altruistic, or quasi-altruistic donation, would effectively end gamete donation in the UK (for example, Craft and Thornhill, 2005; Craft et al., 2005; Pennings, 2005). It has been claimed that the early consequences of the policy change has resulted in a reduction in the number of sperm donors (BBC News, 2006; British Fertility Society, 2006). However, the Human Fertilization and Embryology Authority (HFEA) has both identified the difficulty of accurately calculating donor numbers (Human Fertilisation and Embryology Authority, 2005a) and published donor registration data that do not substantiate fears of a collapse in donor recruitment (Human Fertilisation and Embryology Authority 2006). Further, some service providers have demonstrated their success in recruiting identifiable donors (Adams, 2005; Adams et al., 2006; Witjens and Morris, 2006).

In addition to the removal of donor anonymity, the HFEA amended arrangements for donor compensation (Human Fertilisation and Embryology Authority, 2005b) to implement the European Union’s ‘Tissues and Cells Directive’. This provides that, ‘donors may receive compensation which is strictly limited to making good the expenses and inconveniences related to the donation.’ (European Union, 2004). The HFEA’s new arrangements do not allow donors to receive compensation for inconvenience and endorses the principle of
‘cost neutrality’, by which donors should neither profit nor lose out financially from their donation. Donors will be reimbursed out-of-pocket expenses and only receive modest compensation for loss of earnings (a daily maximum of £55.19, and a ‘cap’ of £250 for each course of sperm donation or cycle of oocyte donation). With the exception of oocyte sharing, which enables a woman to receive subsidized treatment in exchange for sharing her oocytes with another woman, gamete and embryo donation will be modelled on the principle of altruism. The challenge, therefore, is to encourage donor recruitment within the non-anonymous ‘cost neutrality’ context in which donor conception currently operates in the UK.

Materials and methods

In 2001, the government initiated a public consultation to gauge views on the disclosure of information to those conceived by donor gametes about their donor (Department of Health, 2001). The overall response to the consultation was limited and the government was particularly concerned about the lack of responses from donors and assisted conception units. Further investigations were therefore proposed before deciding whether to retain or remove donor anonymity (Blears, 2003).

As part of these investigations, a questionnaire designed by the DH was distributed to donors via licensed infertility treatment centres. Anonymized returned questionnaires that were not subject to confidentiality restrictions were subsequently made available by the DH to the authors for detailed analysis. The questionnaire sought information from donors on:

- the centre at which they were/had been a donor,
- the type of their donation,
- their response to the future removal of donor anonymity,
- their willingness to donate should donor anonymity be removed,
- their knowledge of other potential donors,
- their perception of the main issues or questions raised by the removal of anonymity, and
- their suggestions for recruiting identifiable donors.

One hundred and thirty-three questionnaires were analysed using SPSS (v12). Two questionnaires were excluded, since it was unclear whether these respondents were actual or merely prospective donors.

Respondents identified 16 centres and five respondents did not specify a centre. A single centre was identified by 38% (50) and almost three quarters (99) were donors at just four centres. This suggests that some centres were more successful in encouraging their donors to participate in the study, consequently the sample is biased in favour of a small number of centres. Seventy-five respondents (57%) were oocyte donors, 43 (32%) were sperm donors. Twelve respondents (9%) identified themselves as oocyte share donors. There were no embryo donors. Three respondents did not make clear the type of donation in which they had, or were currently, engaged.

### Results

Just over one-third (47) of respondents identified concerns regarding the future removal of donor anonymity (Table 1). A similar proportion (48) declared they were either not worried about or were pleased with the removal of anonymity. Four respondents did not respond to this question and the remaining quarter was unsure. Almost half of the respondents (20 sperm donors, 38 oocyte donors and 7 oocyte share donors) indicated they would still donate if anonymity were removed. This includes virtually all the respondents who indicated that they were either not worried about or pleased with the removal of anonymity and nearly half of those who were ‘unsure’. Only three respondents who had expressed concern would continue to donate non-anonymously. Only 15% (20) said they knew of another person as a potential donor.

Table 2 summarizes responses to the question ‘what do you see as the main issues and questions raised by the removal of anonymity?’

The overall concern that donors had over the removal of donor anonymity was the future repercussions of such a move. We have grouped these into three categories for purposes of analysis: unfounded apprehensions about what the change in the law would involve (26% of issues raised); the consequences of a donor offspring (on reaching the age of 18) making contact with the donor (32% of issues raised) and concerns over donor rights and confidentiality (7% of issues raised). These issues were of equal concern to both male and female respondents.

### Unfounded apprehensions over what the change in legislation would involve

A number of respondents indicated unfounded apprehensions about the removal of donor anonymity. These were concerns:

- (i) that donors would now have legal and financial responsibilities;
- (ii) that the removal of anonymity would be applied retrospectively;
- (iii) over the purposes for which donations may be used (i.e. that donations could be used for purposes for which the donor has not given explicit consent).

### Consequences of the donor offspring making contact

This was one of the main concerns of the respondents and incorporated the following elements:

- (i) emotional liability, moral obligations, personal involvement,
- (ii) personal security of donors,
Donors’ rights

Donors were concerned that if donor offspring were to be given more access to information about them, would they correspondingly have any rights to information themselves?

(i) any information about the outcome of their donation (such as whether any children were born and, if any, their gender),
(ii) access to information about recipients and/or any offspring,
(iii) practicalities of information giving—how much information would be made available to the offspring,
(iv) whether the donor would be informed that information was going to be released to the donor offspring,
(v) whether identification would be reciprocated to identify adult offspring to donors.

Respondents were asked for suggestions for recruiting non-anonymous donors. Their responses are summarized in Table 3. It is important to note that 43 respondents, nearly a third of the total, gave no response to this question. Nineteen of those who did respond (15% of the total responses to this question) used this opportunity to express their belief that the removal of anonymity would render further recruitment impossible. Fifteen of these had previously stated that they were opposed to/concerned about the proposal to make all donors identifiable. Seven responses recommended accommodating both anonymous and non-anonymous donation and there was one recommendation to increase from 18 to 21 the age at which a donor-conceived person could request the donor’s identity. These responses have been excluded from Table 3.

The main strategies suggested for recruiting identifiable donors were: educating others about various aspects of donating (the procedure, the feelings of donors, recipients and the resulting children); offering a financial incentive to donors’ clarifying legal issues and ensuring donors legal protection and use of the media and/or publicity. Some respondents (9) suggested that the offer of more ongoing support from the clinic and the offer of counselling to help donors manage the consequences of donation could act as an encouragement to donate.

Discussion

Limitations of the study

In considering the implications of this study, we need to acknowledge two important limitations. The first is the limited nature of the information requested and provided. Since no demographic data are available, it is not possible to associate particular responses to different donor characteristics, such as age, marital status and whether the donor has any children of his or her own. Such information might well suggest specific strategies for recruiting particular types of donor. Second, the total number of responses is both fairly low and skewed towards respondents from a small number of clinics, thus limiting any claims to more generalized applicability. Notwithstanding, the HFEA’s (from page 4, 2005a) acknowledgement of the difficulty of quantifying accurately the number of UK donors, it is evident that respondents to this survey compromised only a proportion of the total number.

Nevertheless, these findings provide an insight into what the respondents to this survey felt were problematic features of non-anonymous gamete donation—and eradicating or
mitigating some of these could form a strategy for facilitating donor recruitment. Allowing an increase in donor remuneration as a trade-off for the loss of anonymity has been proposed as an effective way of increasing recruitment (Craft and Thornhill, 2005). Respondents’ views on payment were positive: 18 (18.4%) referred to ‘financial incentive’ among suggestions for recruiting donors should anonymity be removed (Table 2); four responses (2.5%) identified ‘current lack of financial incentive’ as an issue/concern (Table 1). The Human Fertilisation and Embryology Act and the ‘European Tissue Directive’ (see above) afforded the HFEA a measure of discretion to determine both the general policy and the level of donor compensation. Its efforts to avoid on the one hand commercialization of gamete procurement (and by implication the commodification of any resultant children) and on the other disincentives to donors have resulted in unique provisions that allow oocyte sharing, the monetary value of which is considerably higher than the cap on reimbursement of loss of earnings that applies to other gamete donors (Human Fertilisation and Embryology Authority, (from page 4, 2005b; Blyth, 2007). Other than noting that the legislative framework provides the HFEA with further room for manoeuvre regarding donor compensation, space precludes a more detailed discussion of the current HFEA policy here. However, its impact on donor recruitment should be kept under review.

Our discussion below will focus on strategies suggested by participants for encouraging donor recruitment within the non-anonymous, ‘cost neutral’ context in which donor conception operates in the UK.

**Education**

A key area that concerned donors was the possible future repercussions of non-anonymity. It appears that, for some, anonymity had provided a form of protection, which they thought would be lost once donors were no longer anonymous. Anonymity protected donors from legal and financial responsibility for any donor offspring and prevented the child from having any rights over the donor’s family or property. With the removal of donor anonymity, an often-expressed concern was the possible legal and financial responsibility this could place on the donor if the child chose to exercise it. As we have noted above, some of the misapprehensions expressed by donors reflected erroneous understandings of the law change. This illustrates that there is important information concerning gamete donation about which some donors were unaware, despite clinics’ obligations to provide this before obtaining a donor’s consent to donate. Obviously, the survey does not indicate whether clinics had failed to provide this information, whether donors had been told and had subsequently forgotten, or whether they had never properly understood what they were being told in the first place. Whatever the explanation, there is still much that can be done about informing and educating the general public and prospective donors about the arrangements for gamete donation in the UK.

The most cited suggestion for recruiting donors (22.4%) was the education of others. Education can perform a number of functions in donor recruitment: increasing awareness about infertility and the potential role of gamete donation; stressing that donation is a positive altruistic act that has the potential to transform childless people’s lives by helping them build their family; promoting the social acceptability of donation; highlighting the benefits of non-anonymous donation (that future offspring are able to access information, if they wish, that can help form a sense of genetic identity) and informing prospective donors of the legal, ethical, psychological and practical aspects of donation. Emphasising that donors have no legal or financial responsibilities for any donor offspring is evidently a key element of any education campaign. Although the absence of anonymity per se appears to be a disincentive for some prospective donors, others may be willing to donate once their apprehensions about liability are put to rest.

**Provision of information for donors about the outcome of their donation**

Currently, donors in the UK have no rights to information about recipients or offspring, although this is under consideration by the government (Department of Health, 2006). A number of respondents in this survey were interested in having information about the outcome of their donation, ranging from simply being told if a child had been born and their gender to the wish to have identifying information when

---

<table>
<thead>
<tr>
<th>Suggestions for recruiting donors should anonymity be removed</th>
<th>Frequency (n = 98)*</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education of others</td>
<td>22</td>
<td>22.4</td>
</tr>
<tr>
<td>Financial incentive</td>
<td>18</td>
<td>18.4</td>
</tr>
<tr>
<td>Legal aspects considered/protection</td>
<td>15</td>
<td>15.3</td>
</tr>
<tr>
<td>Use of the media/publicity</td>
<td>14</td>
<td>14.3</td>
</tr>
<tr>
<td>Express the rewarding elements – psychological</td>
<td>9</td>
<td>9.2</td>
</tr>
<tr>
<td>Ongoing support offered by clinic/counselling</td>
<td>9</td>
<td>9.2</td>
</tr>
<tr>
<td>Less time consuming/easier to donate</td>
<td>3</td>
<td>3.1</td>
</tr>
<tr>
<td>Chance to meet the receiving family</td>
<td>3</td>
<td>3.1</td>
</tr>
<tr>
<td>Promise of no responsibility</td>
<td>2</td>
<td>2.0</td>
</tr>
<tr>
<td>Safer process</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Increase the age limit/No of live births allowed</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>More accessible clinics</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>98</td>
<td>100</td>
</tr>
</tbody>
</table>

*The total number of identified issues is greater than the number of responses since some respondents highlighted more than one issue.
the offspring reached 18. Extending such rights to donors, while ensuring that the rights and interests of offspring are also adequately protected (especially as regards the disclosure of identifying information), might increase the attractiveness of non-anonymous donation to some potential donors.

**Mediation of contact**

Although donors may not be legally or financially responsible for any donor offspring, the emotional effect of any possible contact is of great concern to donors. The spectre of the offspring ‘just turning up on the doorstep’ and the impact of any contact on the donor’s family was a frequently mentioned concern. Emotional liability was mentioned nearly as much (8.4%) as financial liability (10.8%). Clearly, the emotional and moral obligations to a genetically related child wishing to pursue personal involvement (that might be unwanted by the donor) would be difficult to ignore despite the limit on any legal obligations. To our knowledge, only one published study has examined the intentions of donor-conceived young people who are able to identify their donor (Scheib *et al.*, 2005). This provides no support for the unannounced ‘knock on the door 18 years later’ scenario. However, non-anonymous gamete donation obviously allows this to become a possibility, and some people would find this a sufficient reason for not donating.

Responses reported here, however, suggest ways of alleviating donors’ apprehensions about the potential negative effects of such contact. Some respondents (9) thought that support mechanisms for overseeing contact between donors and donor offspring, and general ongoing support for donors, would be helpful. Although the suggestion for mediation and support was not made by a significant number of respondents, there were a number of concerns (Table 2) that could be addressed by some form of support: psychological and emotional issues for the donor; impact on the donor offspring; personal security of donors and impact on the donor’s family. In light of these concerns, it will be argued that structures should be in place for mediating any possible contact and information sharing between donor and offspring. These structures could go some way to mitigating the effects of non-anonymity on donor recruitment.

That some form of mediation and counselling support is crucial for those seeking their genetic relations has been well established in adoption practice (Marks, 2001). Even though adopted adults in the UK have had the right since 1976 to obtain their birth certificate, it has been recognized that the mechanisms to support them during the process of finding out about their adoption and birth parents have not always been satisfactory (Department for Education and Skills, 2004; Sullivan and Lathrop, 2004). The Adoption Act 1976 made little provision for how information giving was to be handled or what support adopted people might need (Section 51). The recent Adoption and Children Act 2002 aimed to address these problems by improving services for adopted people and their birth relatives. For example, those adopted after the regulations come into force (i.e. after September 2005) will be able to apply to an Adoption Support Agency that will act as a single gateway for gaining access to identifying information. These agencies will act as an intermediary service between the adopted person and any birth relatives and provide counselling if this is desired (Department for Education and Skills 2005). This recent change in adoption law can be used as a lesson for gamete donation practice. It is important that we do not repeat the mistakes made in adoption and recognize that mediation and support are crucial elements in a viable non-anonymous gamete donation system.

The British Fertility Society (BFS) in its response to the HFEA’s consultation on donor-assisted conception has also highlighted the need to provide support for those donating non-anonymously. Its recommendations included: plans for counselling and services around times of information sharing and/or contact with donor-conceived offspring and the availability of counselling and support for a donor’s partner and/or other family members (British Fertility Society, 2005a). There is a precedent for some form of mediation between donor and offspring in the government funded dedicated service for people involved in donor conception in the UK before 1991, UK Donor Link (www.ukdonorlink.org.uk). This was established in 2004 and has already facilitated contact between people involved in donor procedures that took place before implementation of the HFE Act 1990. Further, there has been some pioneering work undertaken specifically to develop ‘donor-linking’ counselling (Kane, 2002; Blyth and Speirs, 2004).

The government has recognized the importance of counselling in this area of information giving and contact. It commissioned The British Infertility Counselling Association (BICA) to undertake some preliminary work on the provision of counselling services when people request information about their genetic origins from the HFEA Register of Information (for children born between 1991 and March 2005 under conditions of anonymity). BICA also recommended that counselling and intermediary services should be available around times of information sharing and/or contact with donor-conceived offspring and be available for a donor’s partner and/or other family members (British Infertility Counselling Association, 2003).

However, to date none of these recommendations has been acted on and the lack of any follow-up action prompted BFS to express its: ‘disappoint(ment) that the UK government currently has no plans to fund mediation and origin counselling similar to those established in post adoption services’ (British Fertility Society, 2005b).

One possible reason for a lack of urgency in establishing any provision for support or mediation may be that the first people to ‘come of age’ under the non-anonymous donation system will not do so until 2023 (assuming there will be no change in the age at which a donor-conceived person may access such information). However, responses from this research indicate that fears of unmediated contact act as disincentive for some potential donors. An assurance that such services will be available, evidenced by their existence now rather than promises of their establishment in the future, could exert a positive impact on current donor recruitment. As the BFS notes, ‘it is essential that from April 2005 donors are given clear and direct information concerning the provision of counselling and future support services.’ (British Fertility Society, 2005a).
Conclusion
This paper has analysed the responses of gamete donors to a DH survey undertaken as part of the government’s review of donor anonymity and focused on the implications for future donor recruitment. Although it has been argued that non-anonymity coupled with non-payment for gametes would effectively end gamete donor programmes due to lack of donors, the views of donors participating in this study suggest that some concerns donors have over non-anonymity can be addressed. Gamete donor recruitment strategies need to reflect the new context in which gamete donation operates, and this research gives some indication of how these could be achieved. Alongside better education and information for prospective donors, support and mediation for all involved parties is a crucial aspect of good practice and could go some way to encouraging donor recruitment. Self-evidently, longer term monitoring of the impact not only of the HFEA’s overall policy, but also of policies and practices at individual clinics will be necessary to determine the most effective strategies for promoting donor recruitment.

Acknowledgements
The authors wish to thank the Department of Health for co-operating with study and the Universities of Huddersfield and Liverpool for funding the project.

References
Blyth E. Ethical and psychological aspects of egg sharing. Paper to be given at ESHRE Annual Meeting. Lyon, 1 July 2007.
British Fertility Society. Fertility specialists welcome sperm and egg donor campaign but call for more action in time for change in law in April Bristol: British Fertility Society, 2005b.
British Infertility Counselling Association. ‘Opening the record’: planning the Provision of Counselling to People applying for Information from the HFEA Register. Report of the HFEA Register Counselling Project Steering Group.

Submitted on October 5, 2006; resubmitted on December 19, 2006; resubmitted on February 7, 2007; accepted on February 13, 2007

1680