



# Public Perceptions of Gamete Donation in British South Asian Communities

## Research Report

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## Executive Summary

### Aim

To examine the public understandings of gamete donation amongst British South Asian communities.

### Methods

Single gender focus groups (10 female, 4 male) with people of Indian, Pakistani and Bangladeshi origin in 3 cities (n=100); interviews with 20 key informants; community engagement event.

### Key Findings

#### *Using donated sperm and eggs:*

- There was a general acceptance of IVF to treat infertility with the couples' own gametes. However, third party assisted conception was seen to encompass many potential risks for the individuals and families who used donated gametes. Less concern was expressed about the use of donated eggs than the use of donated sperm. A genetic link with the father was considered important. Pregnancy and birth gave women an alternative bond with the child conceived via egg donation.
- Disclosure of treatment (including to offspring) and disclosure of donation were regarded by most participants as highly risky actions given a general social disapproval of third party assisted conception and most felt that treatment would not be disclosed. However, many participants felt that the child had a 'right' to know about the nature of his or her conception and that 'accidental' disclosure could be damaging.
- Discussions with Muslim participants demonstrated a significant concern for the religious acceptability of gamete donation. A variety of views were expressed, but most were of the opinion that the third party assisted conception was not permissible in Islam. No religious objections were discussed by Hindu or Sikh participants.

#### *Donating sperm and eggs:*

- There is a low public profile of gamete donation in South Asian communities. Very few participants were aware of a shortage of donors.
- Donation was viewed as a highly altruistic act, and many could see the necessity and advantages of using donated gametes for couples facing the stigma of infertility.
- Many women felt that they would maintain an emotional interest in the donated egg, which could cause them problems on a long term basis. Women were not generally deterred by the physical aspects of egg donation.

- Intra-family or ‘known’ donation raises many important ethical issues, and the research suggests a degree of ambivalence around this, for women especially. Several women suggested that they would consider donating to help family members, but would need to discuss the potential implications. Some counsellors, clinicians and community representatives expressed some concerns about the possibility of social pressure on women to act as family donors.
- Men were less concerned with potential emotional problems of donation, but some expressed concerns about possible economic consequences or implications for inheritance.
- The removal of donor anonymity was troubling to many (especially women), who were concerned by what they saw as the prospect of a child ‘turning up’ on their doorstep. This possibility was viewed as a major disincentive for egg donors especially, since women are perhaps more vulnerable than men to social stigma and ostracism for apparently transgressing cultural norms. However, a small number of male participants were willing to consider donation even in the context of the ending of anonymity.
- There was no clear consensus on the issue of whether or not donors should be paid.

### **Key Recommendations**

- The public profile of gamete donation needs to be raised so that a dialogue can effectively take place between stakeholder groups. For those who wish to encourage altruistic gamete donation, particular efforts are required to inform South Asian communities about the need for donors and to actively engage with communities. Efforts need to be made to include those who are often excluded from mainstream publicity activities. All engagement materials should be culturally inclusive and it is essential that community members are involved in the design of any intervention.
- Infertility service providers should consider the potential additional concerns about the process of using donated gametes which South Asian men and women might have, especially in relation to decisions to use family donors; decisions to disclose treatment and decisions to inform children of the means of their conception. Counsellors have an important role to play in this process and infertility counsellors need to ensure that they are working in a culturally sensitive way.
- Organisations which offer general support to families undergoing fertility treatment, and those which support disclosure to offspring such as Donor Conception Network need to provide culturally informed and sensitive support.
- Additional and more inclusive public consultation by the HFEA and other relevant bodies on this and related issues is needed. Consultation techniques need to be more proactive, using alternatives to “traditional” public consultation methods. Focus groups and citizens juries could be organised in collaboration with a range of community based groups and used in place of, or alongside, existing methods of consultation.

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## 1. Background

Within the UK, approximately 25,000 children have been born using donated gametes (eggs and sperm) or embryos since 1991. However, research exploring public attitudes to new reproductive technologies (NRTs) and third party assisted conception in particular, is limited and has largely focused on the experiences of (mostly white, middle class) individuals and couples who are *users* of NRTs or on the motives of (mostly white) egg and sperm *donors*. There is a small body of work which explores ‘lay’ or ‘public’ perceptions of third party assisted conception more generally. This reveals a general consensus that technological ‘help’, including treatments which use donated genetic material, should be offered to couples so that they can become parents (Kazem et al 1995; Edwards 1998; Kailasam, Sykes & Jenkins 2001).

As far as minority ethnic communities in the UK are concerned, there is evidence to suggest that British South Asian communities may differ from white communities in the meanings which are attached to the experience of childlessness. Such differences may also influence ideas about the acceptability and appropriateness of infertility treatments (Culley et al 2006). The ways in which infertility and infertility treatments are publicly understood is likely to have an impact of the experiences of childless couples and those seeking treatment (Miall 1994). It is important, therefore, to have some understanding of how communities perceive gamete donation.

An additional important aspect of the context of this study is the current acute shortage of gamete donors, especially egg donors, from ‘non-white’ ethnic groups (Golombok & Murray 1999). This has been exacerbated by the ending of donor anonymity from April 2005 (HFEA 2006). South Asian couples, therefore, face very long waiting times for treatment. A project which explores the views of members of South Asian communities is therefore very timely.<sup>1</sup>

## **2. Aims**

The study aimed to: examine the public understandings of gamete donation amongst British South Asian communities and to explore issues regarding the willingness of South Asian women and men to consider donating or receiving gametes through altruistic or other means.

## **3. Methods**

In order to ensure that the project was as inclusive as possible, a team of bi-lingual community facilitators were recruited to work with the core research team. The facilitators, all of whom have previous research experience and are trained interpreters, were given additional training on using the focus group method and on the substantive topic. The facilitators were members of a research advisory group and were involved in organising and hosting the engagement event. The study was approved by the Faculty of Health and Life Sciences Human Research Ethics Committee at De Montfort University and adhered to the British Sociological Association Ethical Code of Conduct for researchers.<sup>2</sup>

### *3.1. Literature review*

An extensive review of the published academic literature on public perceptions of gamete donation was carried out as part of this study. The team also collected UK published Asian (English language) newspaper and magazine items which discussed gamete donation. The results of the academic literature review are to be published in the journal *Public Understanding of Science*.

### *3.2 Focus groups and interviews*

Fourteen single sex focus groups with a total of 100 participants of Indian, Pakistani and Bangladeshi origin were conducted in three English cities. Ten of the groups were with women (n=63) and four with men (n=37). A range of age groups were represented in the study. None of the participants were recruited on the basis of their own fertility histories and were not asked for personal testimonies in the group. Rather the focus groups were

designed to elicit their views on the ‘community’ discourses surrounding gamete donation. The guide for the focus groups was developed in consultation with the facilitators and an advisory group which included user representatives, academics, members of South Asian communities, counsellors and clinicians. ‘Vignettes’ were used in the focus groups in order to give people some information about gamete donation, to ‘depersonalise’ the issue, and to generate discussion through a consideration of the stories. The vignettes were developed in partnership with infertility counsellors drawing from their practice experience. Five of the groups were conducted by facilitators in South Asian languages (two in Punjabi, two in Bengali [Sylheti dialect] and one in Urdu), and nine groups were conducted in English by two members of the core research team. The participants were asked about the importance of children, their attitudes to fertility treatment and in particular how they felt people in their own communities would respond to a number of issues concerning the use of donated eggs and sperm and willingness to act as donors of eggs and sperm in a number of different contexts. The participants also discussed issues of disclosure to children, how they felt about donor anonymity, and the payment of donors. In addition to the focus groups, semi-structured interviews were conducted with 20 key informants including: practitioners (4), counsellors (1), support group and user organisation representatives (7), and community representatives (8) to provide additional context to the focus group discussions.

### 3.3 *Community Engagement Event*

The team also held a highly successful community engagement event: ‘Making Parents: Infertility Awareness and South Asian Communities’ at a South Asian community centre in the city of Leicester in March 2006. Attendees included members of South Asian communities, as well as representatives of the following organisations: British Fertility Society, British Infertility Counselling Association, Infertility Network UK, National Gamete Donation Trust, Donor Conception Network, Human Fertilisation and Embryology Authority, Afiya Trust, ACeBabes, Daisy Network, Ujala Resource Centre Leicester, Eastern Leicester Primary Care Trust, Leicester Centre for Ethnic Health Research, and the Leicester Adoption Agency. In addition to presentations on infertility and its treatment from clinicians and support groups, the team presented preliminary findings from the study for discussion amongst participants, and generated feedback and further data from a series of small group discussions.



## 4. Findings

This section gives a brief summary of key findings, drawing mainly on the focus group data. It is important to point out that the complex, sophisticated and often ambivalent and contradictory views expressed by the same participants, sometimes within the same focus group, represent shifting ‘opinions’ and views which depend on the specific question being addressed and the specific vantage point from which it is tackled (Edwards 1998). Thus it would be misguided to view the findings as a firm, generalisable ‘South Asian viewpoint’ on gamete donation. Participants explored the potential implications of various practices in relation to cultural ideas and values. However, the findings are from specific persons in specific locations and should be considered as tentative suggestions about how people *might* react in a given situation to a given issue.

### 4.1. *Willingness to use donated gametes*

In common with earlier research (Culley & Hudson 2006), participants saw parenthood as culturally mandatory and childlessness as socially unacceptable. Infertility was seen to be a major social problem, with highly significant consequences, especially for women. British South Asian societies are highly pro-natalist. Participants related the social, economic and religious importance of children and the stigmatisation of childlessness. Childless couples and women in particular may face many difficulties, as this Indian woman commented

*You are sort of an outcast really. I think as soon as you get married, you’re expected – it’s an expectation that you will have kids and then when you can’t, it’s ‘Oh my gosh what’s wrong with you?’ You’re rejected, kind of thing.*

For some men, it was a question of proving their manhood in a particular social context. As this man of Pakistani origin commented,

*Our marriages usually take place within families or within communities and rarely outside our own family or community. I want to have a child after*

*marriage so that no one points a finger at me and has any doubt that I am a man or not. It's a question of proving my manhood.*

Infertility is however, seen as something amenable to medical treatment, though few participants had knowledge of treatments beyond a general awareness of IVF. Knowledge of the extreme pressure put on couples, and women in particular, to have children, led most participants to suggest that infertile couples *should* have access to assisted conception.

However, while the use of the gametes of the couple themselves was relatively uncontroversial, the use of third party gametes was considered a much more risky and problematic process. All participants felt that such a procedure would be disapproved of more generally within their communities and that South Asian men and women would feel very uneasy and anxious about the possible impact of such a course of action on family and wider social relationships. In discussing the use of donated sperm, for example, one Bangladeshi man commented

*Relations will become bad between two families...then this will become a community conflict based on the identity of this child. People will say 'you are not the son of your father', he [child] will face a big problem.*

Nevertheless, given their knowledge of the intense social stigma and the deep personal emotional trauma which participants felt that childless couples suffer, most were of the view that despite such disapproval some couples in this situation might use third party assisted conception (using donated sperm or eggs), as a treatment of 'last resort', if no other option for a pregnancy existed.

#### 4.2 *Using donated eggs and donated sperm*

When considering whether people might be willing to use donated gametes, most people felt less concern about the use of donated eggs than the use of donated sperm. Both men and women felt that using donated sperm would be highly problematic since it did not allow the male to play his culturally important role in procreation and it threatened lineage and family continuity. It was generally seen as important that a man had a

genetic link to his children. This was seen as less important in the case of women. As this Bangladeshi woman argued

*I think, in tradition, whether a child has his mother's characteristics doesn't matter much, but it, he, the child, has to have the father's characteristics. And father's side family characteristics.*

Both men and women stressed the fact that in the case of donated eggs, the man would maintain a genetic link and the female would establish a form of connection to the child through the process of pregnancy and birth. In this way, the use of donated eggs was less threatening to the status quo. Women would be able to 'cope' with the fact of having their own gametes substituted, since they would carry the pregnancy, 'nurture' the foetus and thereby generate a 'biological' link between mother and child.

*With a woman, at least she's carrying it for nine months, she's nurturing it...you know, in her stomach, so she's got that bond. (Indian woman)*

*I think once, once you're sort of pregnant and carrying the child, you just think of it as your own baby, yours and your husband's regardless of how it got there, whether it came from the donor. But, you just tend to think of it as your baby and once it's born, it's your baby. (Indian woman)*

Women in particular, also felt that South Asian men might have great difficulty on an emotional level, in accepting a non-biologically related child, whereas women were regarded as more nurturing and able to bond with a child to which they had given birth, despite its genetic origins. Several participants suggested that the man could potentially reject the child if he had not played what was perceived as a central role in its creation. One man of Indian origin commented

*I think the father may react to the child in a different way. He would think that this child is not conceived by his sperm, so he would keep some distance with this child. Whereas the mother, will not, because she would have gone through all natural processes by keeping the child in her womb for nine months and all that.*

It was felt that when going through the inevitably difficult circumstances of raising a child, the man might begin to resent the donor-conceived child when the ‘going got tough’. Some participants drew analogies with adoption and with step-children. As this woman of Indian origin explained:

*It's easier for women to accept children, rather than vice versa. For men to accept [step-children], it's much, much harder.*

It was also felt that for South Asian men, the use of donated sperm would represent an affront to their masculinity and would have the effect of revealing a basic and highly stigmatising ‘defect’. This also has implications for potential disclosure of treatment, which are discussed below.

#### 4.3 *Choosing donors and choosing gametes*

Most participants felt that it was important to ‘match’ the donor with the characteristics of the recipient family. In many cases, this was expressed in terms of the importance of a physical resemblance. However, many people also stressed the importance of cultural connections and ethnic identities, which they perceived could be carried in the donor eggs or sperm especially. So for some participants, especially older ones, it was important that parents could ‘relate’ to a donor through shared cultural heritage. The Muslim and Hindu participants particularly, felt that the donor should be from the same cultural and especially religious background as the recipient family. As this man of Bangladeshi (Muslim) origin expressed it:

*My community, colour, lifestyle. He will have a history, same as my family.*

Muslim women too, expressed a similar view,

*If you're Muslim, you'd want a Muslim background, because you just don't want anybody.*

A minority of participants also felt, however, that eggs from a ‘white’ donor might also be acceptable to childless couples, and that this option should be offered. It was pointed

out that fair skin was often considered desirable in South Asian communities, and could be relatively easily ‘explained away’.

Participants were asked whether donors from within the family would be preferable to an anonymous donor or one from outside the family. This question produced a variety of responses, even from the same individual, often dependent on the perspective or vantage point being considered. On the one hand, a family donation is likely to mean a stronger physical resemblance, a common cultural heritage and a known ‘provenance’, all of which were seen as desirable. On the other hand, family donation, especially in the case of donated sperm, was seen to carry many risks. There was a considerable concern for some that the child would ‘find out’ and that disclosure beyond the family was also more likely to occur, especially if there was some future disagreement within the family. Furthermore, from the perspective of the parents, fears were expressed that the donor may still consider the child to be ‘their’s’ and might want to ‘interfere’ in the child’s upbringing, which was seen to create difficulties for the recipient parents and potentially lead to family conflict.

A further concern for women in particular was that it might be suggested that an ‘inappropriate’ or adulterous relationship had occurred between the woman and her brother in law (in the case of sperm donation), a suggestion which would be highly damaging for the woman concerned. Several women expressed the view that within South Asian communities, the use of donated sperm may be seen publicly as transgressing established cultural boundaries of acceptable behaviour and bodily conduct for women. There was also a more general concern that the ‘sharing’ of a child might ‘create’ in effect an illicit relationship, or pose a threat to existing marital relationships even where people knew that the couple had not had intercourse.

Donation of *eggs* within the family (between sisters), was viewed as less problematic, especially from the viewpoint of the recipient. As we have seen, use of donated eggs generally is seen as more benign than the use of donated sperm. There were, however, still some concerns that family donors may want to have an enduring relationship with a child, which could lead to family tension, and that future claims might be made on the child. As this women of Bangladeshi origin said,

*If your relationship [with the family donor] breaks down, then they can be really bad to you, and it could become like 'that's my child, give it here – I've changed my mind'.*

In discussing family donation more generally, people referred to the practice of 'informal fostering or informal adoption' whereby children are 'shared' within South Asian families, as a relatively common (historically at least) 'solution' to childlessness (see later). These analogies were made to both support the idea of family donation, and also to point out the potential problems.

#### 4.4 *Disclosure and the management of information*

Participants discussed whether or not a South Asian couple using donated eggs or sperm would be likely to share this fact with the family, the community and whether or not they would or should disclose to any ensuing offspring the fact that they had been conceived in this way. The debates here, as in much of the research, were complex, ambivalent and often contradictory, representing the complex ethical and practical issues involved in such decisions (Becker 2002).

People discussed the risks of secrecy and the dangers of disclosure of treatment; the risks and benefits in telling offspring about their conception, and the advantages and disadvantages of identifying donors, including the pros and cons of using family donors.

Most participants suggested that a couple would be highly unlikely to reveal the use of donated gametes if at all possible. Few people felt that a couple would be open about the nature of the treatment, and many felt that it might not even be disclosed within the family. It was felt that knowledge of the use of such treatment could lead to problems for the couple in the wider community and considerable stigma for the child concerned, raising difficulties for marriage prospects, for example. It was felt, by some that the child would be discriminated against and potentially ostracised. This was most forcefully expressed by the Pakistani and Bangladeshi participants.

*This is not an issue that can be broadcast. I think the majority will take it negatively. Best thing is to keep it secret. (Bangladeshi man)*

*They (community) will reject such children as soon as news of their background becomes public or is leaked out. (Pakistani man)*

At the same time, while some participants felt strongly that the child would be ‘better off not knowing’, many participants felt that the child should be told about the nature of his/her conception, although there were different opinions on the timing of this. For a minority, this was because children ‘had a right to know’ about their origins. For most, however, the concern was that there might be inadvertent disclosure at some point in the child’s life and that this would be potentially damaging for the child and relationships with the parents. At the same time, many participants could see the potential disadvantages of telling the child. In response to a question about whether a couple would tell the child, this woman of Indian origin said:

*If you are looking at the community, where it perhaps wouldn’t be easily accepted, then I don’t think they would let the child know. So, ideally, I think they should, but I don’t think they would, because it’s not something that would be easily accepted. They would rather keep it quiet and hold on to their close-knit community and family. Pretend everything is A-OK and nothing happened. Carry on as normal.*

The difficulty of telling the child, but keeping the secret more widely, was a significant dilemma which emerged in the data, though not always explicitly recognised by participants. From the perspective of the social parent, participants identified additional serious risks in telling the child. The child might reject the social parent and want to seek out the biological parent.

As this woman of Indian origin said,

*You would not want to lose that bond, because as soon as you tell them, they’ll obviously want to find out where their biological parent is.*

This would also raise the possibility of wider disclosure and ensuing stigma for child and family.

Recent policy changes promote a culture of ‘openness’ in third party assisted conception (HFEA 2004). However, our findings suggest that there may be different approaches to, and consequences of, disclosure in different cultural/religious contexts and it is important that professionals acknowledge the socio-cultural context of users.

#### 4.5 *Donating eggs and sperm: men’s and women’s views*

*Egg donation:* The donation of gametes was perceived as a highly gendered activity. Most participants (male and female) saw women as having an increased bodily and emotional connection with the reproductive process and as such were considered as likely to find it more difficult to part with their gametes than men. Women are seen as emotionally connected to their eggs in a way that men are not connected to their sperm and both male and female participants felt that men would find it easier to become donors than women.

Women had several concerns about egg donation. Many expressed anxiety at the emotional turmoil involved in donating biological material that would become (or for some already was) a child. Women saw themselves as likely to be emotionally tied to a donated egg and as having some parental responsibility to donated material.

As this woman of Indian origin commented:

*I suppose it wouldn’t be your child as such once you’ve donated it. See, really, I think, it’s my child ... but it isn’t. I think that the hardest bit - is it or isn’t it?*

For family or ‘known’ donation, there was the concern that they would have a constant reminder of what had been relinquished. For altruistic and non-family donation, women were deeply concerned that they might find themselves ‘always wondering’ about the outcome of the donation and the progress of the child. Some younger women also made the point that irrespective of their own views, future male partners might look unfavourably on such an act.

Some women suggested that the potential risks to family relations (and to some extent the emotional risks) might be mitigated by anonymous donation, where they could be



guaranteed never to meet any child born as a result of the donation. However, for many the possibility of an offspring ‘turning up’ at some future point in time was regarded as too emotionally difficult as well as being potentially highly disruptive to existing personal and social relations. They were therefore concerned about the ending of donor anonymity. Whilst some initially commented that they would consider egg donation as an altruistic act, to relieve the suffering of infertility, this view was reversed when it was pointed out that donors were no longer able to remain anonymous. Women were very apprehensive about potential emotional and social consequences if donor-conceived offspring were to contact them in the future. As this Indian woman commented

*But if, if this child turned up and they said, Oh, look, you are my mum or, and, it was true, you, you’d want to perhaps ... it’ll be in your head, ‘Oh, that’s my son or my daughter’, and some sort of feelings might come back. Automatically some sort of maternal instinct would come, sort of thing. ‘Oh, no, that’s my baby, how can I reject it? I, I want to get to know them’, kind of thing. So you’d think twice if, if you know, they’re gonna come looking for you.*

Several women expressed anxiety about the possible response of their partners and of the wider community if it were revealed that they had engaged in this process, as this Indian woman suggested:

*My partner would probably divorce me. [laughter]...Or he’d probably like, just shut the door and say, ‘Oh no’. But I think it would be an initial reaction of disgust...*

*That would put your life in chaos. (Bangladeshi woman)*

Few women expressed concerns about the physical risks of egg donation, even when these were made explicit in the course of the focus groups, through the use of the vignettes.

*Sperm donation:* As we have seen, many participants felt that women have a greater connection with their eggs than men with their sperm. Indeed, the men articulated a much more detached approach to sperm donation and several reported being happy to consider

acting as a sperm donor. This was almost always discussed in the context of non-family donation. Few men felt that men in their community would have any emotional concerns about donating sperm and tended to stress the fact that they would be ‘helping someone’ to achieve fatherhood. Perspective here was also important in the discussions. When considering the *use* of donated gametes, men and women stressed the importance of the genetic link between father and offspring. However, when discussing the possibility of donating gametes, participants’ ideas about the looser nature of men’s relationship to their sperm and ideas about masculinity seemed to produce a position where donating sperm might be a possibility. Few, however, had ever thought about this issue previously and there was less evidence that people were able to consider the longer term implications of sperm donation within the context of the discussions.

Where sperm donation was discussed in the male groups, many men viewed donation as an *emotionally* unproblematic and altruistic act. Some men raised concerns about potential economic consequences of donation such as financial responsibilities for offspring and potential implications for inheritance. For Muslim men, the Islamic prohibition of gamete donation was an additional consideration (discussed below).

In response to questions about donor anonymity, while a minority of men reported that if they were to donate they would like to meet any donor-conceived child, in general most men felt that donor identification was likely to reduce willingness to donate. As this younger man of Indian origin commented

*I mean where you have got two situations, if you’ve donated and that it, that’s the end of it, nobody’s gonna ever bother you. You know that for a fact. But now, with the new law, somebody might just turn up on your doorstep and you know, that would put you off.*

When asked if disclosure of a donor’s identity would affect willingness to donate, an older man of Indian origin also suggested

*Yes, they will hesitate, because as the information can be leaked, then he would think ‘what would my society think of me?’*

#### 4.6 *Alternatives to gamete donation*

Importantly, culturally acceptable *alternatives* to gamete donation were widely discussed. Divorce and re-marriage for infertile couples were frequently mentioned in the context of infertility, usually in the context of men divorcing their wives. It is important, however, to recognise the heterogeneity within and between South Asian communities. Many younger women in particular are able to effectively resist social pressures of various kinds, especially if they are in more educated or higher income groups (Culley & Hudson 2006).

Within the groups with Muslim participants, taking additional ‘wives’ was also discussed as a possible course of action. This Bangladeshi man is clear that the best course of action for a man was to re-marry,

*They can get another marriage, which is religiously acceptable.*

This option, however, is only available to men under Sharia law.

As already mentioned, the practice of informal adoption within kin groups was widely reported as a ‘traditional’ solution to infertility within all groups and for some of the Muslim participants in particular, this seemed to offer a better ‘solution’ to the problem of childlessness, than engaging in a religiously problematic form of treatment. Most groups included participants who reported knowledge of intra-family adoption, although the extent of this practice within the UK is unclear. *Formal*, non-family adoption, however, is less common in South Asian communities (Bharadwaj 2003) although there is some evidence of a growing acceptance of this among some South Asian groups in the UK.

It may be then, that the existence of such options means that some South Asian couples with fertility problems which require what are considered highly problematic interventions may be less likely to accept treatment than white couples. This may also impact on the willingness of individuals to donate gametes, though this requires further investigation.

#### 4.7 Religion and gamete donation

Religion was significant in the study in the way in which it shaped some group discussions. In the groups with Muslim respondents, the discussions were primarily, but not exclusively, framed within the context of an understanding of Islamic teaching. While there was some doubt and debate concerning the acceptability of gamete donation within Islam, many participants raised a series of objections to the practice derived from religious and cultural understandings. This was particularly evident in the female groups and in relation to using donated sperm.

Many of the Muslim women were well informed about religious teachings on the significance of the marital bond and the importance of the genetic connection of father and child in Islam. In this context women felt that it was unlikely that a Muslim couple would accept third party assisted conception, at least using sperm donation.

*...you're not allowed to hide the name of the biological father; it's not allowed in Islam. (Bangladeshi woman)*

*In our Muslim religion it is wrong, so nobody will want to do it. (Pakistani woman)*

There was less clarity about the religious acceptability of egg donation and some of the Muslim women said that they would consider acting as a donor for family or close friends, to relieve the suffering of infertile women. Several participants felt that decisions about using or donating gametes would require guidance from local religious scholars (Imams).

Within the Sunni tradition of Islam (predominant in the UK), several authoritative religious proclamations (fatwas) by esteemed religious scholars exist in relation to gamete donation. While artificial insemination with the husband's semen and IVF using the couple's own gametes are allowed, and the resulting child is the legal offspring of the couple, the use of a third party is strictly prohibited. Islam mandates biological inheritance; preserving the 'nasab' or known biological origins of a child is a moral

imperative and third party donation is seen to confuse issues of kinship, descent and inheritance and effectively destroy a child's lineage. Sperm donation is regarded as *zina* (adultery) (Inhorn 2005) and a child born by forbidden methods is a *laqith*, an illegitimate child.<sup>3</sup>

For Muslim women and men, new reproductive technologies are framed within a discourse of risk which is primarily interpreted through their existing value and belief systems in which Islam plays a key role. The groups with Hindu and Sikh participants were marked by the absence of a religious discourse, with few participants reporting any specifically religious objections to either receiving or donating gametes. It is also important to note, however, that there is a difference between official representations of religious ideas, and the experience of religion as 'lived'. It would be incorrect to assume that someone who identifies themselves as Muslim would not wish to consider using donated gametes in treatment, or donating gametes for the use of others.

This study highlights the importance for some communities, of locating knowledge in relation to understandings of religious teachings. An understanding of the religious context of gamete donation is significant for infertility clinicians, counsellors and support groups. Infertility counsellors and groups who support the process of disclosure, such as Donor Conception Network, need to consider the provision of culturally sensitive support to families in making decisions about sharing information.

#### 4.8 *Public profile of gamete donation*

The need for gamete donors has a low public profile in South Asian communities. None of our participants had seen any request for donors and few were aware of the processes involved in becoming a donor. This was especially acute in the case of egg donation. None of our participants had ever been made aware that there was a shortage of donors from minority ethnic communities, despite a recent national publicity campaign. Equally, few people were aware or had seen any information about the removal of anonymity or payment of donors.

There was no clear consensus on the issue of whether or not donors should be paid. Several men in particular, felt that a financial incentive should be offered and that this

would increase the number of potential donors coming forward. As this Indian man commented

*It depends on the market as well. If you get a lot of response, then you would not think of paying for it. But if there are not many donors available to meet demand, then you will have to pay.*

Most of those who expressed an opinion on this issue were of the view that donors should at the very least be compensated for loss of earnings and inconvenience. However, while many could see that payment may increase the numbers of donors they also expressed the view that this might lead some to donate for purely financial reasons and might later regret this. As this Indian woman pointed out

*So there's a moral dilemma to that. Do we, are we selling life?*

There was also a general feeling, held more strongly by women, that a 'market' for gametes was morally questionable and that a donation by definition meant a 'gift'.

## **5. Conclusions and recommendations**

Despite the fact that few people had ever had an opportunity to discuss such issues previously, the focus groups involved a very sophisticated level of debate. However, it is difficult to identify a consensus or dominant opinion on many of the complex points which were discussed. A range of views can be identified, many of which change as the vantage point changes. People gave different answers to similar questions, depending on whether they were considering the perspective of the child, the parent or the donor. As Edwards (1998) has argued, in many discussions of new procreative possibilities, there is a process of shifting perspectives: there appears to be neither one public, nor one opinion. Different ideas co-exist, therefore, and holding one does not preclude expressing another. Ideas are drawn upon to answer different questions and to solve different dilemmas (Edwards 1998:167). The study has, however, attempted to elicit some issues of importance to the communities involved in making sense of this form of fertility treatment.

The culturally and religiously specific ways in which some members of South Asian communities perceive gamete donation have been demonstrated. This study highlights the importance of locating knowledge in relation to understandings of cultural practices. An understanding of the religious and broader cultural context of gamete donation is significant for infertility clinicians, counsellors and support groups.

Given a strong desire for children, infertile couples and individuals from South Asian communities may wish to access this form of infertility treatment and it is important that service providers are aware of the broader cultural context of family and gender relationships. The research suggests that despite many reservations, the degree of stigma attached to childlessness will lead some infertile couples to use third party assisted conception, although they may face many dilemmas in doing so. Less concern generally was expressed about the use of donated eggs than donated sperm. There was extensive discussion of the dilemmas and difficulties in the management of information in particular. Disclosure of treatment and disclosure of donation were regarded by most participants as highly risky actions and the pros and cons of disclosure were widely debated.

The study also suggests that recruitment of egg donors from South Asian communities may remain challenging, especially following the ending of donor anonymity. Although acting as an egg donor was viewed as a highly altruistic act, and several women expressed their admiration for women who gave such a 'gift', it was nevertheless seen as involving a number of serious and long-term emotional and relational risks, which many felt would deter potential donors. There is evidence, however, that some men may be prepared to become altruistic sperm donors. Men were slightly less concerned than women about the possibility of being contacted by offspring in the future. Women are perhaps more likely to donate within the family, though here too many concerns were raised about this practice and the findings underline the importance of making sure that culturally sensitive counselling is available to women who are considering this.

The findings reported here should not be regarded as representing an essential and fixed 'South Asian perspective' on gamete donation, but as offering some potentially important aspects of how the specific participants in this study explored this issue interactively, at a

particular point in time. It is also important to point out that although the study has demonstrated some culturally specific ways of framing considerations of gamete donation, there are many similarities with the way in which concerns have been expressed by ‘white’ populations. Other studies have identified concerns about possible incest, disruption of family relationships and ‘parental’ responsibilities of donors (Hirsch 1999, Edwards 1999) and concerns relating to donor anonymity and payment (Lui & Weaver 1996, Westlander et al 1998, Lyall et al 1998) which are not dissimilar to those raised by the participants in this study.<sup>5</sup>

## **Recommendations**

- The public profile of gamete donation needs to be raised so that a dialogue can effectively take place between stakeholder groups. For those who wish to encourage altruistic gamete donation, particular efforts are required to inform South Asian communities about the need for donors and to actively engage with communities. Efforts need to be made to include those who are often excluded from mainstream publicity activities. All engagement materials should be culturally inclusive and it is essential that community members are involved in the design of any intervention.
  
- Infertility service providers should consider the potential additional concerns about the process of using donated gametes which South Asian men and women might have, especially in relation to decisions to use family donors; decisions to disclose treatment and decisions to inform children of the means of their conception. Counsellors have an important role to play in this process and infertility counsellors need to ensure that they are working in a culturally sensitive way.
  
- Organisations which offer general support to families undergoing fertility treatment, and those which support disclosure to offspring such as Donor Conception Network need to provide culturally informed and sensitive support.



- Additional and more inclusive public consultation by the HFEA and other relevant bodies on this and related issues is needed. Consultation techniques need to be more proactive, using alternatives to “traditional” public consultation methods. Focus groups and citizens juries could be organised in collaboration with a range of community based groups and used in place of, or alongside, existing methods of consultation.
  
- Further research with a wider range of public groups is required. Social science researchers need to give voice to the feelings and concerns of those who are often marginalised in research on public understandings of science and technology.

## Notes

1. Data from the 2001 census shows that there are 2.3 million of South Asian (Indian, Pakistani, Bangladeshi and 'Other Asian') origin in the UK. This represents 4% of the total population of England and Wales.
2. <http://www.britsoc.co.uk>.
3. Formal legal adoption, as it is known in the West is also not tolerated for similar reasons, although the fostering of needy children is encouraged in Islamic scriptures. The position in the Shi'a branch of Islam is less certain, with some evidence of a tolerance of gamete donation, surrogacy and adoption as legitimate ways to 'save infertile marriages' (Inhorn 2005).
4. The research team have produced a strategy for raising the profile of gamete donation in minority ethnic communities which is attached as an appendix.
5. For an overview of the research literature on 'public' perceptions of gamete donation see Hudson et al. (*forthcoming*).

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## Strategy for increasing the public profile of gamete donation in South Asian communities

Research carried out by researchers at De Montfort University, Leicester suggests that the ‘public’ profile of gamete donation in British South Asian communities is very low at present and this could be due to a number of distinct, but compounding features:

- There is a lack of relevant information/publicity – not one of the 100 respondents in the GAMDON<sup>i</sup> study had seen or heard about any requests for donors. No-one knew that there was a shortage of donors and few people were aware of what was involved. Importantly however, participants reported that there was a growing awareness of issues of infertility and even third party assisted conception, which can be built upon.
- Limited public disclosure by ‘users’ of gamete donation in South Asian communities – very few people reported knowing families who had used this technique although almost all groups discussed cases of childlessness and or/the use of assisted conception in their families or immediate social network.
- Lack of public discussion about acting as a donor – donation was perceived by many as transgressing established cultural boundaries of acceptable behaviour – especially for women, and especially unmarried women (this has particular implications for egg shortages). Therefore there may be limited space for individuals to discuss this decision with significant others

This low social profile is coupled with a number of additional reasons why individuals of South Asian origin may potentially find it difficult to consider donating gametes (especially in the case of egg donation):

- There is some normative resistance to assisted conception techniques which are seen to transgress the conjugal relationship (which is extremely significant in all South Asian communities) with the introduction of a ‘third party’. South Asian donors may need to discuss issues with someone who can understand the particular cultural context in which they live. This may be a counsellor with particular expertise.
- Women are seen as emotionally ‘connected’ to their eggs. Men were seen as less *emotionally* attached to sperm. Women also saw themselves as more intimately related to procreation through the bond of birth and gestation as well as parenthood. Many women felt that they would maintain an emotional interest in the donated egg, which

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could cause them problems on a long term basis. Women were not generally deterred by the physical aspects of egg donation. Men were less concerned with potential emotional problems, but some expressed concerns about possible economic consequences or implications for inheritance.

- Donation was viewed as a highly altruistic act, and many could see the necessity and advantages of using donated gametes for couples facing the stigma of infertility. But donation was also seen to encompass many potential risks for the individuals and families concerned.
- The removal of donor anonymity was troubling to many (especially women), who were concerned by what they saw as the prospect of a child 'turning up' on their doorstep. This possibility was viewed as a major disincentive for egg donors especially, since women are perhaps more vulnerable than men to social stigma and ostracism for apparently transgressing cultural norms. However, several of the male participants were willing to consider donation even in the context of the ending of anonymity.
- Gametes were viewed essentially, by women especially, as being (potential) children and therefore due to the religious and cultural significance of children and procreation in South Asian communities, could not easily be relinquished outside of the immediate family network.
- Intra-family donation raises many important ethical issues, and the research suggests a degree of ambivalence around this, for women especially. Several women suggested that they would consider donating to help family members, but would need to discuss the potential implications. Some counsellors, clinicians and community representatives expressed some concerns about the possibility of social pressure on women in particular to act as family donors in some situations.
- Discussions with Muslim participants displayed a significant concern for the religious acceptability of gamete donation. A variety of views were expressed, but most were of the opinion that the third party assisted conception was not permissible in Islam. This is indeed the dominant interpretation of contemporary Islamic scholars. However, it is also important to note that while religion can be an important influence on behaviour, it is not the sole determinant of it, and it should not be automatically assumed that a person identifying as Muslim will not be involved in gamete donation, as recipient or donor. There is also some evidence that the Shi'a branch of Islam has a more liberal view of third party assisted conception, although Sunni Islam is the dominant form in the UK. Some participants suggested that potential donors might wish to discuss this with local religious leaders. No religious objections were discussed by Hindu or Sikh participants.

It is essential to recognise that in all religions individuals are more or less observant and that cultural influences on behaviour are only one set of influences among many. Individuals may therefore make decisions about donation in relation to their own ethical positions which may contradict 'official' religious doctrine or cultural norms of behaviour. Minority ethnic individuals are not defined solely by their ethnic background. There is an internal diversity within all communities, along the lines of gender, class and age, and that these will also have an impact on decision making.

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The issue of infertility and its treatment was described by the participants in this study and in previous research (Culley et al. 2004<sup>ii</sup>) as sensitive and potentially socially stigmatising. With this in mind, a strategy to raise the profile of gamete donation and to potentially recruit additional donors may be challenging. There are multiple reasons for the shortage of donors, but it is important to bear in mind that each of these reasons may not be applicable in all cases. Some will apply in some cases and not in others. For this reason a strategy to increase engagement of minority ethnic communities in public debates about gamete donation must be multi-faceted in its approach.

A possible strategy may include the following:

- Information giving (rather than assuming that decisions can be made on the basis of previously acquired experience or knowledge) – Crucially, **face to face information-giving**, supplemented by printed/audio materials, is likely to be the most effective strategy to engage the public. Leaflets and posters alone are generally ineffective, but are an important adjunct to personal contact. All publicity material should be culturally inclusive and could make direct reference to the specific shortages for minority ethnic groups. Involvement of community members in the design of such material is important.
- Involvement of voluntary and community based organisations, for example: women's centres, faith-based organisations, playgroups, training centres. The local council can usually provide a list of all such organisations. It is often most useful to **make direct personal contact** with such groups, rather than to rely solely on written contact.
- Reciprocal relationships are crucial – offer to provide an information session/small local event about infertility treatment using donated gametes, with lunch provided, for example. Many groups which meet have a regular discussion or visiting speaker slot. Offering to put on a more general session on infertility and its treatment could potentially attract a sizeable audience.
- Working through/with bilingual facilitators and peer educators and other community development workers, who are able to demonstrate some **cultural familiarity and competence**. People who are already based in community organisations (such as those listed above) or those working in public health may be willing to take on this facilitation role (of course, this may require payment). They may also provide an introduction to community groups.
- Attach an information/discussion session on to a larger community event, perhaps one which is focused on another health issue. The local health promotion team may be able to help with this. Many areas have Asian Melas, or festivals where a stall can be set up. Local councils could provide information about such events in their areas. For national recruitment London, Leicester, Birmingham and Nottingham would be good starting points.
- Use **small group** discussions amongst people who are familiar with one another. Single gender groups often work better than mixed groups (a community facilitator would be able to advise you on the suitability of this for the community you are working with). Engaging with older people is important, since elders often have an important influence in family decision making. Interpreters may be required for

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groups of older people especially, and again local councils or PCTs in areas with high minority ethnic populations will often have a translation/interpretation service who can provide a range of interpreters.

- Consider the use of case studies/vignettes/user testimonials to generate discussion. Taking along a user, potential recipient or former donor, would be ideal.
- Use the discussion/information sessions as an opportunity to do ‘research’ into people’s fears, concerns and existing knowledge about donation. These sessions should be a **two-way exchange of knowledge**. Do not be afraid to ask questions. Advice and guidance on collecting this information and engaging with communities is available, see for example the report by BME Health Forum, Westminster PCT, which is available online<sup>iii</sup>.
- Use local and national minority ethnic media in order to publicise the need for donors and to disseminate information about events. There are many publications who may take stories or adverts e.g. Asian Times, Eastern Eye, Q News. Ensure that the copy is culturally appropriate. The Commission for Racial Equality publishes a list of all ethnic minority media publications. This can be downloaded at [http://www.cre.gov.uk/media/em\\_list.html](http://www.cre.gov.uk/media/em_list.html). It would be helpful to involve locally and nationally significant members of South Asian communities to present such information.
- Potential donors who approach NGDT or clinics, might benefit from speaking with another Asian donor, or perhaps a BICA counsellor who is familiar with South Asian clients.
- NGDT could lead this strategy and offer support to individual clinics who wish to work with a local South Asian population in generating discussion/interest in becoming a donor.

The profile of gamete donation and the need for donors needs to be raised so that a dialogue can effectively take place between stakeholder groups. There is a need for the ‘social marketing’ of gamete donation within South Asian communities in order that public discussion can take place. This is not to say that people are not willing to take part in discussions but that the opportunities to discuss the issues, ask questions, express opinions and raise concerns are limited. The GAMDON study has demonstrated that people are not averse to discussing these issues and generally wish to know more about them. This derives, at least in part, from the very real concern that people express for the suffering of infertile couples within their communities.

### Social Marketing Techniques

A recent document published by the National Social Marketing Centre has explored the application of social marketing in public health (It’s Our Health<sup>iv</sup>). This and other useful supporting documents are available on the organisation’s website: [www.nsms.org.uk](http://www.nsms.org.uk). It is suggested that the techniques of social marketing may be particularly helpful to organisations who wish to increase the public profile of gamete donation and these should be actively explored. In the health field, social marketing has been developed in relation to health



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promotion and development. However, the philosophy and techniques employed could easily be adapted to this context.

This strategy has been developed by researchers at De Montfort University, Leicester in collaboration with the National Gamete Donation Trust.

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<sup>i</sup> ESRC-funded study: *Public Perceptions of Gamete Donation amongst British South Asian Communities*. Grant ref: RES-160-25-0044. Science in Society programme, 2005-2006.

<sup>ii</sup> NHS-funded study: A study of the provision of infertility services to British South Asian communities. 2002-2004. De Montfort University.

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