

This response was submitted to the consultation held by the Nuffield Council on Bioethics on Give and take? Human bodies in medicine and research between April 2010 and July 2010. The views expressed are solely those of the respondent(s) and not those of the Council.

Centre for Family Research, University of Cambridge

**Nuffield Council on Bioethics. Consultation Paper.
Give or take? Human bodies in medicine and research
A response from the Centre for Family Research, University of Cambridge.**

The research work in the Centre includes projects related to the donation of gametes, including follow-up studies of children conceived by donation and their parents. We also conduct research on live kidney donation. In this response we concentrate on issues where we have empirical evidence that may illuminate and provide context for ethical analysis.

We would begin with a general observation that the giving and receiving of bodily material often proceeds – or is blocked – in the context of familial relationships. Notions of kin and parental obligation may lead relatives to donate to other family members. However, this does not mean that within a family there are always shared ideas about what the proper thing to do may be in matters of donation. For example, there may be different views about the appropriateness of post mortem donation.

A significant minority (c25%) indicate they are willing to be post mortem organ donors by acquiring a donor card (usually when they apply for, or renew, their driving licence). However, when it comes to the point, not infrequently relatives object. The National Potential Donor Audit shows that about 60% of families who are approached about a dead relative becoming a donor give their consent.

Some have argued against intra familial donation on the grounds that would-be donors may be put under undue pressure to donate by other family members. Clearly, it is important to establish that any donor has freely agreed to donate. However, rather than taking a sceptical view of intra familial donation, we suggest that we should recognise that donation can be an expression of a familial view of obligation or solidarity. (We have more to say later about motives for donation when we comment on live kidney donation). In some situations, where there are donor shortages, appeals to family members may increase supply. Family donation need not be direct. For example, some fertility clinics operate donation pooling systems in which, if a relative donates gametes to the pool, their relative who is a potential recipient goes up the waiting list for receipt of a donation from another. But, of course, not all would-be recipients have relatives able to donate. And we should also note in reproductive donation some family members view direct donation as an advantage, because there is a blood tie between the donor and the recipient (e.g. mother freezing eggs for a daughter who can't produce her own or because her own carry a genetic defect; sisters donating eggs to sisters).

There are examples elsewhere (e.g. Israel) where there are national pool schemes for tissue donation in which would-be recipients are prioritised for access to scarce donated material if there are family members who have previously donated that or other tissue.

REPRODUCTIVE DONATION

Surrogacy

The consultation documents raise the issue of possible parallels between providers of bodily material and those who provide their bodies on a temporary basis for experimentation. We suggest another potential parallel might be included for consideration: that of those who lend their bodies for the reproductive purposes of others – surrogate mothers (who may or may not also provide their own bodily material, the eggs). Like donation of gametes, surrogacy is a reproductive strategy of last resort which can provide a child who is genetically related to neither, one or both of the commissioning parents. Pregnancy can pose some risk to the health of the mother, and like the experimenter in phase one trials, commissioning parents may impose restrictions of various kinds on the life of the pregnant mother.

The Surrogacy Arrangements Act of 1985 prohibits the making of surrogacy arrangements on a commercial basis, but the Brazier report (1998) found that substantial payments were being made and we may note that couples may travel abroad to find cheaper or less regulated surrogacy than is available in the UK. It has been argued that children may be harmed by the knowledge that their gestational (and possible genetic) mother has given them away for money. However, we are unaware of empirical evidence in support of this. At the Centre for Family Research we are conducting the only longitudinal study worldwide of children born through a surrogacy arrangement. Although the children appear to be functioning well (Golombok et al, 2004a; 2006 a&b; 2010a submitted), they are currently only 9 years old and have not yet been questioned about this issue. It is undoubtedly true that some children of adoption are interested in the reasons why they were given up for adoption and it is reasonable to suppose that children may be interested in the motives of all direct actors in their conception and gestation. In addition to the argument about harm to children, it is claimed that payment commodifies reproduction (as with donor treatments), a baby is produced and money changes hands. However, under law, surrogacy contracts are unenforceable. But while we may regard surrogacy as a treatment for infertility and those joining phase one trials as research participants, both are rather unusual ways in which people can use their bodies for financial reward. Either could be exploitation as there is an inducement of money, but involvement may be fully informed and entirely voluntary. Some argue that a mother cannot freely give away a child. However, that seems as flawed an argument as the one that intra familial donation must be coerced.

Gamete donation

It is important to note that most infertile couples would prefer to conceive their children with their own gametes and the use of donors is generally a last resort for those unable to have their “own” children, and it is relatively rare. In the early 1990s over 40% of fertility clinic children were born following donor treatment – mostly sperm donation. In 1993, for example, there were 2,283 children born from sperm, 169 from egg and 35 from embryo donation. In 2006, despite the significant increase in treatments for single women and lesbian couples, the overall figure had dropped to 10% with more egg donation (562 children) and embryo donation (74 children) and only 693 sperm donation children (HFEA statistics). The decline in the use of sperm donation over that period was largely accounted for by the increasing use of ICSI (intra cytoplasmic sperm injection). This technique involves the injection of a single sperm directly into

the egg and allows some couples, who otherwise would have required a donor, to have their “own” children. Despite the fact that the ICSI technique is invasive, and involves the use of IVF with its low pregnancy rate, and there have been concerns about its safety for the health of the children, it was widely taken up after its introduction in 1993. (Then there were 25,000 donor insemination treatments. By 2002 these had fallen to about 5,000 with 15,000 ICSI treatments).

Most (infertile) couples do not tell their children of their donor origin, though, perhaps not surprisingly, single women and lesbian couples are much more likely to do so. If couples are going to tell, this usually happens early in the child’s life. Follow-up studies of the children conducted at the Centre for Family Research show their development and social relationships are very similar to other children – whether or not they know of their donor origin (e.g. Golombok et al, 1995; 2002; 2004b; 2005; 2010b submitted). Families where there is openness about donation have been found to foster particularly positive parent – child relationships. However, there are indications that serious problems may arise if donor children inadvertently discover the manner of their conception as a teenagers or adults (Jadva et al,2009). There are accounts of young people who express great anger at their parents’ deception in not telling them and there may be serious damage to their parental relationships. Given that parents frequently tell some people inside or outside their wider families, the chances of family secrets being kept is reduced and with easy access to DNA paternity testing it is not difficult to confirm suspicions of donor origins. Since the ending of anonymity, children, when adult, may enquire of the HFEA and be told the name of their donor and some other details. Donors can (most don’t) leave a personal statement for their children which they will also receive. However, given that most children are not told of their donor origins, they will not be seeking this information.

Clinics are now instructed by the HFEA to encourage recipients to be open with their children and to provide counselling on how information could be shared. It is unclear whether the ending of anonymity and the new policies for clinics will lead to an increase in the number telling their children. There are indications that some couples are travelling abroad to find anonymous donors. It would seem likely whilst most donation used by infertile couples will remain anonymous and secret, an increasing minority will tell.

In situations where donation is open and the sperm or egg donor is known, donors may be incorporated into the family as a godparent, or a fictive aunt, uncle or parent.

In recent years a number of websites have been set up to facilitate donor children and their parents to make contact with their donors and other families who share the same donor. In the USA each donor has a unique I.D. number which families know. The USA based Donor Sibling Registry website has 27000 registered users and has enabled several thousand parents and donor offspring to find their donor siblings and donors. We have recently carried out research on the use of the site using a web-based questionnaire (Freeman et al, 2009; Jadva et al, 2009; 2010; 2010 submitted). Most parents using the site were seeking their child’s donor siblings and less than half were trying to trace their child’s donor. Most of those searching for either donor or donor siblings were lone mothers and lesbian couples and only about 20% of these were heterosexual couples. The main reasons given for searching for donor siblings were curiosity (for instance, about similarities in appearance and personality), ‘for my child to have a better understanding of who he or she is’, to give their child a more secure sense of identity, or for their child to have a sibling. The same reasons were given for donor searches but, in addition, wishing

to thank the donor was an important reason for some. Medical reasons were given by a smaller number of searchers. For many it seemed that knowing about the donor was more important than knowing the donor. About a third had told their child about the search; where they had not yet told them this seemed to be because of their young age or because they wanted to avoid disappointment in case the search was unsuccessful. Seventy-three percent of searching parents had found donor siblings and most were in contact with them. About 30% of these parents and children had met these siblings face to face. Fewer (18%) were interested in finding donors and fewer of these wanted contact (10% parents, 5% children). The experience of making contact or meeting donor relatives was generally described as very positive. Parents described the relations with donor siblings in terms of family or friends ('we are all one big family', 'a family of close friends'). They were frequently surprised at how well they and their children got along with both donor siblings and the donor sibling parents. Close and continuing relationships were often formed. In some cases large groups of siblings were found – 10% found 10 or more, with a maximum of 55 in one instance (there have recently been press reports of a US "King of sperm" who claims to have fathered at least 500 children). The ways in which parents described relationships with donors was more varied. Some remained donors ('I refer to her donor as her donor – definitely not her father'), others were seen as 'mentors' and a few as 'Dads' ('He refers to himself as her "dad" and she [daughter] refers to him as dad as well').

Perhaps the surprise (for some) of the study is that parents placed more importance on tracing and establishing contact with their child's donor siblings than with their child's donor, but this is in line with other research. This stands in contrast to the discussion and debate about the ending of anonymity which, until very recently, has been almost exclusively concerned with knowledge of the donor and the child's genetic ancestry and identity.

However, in considering these results we also must be aware of limitations of our study. Based as it is on members of the Donor Sibling Registry, it involved parents and children who have an interest in tracing donors and donor relations, and almost all respondents were women. Of these, three quarters are lone or lesbian mothers. Clearly, a sample more representative of the whole population of donor families might show rather different patterns. But it at least indicates that for some donor families the main interest is in donor siblings. Since the interest of some donor children (and their parents) in half siblings has been appreciated, HFEA arrangements for providing information to adult donor children have been modified, so that where consent has been given, they will also receive information about half siblings (but this will exclude anything about the donor's "natural" (non donation) children). This year the HFEA also set up a UK registry, the Donor Sibling Link, for donor offspring over 18 to make contact with their donor sibs.

Our study also involved 165 offspring conceived by donation (aged 13-61 years). Those born to lesbian couples and single mothers learnt of their donor origin earlier than those of heterosexual couples. Those told later in life reported more negative feelings about their donor conception than those told earlier. Offsprings feelings towards their parents were less clear, with some of those told later reporting more positive feelings and other more negative feelings. Offsprings from heterosexual couples were more likely to feel angry at being lied to by their mothers than their fathers. The most common feeling toward their fathers was 'sympathetic'.

Questionnaires were also completed by 63 sperm donors and 11 egg donors. The main reasons given for donating were financial payment and wanting to help others. Sperm donors had donated between 1 and 950 times (mean 143) and egg donors between 1 and 5 times. The majority of sperm donors and more than a third of egg donors expressed concerns about having donated. These were mainly about the wellbeing of children conceived and not being able to make contact with them. Most donors felt it was important to know how many children had been born using their gametes. 51% of sperm donors and 46% of egg donors wanted identifying information. Not all donors were actively searching for their offspring; some stated that they were making themselves available to offspring who wanted to make contact. Those donors who had contact with their offspring all reported positive experiences and the majority continued to have regular contact.

As we said earlier, these samples may not be representative of the whole population. And all were in the USA where the practice and regulation of donation differs from the UK.

Payment of donors

Most fertility treatment in the UK is carried out in private clinics where recipients will pay for the provision of gametes or donor embryos. Donors receive payment of expenses (in line with the remuneration received by those doing jury service). Most eggs come from egg sharing where women receive free or reduced price treatment in return for providing their “surplus” eggs. While egg sharing may provide access to treatment for women who might not otherwise receive it, it seems that the genetic link is significant here too and, if given the opportunity, many will prefer for their shared eggs to go for research, rather than to be used by others reproductively. In many respects within the culture of clinics, gametes are treated as property (as seen in the Yearworth and others, judgement). Surveys of sperm donors have indicated that their donation is primarily motivated by the money they receive. While in the past the HFEA has aspired to create a “culture of altruism”, what we see is a commercial culture in which gametes are bought, sold and traded.

In a past HFEA consultation, some of those born through donation have expressed strong views that donors should not be paid and the gift relationship should prevail. We can add a little evidence from studies of donor children. It would seem that some are interested in the motives of their donors but (in the USA) some do think that their donation was altruistic (and may wish to thank their donors) even though they will know their donors received money.

However, there is an important caveat here. Things in the UK may have changed since the ending of anonymity for donors. Sperm donors are now generally older, more likely to already have children, and possibly more altruistic in their motives.

There is a shortage of donors. There have been suggestions from some clinicians that payments should increase and/or screening criteria should be relaxed (currently most would-be donors are ruled out by screening). It is not clear that an increase in expenses/fees would necessarily increase numbers of donors. More active recruitment drives by some clinics may be more successful. While a culture of altruism may have its proponents, it is very difficult to see how this might be achieved in a sector of health care dominated by for profit organisations.

Intra familial gamete donation

Concern has recently been expressed about this and the HFEA is currently undertaking a review. Prevalence is unknown and systematic research with families and/or children has not been undertaken. However, we can add a few very limited findings.

Probably sister to sister egg donation is the most common intra familial donation. A few father to son sperm donations take place. At least one mother is recorded as freezing eggs for possible use by a daughter who will be infertile. Numbers may be increasing, possibly because of shortages of extra familial gametes and a wider appreciation of the possibility of involving a family member in donation. We might add that numbers of known donors may also be increasing. As we noted earlier, some clinics run schemes of pooled donation where a family member will donate but not for the direct use of a family member. One clinic has found that about half of sisters may chose to donate directly and half to the pool. Some recipients prefer using eggs from a blood relative to those from a stranger because there is a blood tie.

There seems to be wide agreement that mixing of gametes between first degree relatives should be prohibited – though we should be aware of varying social attitudes and legal regulation of consanguineous relationships.

Some regard cross-generational gamete donation as more problematic than within a generation. Some regard donation from younger to older generation (daughter to mother) as unethical (presumably because they assume coercion is likely).

Our research concerns a small group of (10) egg donation families who used intrafamilial donation and who were part of a larger research sample. By age seven, 3 of the 10 sets of parents had experienced some difficulties in their relationship with the donor. In all but one case, the children had not been told that donation had taken place, and thus were unaware that a family member was their genetic mother. It is not expected that their parents will tell them at a later age. Given that some family members know what has happened, it is always possible that there may be inadvertent – or deliberate – later disclosure. Intra family donation may confirm and build feelings of family solidarity. However, because of unusual reproductive links familial tensions can be engendered.

There have been suggestions that there are higher rates of drop out at the donor screening stage of intra familial donors. Perhaps some of these drop outs may be family members who do not wish to donate but are finding an acceptable way of saying no to preserve good family relationships.

We should also point out that there are old established patterns of intra familial informal adoptions: childless aunts who bring up a sister's child, mothers who rear their daughter's child as if their own; and other examples of fictive kin. We do not have good evidence of significant harm for children or family relationships – but we lack systematic research. But we may also note that such family arrangements and their later discovery seem to figure rather frequently in the plots of fiction about family life.

KIDNEY DONATION

Together with colleagues in the Netherlands (Kranenberg et al, 2009), we have been involved in a study of living kidney donation. This compared the experiences of two groups of adult patients who had or had not been successful in finding a living donor. Anyone, family member, friends, neighbours, work colleagues or stranger can, in principle, be a donor and some in all these groups had become donors. Earlier research had shown that patients are more comfortable accepting family members or friends who offered donation, rather than asking them. Would-be recipients were concerned about pressurising donors, harming their donor's health, or causing pain and inconvenience or compromising future relationships with them.

The study illustrates the complexity of who may be seen as an acceptable donor by the recipient. A few (7%) of those on the waiting list for transplants said they probably would not accept any living donor. They thought risks to donors were too high. They did not want to feel indebted and would feel very guilty if anything happened to the donor. But these people said they might change their mind if it was a matter of life or death for them – or if there was a “Samaritan donor” – i.e. someone willing to donate to anyone on the waiting list. Others (24%) were selective in who they would accept. Some ruled out their own (adult) children, others in the family who had caretaking responsibilities (e.g. wives with young children), or a spouse because they had a son with kidney disease who might need a kidney in the future [N.B. some kidney disease is genetic so family issues commonly arise]. Two individuals did not accept offers they had from neighbours – one thought the neighbour's offer was driven by his depression and another because it would make the patient ashamed of their own family for not offering. But the great majority of people in the sample were happy to accept any offer from a living donor, “even my worst enemy”. Many had children and they were not excluded as potential donors. However, many in the study (among both those who had, and had not found donors) found it very difficult to raise the issue with potential donors. Most said they would not ask directly anyone they knew. They felt the potential donor should take the initiative. Many were afraid of rejection and/or damaging their personal relationships. Those who had talked to potential donors were most likely to have talked with a partner (but one third were single), or less often with parents, siblings, and for mothers especially, with their children, and others outside the family. Often with siblings and children, patients were selective and only talked to those who they thought might donate. The study raised questions of whether the transplant clinic could offer more support and help to patients to approach potential donors.

There is other research underway in the Centre on living donation for children in the UK and Germany (J. Prüfe).

As might be expected, parents may feel a strong moral obligation to donate to their children. Indeed, it may be very difficult for a parent to say no to living donation – unless there are medical reasons which would exclude them. From the child's perspective, a parental donation may well be the best possible treatment – and given the rigours of drug and other treatment regimes, the demonstration of parental emotional engagement in their treatment may be important.

The nature of parental relationship means it may not be appropriate to see their donation as altruistic. Ethically, there have been concerns that family members, in particular, may be pressured into donating. Indeed, the development of living donation in the UK may well have slowed by such concerns. Blood is indeed thicker than water, and the ties of parenthood and kinship lead to expectations that family members will donate and those family members may well feel a moral duty to do so. And on discovering there is a need to donate, many will make an immediate decision to do so, and, may say that they never had any real choice. However, it would seem to be rare that pressure is exerted by others – indeed as the Dutch study indicated, in the case of some adult recipients, there can be a lot of caution in accepting donations from kin. It is current practice as part of the procedures of assessment of would-be donors to try to establish that it is their own wish to donate. However, there are a few cases where a family member has told a potential recipient that they cannot donate for medical reasons, where such indications don't exist. So, as we mentioned earlier in the case of intra familial egg donation, there may be relatives who don't want to donate who feel they cannot be seen to refuse and find a way out by saying there are medical reasons.

In considering live kidney donation, it is important to note that not all transplants are successful. Where the donor knows what the outcome may be, strong feelings may be engendered by a failed transplant – as well as a successful one.

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