

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.

PROGAR (British Association of Social Workers Project Group on Assisted Reproduction)

**Nuffield Council for Bioethics: Consultation on Human Bodies in Medicine and Research.  
June 2010**

**Response from PROGAR (British Association of Social Workers Project Group on Assisted  
Reproduction)**

The British Association of Social Workers (BASW) Project Group on Assisted Reproduction, known as PROGAR, was established in the 1980s originally to provide evidence on behalf of BASW to the Warnock Committee of Inquiry into Human Fertilisation and Embryology. Since then PROGAR has consistently contributed to policy discussions and policy formation in assisted conception, working in partnership with British Association for Adoption and Fostering, the British Infertility Counselling Association, the Donor Conception Network and more recently the Child and Family Court Advisory and Support Service (Cafcass) and UK DonorLink.

The principles underlying PROGAR's work are that people with a personal involvement with fertility problems, especially those conceived as a result of donor procedures, donors of gametes and embryos and people undergoing investigation and treatment should receive the best care possible, including access to information, counselling and support.

**Questionnaire and PROGAR responses**

***1. Are there any additional types of human body material that could raise ethical concerns?***

Surrogacy is not noted in the Consultation Paper although surrogates in effect donate their bodies for the duration of a pregnancy when carrying a child for another person. Some surrogates also donate their eggs, thus giving them the need for additional consideration to women who donate eggs alone. Surrogates are often 'invisible' in discussions about gamete donation despite their not inconsiderable commitment of time and effort, and the potential for their exploitation. Although the motivation of women who become surrogates is complex it should be noted that for some, it is wholly financial, in order to earn 'extras' or in order to maintain the subsistence level income of their families. This is true for surrogates in this country as well as overseas.

We also wish to draw attention to situation involving egg and sperm donation from separate donors (as opposed to embryo donation) used together for one recipient.

***2. Should any particular type(s) of human bodily material be singled out as 'special' in any way?***

We appreciate that different types of bodily material can have varied meanings between people even in the same society, and the meanings may change over time. However, the special status of the human embryo and gametes within the context of assisted conception treatment and medical research was publicly recognised in the 1980s and defined in law through the passing of the Human

Fertilisation and Embryology Act 1990 and we support this. This unique status remains unchanged and the legislation was revised and modernised in 2008. Whilst the donation of other organs and tissues may have a therapeutic purpose in healing or the development of knowledge that may lead to new therapies, embryos and gametes have the potential for life-creation. The autonomous persons so created, and their families, may be adversely affected by the policies and procedures in place for the procurement of this material. It is therefore important to consider the outcome not only for the donor(s) and recipient(s) but also for any intermediary involved in the procurement of gametes or embryos and for the individual(s) who may be created - and hence different principles may apply. In the case of gamete/ embryo donation, genetic material is being passed on to people who would not usually be genetically linked to the donor. In different cultures the meaning given to those transactions is differentially important but in the UK there is widespread belief that genetic links are significant.

In our experience, gametes and embryos can also be considered ‘special’ in this context because:

- they have the capacity to help to create genetic connections between people
- genes have the potential to pass on health, personality and skills attributes
- there are four parties immediately involved in the transaction: the donor, the ‘procurer’ or intermediary, the recipient, and the person created as a result of the donor-assisted conception, each of which may have a different perspectives about the ethics of donation and how the donations are procured and used.
- two further parties are involved in the longer term: the family unit created with a live birth, and the family unit of the donor (if they have one). Policies and procedures need to encompass the family unit since it is different to the individual or couple who enters treatment.
- one or more of the parties involved may change their mind over time about the meaning of the donation and this may have a more significant impact than in the situation of other types of donation because:
  - subsequent life experiences such as involuntary childlessness may cause regret about having donated in the past
  - the gift increases in value (the gamete/embryo becomes a person) and so the recipient may want to express gratitude to the donor.

***3. Are there significant differences between providing human bodily material during life and after death?***

Yes, although they are a matter of degree. Both situations involve the necessity for proper consent to have been given, and in the case of living donation, the safety of the procurement procedures for the donor and recipient must be ensured. In the case of the provision of material after the death of the donor, there is the matter of who owns the bodily material, or even the body, for example in cases where a person’s body is wanted for ‘harvesting’ material. Special consideration has to be given to the impact on the donor conceived person where embryos or gametes are used after the death of the donor and we consider that to be conceived from gametes taken and / or used after the person has died has potential for psychological and social harm.

There is urgent need for research into this area.

***4. What do you consider the costs, risks or benefits (to the individual concerned, their relatives or others close to them) of providing bodily material? Please distinguish between different kinds of bodily material if appropriate.***

**Benefits** include feelings of altruism for helping others to have children, and/or a sense of having handed on one's genes (genetic immortality). If donors were paid, the donation might provide an important source of income as was the case for some anonymous semen donors in the UK in the 1960s and 1970s. There is evidence that some of these donors now regret that they were paid and feel ashamed of it. For women undergoing IVF treatment, sharing their oocytes with other (anonymous) patients may be the only way that they can afford the treatment and there is evidence of the potential for later regret. In surrogacy arrangements the boundary between payment and 'reasonable expenses' can be unclear with some surrogates clearly perceiving the arrangements as financially beneficial for them, again with the potential, for some, for later regret (see below).

**Costs and risks** in embryo and gamete donation and in surrogacy are mostly related to the principles and policies that apply.

- Some donor-conceived people feel strongly that donation should be altruistic given the fact that the donor is their genetic parent and the motivation of that person hence has meaning for them. Payment also carries risks of exploitation of the donor including surrogacy where the motivation to donate is financial hardship alone. Such donors may put their own health at risk by agreeing to multiple donations at one or more fertility clinics or agreeing to 'private' surrogacy arrangements carried out without the help of an official third party.
- The number of families that can be created from any one donor is currently capped at 10. However, even this limit is a matter of concern to many donor-conceived people given that it can lead to multiple genetic half-siblings and to the risk of inadvertent consanguineous relationships. The fact that this risk may be small statistically does not detract from its psychological and social significance. In our view this risk demonstrates the need to lower the limit considerably.
- Furthermore, systems need to be in place to give donor-conceived people equality, in relation to information on their origins, with those who are adopted, and these are not yet sufficiently robust. Donors should be assisted in preparing information about themselves and donations should not be used until it has been completed. Information about the donor should be made available to parents once a live birth has been confirmed in order for this to be used by them to contribute to the growing child's sense of identity and origins. This accords with good practice in adoption. It should be noted that there are times when full information is not available about biological parents when an adoption placement goes ahead, as the child's need for a permanent family cannot be sacrificed when all reasonable attempts to acquire information have failed. Given that a child is not yet conceived at the point when information about donor(s) is being collected, we believe that the requirement for the provision of information to be compulsory prior to any assisted conception treatment going ahead is appropriate.
- Health risks for all parties are a major concern and therefore procurement procedures should continue to be regulated. In addition, robust systems should be in place for the exchange of medical information between parties at any stage that the wish or need for this arises.
- Women whose only motivation to donate eggs is to access infertility treatment that they themselves cannot afford otherwise (so-called 'egg sharing') are not motivated by altruism and there is a risk that some may come to regret their decision, and/or have anxiety about the long-term implications for their own children and any children born as a result of their donations.
- The lack of free follow-up professional support for individuals and families affected, including intermediary services for those later wishing to have contact with genetic relatives, is a matter of great concern.

**5. What do you consider the costs, risks or benefits (to the individual concerned, their relatives or others close to them) of participating in a first-in human clinical trial?**

We have elected not to comment fully on this and a number of other questions below, given that for the purposes of this consultation, our concerns and expertise relate to gamete and embryo donation. However we note that the costs of relinquishing genetic material are not yet sufficiently known. Women passing to others their gametes or babies (in the case of surrogacy) may find that they themselves and their own parents come to regret and resent that their ‘unknown grandchildren’ are being reared outside of the genetic family. Obviously there are risks to surrogates including those attached to pregnancy and childbirth as well as to any additional egg donation.

**6. Are there any additional purposes for which human bodily material may be provided that raise ethical concerns for the person providing the material?**

Where material such as donated gametes and embryos are provided to an organisation and then sold for profit to a third party, the intermediary’s financial gain is an ethical concern.

**7. Would you be willing to provide bodily material for some purposes but not for others? How would you prioritise purposes?**

Individual members of PROGAR have personal views on this but it is not a question that the group is able to answer as a whole.

**8. Would your willingness to participate in a first-in human clinical trial be affected by the purpose of the medicine being tested? How would you prioritise purposes?**

As 7 above

**9. Are there any other values which you think should be taken into consideration?**

One ethical consequence of restricting access to state funded medical assistance for infertility is that infertility investigations and treatment are being shaped increasingly by market forces rather than by ‘social’ values.

Although the consultation paper describes the ethical values at stake (page 16) we wish to note that the Code of Ethics of the British Association of Social Workers elaborates two of the values, namely dignity and justice, in a way that we believe is relevant to the matter of the donation of gametes and embryos and the implications thereof:

“ Human dignity and worth:

- Respect for human dignity, and for individual and cultural diversity
- Value for every human being, their beliefs, goals, preferences and needs
- Respect for human rights and self determination
- Partnership and empowerment with users of services and with carers
- Ensuring protection for vulnerable people

Social justice

- Promoting fair access to resources
- Equal treatment without prejudice or discrimination
- Reducing disadvantage and exclusion
- Challenging the abuse of power”

***10. How should these values be prioritised or balanced against each other? Is there one value that should take precedence over the others?***

The crucial ethical values that should underpin UK policies for the procurement of embryos and gametes are:

- altruism evidenced by no financial gain for such donation
- dignity - evidenced by respect for the special status of the embryo and gametes which should not be commodified in any way
- maximising health and welfare - evidenced by respect for the needs of donor-conceived children/adults and their families, and by avoidance of policies that could lead to coercion or inducement of donors
- autonomy - evidenced by proper procedures for obtaining consent that is both emotionally and factually informed.

These values are relevant in the short and long term and should not be appropriated to fit short-term 'supply' gains such as increasing the number of gamete and embryo donors without taking into account the impact on donor-conceived people.

***11. Do you think that it is in any way better, morally speaking, to provide human bodily material or volunteer for a first-in-human trial for free, rather than for some form of compensation? Does the type or purpose of bodily material or medicine being tested make a difference?***

Yes. We repeat that one consequence of restricting access to state funded medical assistance for infertility is that economic values are now superseding 'social' values, which is an ethical matter in itself as well as having an impact on the values relating to gamete and embryo donation.

Other considerations may well apply to donation of other human bodily material and for other purposes, about which we claim no expertise and about which we make no comment

***12. Can there be a moral duty to provide human bodily material, either during life or after death? If so, could you give examples of when such a duty might arise?***

There can be a moral duty existing between relatives. This is not confined, as is sometimes suggested, to ethnic minority groups in the UK amongst some of whom intra-familial donation is preferred because the donor needs to be known to the recipient. Although care has to be taken that a potential donor is not being coerced, such donation may well be rewarding for the donor because of existing religious beliefs or beliefs about family values.

***13. Can there be a moral duty to participate in first-in-human trials? If so, could you give examples of when such a duty might arise?***

No comment.

***14. Is it always right to try to meet demand? Are some 'needs' or 'demands' more pressing than others?***

It is right to try to meet demand but not at any cost.

***15. Should different forms of incentive, compensation or recognition be used to encourage people to provide different forms of bodily material or to participate in a first-in-human trial?***

- As indicated above, we do not support any form of financial incentive for embryo or gamete donation and believe that the notion of compensation is now routinely and extensively used in other countries to fudge the issue of payment.
- Rather, we believe that attention should be given to providing information about the need for donors and participants. There is evidence that the public consultation about donor information raised awareness of the need for donors to such an extent that a number of infertility clinics were unable to cope with the increase in enquiries from potential donors. The work of the National Gamete Donation Trust shows that information provision and awareness-raising is effective but has to be continuous.
- There is also evidence that gamete and embryo donors value proper care (being treated with respect and consideration by the fertility clinic) and appreciation (in the form of acknowledgements such as letters, flowers etc)
- Unfortunately there is evidence of very poor and discouraging responses to donors and prospective donors by some fertility centres and this does not encourage them to donate again or to encourage others to do so.

***16. Are there forms of incentive that are unethical in themselves, even if they are effective? Does it make any difference if the incentive is offered by family or friends, rather than on an official basis?***

We believe that certain forms are unethical because they compromise the concept of informed consent and exploit the neediness of the donor. As already stated, we are opposed to any form of payment.

***17. Is there any kind of incentive that would make you less likely to agree to provide material or participate in a trial? Why? (are some forms of incentive counterproductive?)***

- Financial incentives can cause cynicism amongst actual and potential donors.
- Informal evidence from infertility counsellors suggests that the perceived generosity of expenses payments is a motivation for some semen donors in some private infertility clinics.
- Financial incentives may be counterproductive to the recruitment of altruistic donors, and in the case of donor-conceived adults, are known to have had a profound effect for some of them on their perceptions about their origins.

***18. Is there a difference between indirect compensation (such as free treatment or funeral expenses) and direct financial compensation?***

Yes. They are presented differently, with the former being made to look acceptable by seeming to avoid the selling and purchase of gametes and embryos. The latter is a commercial transaction. The former can be described as bribery. We repeat our statement above that notions of compensation can be routinely and extensively used to fudge the issue of payment.

***19. Is there a difference between compensation for economic losses (such as travelling expenses and actual lost earnings) and compensation/payment for other factors such as time, discomfort or inconvenience?***

Yes. Payment of expenses and compensation for loss of earnings are well accepted aspects of voluntary and civic duties. Paying for other factors removes the characteristics of altruism and reciprocity from the donation.

**20. Are you aware of any developments (scientific or policy) which may replace or significantly reduce the current demand for any particular form of bodily material or for first-in-human volunteers? How effective do you think that they will be?**

- The practice of ICSI has significantly reduced the need for sperm donation throughout the world.
- Women now have the opportunity, albeit very limited, to store eggs and ovarian tissue for future use either for medical or social reasons thus reducing the risk that they will lose their fertility as a result of medical treatment or advancing age.
- We are aware of research on the development of artificially created gametes which would have the potential to reduce the need for sperm donation. However any such development should be viewed cautiously and proper consideration given to ethical concerns and the implications for people so conceived.

**21. In your opinion are there any forms of encouragement or incentive to provide bodily material or participate in first-in-human research that could invalidate a person's consent? (and does it depend on the nature or purpose of the bodily material or of the drug being tested?)**

We believe that consent is invalidated if donors are not provided with sufficient information on the emotional and social consequences of donation

**22. How can coercion within the family be distinguished from the voluntary acceptance of some form of duty to help another family member? (and does it depend on the nature or purpose of the bodily material or of the drug being tested?)**

We recognise that this is extremely difficult to do but gamete and embryo donors are offered counselling and it is not uncommon for the donor to feel able to disclose the fact of coercion in this setting. The clinic can then support the donor in withdrawing from the arrangement if they so choose.

**23. Are there circumstances in which it is ethically acceptable to use human bodily material for additional purposes for which explicit consent was not given?**

We consider it would be never be ethical to use human embryos and gametes for the treatment of others without the proper consent of the donor given that the intention is the creation of another person.

**24. Is there a difference between making a decision on behalf of yourself and making a decision on behalf of somebody else, for example for your child, or for an adult who lacks the capacity to make the decision for themselves?**

Yes. The ethical value of autonomy has primary place when deciding on donation of our own bodily material whereas, if deciding on behalf of another, our own autonomy should be secondary to the best interests and welfare of that other person.

**25. What part should family members play in deciding whether bodily material may be used after death (a) where the deceased's wishes are known and (b) where they are unknown? Should family members have any right of veto?**

- We support the current UK regulation of posthumous use of human gametes and embryos which requires written consent prior to death and prohibits the use of these materials for any other purpose than stated.

- Family members should have access to good quality, unlimited and free counselling to enable them to reach a decision that is right for them and which takes into account the welfare of any future and existing children.

**26. *To whom, if anyone, should a dead body or its parts belong?***

As 25 above

**27. *Should the laws of the UK permit a person to sell their bodily material for all or any purpose?***

No, we do not support the sale of bodily material

**28. *Should companies who benefit commercially from others' willingness to donate human bodily material or volunteer in a trial share the proceeds of those gains in any way? If so, how?***

It would be reasonable to expect that some percentage of the commercial gain should be donated to psycho-social and medical research in the specific sector affected.

**29. *What degree of control should a person providing bodily material (either during life or after death) have over its future use? If your answer would depend on the nature or purpose of the bodily material, please say so and explain why.***

As previously stated, we support the current UK regulation of the use of human gametes and embryos, whether during the person's life-time or posthumously, which requires written consent prior to death and prohibits the use of these materials for any other purpose than stated.

**30. *Are there any other issues, connected with our Terms of Reference, that you would like to draw to our attention?***

- The ethical complexities involved in the donation of human gametes and embryos, and the practice of surrogacy, require that people have access to good quality, unlimited and free counselling so that people can make the right decision according to their individual, family and cultural contexts. This includes situations where the prospective donors are personally known to the potential recipients, as in intra family donation.
- There is much need for follow up and free psycho-social support to individuals and families affected by donation, both in managing any issues arising such as how to avoid secrecy and be honest with children about their origins and also at the time when young people seek information about or contact with genetic relatives.
- Finally we note that there is a need for much more psychosocial research in order to inform policy and practice.