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.

Responses to questions

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

Distinctions can be made between various types of human bodily material in terms of the consequences of their uses, in as much as some can be used to ***improve*** the life of a recipient, others can ***save*** the life of a recipient while gametes (sperm,eggs and embryos) can be made to ***create*** a whole new independent life, indeed a whole new person, who will be gestated and cared for by the recipient.

Any human bodily material that can create new life deserves to be treated with greater respect because of this very significance. Donor Assisted Reproduction is the only medical procedure in which the side effects of the "treatment" not only impact on the recipient but also directly affect another, non consenting person, the donor offspring. The now routine exploitation and manipulation of human gametes for donor assisted conception has demeaned the very dignity and sanctity of human life. There has never been any real understanding by the medical profession, of the lifelong consequences that the act of gamete donation has on the donor conceived person who is commissioned in this way.

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

In terms of donor assisted reproduction there would be very real differences in the consequences for the donor conceived person resulting from the gametes of dead donors. Under the 2005 HFEA legislation all donor conceived people will have the right to full identifying information about their biological father (sperm donor), biological mother (egg donor) or biological parents (embryo donors) at the age of 18. Allowing gamete collection from dead donors to be used would make it impossible for such donor conceived people to benefit from making contact and building a relationship with their donor. Whilst sperm and eggs are not currently being harvested from dead people it has been suggested that eggs for reproductive research could be harvested from aborted female foetuses. Once such a procedure has become accepted it would then be only a short step to using them in donor assisted reproduction.

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 bodily material if appropriate.

In terms of gamete donation:

i) There are few if any financial costs or physical risks to ***sperm donors***.

There can be emotional consequences for such men when there is an eventual realisation that they have effectively handed over is not mere bodily material but their own flesh and blood children into the care of strangers. There is potential for further emotional and relationship complications, particularly with spouses, when they eventually come face to face with these donor conceived people, 18 years or more later.

There are no tangible benefits to sperm donors, their blood relatives or others close to them, but there is a potential for distress amongst all those who are affected, particularly the donor's parents and legitimate children, at the loss of an opportunity to have a meaningful relationship with blood family members (e.g. grandchildren and half siblings) who are separated from them because of gamete donation.

ii) Egg donation can be undertaken as a deliberate altruistic act or can result from IVF treatment where a patient produces more eggs than they require for their own use and decide to offer them for use in research or reproductive treatment. The financial cost of IVF in private clinics can be enormous while the cost to altruistic ***egg donors*** is minimal but the risks to their physical and emotional well-being and their own long term fertility should not be underestimated.

Egg donation involves greater time commitment for each batch of eggs that is artificially matured and extracted and is a physically invasive procedure, so consequently donors are more likely to suffer longer term emotional consequences. There have been few reports of people created through egg donation having made contact with their biological mothers, but the emotional consequences of such meetings are likely to have considerable impact. There are potential health risks from donating eggs. In the short term there is the possibility of complications (and death) from ovarian hyper-stimulation and in the long term there is a possibility, yet to be confirmed by clinical, rather than anecdotal, evidence that egg donation can cause infertility or cancer in the donor.

There are no tangible benefits to egg donors, their blood relatives or others close to them, but as with the case of sperm donors there is potential for longer term heart ache and recrimination for all concerned and there are possible physical risks to the donor from undertaking an invasive medical procedure for the sole benefit of others.

iii) The physical risks to ***embryo donors*** are broadly similar to those posed to sperm and egg donors. Surplus embryos donated by patients after the completion of IVF treatment cycles may represent a personal financial commitment running into several thousands of pounds to the people who have produced them. On the other hand, donation of surplus embryos may take place under an "embryo sharing"

scheme by which the donating couple have their treatment paid for by wealthier recipients. Embryos can also be created by mixing eggs and sperm donated by individuals who have no relationship to each other and may not have expected or realised that their gametes would be used to create a reproductive foundling.

The emotional consequences of embryo donation can be seen to mirror those for sperm and egg donors, but in the case of "embryo / egg sharing" schemes there is a serious potential for long term emotional distress if the recipient party or parties become pregnant but the donor party or parties remain childless. Such a scenario shows how the donation of human bodily tissue can simultaneously remedy the distress of involuntary childlessness for one person or couple (the recipients) and at the same time cause an equally disturbing one for another (the donor / s). There are no adult donor conceived persons from such a recently introduced scheme able to give their opinions on the long term consequences, but those who are born from such an arrangement will have enormous difficulty trying to reintegrate themselves into their biological families in adulthood, knowing that they have suffered the misfortune of being given away in order for their biological parents to keep a sibling or siblings from the same batch of embryos. The luck of the draw, or the choice of the embryologist means the offspring commissioned during embryo sharing will either be raised in a non-biological family with whom they may have almost nothing in common or they will raised by their own parents who had to "sell" their brothers and sisters in order to experience parenting at all. What real happiness for any of the parties, but particularly the offspring, can come from such cruel social engineering?

9. Are there any other values you think should be taken into consideration?
Truth and ***Transparency***. These are currently lacking in the recruitment of gamete donors and in the provision of donor assisted conception.

Gamete donation is considered to be a "success" by the medical profession and by the even less well informed wider public, if a viable pregnancy ensues. If would-be donors were made aware of the many serious issues involved in living with the long term consequences of using and being created by donor gametes, they might not be so willing to provide them, either for mere expenses or for greater financial gain.

10. How should these values be prioritised, or balance against each other? Is there one value that should always take precedence over the others?
Whenever human bodily material is collected or used, the overriding principle should be that which is enshrined within the Hippocratic Oath: ***to do no harm***. Also, the Human Rights of all parties involved need to be balanced so that the most vulnerable and non-consenting party (and in donor conception that is the child who is being commissioned) is prioritised above the competing interests of the others.

11. Do you think that it is in any way better, morally speaking, to provide human bodily material or volunteer for first-inhuman 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?

Human gametes which are intended for use in donor assisted reproduction are a particular case in which there should be no inducement because any form of financial compensation which commodifies the creation of human life is morally repugnant and ethically undesirable. Payments or inducements (e.g. treatment in return for egg / embryo sharing) made to gamete donors effectively turn the resulting donor conceived offspring into a modern day equivalent of the slaves of history, who were bought and sold, exchanged or bartered by their owners. In a recent study, which is the largest ever undertaken, of young adults conceived through sperm donation [*My daddy's Name is Donor* by Elizabeth Marquardt, Norval Glenn, and Karen Clark] forty-five per cent of the donor offspring questioned stated that, ***"It bothers me that money was exchanged in order to conceived me"***, while forty-two percent felt that "***It is wrong for people to provide their sperm or eggs for a fee to others who wish to have children"***.

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 never, under any circumstances be a moral duty to provide gametes for donor assisted reproduction, which is effectively an act of giving one's own flesh and blood offspring away into the care of strangers during one's life time. There is no moral duty to provide babies for people who would like to rear them, however deserving they might appear to be, which is why adoption focused baby farming is illegal. There is certainly no moral duty to provide babies, or anything else after death. Indeed, the psychological impact for any donor conceived people from such an arrangement would be quite devastating. It would be equally undesirable for donor conception to take place using the eggs from aborted foetuses who are not only "dead" but have never even experienced legally defined "life" or had a unique identity.

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

In a society which is becoming obsessed with 'equality' and 'rights' for all, the pressure to make supply meet demands for any number of situations will only increase. One thing that will not change is ***the inherent wrongness of creating people through any form of donor assisted conception,*** which must be the only medical procedure in which the long term side effects are felt by someone other than the patient. Donor conceived people are the vulnerable, non-consenting party to the practice of donor conception but the medical profession have failed to explore or quantify the long term effects that they experience as a result of their medically arranged conception. Only now, more than 70 years after Artificial

Insemination by Donor first became commercially available on a regular basis in the UK, has it emerged in the *My Daddy's Name is Donor* survey that donor conceived people are significantly more likely than their peers raised by biological parents, or even compared to adoptees, to struggle with serious negative outcomes such as delinquency, substance abuse and depression, even when controlling for socio-economic and other factors. Donor conception has negative benefits for the people it creates.

The demand for donor sperm for the circumvention of male infertility has fallen dramatically in the last 10 years since ICSI has made it possible for many men with sperm quality problems to be able to father their own children. The women who traditionally received 'treatment' with donor sperm were not themselves infertile but could be said to have infertility problems as they were treated as part of a heterosexual couple. The current, alleged shortage of donor sperm, where demand by a new type of consumer is outstripping supply has come about as a result of direct government policy aimed at social engineering, rather than clinical need for fertility services.

The **demand** to have a child through the use of donor gametes is not one that is morally justified in view of the pain it can cause and the unjust discrimination it places on the resulting child in terms of deliberately preventing it from having a life-long meaningful relationship with biological parents and other significant family members. It is not right to meet any medically sought demand that has no basis in medical need and involuntary childlessness is not a disease requiring a medical cure, so while cases of genuine clinical infertility can be looked upon, in terms of gamete donation, with some sympathy, those for single women and lesbians requiring sperm for so called "social infertility" and those for self inflicted infertility (by women who have deliberately left the pursuit of motherhood too late) cannot be claimed to have a pressing ***need***.

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?
Certainly not. It would be unethical, for example, to offer a patient quick access to hospital for a full hysterectomy in return for the patient allowing her ovaries to be transplanted or exploited for eggs, either for research or reproductive use.

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 an 'official' basis?
The recent concept of "egg / embryo sharing" which is a form of compensation based incentive by which financially disadvantaged fertility treatment patients get free or cut price treatment for giving away their own "surplus" children to other patients who pay for the cost of the treatment, is highly immoral and effectively

flouts the current guidelines on payments to gamete donors. The "donors" become little more than vendors because in reality it is the gametes (or indeed, specific children, in the case of embryos) which are being sold to other patients in order to gain the treatment.

18. Is there a difference between indirect compensation (such as free treatment or funeral expenses) and direct financial compensation?
The difference can appear subtle but certain incentives, as in egg sharing, might sway patients to make decisions which they might not otherwise have contemplated without being given the option. There are also implications in terms of fully informed consent.

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?
There is certainly a difference between the current levels of compensation or "expenses" paid to sperm and egg donors and a proposed free market of gametes in which gametes are simply bought from a donor for a generous fee. When large sums of money, or expensive treatment is exchanged for gametes, those who provide them become ***vendors*** rather than ***donors*** to the debasement of the dignity of the people who are created through their use.

21. In your opinion are there any forms of encouragement or incentive to provide bodily material or participation in first-in-human research that could invalidate a person's consent?
Offering the option of "egg sharing" for free or cut-price treatment is an obvious case where such encouragement is presented as giving of a choice but in reality it is nothing more than a coercive inducement.

Other tactics have regularly been used to encourage people to donate gametes, when they would otherwise not have sought to do so. Many clinics, even those within the NHS, target the fertile male partners of women who have been successfully treated for infertility with the suggestion that having been helped to achieve a pregnancy, the couple can show their appreciation by helping another equally desperate couple to conceive, through donating sperm. This enforced guilt trip for the plight of other infertile couples amounts to little more than psychological blackmail and the "we helped you and now you can help us" scenario is all the more duplicitous when clinics know that they will probably use the sperm to provide a pregnancy for their largest group of customers (single women and lesbians) who are not infertile per se.

Traditionally, medical students have been targeted by the hospital in which they are training and many probably feel unable to resist the invitation to donate sperm for fear that it will damage their chances of progress within the medical profession.

Although there is no overt incentive or payment, the validity of the consent in such cases has to be called into question.

True consent can only be valid if the person giving their consent is fully aware of all the relevant factors at play. The general public have been led to believe that fertility treatment is successful if a pregnancy results but few are aware of the disproportionately high numbers of IVF babies who are born with severe physical abnormalities and mental retardation. Consent is invalidated if a would-be donor is misled about how his / her gametes will be used and if they are not fully informed about the potential consequences of donation for themselves and others, but most particularly for any child that is to be deliberately commissioned through the use of their gametes.

22. How can coercion within the family be distinguished from the voluntary acceptance of some form of duty to help another family member?
Coercion within the family, to provide gametes or to be party to a surrogacy arrangement, ***cannot*** be distinguished from the voluntary desire to help another family member. Where there is so obviously going to be an emotional and psychological clouding of judgement by the volunteer, valid consent cannot be assumed. I would prefer the use of gametes and surrogacy amongst family members to be discouraged because of the complexity of the tangled relationships it causes, especially for any resulting child. No child deserves the difficulties that come with having an Aunt who is really its mother or a father who is really its brother.

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?
None, where human gametes are concerned.

25. What part should family members play in deciding whether bodily material may be used after death (a) where the deceased person's wishes are known and (b) where they are unknown? Should family members have any right of veto?
All posthumous use of gametes is morally wrong and completely inappropriate. If all posthumous conception was banned there would be no need to consider the wishes of the provider of the gametes or of any conflicting wishes or rights of his/her relatives.

28. Should companies who benefit commercially from other's willingness to donate human bodily material or volunteer in a trial share the proceeds of those gains in any way?
Advances in reproductive medicine (Donor conception, IVF, ICSI etc) have led to an infertility industry in the private sector from which drug companies and private clinics make millions of pounds. The essence and dignity of human life has been debased and reduced to a vulgar commercial venture. Nobody should be allowed to

make a profit from the manipulation of gametes used to create people. While there are regulations in place which currently prevent UK gamete donors being paid anything more than compensatory expenses, some clinics have been given approval by the HFEA to use imported sperm from the Danish Cryos Sperm Bank which gives generous payments to their donors. This would appear to be in direct contradiction of their own rules.

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.
Gamete donors should always have complete control over the use of any bodily material they have donated, but the reality is that ***they have no control whatsoever once it has left their body.*** Given the number of "accidents" reported to the HFEA, fertility clinics cannot be trusted to use gametes as directed.

Certain expressed wishes or directed donations made by donors may be overridden by equal opportunities and anti-discrimination legislation. A donor requesting that his sperm can only be used by married couples would have no particular right to ensure that at least his biological children got a mother and a father in a stable relationship, which offers the best conditions for the resulting child, despite the absurd dogma and social science propaganda which would have the public believe that all family models are of equal value. Sperm donors should certainly be given the right to refuse their gametes being used with donated eggs as it is one thing to produce a child that will grow up without the benefit of it's biological father but quite another to deliberately create a reproductive foundling. Both egg and sperm donors should have the right to refuse their gametes being used by women well past the age of natural menopause. They certainly deserve the right not to have their gametes mixed with artificial components or used either wholly or partially with other gametes in a combination of more than just the normal one male and one female contribution. Hybrid and artificial gametes should not be used to create people.

30. Are there any other issues, connected with our terms of reference, that you would like to draw to our attention?
It is a pity that the terms of reference only cover ***recent*** advances in biological and medical research as there are many ethical questions about donor conception which need to be identified and addressed. Given that by its nature, donor conception would appear to violate a large number of the rights enshrined in the United Nations Convention of the Rights of the Child, it is high time that the public had a chance to say if they thought the act of commissioning children to appease the wishes of the involuntary childless is ethical at all, given that it is only in the last 15 years that any of the people conceived this way have had a chance describe the real consequences of being the guinea pigs in what amounts to a devastating social experiment.

Public understanding and discussion in donor conception cannot be furthered by the Nuffield consultation when its own background information about donor gametes is ***deliberately misleading***, stating (p12) that sperm, eggs and embryos are "***for use in fertility treatment or research***." A perfectly healthy single woman who wishes not to form a meaningful adult relationship with a man is currently entitled under HFEA regulations, to acquire donor sperm in order to become pregnant. Gametes used in these circumstances are neither required for infertility treatment or research.

I was disappointed that this Nuffield Council Consultation chose to include gamete donation within its remit without highlighting the major difference between human bodily material which preserves or enhances life and that which actually creates a whole new life, particularly as the move to incorporate the Human Tissue Authority and the Human Fertilisation and Embryology Authority was abandoned several years ago.