The British Psychological Society

Response

The Society has no comments to make in response to questions 1, 6, 7, 8, 10, 11, 12, 13, 15, 17, 21, 26, 27, 28 and 30. Our views in response to the remaining questions are provided below:

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

It could be argued that gametes and, in particular, embryos are 'special' compared to blood, organs or other tissues, due to their reproductive capacity. For example, those who maintain that life begins at fertilisation believe that the embryo should be regarded as having the status of 'person', although others view embryos as 'property', the ownership of which can be transferred. Currently, the legal position is somewhat in the middle, treating embryos as somewhere between persons and property. The consensus among those involved in assisted reproduction is in line with this, in that practitioners should be seen as 'showing respect' for the embryo (ESHRE Task Force on Ethics and Law, 2001) but not the same level of respect as is shown to actual persons. Some potential embryo donors view their embryos as 'virtual children' - a view which may discourage them from donation (de Lacey, 2005).

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

The differences between deceased donation and living donor donation are clear, important and significant. One key difference is that living donor organ donation carries with it significant risk to the healthy donor. For example, in liver donation, the estimated mortality risk is one in 200 for the healthy donor (Middleton *et al*., 2006). In a recent survey of the UK general population, respondents were asked to estimate an acceptable level of risk for this procedure. Thirty percent were unable to select an acceptable level of risk and 20% estimated there was no risk at all associated with this procedure (McGregor *et al*., 2008). This finding highlights concerns that the general public often do not fully understand the concept of risk (Neuberger & Price, 2003, Wright *et al*., 2009).

Posthumous donation of gametes and embryos may be more problematic than donation by those still living, especially if these are for the use of third parties, since any resulting child will have to be told that one or both of their genetic parents is/are deceased (ESHRE Task Force on Ethics & Law, 2006). Since the number of requests for posthumous assisted conception has been (and is likely to remain) small, there is a lack of research on the psychological consequences for children of being conceived in this manner compared to children conceived of living donors. The welfare of the children must be carefully considered before agreeing to posthumous donation for reproductive purposes.

Question 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.

For gamete and embryo donors donating for reproductive purposes (under the current system of non-payment), the most frequently reported benefit is emotional gratification at

having helped another couple, often stemming from a genuine empathy for those who are unable to have children (Soderstrom-Antilla *et al*., 2001; Yee, 2009). Those donating embryos for research purposes report the benefits of not having wasted their embryos and of having helped to advance scientific knowledge (McMahon *et al*., 2003).

The psychological costs of donation relate to the child who may be created by the gametes/embryos. The thought of someone else raising a child who is biologically that of the donor can be enough to dissuade some people from donating (de Lacey, 2005). Medically, there is some evidence that oocyte donation increases the risk of later fertility problems for the donor (Kramer *et al*., 2009). This has not been found in the same way with sperm donation, or with embryo donation (where, usually, the embryos are the result of the donor couple's own *in vitro fertilisation* [IVF] treatment anyway).

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

The key issue here, in the Society's view, is that of genuine informed consent. Extreme care has to be taken that the participant genuinely understands the procedure and the risks involved. Many individuals may be willing to take part in such trials for financial gain without fully investigating or understanding the potential risks involved. In many living organ donation teams, a Donor Advocate Team (DAT) is charged with the responsibility of looking after the donor's welfare. Such a procedure may be worth considering for this sort of trial, i.e., fully independent health professionals whose sole responsibility it is to assess and discuss possible participation in these sorts of trials.

Question 9. Are there any other values that you think should be taken into consideration?

Section 3 of the consultation document, *Ethical Values at Stake*, includes a discussion of altruism. At first glance, most acts of donation do appear to be altruistic and are often described at such. However, there is increasing evidence that donation is often not truly altruistic but rather may be described as an act of benevolence rather than of altruism (Ferguson *et al*., 2008). For example, in living organ donation, the donor is usually a partner or family member whose prime motivation is to save the life of their loved one. In a recent study of patients with liver failure who were possible candidates for living donor liver transplantation, interviews with their potential donors revealed that, for many donors, their willingness to donate was driven by selfish motivation, i.e., that their personal quality of life would be detrimentally affected by the loss of their sick loved one. In these cases, the motivation to donate was driven by a desire to save their loved one's life, thus maintain their own quality of life through continuing their relationship.
More worryingly, several interviewees (from the potential donors) described their decisionmaking as 'an automatic response': they would not seriously look into the risks but, rather, donation in these circumstances was seen to be an automatic response driven by the need to save a life. Illustrative quotes include 'I told her I would be willing to donate without looking into any of the pros and cons, simply because it would have saved her life', 'I mean you don't think about these things, it's just a case of, you know, if you can do something then obviously you're going to' and 'obviously we'd have done anything to save his life' (McGregor *et al*., in press).

The Society recommends that the principle of non-maleficence should be considered.

Although it may not be possible, in all donation situations, to avoid doing any harm to the donor (e.g. a live kidney donation will cause harm, even if only temporarily), we believe that clinicians and others should weigh up any possible harm to the donor against the potential benefits of the donation. In the case of donation for reproductive purposes, this principle should be applied when considering any potential harm to a resulting child.

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

The desire to meet demands has, in our view, to be balanced against the cost of doing so. Since the removal of anonymity for gamete and embryo donors in April 2005, fertility clinics and others have reported that there is now an insufficient supply of donors to meet the demand from infertile couples (e.g., The Bridge Centre, 2010) - although the official figures do not support these claims and actually show an increase in new donors). However, it has been argued that the 'right' of donor conceived offspring to access the identity of their genetic parents outweighs these demands and therefore the policy on donor anonymity should not be reversed (Frith, 2001). As a result, a situation has been created where 'demands' are not being met at any cost.

Question 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?

Direct financial compensation for donating gametes or embryos would raise concerns about the commoditisation of children, which many would consider unethical. Such compensation could be even more problematic if offered by family or friends although, of course, this is difficult to monitor or police.

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

For oocyte donors, 'egg sharing' arrangements offer indirect compensation for donors via the provision of subsidised assisted conception treatment. The difference between this and direct financial compensation is that the donor wants to have IVF treatment anyway, so is not being coerced by the possibility of payment into a treatment process that is of no direct medical benefit to her. In fact, some have questioned whether it is ethical to allow oocyte donors who are not also IVF patients (Blyth, 2002), although others see egg sharing as ethically equivalent to financial compensation.

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

This is clearly a very difficult question that is ethically and morally complicated. However, we believe it is entirely reasonable that donors be fully and truly compensated for their actions (e.g., in true recovery of loss of earnings etc.), so that there is no financial cost to acting as a donor.

Question 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 inhuman volunteers? How affective do you think they will be?

There have been a number of recent developments in relation to 'opt out' or mandated

choice systems for organ donation after death. There are many arguments against this proposal and it is notable that the 2008 Organ Donor Task Force report came out against the opt out system. However, the recent analysis by Bird and Harris (2010) suggests that the time has arrived when, in the UK, we need to move towards a carefully considered and fully safeguarded presumed consent system for organ donation.
Advances in stem cell research have also raised the possibility of creating synthetic sperm and oocytes in the laboratory (Kee *et al*., 2009), although this is likely to be at least five years away. The use of such artificial gametes in reproductive treatment is currently banned in the UK. However, while this would reduce the need for gamete donors, the process uses embryonic stem cells so would actually increase the need for embryo donors unless other stem cell sources could be developed. For this reason, it would probably not have a beneficial effect on donor supply.

Question 22. How can coercion within the family be distinguished from the voluntary acceptance of some form of duty to help another family member?

It may never be practically possible to fully eliminate the possibility of implicit pressure or coercion when a family member is dying. However, the utilisation of an appropriate independent DAT to evaluate, educate and establish the consent of all potential living donors is strongly recommended. Common goals for the independent donor advocacy team should be: protocol development, education, medical and psychosocial evaluation, advocacy, support, and documentation throughout the donation process. The appropriate use of genuine, independent DATs is the best way to try and avoid coercion or implicit pressure to donate (Rudow, 2009).

It is not uncommon in altruistic oocyte donation for the donor to be a friend or relation (often a sister) of the recipient. In these cases, it is essential that mandatory counselling for both parties be provided by the treatment clinic. The donor and recipient should have separate independent counsellors and, where resources allow, separate clinicians dealing with the medical treatment. Obviously, coercion could still be occurring but the counsellors should be trained to address this issue as far as is possible.

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

There may be conditions where this is acceptable. The use of standardised NHS ethics information sheets and consent forms which request specific permission for the tissue to be used for a specified purpose ‘(a)’, but with also a second request ‘(b)’ for which the participant is also happy (or not) for the tissue to be used in future medical/healthcare research for other, as yet unspecified reasons, may be the most practical and effective way to lessen the occurrence of such circumstances. Provided clear and simple information is given as to why that explicit consent cannot be sought at that moment in time, it is likely that the majority of people who are willing to donate would be happy for this secondary purpose for their tissue.

Question 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 a child or for an adult who lacks the capacity to make the decision for themselves?

There is clearly a difference here, as, in some instances, making a decision on behalf of an adult who lacks capacity may involve taking decisions with which the individual themselves may disagree.

Question 25. What parts should family members play in deciding whether bodily material would be used after death when (a) the deceased person's wishes were known and (b) they are unknown? Should family members have any right of veto?

The Society considers that family members should not be able to play a role in decisionmaking in cases where the deceased person's wishes are clearly established. However, family members could play a role, including having a right of veto, where the deceased person's wishes are unknown.

Question 29. What degree of control should a person providing bodily material have over its future use?

The situation for agreeing to donate posthumously is very different from living organ donation. It may be the case that there are less robust grounds for specifying the recipient (e.g. in terms of race, gender etc.) if one donates posthumously, than for living organ donation (e.g. to a partner or family member), where there is significant risk to the donor. Directed gamete and embryo donation is currently allowed to an extent; for example, for family members. Further control from donors over who could receive the gamete/embryo does not seem desirable, as it could lead to unequal distribution of recipients across social groups.

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