

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.

Zeynep Gurtin-Broadbent

### **Question 18**

I think there is a difference between direct financial compensation and indirect compensations (in the form of e.g. IVF treatment or funeral expenses). However it is difficult to pinpoint the differences. Some differences between direct and indirect compensation (such as the non-transferability of the latter) may apply across the board, to all indirect compensations. But there will be other differences which are specific to the indirect compensation in question. These specific differences may become significant to a degree that we would agree to indirect compensation in some cases, but may remain insignificant (or less straightforward) in others. Therefore it is impossible to make a blanket statement about indirect compensation and whether it is ethically acceptable without looking at the nature of the specific indirect compensation that is proposed. For example, egg-sharing schemes provide egg 'donors' with 'benefits-in-kind' (i.e. free or cheaper IVF treatment). This seems to me to be quite different from direct financial compensation for several reasons. Firstly, the 'benefit-in-kind' provided has an indeterminacy - the treatment may or may not lead to the donor conceiving. Secondly, the value of the offered 'benefit' for the donor (i.e. the chance to try to conceive) is probably not measurable directly or solely in monetary terms (i.e. some may see (the chance of) having a child as priceless). And thirdly, there is symmetry between what the donation (the eggs) and the 'benefit' (cheaper or free IVF treatment) facilitate, namely the chance to conceive a child. These particular differences do not apply in the case of funeral expenses, wherein the indirect compensation is determinate (i.e. you will get a funeral), of a more easily identifiable value, and asymmetrical. There may of course be other relevant differences between funeral expenses and direct financial compensation. This is not to say that IVF treatments should be offered as indirect compensation and funerals should not - indeed I am not making a judgement on either - it simply demonstrates that whether and how indirect compensation is different to financial compensation will be case dependent at least in some respects. However, it may nevertheless be possible to agree a set of criteria regarding the sorts of differences between direct and indirect compensation that are ethically relevant (e.g. fungibility, transferability), such that any indirect compensation must at least meet certain criteria in order to be ethically acceptable.

### **Question 29**

When thinking about this, I think it is useful to reflect on two considerations. The first concerns not just the degree of control but the type of control the person providing bodily materials should be able to have. For example, might it be worth thinking about control over who may use the bodily material as of a different 'type' to control over when the bodily material is used? Might we feel that such different 'types' of control are ethically acceptable or unacceptable to a different extent? For

example, control over who may use the bodily material may allow the donor to set limits that express prejudices or discriminate against certain groups within the population in a way that we are not prepared to allow. Moreover, we may wish to allow certain types of control over who may use the bodily material (e.g. "I am only willing to donate my heart to a person who is a non-smoker"), but not others (e.g. "I am only willing to donate my heart to a person who is white"), on the grounds that we find it unacceptable to allow a donor to practice discrimination on certain grounds (e.g. race) but not on others (e.g. health behaviour). The second concerns the degree to which the person providing the bodily material may have responsibilities or face consequences regarding the use of their donation, and whether we think this should make a difference to how much control they should have over the use of their bodily material. For example, since the removal of gamete donor anonymity in the UK in 2005, egg and sperm donors must agree to provide identifying information for any offspring that result from their donation, which can be accessed by the offspring once he/she reaches the age of 18. This means that sperm and egg donors may face direct consequences from their donation – in the form of donor conceived offspring (and their families) contacting them. Moreover, the nature of these consequences (e.g. when they are contacted, by what kind of family they are contacted) may vary in relation to when and by whom their gametes were used. Thus, we may think it more reasonable and justifiable for them to have some degree of control, but that it is not reasonable or justifiable in cases when there is no direct consequence which can be varied by the use of the donation (e.g. organ donation after death). However, even if we feel that gamete donors should be able to exercise some degree of control (or more so than donors who face no consequences) over the use of their donations, we may feel differentially about what types of control they should be allowed to exercise (as per the first consideration). This idea is explored by the comparison of two examples below. Example 1 Jack, a man donating sperm at the age of 30, feels that he would be prepared for his sperm to be used for the next 10-15 years, but not for any longer. He reasons positively that offspring conceived using his sperm within this time would be contemporaneous with his 'own' children, thus facilitating an easier connection, and will make contact with him when he is in his late 40s or 50s, when he imagines that he will have the emotional and social resources to meet them. He also reasons negatively that if his sperm was used more than 15 years after his donation, any resulting offspring would be of a different generation to his 'own' children, thus creating complications within his family and that they would contact him in his 60s and 70s when he imagines he will not have adequate resources to deal with a new donor offspring in his life. Example 2 Bob, a man donating sperm, feels that he is happy for his donation to be used by a heterosexual couple, but not by a lesbian couple or a single woman. Although he has agreed to provide identifiable information, he in no way sees himself as a 'father' to any resulting offspring. He worries that offspring conceived by single women or lesbian mothers may want him to play a more important role in their lives, as 'a father figure', than he is prepared to, but feels that offspring conceived

by heterosexual couples (who already have a 'social' father) will be less invested in him. Although Jack and Bob are donating the same bodily material, and may both face direct consequences as a result of their donation, we may feel that the different 'types' of control they would like to have over the use of their donations are differentially ethically acceptable. Jack's reasoning is quite sound and his concerns fit in with wider societal attitudes about generational coherence and age-dependent abilities and resources etc. Bob's reasoning is based on assumptions which may or may not be accurate, and would lead to discrimination on the basis of sexual orientation or relationship status, both of which are no longer acceptable with regards to the provision of fertility treatment.

### **Question 30**

In addition to the very useful categories provided in Section 2 regarding the different types of purposes bodily material may be used for (life-saving; life-prolonging; life-enhancing; and life-creating) and the distinctions regarding the specificity and timing of the use of donated materials, it may also be useful to the overall discussion to think about distinctions that can be made about the bodily material itself. I think different bodily materials may be situated along a continuum with regards to two types of important properties. The first category refers to the extent of 'individuality' the bodily material possesses (in the relevant respect for which it is to be used). For example, we may put gametes at one end of this spectrum, as high in 'individuality', since gametes have specific properties which directly affect the result of their (therapeutic) use. Thus, a recipient may have a strong desire to use one person's gamete rather than another's (for example, for the purposes of achieving phenotypic similarity between themselves and their offspring). Kidneys, on the other hand, we would score low on 'individuality', since for the purposes of their (therapeutic) use (to restore the function of waste filtration etc.) all kidneys should behave fairly similarly. Hearts, may be somewhere in the middle, certainly with much lower 'individuality' than gametes, but higher than kidneys, since hearts from different donors may be better or worse at pumping blood (depending on age, fitness, and lifestyle of the donor). The second category refers to the medical 'compatibility requirement' between the bodily material and the recipient. On this spectrum, we would place gametes as low, and a heart or kidney as high in 'compatibility requirement'. Corneas for example may be somewhere in the middle, since they do not require a high degree of compatibility but may need to be matched for blood type and size etc. If we think of these categories - 'individuality' and 'compatibility requirement' - as cross axis, different bodily materials can be placed on different quadrants of the resulting graph. For example, gametes are high in individuality but low in compatibility requirement. Kidneys or bone marrow are low in 'individuality' but high in 'compatibility requirement'. Skin may be high in 'individuality' (though of course not as high as gametes) and also high in 'compatibility requirement'. Cornea may be low for both 'individuality' and 'compatibility requirement'. Thus for example, bone marrow needs to be matched between the donor and the recipient for

compatibility, whereas gametes need to be matched between the donor and the recipient for the individual characteristics that are desired. I personally do not have the necessary depth of medical knowledge for accurately positioning different bodily materials along such axis, but I think it could be a useful tool for thinking about the distinctions between different types of bodily material, and also thinking about what makes them 'scarce' or 'desirable' etc. These distinctions may also impact some of the legal, ethical and social implications of transactions involving human bodily material. For example, different modes of donor recruitment may be appropriate for different types of bodily materials, depending on whether the material is high in individuality or compatibility requirement. With the former, we may want to genetically limit the pool of donors (as we currently do, for example, in the case of gamete donors by eliminating potential donors with certain genetic or heritable diseases). With the latter, we may want to expand the pool of donors as much as possible genetically (to enable the possibility for more matches), but limit it on other (e.g. fitness) grounds.