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.

University of Leicester Medical School - group 14

Question 6
The donation of human bodily material is thought to be selfless act targeted to benefit society. The two main uses of bodily material are medical treatment and research. Other uses we thought of include education such as the use of cadavers in medical schools or during training, which may raise concerns about dignity and respect of the donors. Another more unorthodox purpose is the donation of bodily material to the world of art, as seen in the Bodyworks exhibition produced by Gunther Von Hagen.

Question 7
Currently, the donation of bodily material can be facilitated by signing up to the donor register or approaching the research facility personally. As a registered donor, although you can specify which organs you will donate, you do not have the choice to specify the purpose. The vast majority of our discussion group, if asked, would donate their bodily material for organ donation rather than to medical or scientific research. Although some suggest that donating bodily material for research purposes is a moral obligation, it has also been argued that the majority of people would opt to donate for clinical purposes over research due to the understanding that their input to medical advancement would be negligible and thus would not outweigh the cost of participation. However preferences are rationalised, it is foreseeable that this may have a knock on effect on advances in medicine. However, if a donor has no preference, we feel bodily material should go to where it is needed most and the clinicians or researchers should be the ones to decide where there is greater need. Similarly, a donor is allowed to choose what they would like to donate (cornea, kidney, heart etc.) but they are not allowed to stipulate the use or the recipient of their donated material. Our discussion group agrees with this current policy, this is because we believe that if the donor is allowed to choose who receives their bodily materials, many ethical issues could be raised. Indeed, donors may attribute lifestyle choices to the development of disease and wish to favour those patients whose illness is genetically pre-determined, or is not attributed to the patient’s own doing. This discrimination may also extend to exclusion of specific sectors of the population based on race and ethnicity. We feel that making donations of bodily materials is a selfless act of kindness, which would be undermined by the donor specifying recipient criteria. References: Schaefer GO, Emanuel EJ, Wertheimer A. The obligation to participate in biomedical research. Journal of American Medical Association 2009; 302: 62-72 Glannon W. Free riding and organ donation. Journal of Medical Ethics 2009; 35(10): 590-591

Question 8
Currently clinical trials are carried out on a volunteer basis so a participant will

choose which trial they want to be involved in and hence prioritise their choices. Within our discussion group, the vast majority would prioritise a life-saving drug over something considered more trivial such as cosmetic medication e.g. anti-wrinkle treatment. However, after further discussion we came to the conclusion that volunteers may be more likely to prioritise risks/benefits to themselves (such as severity of side effects) during the trial rather than the long term outcomes of the study. The willingness of a volunteer to participate in a trial is dependent on their personal beliefs (value of the drug, long term benefits of the trial and value to society etc.) and hence each volunteer would prioritise differently based on their own risk-benefit calculation. This prioritisation may lead to some studies not receiving enough volunteers and possibly leading to ethically questionable means of recruitment. References: Harris J, Erin C. An ethically defensible market in organs. A single buyer like the NHS is an answer. British Medical Journal 2002; 325: 114-115

Question 14
It is important to at least try and meet the demands for bodily material in order for the donation of bodily material to be as useful as possible. However, we as a group do not necessarily agree with some of the proposed methods of meeting that demand, for example payment for donations. It is difficult to say which demands are more pressing because each person's personal situation and experiences will cause them to prioritise differently. On the whole there was a general consensus that research is just as important as donations for transplantation, but we also believe that there is a more pressing demand for organs that can be potentially life-saving than gamete or embryo donation for infertility treatment. Couples who are infertile and are waiting for such treatment are likely to disagree with this statement, but we feel that there are other options open to them and therefore they can live without the donation, unlike those who require an organ donation to survive.

Question 15
As mentioned above we agreed that we did not think that payment for donations was an acceptable method to try and meet demand. The act of donating bodily material should be a gift and requesting payment for a donation raises further concerns.

Question 16
If payment is received for donating, people from poorer backgrounds or with lower socioeconomic status are more likely to donate and possibly via illegal means. Also, only those with the funds to pay for a transplant will be eligible. This opposes the treatment for all policy of the National Health Service. Anything financial directly given to a donor we feel is unethical; many donors feel that this would not influence their choice to donate and for those who are incentivised by financial gain may only do so once for the one-off payment. We feel financial benefits should be

given indirectly, such as covering costs retrospectively i.e. funeral costs or free health care, as a form of gratitude rather than trade. Again we feel that this has the potential to escalate, where the donor becomes the vendor with greater bargaining power over the consumer organisation, and where individuals of poorer economic status may be exploited. In effect, this could lead to trafficking of body parts. Not only do we disagree on ethical grounds, but agree with previous literature that finds such financial reward counterproductive, as it can negatively affect the cost-effectiveness of transplantation . As a group, we feel that incentives offered by family and friends are perhaps even worse; we consider that there is already familial pressure on an individual to donate and that monetary gain in exchange for bodily material may be another form of persuasion. It is personal choice and no amount of beneficial offers from relatives should cloud the judgement. References: Bryce CL, Siminoff LA, Ubel PA et al. Do incentives matter? Providing benefits to families of organ donors. American Journal of Transplantation 2005; 5(12): 2999-3008 Evans RW. Organ procurement expenditures and the role of financial incentives. Journal of American Medical Association 1993; 269(24): 3113-3118 Levinsky NG. Organ donation by unrelated donors. New England Journal of Medicine 2000; 343:430-432

Question 17

Although we do not agree with the use of incentives for donation of bodily material we also do not believe that there is any kind of incentive that could make a person less likely to provide material or participate in a trial. This is because the definition of an incentive is a positive motivation to encourage action.

Question 18

As a group we agree that direct financial compensation is unethical but we also believe that indirect compensation is acceptable. Indirect compensation is entirely different from direct financial compensation. The donor does not benefit directly from indirect compensation (it is a gratuitous measure) and is therefore less likely to be influenced in their willingness and motivation to participate in a trial or in donation. An example of indirect compensation provided in the text is payment of funeral expenses.

Question 19

We feel compensation for economic loss is acceptable as it refunds people after they have taken their own time out and made their own decision to come and donate. However, compensation for time, discomfort and inconvenience may cause donors to alter their motives; it may seem as though donors are exchanging risk for financial gain, rather than truly altruistic behaviour or may be for the ‘helpers high’.

Question 30

After reading section 2, our discussion group felt that certain points needed further clarification. In particular when discussing the donation of bodily material, a

directed donation to us, implies that a donor would be able to specify recipient criteria to a greater extent than is actually permissible. A donor is only able to state whether a family member is a recipient and nothing more. Another statement that caused concern was the implication that donated material may be used within a commercial environment. If this is the case, who is profiting? How is this regulated? And furthermore, is it ethical to use freely donated material to raise revenue? Literature contends that within a commercial setting, tight regulation would be needed by an established monopsony to avoid exploitation of the black market; however, even with such regulation, the vendor may have greater bargaining power than the consumer and could potentially lead to a situation similar to that between the NHS and pharmaceutical companies where drugs have to be rationed due to their cost – a perspective with which the group agreed. On this basis, we feel question the morality and practicality of a commercial setting in which bodily material is donated and feel that this section of the report requires elucidation.