

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 1

Question 21

In the UK there are currently some incentives to provide bodily material in certain areas of medical practice. A prime example of this is the provision of free or substantially reduced cost IVF treatment in return for egg donation by the patient. We feel that this is a form of indirect cash incentive and therefore will influence the decisions of the patient involved in a manner which may invalidate consent. They may give consent which, without the incentive, they would have withheld on moral or ethical grounds: does and should the 'reward' compensate the patient for possibly renouncing their personal values? This system does not affect all patients equally; it divides patients into those who can afford to take the course of action that they want to take and which they believe is ethical, and those who could not afford the treatment without sacrificing their freedom of choice. There will, of course, always be those patients who would consent to egg donation even without financial incentive and who, therefore, will benefit from this system without any loss of their personal choice. However, we feel that those patients effectively bribed into donating their bodily materials, who would not choose to do so otherwise, may be greater in number. The financial incentives for people to participate in first-in-human trials also persuade people to take risks that they would not normally take. It could be said that the number of people who would participate in these trials purely for the benefit of medical science are few in number and that some form of reward is needed to provide the number of participants necessary for these trials. We recognize that people should be eligible for some kind of benefit for taking these risks, but are divided about whether these benefits should be financial. Having said this, we also feel that some incentives sometimes increase the range of options open to the person. For example, receiving IVF when this would not otherwise be possible or receiving a new drug as part of a trial when it would not otherwise be available to them; surely it is not coercive to offer a choice. We acknowledge that it is vitally important to maintain and, if possible, increase donation in certain areas but feel that if consent is given due to incentive, it is not necessarily given freely and this may invalidate that consent.

Question 22

We feel that there is great difficulty in distinguishing coercion within family groups. As future doctors, we considered how we would approach a situation in which a family member needed to become involved with the treatment of another family member, for example when a bone marrow or organ donor is needed. All were in agreement that we would discuss, in detail, the proposed course of action with the patient without the family present, if possible before the family had discussed the

matter in detail to attempt to gauge their personal feelings. Family dynamics should be observed carefully and the patient's reasons for agreeing to treatment should be discussed. It was suggested for counseling to be provided for the person willing to donate to ensure their competency and independence in making the decision to go ahead.

Question 23

Regarding the issue of consent we discussed the revised Human Tissue Act of 2004. We agreed that general consent was not acceptable for the use of bodily material that would be used for display purposes, or for research purposes and feel that explicit consent is required for both these areas. We also, however, feel that consent should not be needed for post-mortem examinations and associated removal of bodily material to establish cause of death, if that cause is suspected to be a potential public health risk – for instance if someone is believed to have died from an infectious disease or foreign agent which has not been identified during life. We believe that if general consent is given for use of human bodily material when the patient is fully aware that their donated tissue may be used in any form of research then that general consent is adequate to allow the ethical use of those bodily materials for any research and specific consent need not be gained. This is covered in the Human Tissue Act 2004 by saying that general consent is adequate for bodily materials to be used in any ethically-approved research project. We agreed that seeking explicit consent from the next-of-kin for every purpose to which the deceased's bodily materials could be put would cause unnecessary distress to the family and would not make the usage of those materials more ethically sound, as the deceased has already consented and that consent has been accepted. We found it acceptable that the act found exception to the use of materials from living donors if the researcher is not in a position to identify the person of origin and if a Research Ethics Committee has approved the project knowing that explicit consent has not been given.

Question 24

We feel that there is a substantial difference between making a decision for oneself and making one on behalf of someone else. When making choices about one's own care that decision can be based on personal beliefs and wishes, without any bias involved, whereas when making a decision on behalf of someone else there will inevitably be differences in opinion or values between the decider and the person being decided for. We discussed the fact that it is most usually next-of-kin who are entitled to make decisions on behalf of those unable to do so for themselves. This is logical in the sense that they are the people most likely to be aware of the wishes of the person and understand what course of action they would be most likely to take, were they capable of doing so. However, we discussed the fact that those closest to the patient would also in turn be those most likely to be affected by any choice they make about the treatment or care of that patient and would this therefore mean that the decision making process is not necessarily going to be

based on the wishes of the person receiving treatment. Also mentioned were cases of parents making decisions about the care of their child; we feel that the strong emotional involvement that parents have with their children may mean that they are not always the best people to make decisions on behalf of that child. We agreed that this was different if the issue in question was giving consent after death, for example for organ donation, and feel that parents should always be able to decide about post-mortem donation from their children. However, in a treatment setting, we feel that it is the responsibility of the medical and social care team involved in the care of that child to judge whether the parents are capable of making decisions and giving consent or, in particular, withholding consent for any reason on behalf of their child. We acknowledge that there are differences between making a decision on behalf of a child and making a decision on behalf of an adult who lacks the capacity to make the decision themselves. We feel this is particularly relevant in cases where an adult lacks the capacity to make their own decisions and will not, in all likelihood, regain that capacity in the future. This is due to the fact that when making a decision on behalf of a child, it is likely that they will, in the future, develop the capacity to judge those decisions that were made on their behalf, whereas when a person is never likely to have that ability to respond to the decisions made for them it may affect the responses of those deciding on their behalf. Essentially, will those responsible for decision making be more likely to take into account the possible wishes of the person involved if they know that this person will be able to express their opinion on the matter at some point in the future? Surely people will be less inclined to take this into account when they are aware that the person they are deciding for will never be able to judge their decisions, and are more likely to decide based on their own personal beliefs, feelings and priorities. Decision making on behalf of another person should, in an ideal world, be totally selfless and based purely on what one believes that person would decide, could they do so competently themselves. However, families and those faced with making decisions for their closest friends and relatives cannot be expected to be emotionally detached from the situation in any way. The question we pose is; if these people are so emotionally involved and potentially self-interested in the case of a patient, are they really competent and in possession of the capacity needed to make decisions on their behalf? Should it not, perhaps, be a process which involves family members, but does not give them full decision-making powers in all cases?

Question 25

As a group, we feel very strongly that if a deceased person's wishes are known, then these should be followed. If a person did not express any ideas on the matter of donation of bodily material before their death then we feel that the immediate family should be allowed to make the decision on behalf of that person, as they are most likely to have been aware of any wishes the deceased may have had regarding donation. We have also discussed the situation in which a deceased person has not expressed any wishes but has a nominated power of attorney. We

believe that in this situation the nominated person should be allowed to make a decision on behalf of the deceased, as they were chosen to be the person responsible for giving consent and making decisions on behalf of that person when they are unable to do so themselves. However, in the instance that wishes were expressed by the deceased, no matter how the family feel about a deceased person's decision to withhold or give consent for the use of their bodily materials after death, the family should have no right of veto. We feel this because when a person gives consent for any form of treatment or procedure during life, if they are competent when making that decision, that decision will stand unless reversed by that person themselves whilst still competent. We discussed the fact that death results in 'the ultimate incompetency' – the person involved will never be able to make a competent choice again. However, if decisions were made and consent given with competency during life there is no reasonable basis to allow the reversal of those decisions after death. We do acknowledge that the family and friends of the deceased are those who will have to experience the repercussions of that decision and that this may cause upset. We do not, however, feel that this is a good enough reason to allow the family power of veto.