

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.

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Question 2

: Should any particular type of human bodily material be singled out to be 'special' in some way? Living kidney donation differs from other forms of donation because of the seriousness of the surgical intervention, the potential for impact on the long-term health of the donor, and the critical necessity for an atmosphere of mutual trust between the medical team, recipient and donor. The adverse consequences of commercialized kidney 'donation' on the health of both the kidney donor and recipient have been repeatedly documented (1,2). It has been suggested that if in some countries young women are permitted to sell eggs, and men their sperm, and in some cases the selling of blood and blood products is permitted, why not permit the selling of kidneys. Of note the market for reproductive material seeks donors because of their intelligence, and other socially idealized genetic traits. The market for kidneys always targets the poor and the vulnerable. The financially secure do not sell their organs (3). (1) Gill J, Madhira B, Gjertson D, et al. Transplant tourism in the United States: a single-center experience. *Clin J Am Soc Nephrol* 2008;3:1820-1828 (2) Rizvi A, Naqvi A, Zafar M et al. Commercial transplants in local Pakistanis from vended kidneys: a socio-economic and outcome study. *Transplant Int* 2009;22:615-621 (3) Danovitch G, Delmonico F. The prohibition of kidney sales and organ markets should remain. *Curr Opin Org Transplant* 2008;4:286-294

Question 14

: Is it right always to try to meet demand: Are there some 'needs' or 'demands' more pressing than others? Living organ donation must not turn into a form of 'human sacrifice'. This issue is addressed in the Declaration of Helsinki (4). For instance, there is an ongoing need for new pharmaceutical agents to treat life-threatening illness just as there is a shortage of organ donors for recipients with advanced organ failure. Yet the introduction to the Declaration of Helsinki includes the following statement: "...considerations related to the well-being of the human subject should take precedence over the interests of science and society". With this point the Declaration is reminding us that the welfare of the research subject should be more important than the success of the project in which he or she is engaged. Similarly the welfare of the living donor must not be sacrificed because of the needs of recipients: the ends must not be used to justify the means. A long waiting list for kidney transplants is not an adequate reason to loosen concern for the welfare of donors: on the contrary, it is a cause for even greater vigilance lest the threat to the long-suffering recipients become an alibi to lower the standards for donor protection. Further, the Helsinki Declaration is cognizant of the fact that research subjects may come from populations who are vulnerable, either because of illness or because of social status: "The particular needs of the economically and

medically disadvantaged must be recognized. Special attention is also required ...for those who may be subject to giving consent under duress". The same concerns certainly apply to living organ donors in the event that they come from economically or otherwise disadvantaged populations (5). (4) WORLD MEDICAL ASSOCIATION DECLARATION OF HELSINKI Ethical Principles for Medical Research Involving Human Subjects Adopted by the 18th WMA General Assembly, Helsinki, Finland, June 1964 (5) Danovitch G. From Helsinki to Istanbul: what can the transplant community learn from experience in clinical research? *Nephrol Dial Transplant* 2008;4:1089-1092

Question 17

17 Is there any kind of incentive that would make you less likely to agree to provide material or participate in a trial? Why? The term 'crowding out' refers to behavioral phenomenon whereby the moral commitment to do ones duty can be weakened by financial compensation and monetary reward (6). This phenomenon has been observed in several countries where there has been an inverse relationship between financially incentivized donation and voluntary, unpaid, or 'altruistic' donation (7). No country that has overt or tacit commercial kidney donation also has robust programs in voluntary donation and deceased donation (essential for non-renal organs organs) (8). (6) Rothman SM, Rothman DJ: The hidden cost of organ sale. *Am J Transplant* 2006;6:1524 –1528 (7) Danovitch G, Leichtman A. Kidney vending: the "Trojan horse" of organ transplantation. *Clin Am J Amer Soc Nephrol* 2006;6:1133-1135 (8) Danovitch G. Cash, rewards, and benefits in organ transplantation: an open letter to Senator Arlen Specter. *Curr Opin Organ Transplant* 2009;14:129-133

Question 18

Is there a difference between indirect compensation (such as free treatment or funeral expenses) and direct financial compensation? The issue is the coercive potential of the compensation or payment. The Declaration of Istanbul uses the term "material gain" and National Organ Transplant Act (NOTA) (9) in the United States uses the term "valuable consideration" to avoid the obfuscation of direct monetary payment. Medical treatment, "free" or otherwise, should not be conditional on the willingness to donate an organ. Donation of organs after death should not be the means by which those in need pay for funeral expenses. (9) National Organ Transplant Act (NOTA-42 USC 274e).

Question 19

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? The text of the Declaration of Istanbul (10) avoids the use of the word 'compensation' and prefers the term 'reimbursement' precisely because the latter only considers economic losses, which

can be accurately assessed, while the former includes forms of frank payment. The following is taken from the text of the Declaration: 6. Comprehensive reimbursement of the actual, documented costs of donating an organ does not constitute a payment for an organ, but is rather part of the legitimate costs of treating the recipient. a. Such cost-reimbursement would usually be made by the party responsible for the costs of treating the transplant recipient (such as a government health department or a health insurer); b. Relevant costs and expenses should be calculated and administered using transparent methodology, consistent with national norms; c. Reimbursement of approved costs should be made directly to the party supplying the service (such as to the hospital that provided the donor's medical care); d. Reimbursement of the donor's lost income and out-of-pocket expenses should be administered by the agency handling the transplant rather than paid directly from the recipient to the donor. 7. Legitimate expenses that may be reimbursed when documented include: a. the cost of any medical and psychological evaluations of potential living donors who are excluded from donation (e.g., because of medical or immunologic issues discovered during the evaluation process); b. costs incurred in arranging and effecting the pre-, peri- and post-operative phases of the donation process (e.g., long-distance telephone calls, travel, accommodation and subsistence expenses); c. medical expenses incurred for post-discharge care of the donor; d. lost income in relation to donation (consistent with national norms). (10)The Declaration of Istanbul on Organ Trafficking and Transplant Tourism. International Summit on Transplant Tourism and Organ Trafficking. Clin J Am Soc Nephrol 2008;5:1227-1231

Question 27

NO!