

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 6

There must be a clear principle of equity, that voluntary donation be recognised and respected and ANY commercial use for donor use, research, or other forms of profit be comprehensively prohibited. This should include the limiting of any bodily tissue so donated remaining in the UK and at all times under the complete control of the public agency that administers the donor scheme. This agency must be established within and remain within the public sector, with NO private interests whatsoever being permitted, now or at any time in the future.

Question 7

I am only willing to donate bodily material within an equitable scheme, to others who are members of the scheme, or for use in research that is entirely and absolutely free of commercial gain, or any use of or access to tissues, or research findings relating to research on such tissues by private organisations.

Question 9

Within the notion of Dignity there must be a recognition that any substance derived within the donation scheme must not UNDER ANY CIRCUMSTANCES be made available to private organisations for any purpose whatsoever. This includes the patenting of any aspect of a sample, the private interests of corporate or profit driven companies.

Question 10

Equity must be a central component of every aspect of a scheme within which individuals donate any substance, whilst living or after death.

Question 11

I consider that the system should be for free, the value of which is socially advantageous to all who are a part of the scheme. No organ, tissue or any other substance should be made available to any person who has not opted to be a full part of the scheme.

Question 15

The incentive should be limited to that of enjoying the rights that membership of the donor scheme confers. There should be no aspect of compensation or recognition.

Question 16

The only valid and equitable foundation for the scheme of organ and tissue donation is one of voluntary registration for social reasons, that an individual shares

in both the obligations and advantages conferred by membership of the scheme.

Question 17

I should opt out of any scheme that involves an incentive beyond enjoyment of participation in the scheme for the benefits that participation bestows. Any incentive could be interpreted as a commercial mechanism which then permits exploitation of the scheme by private, profit motivated agencies, which is inimical to the social principles of donation.

Question 23

There may be future use as yet entirely unknown, but the principle of not for profit use by public agency, excluding all possibility of commercial gain or private profit must be guaranteed in perpetuity.

Question 28

There **MUST** be no possibility of companies benefiting commercially from any tissue donated, **UNDER ANY CIRCUMSTANCES**. The system should be wholly and entirely for the good of those who opt for participation in the scheme. Equity **MUST** be central to the scheme, and since I consider that donation should be voluntary with no financial reward, then the principle must be such that no other agency should profit from the scheme.

Question 30

Recent research has established a clear link between equality and well being across a wide range of social and health factors. This principle should be central to the endeavour to encourage organ and tissue donation among the citizens of the UK. I propose a scheme in which a register of donors be established and maintained by means of individuals either 'opting in' or 'opting out'. Central to this scheme there must be a clear rule that an individual shall not enjoy any access to organ or tissue without being a registered member. I would favour an 'opt-out' basis for the scheme, in order that individuals wishing to take no part shall need to actively remove themselves from the register by formal means. I consider that it shall be necessary to establish some mechanism to prevent those individuals who have opted out from opting back in should they become in need of a donor organ or tissue. This should be via a probationary period through which a person may apply for re-registration at any time, though they shall be prohibited from receiving donor organs or tissue for a period of 5 years. This point is essential in order to maintain the equity of the scheme. I propose that the register should include all UK citizens from the date of their eighteenth birthday, and that individuals who have a medical condition that means their organs or tissue may be unsuitable for donation for transplant are exempt from the obligation to donate, whilst maintaining the right under the scheme to receive organs or tissue should they become in need. Children and young people under the age of 18 should be considered eligible for transplant within the scheme, without any membership of the scheme, for reasons of social

equity and issues relating to informed consent.