

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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Nuffield Council on Bioethics: Give and Take? Human Bodies in
medicine and research
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Summary:

My responses are mainly based on research I have previously conducted in the areas of organ donation and DNA databases. This includes 1) interviews with cadaveric organ donor families 2) a survey of public attitudes to alternative organ procurement systems including financial incentives 3) findings from a public consultation about a DNA database.

1. Nature of human bodily material and first-in-human trials

3. Are there significant differences between providing human bodily material during life and after death?

It is vital to differentiate between the different contexts that involve giving, the gifts and the givers that are involved in the unilateral transfer of bodily materials. Otherwise, this risks leading to the development of policy based on a highly decontextualised model of human action neglecting important social and cultural values often associated with donation in the Western world. Hence, blood and cadaveric organ donation (for therapeutic use) are both procured in the UK on a system based on the principles of altruism that is, voluntary, without reward and with another's need in mind they are obviously different bodily materials. Blood is replenishable whereas most organs are not replaceable, blood is donated by a living donor on more than one occasion whereas in cadaveric donation organs are donated by the relatives of the deceased (thereby considered 'proxy donors') and the donation is a 'one-off' event. Hence, in the case of cadaveric organ donation, the donor's intention to donation is mediated by their family. This brings into play factors the families' own beliefs about the value of organ donation, death and the dead body.

4. What do you consider the costs, risks or benefits (to the individual concerned, their relatives or others close to them) of providing bodily material? Please distinguish between different kinds of bodily material if appropriate?

Given the above, the calculation of risks and benefits is often highly subjective and therefore variable dependent on the individual/s involved, the bodily material donated and the context in which it is given. From interviews conducted with the families of cadaveric organ donors for example, most benefited emotionally from the knowledge that they had carried out the wishes of the deceased (to donate); from the knowledge that they have benefited another; and some had reported that they received 'public kudos' from others around them. However, such benefits in no sense recompensed them for their loss. A 'cost' (loosely defined as a detriment) for some families was overcoming the idea that in order for the donation to take place, transplantation removal procedures would be necessary. For some, this brought about concerns regarding the mutilation of the identity and integrity of the body (see Haddow, G. (2005). The Phenomenology of Death, Embodiment and Organ Transplantation. *Social Health & Illness*, 27(1), 92-113.). Others have argued that this can be thought of as a 'sacrificial act' (Sque and Payne ref).

3. Ethical Values at Stake

9. Are there any other values you think should be taken into consideration?

Before taking 'other values' into consideration, a clearer exposition and definition of altruism is needed that delineates it from the concept of obligation or duty and understands the role of reciprocity within the gifting act. For example, obligations to others can work directly in a face-to-face setting (for example, in living organ donation when a family member donates to another), or obligation can play a part in the decision to donate the deceased's organ as it is based on knowledge of the deceased wishes). Obligations can work indirectly and less powerfully when relationships are more distant i.e., action can be through the knowledge that a life may be greatly enhanced or saved through donation as in the case of blood and organ donation. Hence, donation can be weakly obligated through citizen participation in systems and institutions that encourage altruistic actions (*pace* Titmuss, R. (1970). *The Gift Relationship: From Human Blood to Social Policy* London: Penguin Books). This certainly complicates the 'voluntary' element to altruistic donation. Further, all anonymity is maintained between donor family and recipient by health professionals thereby negating the opportunity for a direct form of reciprocation, as stated, some families reported emotionally benefiting from the donation experience. Understanding and building upon a more nuanced approach to altruism and the 'pure gift' therefore can help connect organ donation to members of the public more so than appeals to need such as the 'dying child' rhetoric used by the media to promote organ donation currently.

12. Can there be a moral duty to provide human bodily material, either during life or after death? If so, could you give examples of when such a duty might arise?

Yes, again based on research with cadaveric organ donor families they report a powerful obligation, to carry out the wishes of the deceased. Hence, for some it was not a decision that they made they were simply carrying out the wishes of the deceased hence why they can be considered 'proxy donors' (see Haddow, G. (2002). *Organ Donation and Transplantation: The Paradox of Gifting and Dis/Embodiment*, *Unpublished thesis*. Sociology Department: Edinburgh University.). This obligation is also indicated in the statistics from UK NHS Blood and Transplant. As of 1 April 2008 to 31 March 2009, in cases where the wishes of the deceased are not known, then 40% of families will refuse. When the wishes are known then refusal is less than 10% (Personal communication with the Statistics and Clinical Audit at NHSBT. The 'Potential Donor Audit' audits deaths in ICUs (excluding Cardiothoracic ICU) for patients aged under 76 years).

4. Responding to demand

18. Is there a difference between indirect compensation (such as free treatment or funeral expenses) and direct financial compensation?

According to the results of a survey (see Haddow, G. (2006). *Because you're worth it? The Taking and Selling of Transplantable Organs. Journal of Medical Ethics*, 32, 324-328) conducted with a representative sample of the Scottish public views about alternative organ procurement systems including a range of financial incentives, results suggested that indirect compensation to families in the form of a contribution to funeral expenses, to a favourite charity or a direct payment per organ were viewed more favourably than direct financial compensation to the living donor. For example:

- The "living incentive" schemes we offered respondents had little effect; we asked how likely the following would positively affect their decision to donate: a cash payment of £20 to register on the NHS Organ Donor Register, (18% much/more likely) followed by £2000 offer for a kidney while alive (24% said much/more likely) , then life assurance reduction (25% much/more likely). The highest socioeconomic group (A/B) seemed more predisposed to reductions in life insurance.
- Approximately 40% of respondents reacted positively to the grants after death of a £2000 payment per organ to the family (43%), to a favourite charity (39%), or toward funeral costs (39%).
- Importantly, there is a prominent level of "would make no difference" response to all options—even the favoured "cash to relatives" option.
- We found certain groups to be more favourable toward incentives, especially the 16–24 age cohort and men. However, those unwilling to donate were more likely than average, to be against incentive proposals although the

“unsures” seemed slightly more in tune with the overall response to the options.

- Some element of sympathy towards organ donor families is likely to be influencing the responses about indirect compensation. When talking to donor families about how they would feel about such compensation, the majority were vehemently opposed, some going so far to suggest that this would stop them donating. In a sense, they saw it as their ‘right’ to give (see also response to (5.25 a below)).

20. Are you aware of any developments (scientific or policy) which may replace or significantly reduce the current demand for any particular form of bodily material or for first-in-human volunteers? How effective do you think they will be.

Xenotransplantation involves the animal-to-human transfer of solid organs. Though research and funding appears to have waned somewhat over the past few years, many researchers remain confident that xenotransplantation will one day be a viable alternative to allo-transplantation (Groth 2007). Some suggest that the development of transgenic pigs will overcome the current problem of rejection that any transplanted organs (human or animal) faces. In 2009 research into creating pigs with “humanized” organs was moved from the UK to the US after British regulations prevented experiments (Connor 2007).

5. The role of consent

25. What part should family members play in deciding whether bodily material may be used after death (a) when the deceased wishes person’s wishes are known and (b) where they are unknown? Should family members have any right of veto?

Family members have a role to play in cadaveric organ donation however ascertaining what that role should be and whether they can over-ride the wishes of the deceased is subject to debate. One reason the family are asked for their ‘authorisation’ (HTA Scotland 2006) is that they would have known the wishes of the deceased and whether these had changed or not. The current regulatory climate, some might argue, has taken this too far and added too much weight to the involvement of the family and not enough to the individual’s wishes. To a certain extent, this is a moot point and stalls discussion; as discussed above at 3.12, when the family knows the deceased wishes over 90% will fulfil their obligation to the deceased and carry these wishes out.

It is when the wishes of the deceased are not known that makes the families position more acute as they do take over as the main decision-makers (thereby truly becoming a donor and not a proxy donor). For some families finding themselves in this position it is easier to say no, than it is to say yes. Why this is the case relates to the ‘double-edged sword’ that transplantation rests upon; in order for organs to be donated then they have to be removed. The dead body is

not simply a value neutral entity and we attach great symbolic significance to certain body parts (eyes are the least likely to be donated often due to concerns about the aesthetic repercussions of their removal but also because they are believed to be the 'windows to the soul'). Based on such social and cultural fears, concerns also arise about the mutilating the integrity and identity of the body, and somehow the person will be further harmed. This fear arises, quite simply, because death is not an event but a process. As a process then, we do not simply cut ties with the deceased once death has been pronounced, but we continue to have a relationship with them. Therefore, harm to the dead body, for some relatives, constitutes harm to the person despite being simultaneously aware that brain stem death has occurred. For this reason, the family will have some involvement (either as donor or proxy donor).¹

This begs the question, should family members have the right of veto over the individual's wishes? In general, the answer might be that their role is one in carrying out the wishes of the deceased (similar to the executor of a person's last will) not to over-rule. As I have stressed already, when wishes of the deceased are known very few families 'veto' their decision. However, a minority of cases (less than 10%) will find carrying out these wishes to donate, simply too arduous, at a time of intense grief when faced with an unexpected loss. *We need to know more about these relatives; who they are and why they veto the wishes of the deceased in order to provide more support to them and to the health professionals who are expected to mediate in the situation. Although some research is available into the UK relative refusal rate it is neither comprehensive nor compelling.*

The system of organ donation is based on public confidence and trust. In France, an incident in the early nineties caused up-roar and a drop in donation rates, when corneas were removed against the wishes of the parents. Essentially, removing the 'right of veto':

1. Does little to recognise the (social) propriety that the family has over the body given the continuing relationship they have with the deceased.
2. Ignores the fact that if families are being asked to 'give' then they may arguably also have an equal right 'not to give'.
3. Given the current UK climate whereby trust between the medical profession and public is currently in rehabilitation, offending grieving families by refusing them the right of veto, might resurrect charges of medical paternalism (at its worst) and fuelling 'urban myths' of health professionals as 'organ chasers'.

Perhaps the question might be 'should the wishes of the deceased be strengthened'? The answer to this would be yes; insofar as an individual's

¹ This is the case for procurement systems such as 'opt-out' or presumed consent preferred by roughly fourteen other European countries. In the absence of an individual's objection to donation, health professionals can remove their organs. However, most countries (Spain included) use a 'soft' version of presumed consent whereby if the family object; the organs will not be removed.

negative and positive wishes are recorded. This is an option known as mandated choice (Chouhan, P., & Draper, H. (2003). Modified mandated choice for organ procurement. *Journal of Medical Ethics*, 29, 157-162). As stated above, when the family knows the wishes of the deceased they are under a powerful obligation to carry them out.

6. Ownership and Control:

28. Should companies who benefit commercially from others' willingness to donate human bodily material or volunteer in a trial share the proceeds of those gains in any way? If so, how?

According to a focus group study and survey work we conducted with members of the Scottish public about their views of commercial company access to a DNA database, we found high levels of suspicion and unease about such access, although this may not affect decision-making about participation (See Haddow, G., Cunningham-Burley, S., Bruce, A., & Parry, S. (2008). Generation Scotland: consulting publics and specialists at an early stage in a genetic database's development. *Critical Public Health*, 18(2), 139 - 149 and Haddow G., Cunningham-Burley, S., Murray, L., Myant, K., & Carlsson, A. (forthcoming). Can the governance of a population genetic data bank effect recruitment? Evidence from the public consultation of Generation Scotland. *Public Understanding of Science*).

In both our survey and focus group work, we found high levels of support for the principle of benefit-sharing; a specific mechanism and model for benefit-sharing we go on to suggest might be based on the Newfoundland and Labrador model whereby commercial proposals to access a DNA database are judged by a Standing Committee on Human Genetic Research (SCHGR) based on the principle of distributive justice, a recognition of the communal status of DNA information and the promotion of health as a common good (see Haddow, G., Laurie, G., Cunningham-Burley, S., & Hunter, K. (2007). Tackling Community Concerns about Commercialisation and Genetic Research: A Modest Interdisciplinary Proposal. *Social Science and Medicine*, 64, 272-282.)

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