

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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Comments for Nuffield Council on Bioethics Consultation:

Give and Take? Human Bodies in Medicine and Research.

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I refer particularly in the following paragraphs to whole body and organ donation, although some comment is included on other body parts also. I write as an anthropologist noting some salient aspects of the cultural world in which we live in the UK, and the stance I take is based on this perspective.

Three sets of points, set out below, seem to have been especially important in the UK where exchange involving bodies or body parts is concerned. They all relate to consent, donation and recognition of this donation.

(1) The individual, society and consent.

Individual.

The idea of an autonomous 'individual' bounded by the skin, an individuated human subject with a will, is an important and normative notion that now permeates and guides a range of action and experience in Europe and North America – from our sense of self, for example, to our understanding of the workings of the market, and on to obligations of informed consent in medical practice. The Human Tissue Acts (2004 and 2006) in the UK enshrine this idea of the individual – and expressed or informed consent, which places emphasis on this moral individual, has been of primary importance in donation in the UK.

This individual choice may change through a person's lifetime, however: in the practicalities of gaining or registering consent, more careful provision needs to be made for a change of circumstances and changes of mind. Expressed consent should not become a form of presumed consent years afterwards.

Society.

Talk of the 'individual' often evokes that of 'society'. Whatever the differences in shape, evocation and salience, the duality of individual/society is well-established in Europe, and both 'society' and 'donation' are everywhere metaphors of connection. The 'donation' of whole bodies, and later of

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body tissue and organs, seems to have begun in the early 19th century in progressive attempts to extricate anatomical dissection from its associations with punishment, the bodies of executed criminals, and body-snatching. 'Donation' to science and medical science gained momentum as the sciences took disciplinary shape and were seen to offer benefits. A new understanding of blood types in the 1920s gave 'donation' further momentum. The Second World War both reinforced and broadened these imaginary relationships of reciprocity – seen as 'society' congruent with a nation in peril and need. To this 'society', post-war welfare states gave further impetus and practical form. In Europe, the social imaginary has been varied and changing but nationalisms and socialisms have historically supplied important frameworks of connection (generating concern in some contexts about outsiders or foreigners benefitting from home organs¹). Whilst in the now heavily marketised world of the US and the UK, it has always remained a decision of the 'individual' to 'opt in' to the relations of donation for organs, in other European countries, where a notion of 'society' has been given greater force, and where sovereign power has been greater, consent to organ donation might be presumed unless a person chooses to 'opt out'. The Organ Donation Task Force felt in 2008 that the UK was not ready for presumed consent.² Their investigations were not concerned with the broad cultural and historical differences in Europe that might explain its absence in the UK – both its strangeness and the cultural achievement of its absence.

Wales may now be set to become an experiment in a soft form of presumed consent. One difficulty may be that those who die without families may be seen as 'bioavailable', and this could be evocative in the UK of the historical fate of the unclaimed bodies of the destitute, of the socially unconnected.³

The fictional nature of the UK 'individual' is underlined by the important role of the family in matters of consent where deceased organ donation is concerned. It seems to be part of the lore of UK transplant coordinators that in the Spain, a part of Europe known for its high donation rates, a relatively 'aggressive' stance is adopted by medical transplant coordinators towards family members. A greater allowance for resistance and refusal may need to be made in a situation such as that of the UK particularly where, amongst other differences, 'society' is not of the same historical salience. Consent can seem to medical practitioners to be a difficult and burdensome decision for bereaved families in the UK as in the Netherlands (where individual, expressed consent is also required), but neither expressed not presumed consent do away with this, and resistance and refusal are everywhere part of the caring practices of the family. It seems important not to promote donation of body parts at the expense of this. At the same time, it is not uncommon for a sense of broader social, public or civic virtue on the part of the deceased to offer solace in a family's bereavement.

In connection with this last point about solace in bereavement, there is further practical point: anyone raising the possibility of organ donation with the families of dying persons might wish to encourage families who consent to organ donation to consent also to the use of tissue or organs for

¹ Buggins, E. *Allocation of organs to non-UK EU residents*. London: Department of Health. 2009

² Organ Donation Taskforce. *The potential impact of an opt out system for organ donation in the UK*. London.2008.

³ Richardson, R. *Death, Dissection and the destitute: the politics of the corpse in Victorian Britain*. London: Routledge Kegan Paul. 1988. On 'bioavailability' see L. Cohn 'On Operability, Bioavailability and Exception' in A.Ong and S. Collier (eds) *Global Assemblages*. Oxford: Blackwell.

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research purposes. It seems that when organs have to be refused for donation by the transplant team subsequently due to quality issues, the fact that they are being used for research purposes instead is often a matter of some comfort for the families concerned. Control of the material by those who consent here requires, of course, careful consent practices. It should not be ignored, in transplantation as well as in research, that genetic information may be involved or genetic material passed on, albeit far less obviously so at present than in the case of gametes (see footnote 5, below).

The current UK government has proclaimed a forthcoming 'Big Society'. Common ideas of 'society' in the UK do not take their shape solely in relation to the 'individual'; they also take their shape in opposition to the 'State', and this is what the Conservative-Liberal Democratic 'Big Society' seems to be doing. It is a 'rolling back of the state' to create a notional space in which private or individual efforts can take over. This is not the 'society' of presumed consent but a world of private voluntarism; it is an unlikely political climate for the adoption of presumed consent unless it manages in some way to ride on or co-opt dissent.

Culture.

It is worth noting that practices of disconnection persist. Amongst these can be the metaphors and practices of 'culture' and 'ethnic community'. Such inventions – 'culture' invented in the 19th century and 'ethnic community' in the 1960s - have been well-intentioned and they can make, and have made, important statements about difference and mutual respect. However, their invocation can be double-edged, well-meaning but also insidious. The reification of 'culture' - so common now and often unreflecting but sometimes deliberate - readily erects barriers through plotting human relational differences in particular ways that can require little empirical confirmation to justify insurmountability or exclusion, on all sides. It is perhaps not surprising that there is relatively little organ donation from those who are placed under the banners of minority or ethnic culture or community - from those who experience, and who may be required to experience, significant social disconnection.⁴ At the same time, there appears to be a higher need for organs – for kidneys amongst the Asian population, for example, related partly to high rates of diabetes. For histocompatibility, NHSBT has been able to map the closest HLA match for kidneys to facilitate allocation but blood group differences still present problems, for organs from deceased donation particularly. A system of presumed consent would not necessarily be a solution here – family refusal is high and would still be operative. Targeted campaigns may help to raise donation rates, providing they are careful not to re-instantiate the very differences they seek to go beyond. There is a serious danger of conflating too neatly the biology and the 'ethnic' identification such that 'race'

⁴ Randhawa, G The impending kidney transplant crisis for the Asian population in the UK. *Public Health* 1998, 112 (4): 265-68. On some of the wider issues here, see e.g. Baumann, G. *Contesting Culture: Discourses of Identity in Multi-Ethnic London*. Cambridge, UK: Cambridge University Press 1996; Gingrich, A. and Banks, M, eds. *Neonationalism in Europe: Perspectives from Social Anthropology*. Oxford: Berghahn 2006 ; McDonald, M. *The Construction of Difference: an Anthropological Approach to Stereotypes* In: Macdonald, S, ed. *Inside European Identities*. Oxford: Berg Publishers 1993.

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appears to receive public endorsement where a more careful population genetics or a focus on commensality, kinship and marriage would provide more appropriate analytical approaches. Broader social connection and – in the case of kidney donation - the problems of diabetes and blood group incompatibilities would seem to be the required focus.

(2) A distinction between person and object.

Individual subjects do not appear legally to own the bodies that constitute their corporeal selves. We might say that the matter of property in the body has been resolved in the UK partly by avoiding it. Putting the matter rather simply, one dominant view has been that intellectual property can be claimed from work, discovery or invention to do with body parts, for example, but there are otherwise no property rights in the unworked parts themselves. The distinction between person and object is culturally achieved. Whilst the case of Henrietta Lacks in the US has demonstrated that a continuity can be asserted culturally between a cell-line, say, and a person, it is some form of discontinuity that has more generally been asserted in both the US and Europe, effecting a distinction between person and object, only the latter of which can be 'owned' such that it can be sold. This does not mean of course that there are not other means of control, relating closely to modes of consent and knowing what is consented to. In the field of deceased organ donation, directed donation should be limited as it is at present and the ideal of a more general solidarity preserved. Greater control of genetic material, its moral necessity and its difficulties, has perhaps been argued most carefully in the field of gametes.⁵ Whilst there may be possessory, disposal or control rights of various kinds in the UK - and should properly continue to be so - bodies are ideally not property that can be bought or sold. This seems to be an ideal worth preserving - not as some given distinction of nature protected from commercial inroads - but as an important achievement that allows the simultaneous constitution of commodities on the one hand and what it is to be human on the other.

There are at least two sets of distinctions that seem to be important here - between person and object, and between gift and market - the first legally emphasised since the abolition of slavery while the second can feel as if it is a matter of everyday experience. Whereas, in stereotypical form, market relations may be the one-off transactions of individuals out shopping, for example, the gifts they may buy will be used to effect and renew social connection. The 'donation' of organs is, in this sense, an acknowledgement of social connection. Donation implies a world of individuals making or renewing relations that are ideally other than market relations - or not relations of exploitation. The

⁵ See, for just one example, Pennings, G. What are the ownership rights for gametes and embryos? *Human Reproduction* 15(5): 979-986. 2000. Perhaps the best-known, broader summary of the relevant UK legislation here can be found in Price, D. *Legal and Ethical Aspects of Organ Transplantation*. Cambridge: CUP 2000, and *Human Tissue in Transplantation and Research*. Cambridge: CUP 2010. Otherwise, on achieved distinctions between persons and objects, see Pottage, A. The inscription of life in law: genes, parents and bio-politics. *Modern Law Review* 61:740-65 1998; Landecker, H. Between beneficence and chattel: the human biological in law and science *Science in Context* 12:203-22 1999; Pottage, A. and Mundy, M. (eds) *Law, anthropology and the constitution of the social: making persons and things*. Cambridge : CUP 2004.

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distinctions of person/object and gift/ market have to be worked at. The sale of organs has been rigorously excluded in European legislation.

(3) The framing of reward: non-market recognition.

Payments.

Health technologies now often involve the exchange of human tissue or body parts and whilst money is often generated somewhere in these transactions, it is not framed as purchase or profit. Concerns about the commodification of bodies or body parts should be taken seriously and any transaction which is framed as the purchase of organs, tissues or bodies avoided. The problems of possible coercion, harm and exploitation have been well-rehearsed, and turning the act of any tissue, body or organ donation into tissue, body or organ 'selling' would be to tinker quite radically with current ideals of human dignity and with the nature of reciprocity built into such notions as 'society', 'welfare', or the 'public good'. In the NHS, medical science depends on such imagery, with the one feeding the other. These are important metaphors of accountability and should remain so in the field of the corporeal transactions discussed here. The 'market' is a cultural metaphor of accountability for a wholly different set of individually interested, calculative practices – practices which, moreover, are often seen empirically to be at serious odds with a logic of care⁶.

The one potential exception for direct payment here can appear to be that of blood, a tissue that regenerates and has not culturally carried personal identity or reproductive potential with it. However, blood has been a paradigm case in the UK of national, welfare reciprocity and it has also become a substance carrying more than type anonymity. Regulation needs to continue to concern itself with consent issues and with matters such as traceability and purpose or use rather than considering financial incentives for the donor here.

Where first-in-human clinical trials are concerned, just what is being paid for what might be worthy of further examination. Although private pharmaceutical companies may be involved, it is important that payments should not be framed as the 'purchase' or 'renting' of a person or 'their' body. The de-coupling of payment level and risk is similarly important, and avoids positive incentives for bodily harm. It is significant in these trials that motivation and purpose can seem to involve some notion of altruism or public good – the advance of medical science, for example, or the potential medical benefit for others. This makes it all the more important that personal risk be carefully calculated on the best information available, and carefully explained.

In general, where any payment is made or required, then constructing payments that keep bodies and body parts out of the commercial market seems to be important to continue. The amounts of money involved in these transactions and the way payments in relation to organs or other body parts are framed are important matters that require careful monitoring. 'Compensation' (e.g. for time, inconvenience, commitment, loss of earnings) and 'expenses' may be paid to individuals.

⁶ For some more general but not unrelated concerns, see Mol, A-M *The Logic of Care*. London: Routledge 2008; and for a tougher condemnation of market ethics in US healthcare, see W.B. Bondeson (ed) *The Ethics of Managed Care*. Dordrecht: Kluwer 2002.

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Hospital accounts often quite properly avoid costing organs - even if they do cost the different procedures and compare them within a market framework (e.g. kidney transplantation versus dialysis).

All this does not mean that there cannot be transparent forms of benefit-sharing in any monetary profit from human biologicals that would bring individuals closer to any profit made from their involvement in trials or from biological material sourced from themselves or their kin, profit from which they seem to be currently separated (notably by patents). One way to do this would be to impose quite specific or higher forms of taxation on such profits that would then go directly and transparently to local public health projects, projects that the donors or participants themselves name or select.

At the same time, financial disincentives should be avoided. Expenses and fees covering reasonable expenses and inconvenience for individual, live tissue or organ donation are acceptable. 'Compensation' for donors of gametes should cover loss of earnings without the current low cap or difference for men and women.

Living organ donors present another aspect here. These donors have an expectation of living a life of health bodily integrity after their donation. They should not have to lose out or experience serious financial disincentives, as would still seem to be the case sometimes now. Any time taken off work to undergo, and to recover from, the necessary operation needs to be properly recognised – e.g. by State compensation of the workplace, for example - such that there is no loss of earnings or, at the very least, such that payments are continued as for any other person who is 'sick'.

It might be argued that 'commodification' fears are unreflecting echoes of old boundaries and should be re-thought - or that fees and expenses are merely 'disguising' financial incentives. Such provocation is useful but tends to underline the moral weight and cultural importance of the boundaries it seeks to expose.

Memorials.

A more acceptable way of recognising donation that avoids fears of commodification, exploitation and bioavailability, might be collectively to memorialise the act of donation. This is already practised in Anatomy schools in the UK where cadaveric material is used in teaching. Whole body donation for anatomical dissection, a donation made through Medical Schools and the Human Tissue Authority, has traditionally come from the older population, usually beyond an age where organs (donated through the local hospital and NHSBT) might be considered usable. However, the old categories of 'extended criteria donors' or 'marginal donors' in the field of organ donation are being progressively eroded (and persons aged over 80 years have now donated kidneys, for example). This will seem increasingly to place the two posthumous donations in apparent competition; in practice, the two remain quite distinct, however, whilst at the same time sharing a strong sense of 'donation' and a requirement for recognition. Payments would be inappropriate in either case. It should be recognised nevertheless that whole body donations result in no funeral expenses for the family, and memorial services are important events for the Anatomy schools. Where families are invited, these

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services seem to be much appreciated. Families of organ donors have similarly asked to have some sort of service and, especially, a physical memorial of the donations made by their relatives. It tends to be the memorial aspect that these families seek to emulate⁷, not the incentive of funeral payment. Various physical, sculpted memorials to organ donors have already appeared in the US in the grounds of hospitals.

Memorials of various kinds and non-market payments seem to be positive ways forward to offer recognition in matters of whole body and body-part transactions. This would be better than, for example, attempting to flesh out reciprocity quite literally by giving priority on an organ waiting list to those who have registered themselves to give organs. This suggestion has often been made by those keen to lessen the organ shortage but it would be unworkable in any simple, unobjectionable and transparent way. Moreover, it seems imperative, for the sake of maintaining trust, to keep unsullied the public objectivity of organ waiting lists. Objectivity is an important cultural achievement and the work of recipient transplant coordinators is difficult enough without having to suffer further anger and accusation from sick patients already begging to find ways to be moved up the list and always ready, in their desperation, to find corruption in the system.

Conclusion

The language of 'organ shortage' accompanied by that of 'supply' and 'demand' evokes a market language that is otherwise inappropriate in this field. Changes in surgical techniques and new findings in immunology and immunosuppression will continue to save and improve lives - and increase the 'organ shortage' - whilst research in stem cells, along with other bioscientific inventions, may well alleviate some of the problems but will pose others. Unless we wish to re-think and perhaps jettison ideals such as human dignity and disinterested public good that have been hard-won achievements, then the steadfastly non-market aspects of the corporeal transactions involved seem important to maintain. This is not a naive conservatism nor a fear that marketisation and processes of quality and safety monitoring are incompatible. It is rather an argument for the promotion of relations of public care and for a specific public taxation of profit from human biologicals for transparent and public benefit-sharing.

⁷ See the website of the UK Donor Family Network, for example: <http://www.donorfamilynetwork.co.uk/>.