

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.

RESPONSE

to

Give and take? Human bodies in medicine and research

by

PATIENT CONCERN'S SPECIAL ADVISORY TEAM

10 July 2010

Introduction

We were very interested to read your wide-ranging consultation and appreciate your wish to collate as many views and approaches as possible. However, we regret that the consultation is written in a manner not easily accessible to non-academics. It is difficult for the ordinary reader to see the wood for the trees. We would be surprised if you receive many responses from the general public, though most people have a strong sense of what is right and wrong and where the boundaries lie.

We also note the composition of the working party, which consists entirely of 'experts'. Since you have allowed eighteen months for evaluating the consultation, perhaps you might consider occasionally recruit patient representatives or members of special interest groups for some of your core discussions to test whether the views of your experts are in any way in touch with those of ordinary folk.

Valid consent

Patient Concern contends that the most fundamental principle underlying donation of bodily materials or participation in research is valid consent: the person involved must understand what is involved and give explicit consent.

Whatever the bodily material provided, donors must know for what general purpose it will be used, i.e. transplantation, treatment, training or research, and must be able to limit the area of use.

We believe that it is always ethically unacceptable to use bodily material for additional purposes for which explicit consent was not given. Special approval from a Research Ethics Committee does not suddenly transform this into an acceptable practice.

As the Code of Practice for the Human Tissue Act states clearly, 'the absence of refusal is not consent' and any move towards an opt-out system for organ donation after death would be wholly unethical. This would be pretending that consent had been obtained when no such thing had occurred. There is no way of ensuring that every member of the population – the elderly, those with learning disabilities, those whose first language is not English – would understand the newly introduced concept of 'presumed consent'. The 'hard to reach' groups are given that name for good reason.

The reasons that many fail to sign up as potential donors may be inertia, ignorance or unwillingness to think about death. It cannot be right to turn around the rules in order to use these same reasons to bring about the desired result of more available organs – even if we could be sure that this would be the result. Such a system would inevitably lead to organs being taken from those who had not opted out but were none the less unwilling to donate.

We cannot possibly talk about 'donors' in the same breath as an opt-out system. The organ would no longer be a gift willingly given; it would simply be requisitioned by the state. Donating an organ should be a personal choice; it is not a moral obligation.

The question of incentives

Consent can be invalidated by any form of pressure or undue influence. It could certainly be invalidated by any financial incentive of such an order that it could change a decision or induce someone to go against their beliefs and values, or act against their own health interests, in return for reward.

The range of bodily materials under consideration makes the question of incentives complicated.

There seems no ethical reason to prevent paying for blood or sperm, for instance. These are renewable resources and donors are not required to put themselves at risk.

Eggs and bone marrow are also renewable resources but here there are potential risks for donors and we find it worrying that in much of the literature these are underplayed or even ignored. This makes direct payment for these bodily materials more questionable and though compensation for inconvenience or time lost is reasonable, there is something of an invisible line here. Perhaps it is only crossed if the payment reaches a level that could persuade the donor to make a decision they would not otherwise have made – which may be very difficult to estimate.

Offering free IVF treatment as an incentive for egg donation, when the two processes are so closely linked, seems an acceptable quid pro quo.

A similar incentive to increasing the availability of donor organs by offering a preferred place on the transplant list (should this be necessary in the future) might seem to be in the same

ball-park. However, the National Health Service is predicated on the rule that treatment is offered according to need and it is important not to lose this concept. On a purely practical level, this inducement will lose its power if we succeed in vastly increasing the numbers on the organ donor register.

In Patient Concern's submission to the Organ Donation Task Force we suggested 50 ways in which we could boost the numbers on the register. We did not include the idea of payment or reward. We see nothing ethically objectionable in offering a t-shirt, mug, badge or even a small amount of money as a gesture of gratitude for signing up. We do however feel that it is not cost effective, as it is estimated that between 25,000 and 50,000 registrations are needed for one successful donation.

We consider that the only acceptable form of direct financial incentive for organ donation would be a contribution to a charity of the donor's choice. Donors could be asked to nominate a charity when registering. This could have a secondary benefit in that families might be less inclined to override the donor's decision. Though the legal position on this was changed to facilitate donation it has made no difference to the 40% refusal rate because doctors are unwilling to go against the feelings of grieving relatives. The fact that a donation was going to a favourite charity in the name of their loved one might be just the spur to convince relatives that they are acting according to that person's wishes.

Any other type of financial incentive is problematic. A sum of money offered directly to the donor's family, whether as a direct payment or a contribution to funeral expenses might well influence or change a decision by making people feel that they have an obligation to help their family in this way, thus bringing the validity of their consent into question.

Financial incentives offered to the family of a donor could pressure them into making decisions based on their own wishes rather than those of the deceased. Other risks include inducing families to withdraw care prematurely or influencing them to withhold medical information that might prevent the use of an organ, possibly resulting in the transfer of disease. On the other hand, it might discourage families who felt that they were selling part of a loved one.

Introducing any form of payment for organs from the dead would inevitably lead to the question: if we can pay for organs from the dead, surely the living should be able to profit from the sale of an organ? This type of sale is illegal in most countries as it is likely to create a market that exploits the disadvantaged and vulnerable. Those who badly need money can be pressured into putting their own health at risk.

We would prefer to get away from the idea of financial reward – we do not believe that this is what most families will be looking for. We feel that it would be preferable to institute some form of permanently recognising donors – a board in hospitals for instance or a roll of donor's names on the net. Families could feel that their loved one had been honoured for making an altruistic gift of life.