

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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# Human bodies in medicine and research: The ethical values at stake

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The human body is a resource which all cultures hold very dearly. It is the one entity in existence that we can each say is truly our own, in life at least. As such the idea of using our bodies for research, teaching or medicine conjures many emotions. As a result ethical issues also arise which need careful consideration to create a climate in which we feel we can participate without losing control of what happens to our own body and believe it is being appropriately valued and respected.

**How should altruism, autonomy, dignity, justice, maximising health and welfare, reciprocity, solidarity be prioritised, or balanced against each other? Is there one value that should always take precedence over the others?**

As a rule, each of these values is very important when considering the ethical implications of the many uses of bodily material. However, in order to compare the values involved, they must be looked at individually.

*Altruism* is the value that allows clinical trials to take place and is very carefully legally restricted. According to GMC guidelines for medical research, "financial remuneration ... should be limited to administrative costs involved". If no one was willing to volunteer, many research projects could not happen. Also, the GMC's limit on remuneration prevents the organ market from being dominated by those who can afford it. However, in the case of organ donation, it is suspected that there are hidden coercive pressures on people to donate organs, particularly within families, for example: the family members who are not a match for their relative who requires an organ replacement may put pressure on a family member who is a match. In this instance, *reciprocity* is contradicted; people are expected to display altruism over reciprocity. The guidelines concerning altruism may also be seen to oppose reciprocity, if there can be no financial remuneration or anything other than a sense of good will is this reciprocal?

*Dignity* should be maintained and to some people may be seen as the most important value due to its link to the sanctity of life. “All human beings are born free, equal in dignity and human rights” (Universal Declaration of Rights (1948)). Dignity is a sense of self-worth, being valued and having purpose; it is maintained by being shown respect. It could be argued that after death the donor or research participant cannot have a sense of self-worth no matter how well it is treated. However the bodily material to be used for research or for donation still has purpose and still should be treated with respect to maintain dignity. Again money comes into play with this particular value: to put a price on an organ or any other bodily material takes away from its sanctity and it could then, theoretically, be seen as a tradable substance. To take this to the extreme, there would be uproar if theoretically organs were as widely available as groceries or clothes.

*Justice* brings the idea of “fairness”. If 100 people agree to participate in in-human trials is it acceptable that the whole population could benefit from the treatment that is discovered? This also raises the values of *solidarity* and *reciprocity*. If solidarity held more worth as a value within the population there could be scope for more extensive research and trials in order to maximise health and welfare and to make more medical advances. In this country, there is a general attitude of “every man for himself”. It could be said that almost anyone would be willing to receive an organ, or would hope for an organ for their family members if they were in need but only around 25% of the people living in the UK are on the NHS Organ Donation Register, this shows that reciprocity is not currently prioritised by today’s society when compared with other values.

*Maximising Health and Welfare* is a rather controversial topic. Clearly it is the aim of many uses of bodily material to maximise health and welfare, saving those patients whose organs are failing and testing treatments, and possibly cures, for many of the health problems that affect the nation. This again overlaps with other values; if the aim is the benefit of everyone one could argue everyone should be required by law to take part in trials and join the donor register.

Each of the values must be taken into account and clear overlap can be seen between these values and their implications on the guidelines surrounding the uses of bodily material. However, in our opinion, the most important of the values is *autonomy*. This is a view that is reflected in law and medical codes. In order to maximise the benefits for everyone and advance medicine further it can seem like a good idea to place emphasis on solidarity, altruism and justice. However, it is unacceptable to ignore autonomy. The bottom line is that our bodies are our own. Legally it is battery for us to be touched without consent which illustrates the inviolability of the human body.

#### **Are there any other values that should be taken into consideration?**

*Confidentiality* is vital so that a trial participant would not be deterred from involving themselves in trials for fear of their medical history becoming public knowledge. To allow your

body to be used pre or post mortem is a very private decision and should be respected accordingly

*Nonmaleficence* is a difficult value to accommodate. Whilst the Hippocratic maxim, *primum non nocere* makes this clear for doctors, during a research trial (and due to the state of equipoise) it may (or may not) be harmful to the volunteer. During tissue/organ donation the outcome for the donor is also unknown and harm may be indirectly inflicted. Nevertheless consideration is certainly warranted

*Beneficence* has similar limitations as, for example in the context of organ donation; it will not be in the best interest of the patient donating but will be in the best interest of the receiver. The outcome of research trials are unknown so it is impossible to say whether this is promoting the wellbeing of the volunteer.

*Respect* not only for the person physically but also for their motives is important. People don't all present with a unified reason and these should be respected accordingly and individually.

*Honesty* applies not only to the institution benefiting from the body in whichever capacity but also the volunteer who could also lie about their current state of health to take part in a research trial due to the incentives given

*Loyalty* is important when considering wider family wishes. An organ donor's family may not want their deceased loved one to donate their organs despite the deceased's wish. This loyalty is more a value to consider than to base practice upon.

**Do you think that it is in any way better, morally speaking, to provide human bodily material or volunteer for a first-in-human trial for free, rather than for some form of compensation? Does the type or purpose of bodily material or medicine being tested make a difference?**

Donating an organ, body or volunteering in a trial often involves putting an individual at risk for the benefit of others and not their self (as already discussed). It could therefore be argued that it is morally unjust to offer no form of benefit to the volunteer in this case. If the donor is at no risk, i.e., donating their body after death, then a lack of personal gain for the donor or their family may be more acceptable. However, often donations are given altruistically by people who simply wish to help others. In this case they would happily accept little or no financial reward except for perhaps reimbursement for expenses accrued in the process of volunteering themselves. Some may argue that it is still an altruistic act even if payment is received, perhaps using the analogy that whether someone's life is saved by a bystander or paid fire-fighter the salary is irrelevant. This view is contentious and not held by everyone.

The key importance may simply be to treat all donors equally. One suggestion for increasing the number of organ donors is to have an opt-out system for donation rather than an opt-in system. This may help to reduce the number of missed opportunities to harvest organs from cadavers which may have otherwise been willing, but may not have considered consenting to organ donation prior to death.

Many countries currently face a shortage of donors and volunteers for medical treatment and research. An incentive based approach has often been considered to try and encourage wider participation. Some people believe that this is not ethical on the grounds that donating or volunteering for money is not altruistic and is open to abuse. A recent example of this is organ trafficking, where wealthy recipients have travelled to poorer countries to buy transplants, i.e., kidneys, from poorer individuals. Although by offering a financial incentive, the number of donations and volunteers does increase. This type of incentive only targets a specific portion of the society, namely the poor and could therefore be considered exploitative. The payment may be considered a form of coercion and could therefore invalidate consent.

The intended purpose of the donation will affect a person's decision as to whether they will donate their body or volunteer for a trial. This will depend heavily on the individual's beliefs and values, as no one would give their body to a cause they did not agree with or support. Also the likelihood is that the person donating may have an idea in mind of exactly what they would like their body/ donation to be used for, i.e. for organ transplant only, and what they might like to avoid, i.e. dissection by medical students. The type of tissue being donated can also be a very contentious issue, for example, embryonic or foetal tissues, which are of a particularly sensitive nature to both the public and the donor. For some, the beliefs and values may be significant enough to deter them from donating or participating in any trials regardless of incentives offered.

An interesting method of increasing the number of kidney donors has been the kidney exchange programme, where willing donors wanting to give a kidney to a loved one, but who are not a suitable match for them, can effectively swap their kidneys with those in a similar position who are suitable. This type of incentive can be morally justified, as both parties are equally benefiting from the exchange. The reciprocating nature of the exchange allows the risk of abuse to the system to be reduced or removed with appropriate regulation.

**Can there be a moral duty to provide human bodily material either during life or after death? If so, give examples when such a duty may arise?**

Human bodily material could be considered as tissue, organs or blood. It could be said that yes a moral duty could arise such as in "solidarity" and "reciprocity". Anyone at any point within a community may require a blood transfusion or organ transplant.

Furthermore such a duty may become more apparent when the huge waiting lists are looked at for organ donation. There is a shortfall in donors and people die while waiting on this list. It could be argued that society should respond to rectify this in its own best interests

A counter argument is that there can never be a moral duty to provide human bodily material. Someone may feel they are being pressurised into providing bodily material if it was considered as a moral duty. People may also refuse due to religious beliefs or for even simpler reasons that they are too scared to do so and want the right to choose.

Autonomy is paramount and 'duty' could be seen to compromise that. The question is whether autonomy is a product of duty; specifically do I choose to do something because my values say I

ought to? If society's inherent values are considered when an individual makes a choice and weighs it against reasons not to act then the two are not distinct and duty should have no bearing on autonomy.

Overall we do think a moral duty can arise it can be thought of as mutual exchange and support within a community.

### **Can there be a moral duty to participate in first-in-human trials?**

First-in-human trials are the initial experiments performed on a select few individuals after the drug/treatment has previously recorded a positive result on animals. These trials are clearly critical in the development of such treatments that could potentially be life-saving. The issues of humans having a moral duty to participate in such trials and the question of whether or not one individual may have a differing level of moral duty than another are complex concepts and shall now be discussed.

Some people may argue that every individual has an intrinsic responsibility to help other people and generally help in health developments of the human race to work towards a healthier population. First-in-human trials can be portrayed as the initial, critical step towards the development of a treatment that could halt the spread of a disease before it has the chance to become an epidemic etc. For this reason, some may believe that since each individual is born with this intrinsic responsibility to help others, we have a moral duty to participate in such trials.

Other people may oppose these views due to the simple principle of Autonomy. They believe that this principle overrides any religious beliefs and that one should not be inclined to participate in these trials despite any beliefs that we have a moral duty to do so.

Selfishness is generally frowned upon. It is seen across many religions that selfless acts are a way of proving oneself to be a good human being who is capable of placing other individuals before oneself. Altruistic views are that donation of oneself for such first-in-human trials is a particularly selfless act. Since most religions voice the opinion that believers should work to becoming a better person, one could argue that such individuals are duty bound by their religion to participate in such trials, to develop their intrinsic goodness so that one day they can successfully enter their particular place of afterlife.

On the other hand, the concept of free will is often used to tackle dilemmas such as the one in question. Free will is foreseen by many as the factor that truly defines us each as human beings and separates us from other living creatures. Each individual has the right to make their own decisions and thus be morally responsible for the particular actions they may take. With differing rational thinking between individuals, combined with free will, follows actions specific to that individual and therefore it is possible to argue that we do not have a moral duty as human beings to participate in such trials but that we are free to make our own decisions which should be respected.

In conclusion, there are many beliefs for and against whether or not individuals have a moral duty to participate in First-in-human trials and many of these issues are dependent upon

religion. Personally, we see the merit of the concept of 'Utilitarianism' in which one should work towards obtaining the greatest amount of goodness for the greatest number of people. First-in-human trials mainly possess the potential of saving a population from an epidemic etc, albeit with a risk involved to those in the trial. However I believe that the 'greatest good for the greatest number' should be weighed against other principles such as autonomy, and the harm to the participant. We all have a moral responsibility to participate in First-in-human trials and as time goes on I believe society will evolve with his view more and more commonplace. Even though some may argue that the degree of moral duty may differ from person to person due to factors such as religion etc, we hold the view of justice in the sense that there should be a fair distribution of responsibility within or between different societies. The moral responsibility acquired to each and every individual is equal and constant.

**If so, could you give examples of when such a duty might arise?**

1. One may argue that all individuals have an intrinsic responsibility to help other people and so hold the view that we, as human beings, have a moral duty to participate in such potentially life-saving trials. This would suggest we each have a duty at all times
2. Perhaps only those that are bound by their religion to become a better person by performing selfless acts such as participation have a moral duty to do so. In which case it is religious figures or one's own interpretation of religious texts which confers duty upon an individual
3. Some would argue that those who have inflicted bad things on individuals perhaps have a higher level of moral duty than others to redeem themselves by working towards the greatest goodness for the greatest number. This is a sense of duty generated by one's own conscience and so the duty would arise when an offence had been committed.
4. Perhaps when called upon, the moral duty to participate arises. In which case the duty reflects the needs at any given time. Perhaps if there was to be a resistant strain of virus break out and potentially cause an epidemic people would have a duty to partake in controlled emergency trials to ascertain as far as possible whether a drug in development is worth investing in to control it.

It will always be necessary to try and understand how better to balance the needs of the academic and clinical community with the reservations and values of the public. This can only be done with significant reflection and widespread appreciation of the diversity of views held by individuals and society as a whole. However it is also vital to assess the changes in these values and understand that people get used to new ideas. The idea of having another person's heart was an alien and in many circles offensive concept. It is now widely accepted. Progress should not lean too far towards maintaining the status quo but equally those in power have an enormous responsibility to make sure steps forward will not be detrimental to the aims they wishes to address.

