

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.

University of Leicester Medical School - group 24

Question 26

Ownership is defined as the state of having complete legal control of the status of something. Possession is defined as the act of having and controlling property. The law has established that there can be no ownership over a corpse. The only exception to this rule is when body parts or corpses acquire attributes by virtue of application of skill, for example dissection or preservation. However, people have the right to possess a body in order to dispose of it. Generally, this right falls upon the next of kin i.e. the executor (appointed in the will) or administrator of the deceased's estate. This will either be the spouse, nearest relative, next of kin or parents. Other people may be entitled to lawful possession of the body. If the corpse is on hospital premises, the hospital will then be in possession. If the Coroner has jurisdiction, then for the purpose of inquiries, he or she may take possession of the body. Death is the ultimate state of incompetence, so the next of kin is responsible for any decisions made, however, the next of kin also has the right to override and withhold the deceased's desire to donate. There is an argument that, as the deceased made this decision whilst they were fully competent, the family should respect these wishes, and they shouldn't be allowed to overrule this choice. If a person, whilst alive, has donated their body, we believe it should then belong to the institution it was donated to, i.e. medical research, education or organ donation. We believe that it is right that no-one owns the body, but this brings up issues of theft and damage; how can it be stealing if it doesn't belong to someone.

Reference: <http://jme.bmj.com/content/31/10/587.full> <http://www.yourrights.org.uk/yourrights/rights-of-the-bereaved/the-rights-over-a-dead-body/possession-of-a-dead-body.html>
<http://wordnetweb.princeton.edu/perl/webwn?s=ownership>

Question 27

"We make a living by what we get, but we make a life by what we give" – Winston Churchill
Human tissue can be defined as material which has come from the human body that consists of human cells. In accordance to Human Tissue Act 2004, consent is the most important principle for the lawful retention and use of human tissue. It also states that it is an offense to have bodily material (including hair, nails and gametes) with the intention of analysing the DNA, without the consent of the individual it was obtained or those close to them if they have died.¹ One particular bodily material that is regularly in the spotlight is organ donation. It is a widely known fact that currently the demand of organs far outweighs the supply as only a small proportion of people in the UK have made the arrangements

¹ Office of Public Sector Information: http://www.opsi.gov.uk/acts/acts2004/ukpga_20040030_en_1 [Accessed:23 June 2010]

necessary to ensure their organs are harvested after death. Because of the great imbalance, there will always be a patient on the transplant list who will not live long enough to receive their organs. Perhaps, to avoid such situations occurring, UK laws should permit a person to have the right to either sell or buy bodily material for any purposes. This would increase participation of donors and thus result in more lives saved each year. There are many benefits that could arise if such laws became active. Some donors may wish to donate an organ during their lifetime such as a kidney, and should be allowed to do so provided they are competent in making that decision. Some may argue that this decision may be influenced by other factors such as a person's financial status, however this should not be a reason to exclude potential donors. By making assumptions that those with a poorer quality of life should not be allowed to sell or buy an organ, will dramatically reduce the number of organs available. If anything, knowing a sum of money will be paid for their organ, this will be an incentive for donors to carry out a healthy lifestyle, as this will increase their chances of being selected. As with all decisions made, the decision to sell an organ should not be made lightly and requires discussions with the individual or close relatives. Laws would also be set in place to ensure that only the best organs are selected for example, ensuring the donors did not smoke or drink a year prior to selling their organs. If the law recognises our right to give away an organ, it should also recognise our right to sell an organ. If a person wishes to donate their body once they have died, the money gained from this can be used to ease the financial burdens of the deceased family and can be seen as a "parting gift" to their loved ones. Charitable organisations and transplant patients in need of a vital organ should be given the legal right to buy organs/human tissues from individuals. This could lead to socio-economic prejudice because buying an organ will only benefit those who can afford to pay and not necessarily those who are most in need. But those who can't afford to pay should still be able to rely on charities (NHS Organ donation register) as they do today. Pharmaceutical companies should also be given the legal right to buy organs/human tissues if the individual is willing to sell them so as to further medical research and benefit the overall population in the future. Human tissue prices can be nationalised to avoid tissues being sold to the highest bidder but this in turn will empower the government to how much one is worth? This would avoid the risks associated with the black market and avoid situations such as the recent scandals in India. In conclusion, we believe that laws in the UK should permit a person to sell their bodily material for all or any purpose as long as stringent rules and regulations are in place. This in turn will avoid any potential socio-economic prejudice from arising. After considering both aspects, we feel that the benefits of sale of human bodily material will outweigh the risks.

Question 28

The question which arises is should they be under obligation to share profits. Strong arguments could be made for both sides. We will first discuss arguments

against sharing profits. These are:

- The research companies are investing their own time and resources and so have the right to any profit earned. This means that researchers should have the right to benefit from their work, in this case financially.
- The research findings themselves benefit the community as a whole thus the company has fulfilled its debt to society for the services/tissues provided by volunteers/donors.
- Sharing profits with clinicians could produce a significant conflict of interest. This could lead to bias in the results of a trial or coercion of an individual by the surgeon to donate an organ.²
- Payment of money for participation in a trial may increase cynicism and suspicions in the population about the safety and possibly validity of the trial.³ This however is a difficult point to argue without a proper survey.
- The payment of any amount for human tissues could reduce human dignity. What price would be put for a pair of lungs? It is a popular belief that the human body is without a price. If profits were shared, it could be viewed as a commoditisation of the body. People will not like the idea of being paid for a part of their body, their corpse or to put their health at risk such as in a clinical trial. On the other hand, many arguments can be put forward for making it mandatory companies share their gains with participants or with the general community.
- The sharing of monetary proceeds can be a powerful incentive. The argument for this can be quite strong as people are generally thought to act in a way that promotes personal gain. However, the counter-argument, namely that this creates a very exploitable situation, also exists. People may go to great and unethical lengths to secure possible payment for their tissues or time.
- A mandate to share profits with participants can prevent researchers with poor financing from producing small trials which give insignificant results, or results which are extremely unreliable due the size of the study. The idea would be that only researchers who have a very well thought out plan would be able to secure the large amount of funding needed and be able to carry out a study. The argument against this is fairly obvious- small trials may be needed to maintain the diversity of results within the research pool. Also, researchers who have a very good plan of study may not get much funding because no organisation wants to fund the study. The added burden of sharing any small profits received may be overwhelming to the latter.
- Doctors are called upon, by paragraph 33 of the Declaration of Helsinki (amended

2. Foy R, McAvoy B, Parry J. Clinical trials in primary care. BMJ. [Internet]. 1998;317:1168-1169 [Cited 2010 June 24]; Available from: <http://www.bmj.com/cgi/content/full/317/7167/1168/>

3 Hawker S, Kerr C, Powell J, Raftery J. Paying physicians for conducting clinical trials: motivation or inducement? Indian Journal of Medical Ethics. [Internet] 2009 Mar; 10: 15. [Cited 2010 June 24]; Available from: <http://www.issuesinmedicalethics.org/173SS160.html>

2008), to allow patients entered into a study to “share any benefits that result from it” at the conclusion of the study.⁴ This declaration by the World Medical Association is the international standard for medical research. The ethical basis behind the creation of this paragraph was to prevent the exploitation of a population by using it for a study whose results would never benefit them.⁵ Such a principle should surely allow benefits like money made from the studies or other uses of donor tissues to be available to the volunteers or donors. The complex nature of this question is not one for which we could settle on a simple solution. In view of the strong argument we have stated for both sides we have decided that it is probably a matter that can be addressed by collaborative decision making which involves the researchers, volunteers/ patients/ donors and, if necessary, an independent ethics committee. By letting the volunteers/ patients/ donors get involved we believe the issue of sharing profits will be dealt with in a way that is appropriate to the particular circumstances. It is highly likely that participants will feel differently, depending on how directly their donations or time are used in the procurement of commercial gain by the company. We believe that if sharing of benefits is deemed to be viable that the way it is done will also need to be relevant to the particular circumstance and nature of the trial/ research/ treatment.

Question 29

The donation of body material has two main purposes; for organ donation and for medical education. In both cases the individual donating the body material has some control over its use. However, control over the donations by the individual is limited, varying under different circumstances. Adults of all ages and backgrounds can donate their organs, providing they have a donor card and are on the donor register. The individual decides which body materials can be used, enabling them to have some control of their future use. This is vital for encouraging organ donation as many individuals may feel dissuaded from organ donation if they had no control over what was going to be used. For example, some individuals may feel it acceptable for internal organs such as lungs to be taken, but may feel uncomfortable about donating the cornea of their eye, since it can be a more personal and aesthetic feature. However, having such control may not be beneficial for the population as it may lead to a shortage of certain organs. Although individuals may be listed as organ donors, the ultimate decision lies with their relatives. This means even if the individual has consented during life, their relatives can stop donation taking place once they have died. Some may argue this is acceptable under the concept of competence. Individuals have the right to make choices concerning their health and body if they are in a competent state of mind. As death is the ultimate state of incompetence, it may be judged that the deceased individual doesn't have the right to decide if they donate their organs, even if they

4 WMA Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Subjects [Internet]. [Cited 2010 June 24]; Available from: <http://www.wma.net/en/30publications/10policies/b3/index.html>

5 Leicester Medical School. Health and Disease in Populations Module Book.-Academic session 2009/2010.

consented when living. On the other hand, preventing the organ donation when the individual consented during life may be deemed as disrespectful as it undermines the autonomy of the individual when they were alive and competent. The control given to relatives to decide whether organ donation can take place is in itself questionable. This is because it raises the issue over who owns the body post death. There are four possibilities to who owns the body: the state, the hospital, relatives and the dead person's appointees. It may be argued the relatives or appointees were closest to the deceased and so they would be able to respect the deceased wishes to the greatest extent. However, others may argue it is the responsibility of the state or hospital since those close to the deceased may not be in a competent state of mind to make such decisions. In either case, this reflects how the deceased individual doesn't have full control over whether or not they can donate their organs. As discussed previously, an individual can decide which bodily material can be used for donation, yet the control over who the donations go to isn't as certain. When a living individual makes a donation, for example a kidney or bone marrow transplant, often the individual donating will know the patient - normally a relative or partner. However, when a donation is being made from a deceased individual, the individual when alive or the relatives can't decide who receives them. Although this may deter people from supporting organ donation, it is an important in preventing discrimination. Under the NHS, healthcare is available to all and if individuals decide where their donations go to then sectors of society may be disadvantaged, undermining the principles of the NHS. Despite these regulations that have been put in place to respect donor wishes and make organ donation more appealing there is still a large shortage across the country. To counter this problem it has been suggested that Britain should follow in the footsteps of many other countries, such as Spain, and adopt an 'opt-out' scheme for organ donation. Under such conditions there is presumed consent that people are willing to donate from birth and so must choose against donating if they do not want to as opposed to the system in place at present where patients must choose to donate. This would be beneficial for organ donation as ultimately the number of people on the organ donation register would be much greater. However, does it not undermine the autonomy of many individuals? In those countries with the 'opt-out' situation only a very small proportion of individuals choose to opt-out (around 0.05%), this percentage is significantly lower in comparison to the researched statistics that imply approximately 20% of patients would normally decide against donating their organs, suggesting many are not aware of their organ donor status. Thus, some individuals may be donating against their wishes inadvertently. Additionally it may also undermine the wishes of relatives, who currently have the final say in whether a donation can take place. Whilst organ donation remains the most popular form of bodily material donation the other purpose of this material is in the case of whole body donations given to medical schools in order to teach and train medical students. One can donate their body by giving a written and witnessed consent, as regulated by the Human Tissue Act 2004. This must be given before death and consent cannot be given by anyone else after an individual's death. The person

who is donating their body should also inform their family, close friends and GP that they are doing so. The medical school usually keeps the body for three years, which is the period of time that is limited by law. But the donor, before death, can agree for parts of their bodies to remain with the medical school for more than three years. Next of kin of the donor can also do this but only after the donor's death. A written agreement is compulsory by the next of kin to confirm that a part remains for more than 3 years. The donor is free to withdraw the consent of donating their bodies at any time. With the present law, the next of kin can also refuse to initiate the donation. Most of the donors take the view of 'I don't mind what you do with my body after I have gone', as many say so within their donation application documents. Taking all the above points into mind, we believe that patients that donate their bodily material should be able to do so under the pretence that their bodies will be treated with the upmost respect and as the gift that it is. However this should be the extent of their control over the future use of their bodily materials. Whilst wishes with regards to which parts of their bodies are donated should be fully respected they should not be able to control what the fate of these donations will be, for example specifications as the recipients of any organs should not be taken into account in after death organ donation.

Reference:

1. <http://www.nlm.nih.gov/medlineplus/organdonation.html>
2. <http://www.hta.gov.uk/donations/howtodonateyourbodytomedicalscience.cfm>