

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.

## **Graham Brushett**

### **Question 1**

I am presuming that the list of bodily materials in the consultation paper is not intended to be exhaustive. I suspect we could itemise all body materials as having some research potential that raise ethical implications. For example, the brain has not been listed in the consultation paper. I have specifically referred to the brain because it is a human organ that can be donated by anyone for research purposes that has huge potential to help thousands of people suffering from neurological disorders that blight the quality of many lives, particularly in old age. Conditions such as Alzheimer's, Huntington's disease, motor neurone disease and dementia impact on thousands of people in the UK placing many families under tremendous strain. I would like the consultation paper to highlight the importance of brain donation. This consultation paper is focussing on the moral duty of individuals to consider donating bodily materials. But there is also a civic and professional duty placed on health care professionals to offer all dying patients or bereaved family members the opportunity to consider donation in a compassionate and timely manner. Brain donation for research purposes has the potential to facilitate medical solutions for very large groups within society. As most deceased donors die in hospital locations the NHS has an obligation to honour the dying wishes of their patients. This should include the option of donation. Most acute trust hospitals discuss solid organ donation for transplantation as part of their end of life care pathways, less so tissue donation and very few offer the request for brain donation. People that have signed the Organ Donor Register may have died in circumstances and with medical conditions that prevent them from becoming donors of solid organs for transplantation. The NHS should not deny people the option of other types of donation.

### **Question 2**

Cultural and religious values or beliefs have attached a "special" significance to certain parts of the human body in what appears to be a hierarchical manner of importance. When the first lung transplant was carried out in 1963 public interest in this medical achievement was very low key, despite the remarkable life saving skills developed by Dr James Hardy to carry out this pioneering technique. Progress towards the first heart transplant aroused great public interest because of the perception that the heart embodies or defines the personality or soul of an individual. I suspect that it is for these reasons that certain social and religious groups do not support donation of bodily materials for any purposes. Some members of the public attribute non-physical qualities to certain body parts. They associate the brain and heart as manifesting key aspects of personhood and personality which they believe should be kept intact. According to this view bodily integrity after death should not be violated because this might jeopardise the individual's perception of the afterlife. As such deceased donation is viewed as a

deseccration of the body that runs counter to religious beliefs and jeopardises the possibility of a spiritual existence after death. This is a view expressed by some individuals with regard to corneal donation – “I couldn’t donate my eyes, how would I see in heaven?” This categorisation of “special” is a significant barrier to donation of any type. The Council wants to examine ways of encouraging a more benevolent approach to donation. I suspect that the cultural and religious barriers briefly outlined here will always remain as a deterrent to donation for certain groups in society. I suspect that any measures to ‘incentivise’ donation would further alienate such groups from the donation process. If a religious conviction prevents donation the offer of material reward to change such attitudes would create further insult to such sensitivities. In addition there are individuals who find the whole process of transplantation unnatural and abhorrent who would never be persuaded to donate any bodily material under any circumstances. People who do not want to be donors are in a small minority – at least this is what public opinion surveys tell us. We are frequently informed that at least 90% of the country support donation – yet only 27% of the population have signed the Organ Donor register, only 1.6 million people regularly give blood, fewer than 500,000 people are registered to be bone marrow donors and we have even fewer gamete donors. There is clearly a big divide between what people say they would do and what they actually do. If you ask anyone if they would save another person’s life, virtually everyone would say “yes”. Then they pause and start to evaluate what risks they would be prepared to entertain in order to save a life. This risk assessment invites them to consider their own mortality – how far would they be willing to go in order to save a life? Would this extend to donating life saving organs after death? At this point most people prefer to avoid the subject altogether. This partially explains why 90% of the public support donation but only 60% of families say “yes” to the request for donation following the death of a loved one. Organ donation for transplants is associated with death. Death remains a culturally taboo subject in Britain. Rarely is this subject discussed in schools, work places or homes. Training courses for medics and nurses rarely incorporate issues such as breaking bad news or donation/transplant topics. Death is seldom a topic of family conversation over the kitchen table. If this line of reasoning is valid the challenge of encouraging more people to be donors will require long term changes to the way socialisation agencies such as families and educational institutions discuss death. This challenge is heightened when considering black and minority ethnic groups. Three percent of people on the Organ Donor Register are non-white, yet nearly 25% of people on kidney transplant waiting lists are from black and minority ethnic groups. Social inclusiveness and health equalities are at risk because of these facts. Can society tolerate this situation? In Singapore presumed consent has been introduced to stimulate more donation, but Muslim groups have been given exemption from this opt-out system. Muslims can opt-in to be donors. Anybody in Singapore who is not prepared to be a donor, (i.e. people who have opted-out or Muslims that have not opted-in), are NOT prioritised on transplant waiting lists. Israel is in the process of introducing a system that gives preferential treatment to citizens that are signed up

to the national organ donation register too. If a member of the family has actually donated an organ a relative is given preferential treatment on a transplant waiting list using a points allocation system. In real terms Israeli's who are not on the donation register; do not have relatives on the register or who have not donated an organ have very little chance of receiving a transplant procedure. This approach positively encourages self interest and penalises free riders. Should Britain consider this 'carrot & stick' approach? This would certainly be a radical departure from the NHS ethos of treating everyone on equal terms. The preferential system runs counter to the ideas of social inclusiveness and equal access to treatment, but it could motivate people to become donors. On a different level in my view certain body part donations are more "special" from the point of view of what they achieve for society and individual recipients. Undoubtedly certain types of donation have an immediate life saving or life transforming impact on the beneficiaries. Dialysis provides a bridge to a life saving transplant that can keep patients alive that have end stage kidney failure. Although certain cardiac support devices exist they are not as effective as their renal equivalent. The same is true of lung support. No support is available for a patient with acute liver failure to my knowledge. Therefore in my judgement heart, lung and liver organ donations do have most "special" significance. To a partially sighted person similar importance would be attached to a corneal transplant. It is trite to say that all things are relative. A pint of blood or some platelets can be just as life saving as a bone marrow or solid organ transplant. Similarly the research on donated brains that might pave the way to cures for dementia would have a major impact on the quality of life well beyond the numbers involved in transfusions or transplants. What is the value of designating certain bodily materials for donation as "special in some way"? It is little comfort to a Cystic Fibrosis (CF) sufferer that we might designate lung donation as more "special" unless this fact stimulates increased public support for lung donation. Currently the fact that 50% of CF patients listed for a lung transplant will die waiting does not motivate people to be lung donors when they die. Does that mean society should make a special case for encouraging lung donation? All patients on transplant waiting lists could put forward a strong case for prioritising their particular needs. Taking this line of reasoning further if we accept that the therapeutic benefits of certain body parts are more significant than others then logically we ought to invest more effort in encouraging their donation. What form might this take? More education, awareness raising or publicity campaigns for heart, lung and liver donors? From a societal perspective the greatest good would be achieved by concentrating on kidney donation as over 75% of transplants are related to renal failure. Take the logic a step further – a £10,000 incentive for a heart, lung or liver donation – a £50,000 bonus for multiple organ donation – an increased reward if the donor was young & healthy on a reducing scale of reward for sub optimal organs? £100 a pint for 'O rhesus negative' blood - £10 for 'O positive'? This type of reasoning establishes a very slippery slope. But like all slippery slopes the process can be halted and reversed if society changes its views on a process that leads to unintended and undesirable consequences. The

dilemma still remains though. What value do we place on the lives of hundreds of people who suffer avoidable deaths because of the limited supply of transplantable organs? Relying on altruism alone does not work despite significant increases in publicity campaigns. However uncomfortable it may appear society has a responsibility to resolve this dilemma by considering all options to increase the supply of organs for transplant. Every citizen in the UK has the right to a transfusion or transplant if they meet the prevailing medical criteria. But with this right comes certain responsibilities which currently many people are avoiding with regard to donation. I work on the simple premise that life is precious. This is enshrined in various legislation and charters – we all have the right to life. Transplants offer the alleviation of suffering and the promotion of life. These are fundamental, core human aspirations. The challenge facing us is how to nudge more people to recognise their life saving role as donors. The approach of the 1950's was based on collective values and ideals that nurtured the National Health Service and was guided by the thinking behind the 'social gift' concept, as expressed by Richard Titmuss and others. In the twenty-first century this needs serious re-appraisal. This is because the current system based on altruism fails too many families in the UK. Welfare collectivism has been challenged by competitive individualism and market values in the post-Thatcher period. Maybe, in the twenty-first century, however unpalatable this may be to some people, donation procedures need to harness the values of self interest and the markets to stimulate greater public interest in donor activity in order to save more lives. To me it is far more unpalatable to stand by and watch patients die needlessly in the absence of a transplant. The moral benefit of reducing avoidable deaths far outweighs the moral concern some people express about rewarding donors.

### **Question 3**

In my secular mind I share the view that 'death is the cessation of sensation' as expressed by the Greek philosopher Epicurus. "When you're dead, you're dead." This is the view expressed by many students with whom I discuss donation. As discussed in the response to question 2 above, this view is not shared by all people for various cultural or religious reasons. Donation after death is not acceptable to certain people who believe that donation would desecrate their bodies and jeopardise their journey into the afterlife. Tissue or organ donation would damage their bodily integrity and their soul. I respect this belief, but from a functionalist point of view I do not agree with it. My personal perspective is that my personhood amounts to more than the sum of my bodily parts. My biographical details make me the person and personality that I am – not my physical composition. I no longer possess the heart I was born with. In the eyes of some that makes me a 'soul-less' person too. When my donor died his family consented to donate his heart and kidney to me. Does that make either of us any more or less a person? If there is a heaven and afterlife surely the generosity of my donor merits a very special place in that afterlife – yet he benevolently chose not to be bodily intact following his death. For clinical reasons we do not retrieve gametes, blood or bone marrow from

deceased donors – though I believe this is technically feasible. Therefore these bodily materials have to come from living donors as there is no alternative. Practical expediency transcends ethical considerations. Provided that the health of the donor is effectively screened there should be minimal threat, risk or cost to the donor for donating bodily materials. A healthy living donor can replace the donated cells fairly quickly and without detriment to their health. The donor gives up time, possibly some income, endures inconvenience and some pain. These are very small risks or sacrifices in the context of the life enabling benefits that can be derived from the generosity of the donation. The living donation of abdominal solid organs is a different matter. The donation of liver and lung lobes is a very high risk procedure. To my knowledge no one in the UK has died as a result of lobe donation. The sample data is so small and the procedures are a recent medical innovation so we do not yet know the long term risks and benefits of lobe donation. Very thorough physical, emotional and psychological assessments are carried out before a living donation is permitted by the agencies licensed to do so by the Human Tissue Authority. Despite this extensive regulation the emotional pressure to donate an organ to a relative or friend facing premature death is very difficult to assess. Last year nearly half the kidney transplant programme was facilitated by living, related donors. Can we ever be entirely sure that the donors were not subject to emotional duress or possibly physical coercion? Ethicists debate the ‘tyranny of gift’ which presumably alters the quality of relationship between the person who could be a donor, but refuses and the potential recipient. Equally the person who does donate then has to endure a changed equilibrium in the nature of their relationship with the recipient. It is very difficult to guarantee individual free will and choice for the potential living donor. With the current shortage of organs most people would choose to help a loved one by donating an organ provided that this did not imperil the donor’s life. Is it not an indictment of our donor system that we force families into to this situation because of the shortfall of organs donated after death? Donation after death does not come with the same emotional baggage for the donor as living donation does. That is a significant difference. The emotional impact probably falls harder on the next of kin when a deceased person becomes a donor – even when the person had explicitly given their informed consent for donation during their life time. Provided the ‘dead donor’ rule has been stringently observed there are no risks incurred by the deceased donor, unlike the risks that confront a living donor. However, the decedent’s anticipated journey into the afterlife without their body intact may be put at risk if they share such a belief. Another distinction between living and deceased donation is the quality of consent that is obtained by the health services prior to retrieving organs. The rigour of the living donation consent procedure is exhaustive compared with the simplicity of signing the Organ Donor Register (ODR). Signing the ODR requires no knowledge of what will take place when a potential donor dies other than at the most superficial level. This is explicit consent, but it is not very informed when contrasted with living donor consent. All parties to the living donation process can discuss the merits of donation in a detailed and timely manner. In recent years there have been between

600 and 900 deceased organ donors each year, (plus over 2,000 corneal donors per annum), 70% of whom had not signed the ODR. In these circumstances the custodians (guardians or stewards) of the deceased are placed in a surrogate role – consent on this basis cannot be guaranteed to further the best interest of the deceased donor. Presumably this is why 40% of families say ‘no’ to donation when their deceased relative was not on the ODR because they do not know the person’s wishes and are not prepared to speculate on such a sensitive matter. Living donors in the UK invariably donate to a close family member. A full, open and frank discussion can be conducted about the merits of donation. The deceased donor is not afforded this luxury – invariably they are unconscious for a period of time or their death is very sudden. The living donor enters the process with eyes wide open. Urban myths or genuine public fears about donation for transplants after death concern two main issues epitomised in the following questions: • Will the doctors fight to keep me alive if they know I am on the ODR? • How will they know that I am actually dead before my organs are removed – can they be certain I am dead? Living donors do not have their commitment to be donors challenged by either of these questions. The debate surrounding the dead donor rule has existed throughout the history of human organ transplantation. Amongst theologians and clinicians there are disputes about the definition, diagnosis and confirmation of death. Some clinicians will not accept brain stem death if there is any higher brain activity – certain religious groups will only accept the irreversible loss of cardiac and respiratory function as the only legitimate definition of death. We have insufficient empirical data to know how many people oppose donation because of their fears about premature diagnosis of death. But the interpretation of and lack of consensus over the dead donor rule remains a serious barrier to donation. Research undertaken with families that have refused donation after death refer to the notion of sacrifice. The next of kin reason that their loved one has suffered enough through the dying process and that to desecrate the body for the purposes of donation would be an additional sacrifice that they could not bear. Living donors are not perceived as making a sacrifice in terms of giving an organ to benefit a loved one. No doubt there are other barriers that prevent people giving consent to donation – I have listed three: • Possible denial of afterlife on spiritual/religious grounds • Distrust of diagnosis of death • Desecration and sacrifice These are issues that distinguish deceased donation from living donation. We do not know how many people refuse donation on these grounds. If society is motivated by the desire to increase donation in order to alleviate suffering and promote life these three considerations need to be addressed. Given the substance of these obstacles there are no easy solutions. Challenging values based on faith or mistrust of scientific judgements can create further alienation from the very process that society is attempting to promote. Advertising appeals by NHSBT cannot address the concerns outlined above to encourage more people to be donors. Such advertising campaigns are too superficial and shallow. I suspect if the process of dying was explained in an attempt to reassure the public that dead means dead, (either brain death or cardiac death), even more people would be repelled by the

thought of donation after death. Generally people do not like to confront their mortality in such a manner. Death remains a taboo subject for many individuals. To challenge the rationality of a person's faith and their belief in the afterlife is a non starter. I suspect that both these barriers to donation are immutable. Any incentives devised to persuade people to the contrary would be counterproductive – such attempts would be viewed as patronising, insulting and offensive.

#### **Question 4**

As stated in my response to question 3 I do not believe that there are any risks in donating organs, tissue or other bodily materials after death. That presumes that you implicitly trust clinicians to diagnose brain stem or cardiac death accurately and definitively – which I do. Clinicians fought to keep me alive for more than two years prior to my heart & kidney transplant. There were several episodes when it would have been much easier to let me die – but the health care professionals chose not to take this easy option. Maybe I am naive – but I accept the professional integrity of clinicians to fight for the best interest of their patients to keep them alive – unless the patient has given explicit, informed consent to do otherwise. Personally I do not have any problems with donation jeopardising my journey into the afterlife – but I am a godless person. Similarly I do not see donation as a sacrifice. A sacrifice is something that you can only consciously endure. When I am dead I do not believe that I will have such sensibilities – although loved ones may take a different view. I sincerely hope they would not overrule my personal view. However, I do accept that next of kin have to live with the end of life choices that may be made on my behalf. Their potential grief and distress should outweigh my personal desire to be a donor. Ideally my family will respect my wishes to be a body donor. I fully recognise that many people do not share this perspective. They would argue that the donor's wishes are paramount – I do not share this view in all circumstances.

#### **Question 5**

I have participated in two first-in human clinical trials related to the specific medical conditions that I was experiencing at the time. One drug trial was actually a placebo – but it had the same effect of lowering my cholesterol levels as the real trial drug! The risks were explained and deemed to be negligible. No costs of any kind (financial, emotional, physical, and psychological) or inconvenience was incurred as the trial coincided with routine medical checkups. Financial costs and loss of time would have been incurred if this coincidence had not happened. The outcome of the trial has been highly beneficial because the medication now forms part of the cholesterol lowering drug regimen for post heart transplant care. I suspect my spouse was anxious about my participation in the trial given the medical journey I had been through prior to this trial, but she was ultimately reassured by clinicians that the trial would not put my post operative recovery at risk. My experience is vastly different to other more complex and risky trials that have been carried out that impose significant pressures on the participants and a

certain degree of risk. In March 2006 eight men received \$3,500 for participating in a trial involving the drug TGN1412. Two were given placebos. The other six ultimately received \$25,000 compensation for taking part in a drug trial that nearly ended their lives run by the company TeGenero. Clearly their experience is not typical. The patients that took the pain relief drug called Vioxx, manufactured by Merck, did not anticipate experiencing an increased incidence of heart attacks and strokes before it was withdrawn from the market in 2004. In both cases extensive trials on animals had not indicated the side effects that manifest themselves in humans. The distress inflicted on these people and their relatives far outweighs any possible benefits that may have been gained in terms of scientific/medical knowledge. Yet in both cases the risks were scientifically validated as minimal.

### **Question 6**

It is difficult to answer this question. I do not know the full extent of how bodily materials are legitimately used at the moment; let alone what purposes they could be used for in the future. I am of the opinion that explicit consent for donation should be given by the donor that clearly defines the precise uses that the donated materials can be used for. If further uses are later considered by the end-user then another request for consent has to be made. This is easier said than done if the donor dies or was dead at the time of donation. Consent should then be sought according to the regulations outlined in the Human Tissue Act and Mental Capacity legislation by contacting the 'significant others' that were close to the now deceased donor. Consent establishes a 'contract of trust' between the donor and end-user. This bond of trust encourages people to participate in donor enterprises. There will be people who might donate and set no conditions on how their bodily material is used. However, the public reaction to the Alder Hey organ retention scandal suggest that society does not want bodily materials retrieved and used for unspecified purposes without explicit authority being given by the donor or their close relatives. The growth of living kidney donation demonstrates that donors are willing to participate in this process when they can specify the terms and conditions of how the kidney is allocated and used. The smaller number of 'stranger donors' backs up this view. The recent NHSBT statement on requested organ allocation recognises the fact that some people believe that even cadaver organ donation should be conditional (i.e. dying patients that have not been assessed in the living donation programme have the right to request that organs are allocated to family members or close friends -

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_114800](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114800)). Deceased organ donation should not be conditional unless a close family member is in need of an organ. In all other circumstances deceased organ donation should be unconditional after consent has been given – organs should be allocated according to transparent regulations that prioritise recipients in the greatest medical need. Organs given for transplant purposes should not be used for other purposes such as research unless explicit consent has

been given for this purpose.

### **Question 7**

Provided that I believe that I am entering into a voluntary and transparent relationship that is fully regulated I would be willing to donate any bodily materials. I would give informed and explicit consent for clearly defined, specified purposes only. I would then evaluate each invitation to be a donor on its specific merits. However, I would not donate sperm for IVF purposes because of the legal responsibilities attached to that process (I would if anonymity prevailed), but I would donate sperm for research purposes.

### **Question 8**

Yes. Each request for donation would need to be evaluated on its own merits. I would have to be convinced that the bodily materials were being retrieved for legitimate and tightly regulated purposes. I would want the safeguard of knowing that the regulatory authorities could ensure that the bodily materials were being used only for the purposes for which I had given consent. I would only be willing to donate for research purposes within the prevailing framework of regulatory authority that applied at the time.

### **Question 9**

Altruistic donation alone does not alleviate the full extent of suffering experienced by our citizens. 750,000 people registered as bone marrow donors, 1.6 million regular blood donors, 18 million people on the Organ Donor Register, fewer than 1,000 deceased organ donors each year. This data illustrates the fact that altruism stimulates some people into action, but not enough. Notions of solidarity and reciprocity are well understood in the public domain, but are not strong enough motivators to turn thought into action. Maybe we should promote self interest and compassion alongside those values offered in the consultation paper. In crude terms as a society we need to pursue an approach that explains "what's in it for me?" This requires far more direct education to run alongside advertising appeals in the mass media. The mass media approach does not generate an on-going response that demonstrates a real return for the money that is invested. Too few people appreciate the tangible benefits of transplants, transfusions or medical research until these activities impact directly on them or someone they love. We invest a lot of energy in appealing for donors, but insufficient resources in explaining the tangible benefits that society can accrue from increased donor activity. In this context donation should be promoted as a collective social insurance that benefits everyone. The benefit is either direct in terms of improved quality of life for the recipients or indirect in relation to the social and economic costs saved by not having to support people with curable medical conditions. Altruism is a very elusive concept – people do give gifts without any desire for extrinsic acknowledgement. But intrinsically I suspect that people derive an element of satisfaction at the pleasure that their generosity or benevolence may give to the recipient of their

good deed. An act of compassion is qualitatively different to an act of altruism. Appealing to human compassion introduces an element of obligation that does not feature in an act of altruism. Given the limited success of the altruism route to donation perhaps society ought to promote the benefits of donation by other means that would challenge the compassionate responsibilities that one person has for another, regardless of the nature of their relationship. 10. How should these values be prioritised, or balanced against each other? Is there one value that should always take precedence over the others? Attempting to prioritise values that are not universally perceived as moral norms is a very challenging task. One person's concept of a moral duty is another person's gross intrusion into their individual will and civil liberties. The patient dying of lung, liver or heart failure has a right to life. This right has been offered to them by the medical community as a consequence of placing them on a transplant waiting list. The autonomy and dignity of these patients depends on the autonomous decision making of potential donors. If society can agree on any moral norms, duties or obligations presumably the right to life and the alleviation of suffering would gain greatest universal approval – though not everyone would necessarily agree about the lengths we might go to in order to preserve and promote life. Some individuals cannot tolerate a needle being inserted into an artery to give blood, let alone a 14 hour operation to become a living liver lobe donor. Other people object to the desecration of the human body to retrieve solid organs post mortem, despite the life saving benefits of such a procedure. The autonomy and right of a potential donor NOT to donate delivers justice and liberty to that individual, even though this response denies life to another dying person languishing on a transplant waiting list. My belief is that the patient facing imminent death (if they do not receive a transplant) should have their needs for justice and welfare given greatest priority in the context of deceased donation. Moral values that serve to delay death should have primacy. If forced to make a judgement on the competing importance of the moral values listed in the consultation paper I would prioritise "maximising health and welfare". But this view has to be immediately qualified. This 'end' cannot justify the use of any 'means' to deliver it. For example, it would be intolerable to hasten the death of a dying person purely to carry out a life saving organ transplant. The dignity, just treatment and autonomy of the dying patient transcends the needs of the patient waiting for a transplant. Public support for the process of donation and transplants would disappear if they believed that the interest of the potential recipient led to the 'grooming' of donors. I strongly believe that the request for donation should honour the wishes of the bereaved family relatives. If the wishes of the deceased patient are not known then organ retrieval should not take place unless the support of the family or 'significant others' has been given. The family members have to live with the end of life choice exercised on behalf of the dead person. Support for the donation and transplant system would soon evaporate if organs were retrieved from people who had not given explicit consent directly or by proxy through their next of kin/partner. Assent by 'significant others' or objection should always be sought according to the prevailing regulatory/statutory guidelines. Even when a

person has signed the Organ Donor Register health care professionals such as Intensivists and Special Nurses for Organ Donation should always gain the approval of the next of kin for donation. The registered donor may have changed their mind without altering their registration.

### **Question 10**

Attempting to prioritise values that are not universally perceived as moral norms is a very challenging task. One person's concept of a moral duty is another person's gross intrusion into their individual will and civil liberties. The patient dying of lung, liver or heart failure has a right to life. This right has been offered to them by the medical community as a consequence of placing them on a transplant waiting list. The autonomy and dignity of these patients depends on the autonomous decision making of potential donors. If society can agree on any moral norms, duties or obligations presumably the right to life and the alleviation of suffering would gain greatest universal approval – though not everyone would necessarily agree about the lengths we might go to in order to preserve and promote life. Some individuals cannot tolerate a needle being inserted into an artery to give blood, let alone a 14 hour operation to become a living liver lobe donor. Other people object to the desecration of the human body to retrieve solid organs post mortem, despite the life saving benefits of such a procedure. The autonomy and right of a potential donor NOT to donate delivers justice and liberty to that individual, even though this response denies life to another dying person languishing on a transplant waiting list. My belief is that the patient facing imminent death (if they do not receive a transplant) should have their needs for justice and welfare given greatest priority in the context of deceased donation. Moral values that serve to delay death should have primacy. If forced to make a judgement on the competing importance of the moral values listed in the consultation paper I would prioritise "maximising health and welfare". But this view has to be immediately qualified. This 'end' cannot justify the use of any 'means' to deliver it. For example, it would be intolerable to hasten the death of a dying person purely to carry out a life saving organ transplant. The dignity, just treatment and autonomy of the dying patient transcends the needs of the patient waiting for a transplant. Public support for the process of donation and transplants would disappear if they believed that the interest of the potential recipient led to the 'grooming' of donors. I strongly believe that the request for donation should honour the wishes of the bereaved family relatives. If the wishes of the deceased patient are not known then organ retrieval should not take place unless the support of the family or 'significant others' has been given. The family members have to live with the end of life choice exercised on behalf of the dead person. Support for the donation and transplant system would soon evaporate if organs were retrieved from people who had not given explicit consent directly or by proxy through their next of kin/partner. Assent by 'significant others' or objection should always be sought according to the prevailing regulatory/statutory guidelines. Even when a person has signed the Organ Donor Register health care professionals such as Intensivists and Special Nurses for Organ

Donation should always gain the approval of the next of kin for donation. The registered donor may have changed their mind without altering their registration.

### **Question 11**

It is very tempting to propose that bodily materials donated for research purposes in a commercial environment should be conducted on a financial basis. The end user expects to generate income and profit from the research they are conducting, so why shouldn't the suppliers of the raw materials? The financial reward would then be quantified in terms of the risks involved and the scale of commercial surplus that the research might generate. In most circumstances all the other participants or stakeholders in the donation process get a financial reward or some form of extrinsic gratification. Why shouldn't the donor or their designated beneficiaries be rewarded too? It seems bizarre that the very person that enables the donation process to take place, the donor, is the only person who is not remunerated for their contribution. I fully appreciate that this position attracts criticisms around the commodification of the human body and the risks of exploitation. There are justifiable claims that the poorest in society will be exploited by the opportunity to sell bodily materials or that medically unsuitable people would sell their organs in order to fund their addictions. No doubt these risks are real. But the same is true for the current system of living organ donors. We accept that the regulatory authorities have robust assessment procedures that minimise the dangers of exploitation and coercion. (We can never guarantee, however, that an individual is not manipulated into being a donor under emotional, physical or financial pressures that they cannot resist.) Why shouldn't the same assessment mechanisms safeguard the poor? Ultimately no-one can overtly force a person to sell an organ – the danger will always be the potential for covert pressure. Whose body is it anyway? In the labour market we rent out our bodies as a factor of production in the market place, so why not allow individual choice in terms of selling bodily materials for research or transplant purposes. Undoubtedly this view raises religious and moral objections, but no-one is being forced into such market exchanges. Provided that it is effectively regulated, exchanging bodily materials for reward provides recompense to the donor and benefit to the end user. And this could just save lives! Existing data proves that altruism alone does not achieve the objective of minimising avoidable deaths. This is likely to get worse in the future. An alternative strategy to this could be the use of statutory directives compelling people to donate, but that would be political suicide in a liberal democracy. Compulsion would arouse bitter opposition in the UK. But compassion does not bring the desired outcomes we seek for donation. If regulated market mechanisms are introduced to supplement voluntary donation at least people can choose to participate in the manner that suits them. Market mechanisms can co-exist alongside voluntary donation. They are not mutually exclusive procedures. In an ideal world voluntarism would suffice, but in British society kindness alone is not sufficient. We do not place a high enough value on the life of strangers. Maybe the introduction of incentives would help us to re-appraise our responsibilities in

relation to our fellow citizens.

### **Question 12**

Should there be a moral duty? Yes – especially if a life can be saved immediately at the point at which a potential donor dies. Is there a moral duty? No. The data on donation confirms that the life saving benefit of donation is valued by only a minority of the UK population (750,000 people registered as bone marrow donors, 1.6 million regular blood donors (4% of population), 18 million people on the Organ Donor Register -28% of population, fewer than 1,000 deceased organ donors each year - 950 living donors.)

### **Question 13**

No. Despite the fact that all of society can benefit from the outcomes of first-in-human trials we live with the fact that the vast majority of people are prepared to be free riders. They acquiesce with the fact that some people are willing to participate in the donor process and are happy to sit back and benefit from what others have achieved without making any contribution themselves. The free riders have no moral compunction in taking this stance. Do I find this acceptable? No, but I was socialised with a different conception of social responsibility that is not universally valued or upheld. We have to deal with the cultural value system that exists and not bemoan the fact that most citizens are prepared to leave good deeds to other people. Either indifference, apathy, ignorance or avoidance leaves the UK with a shortfall of suitable donors of all bodily materials. We should acknowledge this situation, work within these limitations and introduce incentives that may motivate people to become donors. At the same time we should continue with social education strategies to stimulate compassion and citizenship responsibilities, but attempts so far have been under-funded and lack lustre which reflects the degree of importance that society attaches to donor/transplant issues until recently.

### **Question 14**

The laws of economics demonstrate that not all needs and wants can be satisfied because resources are finite. Frequent reports from the National Institute for Health and Clinical Excellence illustrate this fact. Demand cannot always be met – so difficult priorities have to be agreed and resources allocated accordingly. The question posed is enormous. There are so many political, social, moral, philosophical and economic ramifications to consider. Developments in medical technology and expertise are limited only by our current state of knowledge and the resources we choose to allocate to advancing medical excellence. But everything has an opportunity cost. One heart transplant could be worth 10 hip replacements or one stem cell researcher. For example, more of the £110 billion currently spent on the NHS budget might be better invested in improved public health education to encourage people to modify their life styles before they need hospital care. Sometimes serious decisions have to be made to deny certain demands e.g. limiting the number of IVF treatments funded by the state, making liver transplants

available to alcoholics, providing very expensive drugs for terminally ill patients. If resources were infinite such judgements would not have to be made. Life is about fulfilling hopes and aspirations; endeavouring to maximise the quality of life and full potential of as many people as possible. As a society we ought to support our citizens in achieving these goals. Some demands are more pressing – a person facing imminent death in the absence of medical treatment should always attract priority resources when competing options are being considered. But this begs the question about how far should society go in defying death. Everyone will eventually face imminent death – is it desirable to prolong life in all circumstances? Or only when death is perceived as premature and unexpected? Do we want to fund the pursuit of eternal life? I think not. The imponderable philosophical question is how far society is prepared to go to deny death.

### **Question 15**

It is interesting to watch commentators squirm around the semantics of exchanging body parts for money or payment in kind. Somehow it is viewed as tacky or morally debased to pay cash to a person who has spent 14 hours in an operating theatre to give part of their liver to save another person's life. Why? The recipient benefits and society saves considerable resources in the care of the formerly dying patient. Surely the living donor presents a 'win-win' situation to society that is worthy of reward. Or would we prefer the term 'acknowledgement for services rendered'; or recompense; or compensation; or expression of gratitude; or inducement; or incentive? No-one should be financially penalised simply because they have given up their time to be a donor. The minimum a donor should receive is generous compensation for their inconvenience and the potential risks they have incurred. They should not bear any out-of-pocket expenses. (Rewarding an organ donor ranks higher in my estimation than contributing to a collection box following a sermon at a church, synagogue or mosque where no doubt the congregation may have been advised against the donation of bodily materials – life is full of such double standards!) No doubt different groups in society will argue that some donor activities are more important than others and that complex sliding scales should be applied depending on who is donating what. For example, a young living donor giving a kidney to a relative – does this merit more or less than an older person giving a kidney to a stranger? A high risk first-in-human trial activity deserves more reward than a low risk one? A deceased multi-organ donation from a young athlete merits greater acknowledgement than a single cornea donation from an elderly person? And so on. No system will receive universal agreement and there will always be objectors. No doubt, in true British style, we would appoint a Compensation or Reward Board to make these decisions on our behalf – such entities already exist in other spheres such as the Criminal Injuries Compensation Authority. A range or combination of inducements, compensations or incentives could be offered:

- Providing tax credits or increased personal tax allowances for people who register

as donors – even higher credits for actual donors.

- Give funeral vouchers to families that have agreed to donation after death.
- Pay the tuition fees for students have registered and/or who have donated.
- Issue certificates or medals to donors and/or their families or some other form of honour.
  - Create a national memorial where the names of donors could be listed, but only with their approval or the family's approval.
- Registered donors could be given preferential NHS treatment and given priority status if they needed a transplant – the same could apply to the family members of someone who has been an actual donor.
- Good old fashioned cash would encourage living donors – fully authorised and regulated by the state; no private transactions allowed. The state fixes the going rate for the exchange of bodily materials which is not open to negotiation.
- Generous compensation payments to offset expenses and inconvenience incurred by donors commensurate to the benefits gained by society.

There is the danger that certain groups in society will be offended by the concept of rewarding the donation of bodily materials. I suspect this will cause some people to boycott the donor process, but I believe the gains would more than offset the losses. The most articulate objectors could just turn out to be people who would not donate under any circumstances, but I have no evidence to support this view. I find it ironic that of all the stakeholders involved in the donor/transplant process the only individual that is not rewarded is the donor! Yet without them the whole enterprise would grind to a halt. People who want to donate, but without reward, can always decline the incentive or donate it to a charity of their choice. Ultimately we need to remind society that it is even more offensive to allow families to endure avoidable deaths on transplant waiting lists. If the UK ultimately decides to introduce incentives to encourage donation extensive research should be carried out to ascertain whether more lives would be saved by going down this route.

### **Question 16**

All incentives must be expressed in positive terms. For example, if a person participates in a human trial it is because they have chosen to, free of coercion, with the added advantage that they will be rewarded for their cooperation. The threat of withholding treatment if they do not cooperate (a negative incentive) would be unethical. In Iran and some parts of Pakistan the state funds the compensation/reward to donors for participating in the living kidney donation programme. The families of the recipients are also encouraged to extend their gratitude by whatever means they have at their disposal. I would prefer to see the UK introduce a state regulated system where donor anonymity is guaranteed unless they choose otherwise. There should be no expectation placed on the end user of the donated bodily materials to pay or reward the donor (i.e. donation for transplant/transfusion purposes), unless the donation is for commercial research purposes. In the UK the NHS funds medical care for the majority of the population

according to need. In most cases this is a fair and equitable process (although health inequalities do exist) because individual wealth does not determine who receives care in the state system. This should remain the same guiding principle if incentives were introduced for donation. The cost of annual dialysis is around £35,000 – the net on-going cost of a kidney transplant is significantly lower. The benefit to the recipient is phenomenal (I know!) and society as a whole achieves net gains in a variety of ways – reduced medical care costs, improved quality of life for the recipient and their family members, a more productive citizen able to contribute to wealth creation and the national exchequer. Therefore the responsibility rests with the state to finance the incentives and to ensure probity.

### **Question 17**

If there is such a thing as a malevolent incentive these should not be allowed. As mentioned earlier it would be unacceptable to hold a person to ransom if they refused to be a donor e.g. a family member emotionally blackmailed to be a living kidney donor or a person being refused treatment if they did not agree to take part in a human trial. Incentives should be proportionate to the risks incurred by becoming a donor. No-one should be asked to donate or take part in a first-in-human trial if their own life would be placed in serious risk.

### **Question 18**

Not in my view – see questions 15 & 16 above for explanations. Most people would attach significant value to the benevolence of donating an organ. Attaching a 'price' to this deed challenges all sorts of sensibilities. Straight cash payments are seen as devaluing the worth of the human body. Somehow this debases human worth. However, indirect compensation ultimately has a transferable monetary value. But I can recognise the argument that funeral vouchers are harder to convert into cocaine or alcohol than cash for those who choose to donate in order to feed their addiction – a fear which seems rouse a widespread concern.

### **Question 19**

Most definitely there is a difference. Compensation for economic loss should be automatically guaranteed - there is no way a person should experience a loss of any kind by contributing to a donor programme. This should be easy to quantify and regulate. No-one should be out-of-pocket as a result of expenses incurred because they have chosen to be a donor. The other factors are more difficult to measure and evaluate, but should also be compensated for. Presumably an arbitrary amount would have to be established by some type of compensation authority that distinguishes between the various levels of sacrifice that donors have to make.

### **Question 20**

In addressing developments related to transplant initiatives I am aware of the following:

- Public health policies designed to increase health awareness that could in turn reduce the incidence of end stage organ failure e.g. targeting smoking, diabetes, industrial diseases, alcohol and drug abuse, obesity and so on. These educational initiatives will have some impact in reducing the demand for organ donation but over a long term period. At the same time improvements in road safety, health and safety in the work place, more effective management of strokes, head injuries and heart disease reduce the number of potential donors. So maybe these policy initiatives cancel each other out.
- Stem cell therapies offer the possibility of 'growing' organs or helping patients rejuvenate diseased organs that would otherwise have required transplantation in the past. The benefits of these developments have been promised for a number of years, but have yet to be proved as a serious substitute for transplanted organs. Having no medical or scientific knowledge I cannot gauge whether the success of stem cell engineering will ever eliminate the need for donated organs. I suspect not. There is also the danger that stem cell experiments may be so tightly regulated that the potential benefits that could be accrued never materialise.
- Ex vivo perfusion, organ transport and resuscitation techniques promise the potential to increase the number of viable organs from each deceased donor. The ability to resuscitate lungs from donors that are cardiac dead should increase the number of lung transplants using the Steen/Vitrolife system. The Organ Care System offers the same potential for hearts and lungs. The LifePort technology maintains the viability of kidneys over a longer time frame than conventional cold perfusion techniques. UK investment in these technologies is low even though they have led to a reduction in the number of rejected organs. The future potential of these technologies is dependent on public investment which under threat right now.
- The implementation of the 14 recommendations of the Organ Donation Taskforce has led to a significant increase in donation following cardiac death. Developments in hospital trusts are examining ways of looking beyond intensive care units for potential donors, such as Emergency Departments and other high dependency areas. The perennial concern about the diagnosis of neurological or cardiac death remains a barrier to donation rates. So too does the level of medical intervention that is acceptable to maintain organ viability. With experience these concerns may be resolved. But there will always be a finite and limited number of people that die in circumstances that would facilitate organ donation.
- Genetically modified pigs (or other animals?) could make up the shortfall of organs from human donors, but xenotransplantation has not been perfected and remains a very grey area in terms of ethical and religious acceptability.
- There are acute trusts in the UK that have distinctly high donor and conversion rates per head of population, well beyond the national trends. These tend to be trusts that have intentionally brought together bereavement support with the role of requesting tissue/organ donation. The interlocking method of bereavement and donation coordination merits closer examination because of the success achieved in the trusts where this approach has been developed e.g. The Royal Bolton Hospital

has been cited as best practice in this respect. The introduction of embedded Specialist Nurses for Organ Donation (formerly known as Donor Transplant coordinators) in every trust may enable this approach to expand into all trusts if NHSBT choose to support this development.

### **Question 21**

I am surmising that this question is seeking to assess whether there are circumstances that make inducements to donate so irresistible that people may take risks that are not rational or in their best interest. If I was offered £1 million to donate a lung lobe I would be sorely tempted despite the fact that the procedure carries with it very high risks. But if I agreed to the process in a fully informed manner I am exercising my free will to participate in the activity. Does the 'carrot' of £1 million constitute duress? Possibly it does, because if the sum offered had been £1000 I would not even contemplate the proposal. Does the 'carrot' invalidate my consent? No – provided that I am fully informed of the risks involved. "Forms of encouragement" can come in a variety of guises, both negative and positive. Emotional blackmail, intimidation and bribery are levers that can be applied to 'encourage' people to take actions that they would not otherwise contemplate. It is not difficult to envisage a situation whereby a young member of a family is 'encouraged' to give a kidney to a dying parent. This scenario is made more complex if there are mental capacity issues involved e.g. special learning needs. It is a very difficult challenge to assess what is in someone's best interest in this context. The child who could give part of their liver to a parent could never be isolated from the emotional and psychological pressures of their circumstance that would enable the child to make a purely rational decision. Presumably if the child is dependent on the parent for their wellbeing the decision to be a donor is a rational and valid one. By the same token it can be argued that it is totally unreasonable to place a child in this situation in the first place. The mere act of seeking consent for donation could be construed as unreasonable. Assessment procedures utilised in the current living donor programme in the UK can never eliminate all subversive behaviours that may lead people to donate under duress. The introduction of incentives would be subject to the same risks.

### **Question 22**

If you place any idea into the mind of someone who might not otherwise have had that thought, this could cynically be construed as coercion. I suspect that no system of assessing donor suitability will ever totally eliminate the risk of coercion. Family politics and power relationships within social groupings do not readily lend themselves to checklist assessment criteria. When the assessment concerns sensitive life or death issues the emotional and psychological challenges do not conform to the logic of rational thinking or expression. Balancing the best interest of the potential donor against the needs of the intended recipient has to ultimately be resolved by the internal dynamics of the family relationships. Regulatory

authorities can do no more than guide this process. However thorough an assessment and validation process might be, we can never guarantee that the genuine best interest of all parties to the process are being fulfilled.

### **Question 23**

No. Public reactions to the Alder Hey organ retention scandal demonstrate that matters relating to tissue and organ retrieved by medics, researchers and other health care professionals require absolute trust. Transparency is a key factor in establishing trust. A clear exchange of information communicated in a straightforward manner helps to engender trust. Explicit and informed consent has been designed over decades to safeguard the best interests of patients/donors and health care professionals. Situations that undermine these prerequisites based on trust and consent have the potential to alienate public support for the donor/transplant process. If circumstances change from when the initial consent was given, further consent has to be gained. Consent should be viewed as a binding contract otherwise it becomes a worthless concept. The only exception I could envisage that might cut across this dogmatic stance is if a deceased donor had consented to solid organ donation and it was then realised that the whole heart was not suitable but the heart valves could be used. Then perhaps this deviation in usage could be justified, rather than wasting the donation opportunity in its entirety. It is the wish of the donor that has to be honoured, not the convenience of the end user.

### **Question 24**

Yes. The surrogate or proxy decision maker can never be absolutely certain that the best interests and wishes of the donor lacking capacity are being honoured. Even if earlier discussions have taken place when the potential donor had capacity, the decision maker can never be certain that the person may have changed their mind. Even if an advanced directive has been made this is not an absolute guarantee that the best interest of the donor is being carried out – but this element of doubt will always exist. The framing of the question highlights the importance of encouraging families to have open and frank discussions about donation. To facilitate meaningful discussions there is a need to provide more detailed information through state education so that people can make informed decisions. The consent that is then given for donation is far more robust than the current procedures that apply. Ideally consent should be based on a detailed understanding of the consequences of donating and the implications for society by not doing so. The thought processes involved should be gone through well in advance of the circumstances when the request for donation is made. Explicit and informed consent should be given, preferably in writing. With regard to organ donation the above conditions do not apply. Even the 28% of the population that have chosen to opt-in to the Organ Donor Register (ODR) do so with very limited knowledge of what they are giving consent to – they have no idea about the processes involved in retrieving viable organs for transplant. In recent years about 70% of donations have been from

individuals not even on the ODR. Recent discussions on improving the donation rates have focused on moving to an opt-out system called presumed consent. This has to be an oxymoron. It is the antithesis of informed consent. If the default position became one where everybody would be regarded as a potential donor the discussions we would want families to have about end of life choices would be less likely to take place. Deceased donation is an end of life choice for the family too. Presumed consent could marginalise families in the dying process at a time when their involvement is crucial, not just for the dying person but the family members also. The family has to live with the consequences of the bereavement and how that process is managed. A preferable option to the current opt-in system or to presumed consent is mandated choice. Without wishing to go through all the arguments relating to each system I would like to highlight the strengths of the mandated choice approach. In the UK we value and respect individual freedom and human rights which is why we do not make organ donation a compulsory civic responsibility. But the current opt-in system does not provide enough consented organ donation to provide the human right to life for all people on transplant waiting lists. We have a moral obligation to investigate all possible solutions to avoid these unnecessary deaths. In 2008 the Organ Donation Taskforce rejected the proposal of presumed consent because this does not guarantee an increase in public support for donation and is deeply resented by human rights campaigners because it removes the individual's right to choose. There is a strong belief that donation should be based on altruism and compassion – not state compulsion. The Taskforce was not given the scope of authority to assess the merits of a Mandated Choice system. The Taskforce is implementing 14 proposals to increase the organ donor rates and transplant procedures in the UK. Some of these recommendations have already achieved positive results. This is an appropriate time to put together an evidence based assessment of whether a move to a Mandated Choice system would also increase the donor rate. If Mandated Choice was introduced in the UK this should only be considered if we believe it would increase the rate of organ donation that would lead to more lifesaving transplants being carried out each year. This would reduce the grief of long waiting times for patients and the distress for families watching their loved ones die. Mandated Choice would involve all people over the age of 16 years (or an agreed age of responsibility which might be 12, 14 or 18?) signing an advance directive to be tissue and organ donors when they die. The directive would be in the form of registration literature sent to every household in the UK maybe in conjunction with electoral roll information, council tax documents, national insurance documentation etc. The form would offer four responses: a) Yes I want to donate my organs when I die for transplant purposes b) No I do not want to donate my organs when I die for transplant purposes c) I want to leave this decision to my family at the time of my death d) I do not want my family to overrule my decision stated on this form. There would be the opportunity to change the decision at a later date through an agreed formal procedure. This system could only be implemented following a long period of public consultation and education that explains the benefits of transplantation. We all have the right to

a transplant through the NHS if we meet the relevant medical criteria. Consequently we all share a collective responsibility in enabling this to happen – the saving of just one life from avoidable death benefits the whole of society. What are the merits of introducing a Mandated choice system? Mandated Choice allows everyone to declare their explicit view on organ donation in a private and confidential manner. Unlike Presumed Consent the mandate allows people to give explicit consent in a manner which retains the ‘gift ideal’ so valued in British society. Altruism is protected as a virtue because people have to positively agree to donation. Presumed Consent (an oxymoron) takes away the act of altruism because it relies on a lack of objection. By introducing this system it ‘nudges’ people towards making a decision that many of us agree with already but simply do not get around to fulfilling. Ninety per cent of people support organ donation yet only 28% have signed the Organ Donor Register. By sending registration literature to every household everyone is given an equal opportunity to declare their position. How many people die in hospitals that would have chosen to be donors if only they had opted-in to the current process? How many actual donors were volunteered by their relatives when in reality they did not want to have organs retrieved? Mandated Choice eliminates this doubt and confusion. It preserves personal autonomy. This system guarantees legitimacy and safeguards the interests of health professionals and the potential donor. The process delivers certainty rather than ambiguity. All citizens of the UK would receive the registration literature conveniently at their households. This would negate the claims often made that donation registration is hard to understand, it is not convenient, people do not know how to access it and so on. Failure to register because of ignorance, hectic lifestyles or apathy would be significantly reduced. No-one is compelled to be donor through this system, but everyone is asked to discuss their wishes with family members and proactively declare their view. Individual choice and human rights are preserved because people can choose from four options. No presumptions are made about people’s views and no-one is compelled to become a donor. Personal autonomy is maintained using a Mandated Choice approach. People are generally highly protective of their right to decide their own destiny. That is probably why no government in a liberal democracy would ever make organ donation compulsory. The Presumed Consent proposals were criticised for making assumptions on behalf of people who may not have ability to register their objection to organ donation and exercise their right to opt-out. Mandated choice protects individual freedom of choice and treats everyone the same to either say ‘yes’ or ‘no’ to organ donation, or allow their family members to decide. There is, however, the criticism that the state should not force an individual to make such a declaration. What right has the state got to put this issue onto the agenda of all people who might prefer not to consider organ donation at all? On balance though asking someone to decide about donation is a very small loss of personal liberty when balanced against the possibility of saving over 1,000 lives a year. The moral equivalence of saving lives far outweighs the minuscule loss of liberty entailed from having to declare a choice by filling in a form occasionally. The human right to a transplant is definitely greater

than the liberty lost by having to complete a donation registration form that gives you the option not to be a donor. The issue of organ donation occurs in the lives of families at a time of emotional distress. End of life choices for the deceased relative require the input and support of close family members. It is after all an end of life choice that the family has to live with after the decedent has been buried or cremated. Should family members have the right to overrule the declared donation wishes of the dead family member? Currently that is the informal position. Clinicians and donor transplant coordinators will not pressure families into accepting donation even if that is the wish of the dead person. And rightly so. But by the same token though, every family should be asked about organ donation as part of the bereavement support process. The legal position in the UK outlined in the Human Tissue Act (2004) states that health professionals should make every effort for the registered donor's wishes to be honoured. All families should be consulted about their end of life choices and given the option of organ donation on behalf of their deceased relative. The family's position on this issue should never be presumed however distressed they may be. The request for organ donation can restore some degree of comfort to the bereaved family. The opportunity for donation should never be denied to families by clinicians, even if their motives are well intentioned. Research shows that when a person has declared that they want to be a donor when they die families are more inclined to support the request for organ retrieval. The requesting role of the Intensivist or transplant coordinator becomes more straightforward under these circumstances. If the UK moved to a mandated choice system most of the doubts relating to the validity of consent under the opt-in or opt-out systems would be removed. Clearly mandated choice would not eliminate all the concerns implied in question 24, but it would hopefully stimulate family debate and more openness about end of life choices particularly in relation to organ donation after death.

### **Question 25**

When the wishes of the deceased are known the family's role ought to be minimal. Ideally they should respect the wishes of the dead person as expressed during their life time, unless there are strong doubts that the person may have changed their mind about donation without notifying the authorities. That is why it is essential that qualified and expert health care professionals always discuss end of life choices with family members, regardless of the donation issue. It is essential to ask family members or 'significant others' what they believe to be the deceased's end of life wishes on a range of matters, not just tissue/organ donation. In fact this should be a high priority in all acute trusts. Hospital trusts that link donation to a comprehensive bereavement support policy discuss a range of issues that will trouble family members when a loved one is dying. Hospitals that interlock bereavement support with donor coordination have demonstrated higher responses to donation requests per head of population than trusts that do not. The model developed in the Royal Bolton Hospital is now being implemented in a number of other trusts with great success. One of the key principles of this approach is that

the family is allowed' to say 'no' to whatever options of support are offered in relation to end of life choices. The right to veto the potential donor's living wishes is a contentious issue. I know of one family where the daughter had Cystic Fibrosis. She died waiting for a double lung transplant. The family had witnessed her suffering over a prolonged period in hospital and could not agree to donation. The family did not want further distress. Their son then died in a drowning accident – he was a registered donor and the family supported his wishes. Their remaining daughter also needs a lung transplant. She too has Cystic Fibrosis. She is a registered donor – would it be compassionate for health care professionals to impose her wishes on her family members if she were to die? If this increased the suffering and distress for the family surely that would not constitute acting in the best interests of the deceased person. I strongly believe that the family should always be given the option to say 'no'. If, however, the proposal for a mandated choice system was introduced, with the four responses clearly indicated in question 24 above, the family's potential veto is less likely to be exercised. All of these considerations assume that the family members are able to make informed decisions about the donation processes and that the discussions are conducted in an open, honest, timely, transparent and compassionate manner. It also assumes that the discussions are conducted with health care professionals that are expert in bereavement and donation matters in an environment that is not pressured and respects confidentiality.

#### **Question 26**

The concepts of property and ownership do not really apply to the human body – hence the reticence to define this in English law. My understanding of this issue is very limited. I believe that the only legal authority that can be imposed on a corpse is derived from the powers of the Coroner's court with regard to post mortem enquiries. Family members have no right to oppose this type of post mortem. The corpse does not become the property of the Coroner's court. The court assumes a custodian role on a temporary basis and which point stewardship for the body is restored to the family or the local authority in the absence of any next of kin. Family members remain the custodians of the dead person, but I am not sure whether in a legal sense that means the body 'belongs' to the family in property terms. Donated bodily materials belong to the recipients or end users in a commercial context. The law needs clarification on these issues. I do not have the legal expertise to suggest how reforms could be carried forward.

#### **Question 27**

Yes – provided that the welfare of the donor is maintained as paramount and distress to family members is minimal. This also assumes that the retrieval process is performed by a licensed authority following statutory guidelines and that fully informed consent has been given.

#### **Question 28**

No. The contract is struck at the point at which informed consent is given to participate in the donation process. Would the reverse apply? If the research led to a loss being incurred would the donor be expected to take some liability for those losses? How would you quantify the additional remuneration for a successful contribution to a commercial research process? Over what time span? Who would receive the additional gratuity if the success did not materialise for several generations and the donors had subsequently died? The idea is fraught with legal difficulties that would probably only benefit lawyers and accountants rather than the donors. It would be very difficult to assess what should be made payable and how such payments would be equitably distributed between a variety of stakeholders.

### **Question 29**

Explicit and informed consent to be a donor should mean that a contract has been struck at the point at which the agreement is made. I would question the legitimacy of the consent given if agreement to donate was not based on a precise understanding of how exactly the bodily materials would be used. The terms and conditions of the agreement would have to specify the exact uses for the donated materials; how they are to be stored, for what time period and how/when they are to be disposed. In my view, if these conditions are satisfied at the outset the donor relinquishes any further legal authority over the bodily materials. But what rights does the donor have to monitor this process? Can we rely on the integrity of the end user to fulfil their contractual obligation? Do regulatory licensing authorities have the powers and manpower to scrutinise these procedures? Do they have sufficient investigative resources and sanctions at their disposal to deter end users from abusing their position?

### **Question 30**

I would like to point out that it is with great reluctance that I advocate the use of inducements to encourage people to become registered/active donors. Altruism and compassion have to be the preferred motivation for donation. But this approach leaves too many families devastated by the death of a loved one who simply needed an organ transplant. As a society we have to examine alternative ways to encourage people not to burn or bury their organs when they die. We should very carefully consider the introduction of inducements/incentives in an attempt to reduce the shortfall of organ donation. Perhaps the focus should be on the living donation programme in the first instance as I suspect that rewards for donation after death may arouse greater controversy. There is very strong concern that deceased organ donation should remain as a gift. I want to re-iterate the point that many people die in circumstances that do not facilitate their wish to be an organ donor. Many of these people could easily be tissue donors. Tissue donation brings huge life enhancing benefits to thousands of UK citizens. Heart valves save lives too. NHSBT should focus more in encouraging acute trusts to give people the opportunity to be tissue donors. The frequency of this activity has much greater

potential to change cultural attitudes to donation than the much rarer occurrence of solid organ donation. I believe the recommendations of the Organ Donation Taskforce should be extended to encompass tissue donation too. In my response to question one I emphasise the fact that certain individuals have medical contraindications that prevent them from being donors even though that was their dying wish. Very few acute trusts make the effort to provide the opportunity to donate for research purposes. This has to be addressed too. Through the many talks that I have delivered to students the concept of donation is a subject that people prefer to avoid because it challenges our sensibilities about death. Often I hear people say that they do support donation but do not have the knowledge or opportunity to register. I suspect the failure to register as donors goes well beyond these practical issues to much more fundamental emotional and psychological factors. Mass media appeals for more donors cannot address these deeper barriers to donation to bring about a cultural change in values with regard to end of life choices. I believe that we need to examine how state education can be used to deliver opportunities to discuss end of life choices that would include an appreciation all donor opportunities. By placing these issues on the agenda of compulsory education avoidance people will have the foundations to make more informed choices about these sensitive subjects. Following in from the above point training for undergraduate nurses and medics ought to have a compulsory module of study on end of life choices, donation and transplantation. Training within hospitals focuses on the clinical responsibilities of donation/transplants with a very small number of trainees who will be expected to have direct hands-on experience with end of life choices. There is the need to broaden the understanding of donation to all health care staff simply because they are citizens who can also be donors and potential recipients. The NHS provides training for one of the largest work forces in the country who can also be called on to be ambassadors for the cause of donation in their local communities. These measures would genuinely help to bring about the cultural change in attitudes that is called for by the Organ Donation Taskforce. The Taskforce recommendations are effectively addressing the infrastructure barriers to donation within acute trusts with the creation of Donation committees, CLOD's and the unfortunately named SN-OD's. The donation/transplant process is very much a collaborative one involving NHS staff from a variety of disciplines and status. The structure is very hierarchical which can create a tension between clinicians and nursing staff as to the roles and authority retained by different colleagues in the donation process. Where an integrated team approach is able to flourish, evidence shows that the duty of care to honour the best interest of the patient can be achieved most effectively. With regard to donation when bereavement support is linked to requests for donation very positive results can be gained. Finally the mind set in the UK tends to be very apologetic and defensive about asking people to consider donation after death. Yes, it is a profound and sensitive subject worthy of great care and compassion. But I see no need for health care professionals to apologise to families for asking about donation following the death of a loved one. Virtually all donor families are grateful for the

opportunity to enable some positive outcome from a sad and distressing death of a relative. Families gain at least a crumb of comfort from the idea that the legacy of a loved one lives on through helping the life of a stranger. We should not be apologetic or defensive about this. This is the message that we need to get across to the public at large. The joy that transplants bring to families is beyond belief. The denial of a transplant that leads to an avoidable death is devastating. Self-evidently any measures that reduce the stressful waiting time for transplant listed patients has to be given serious consideration. Anything which increases the quality of donated organs and minimises the need to use sub-optimal organs has to be encouraged. I cannot imagine the anguish of families that have waited for a loved one to receive a double lung transplant to then endure the death of the recipient months later from lung cancer inherited from the donor. That is why this public consultation is so important.