Professor Peter Furness

Question 1
Please note that the list provided is not congruent with the definition of human tissue in the Human Tissue Act 2004. That Act deliberately excludes gametes, because they are regulated by other means, but its definition does include faeces and body fluids, including urine. This lack of clarity about what 'human bodily material' includes has caused problems with interpretation in various contexts.

Question 2
Yes. Indeed, I would argue that any attempt to treat 'human bodily material' as a single ethical issue, or even a small number of issues, is fundamentally flawed. The problems generated by this approach were illustrated by the debates around the Human Tissue Act 2004, which concentrated on the post-mortem organs of deceased babies, but which (largely without MPs considering the matter) produced legislation that covered faeces and urine. Each different type of 'bodily material', however that is defined, deserves different considerations; and the same type of tissue may demand different consideration depending on how it is obtained (e.g. post-mortem sampling, live donation or surgical resection as part of an operation to remove diseased tissue)

Question 3
Yes. In fact I would draw three broad categories (subject to comment (2) above). 1. Tissue (usually but not invariably blood) donated by the living specifically for research. This is unequivocally a gift. Naturally the donor must not be harmed. 2. Tissue that was otherwise to be discarded, whether down the sluice (e.g. urine) or as 'clinical waste'. Many regard using this in research as a gift, but I would argue that if it is otherwise to be destroyed as waste, the assumption ought to be that it should be made available for the good of mankind unless there is reason not to (such as a risk of any harm to the person whose body produced the tissue) 3. Post-mortem tissue. Some (notably Harris) would argue that the inevitable destruction of such tissue puts it into category (2), and furthermore the donor cannot be harmed. However, the fact that post-mortem tissue is a focus for grieving and funeral ceremony, with consequent benefit for the bereaved, makes it inappropriate to consider it in the same category as 'clinical waste'.

Question 4
Complicated question! In brief: For the living to donate an organ has obvious physical risks. A blood sample is less risky. Urinating into a bottle is arguably not risky at all. For the dead to donate carries no risk to them (unless you believe bodily integrity to be essential to an afterlife or reincarnation). But its use risks adding to

the grief of the bereaved. Other risks depend entirely on the use of the sample; this is too complex to discuss here. Anonymisation should eliminate these risks. Benefits are to society; explicitly accepting some responsibility for delivering some of the things that individuals are often keen to demand as rights. . In a discussion of ethics, surely this deserves more weight than it often seems to get!

Question 5
Not my area of expertise

Question 6
If donated by the living specifically for some purpose, then the risk depends on the nature of the material. Donating eggs is inherently more risky than donating sperm. Some uses of tissue would be regarded by most donors as ethically outrageous – for example, developing weapons of biological warfare. But there are areas that may be regarded as unethical by smaller sectors of the population; e.g. research into contraception, research that uses living animals.

Question 7
Of course! I would not support using tissue samples to develop weapons of biological warfare! The Nuffield Council on Bioethics report on human tissue from 1995 set out how to distinguish between ethical and unethical uses of human tissue. If, by those criteria, a use is ethical then it is very difficult to prioritise because the outcome is difficult to predict. It is tempting to say 'saving life', but hard to predict what will do that. A transplant tries to save life, but may fail. To use a specimen for teaching may seem less important, and often will be; but the lesson learned may over years lead to the saving of many lives. I would not personally prioritise uses intended to create more babies, because the world's human population is already worryingly large, and to help those with reproductive problems to reproduce is to attempt to reverse natural selection. But I suspect I am in a minority, and perhaps rightly so; to take that position will cause great distress to some.

Question 8
Yes, but my priorities are based on personal experience and would not be shared by others. Perhaps broad prioritisation is possible based on the level of suffering caused by the condition. But do I mean suffering by an individual or by mankind?

Question 9
Not if those listed are interpreted broadly.

Question 10
All the values listed are important. I do not believe that any one should automatically take precedence over the others. However, I strongly feel that recent debate has over-emphasised individual autonomy and under-emphasised other

values, notably reciprocity and solidarity.

Question 11
Concerning the provision of human bodily material, I believe that where the material would otherwise be incinerated as clinical waste (e.g. surgically resected material) there should be a presumption that it is available for any ethically legitimate purpose unless the 'donor' takes active steps to object. This is the position advocated by the Nuffield Council in its publication on the use of human tissue published in 1995. I believe the arguments in that document are still valid. Where this does not satisfy the need, and living donors / live healthy subjects are needed, there is a need to avoid financial coercion of donors. The line between 'expenses' and 'payment' is often difficult to draw.

Question 12
Yes. Where the human bodily material would otherwise be incinerated or disposed of as clinical waste (without risk to the original 'owner'), but it could be used to help others, there should be a duty to use it to help others rather than to destroy it.

Question 13
I can't think of one. I suspect this should be down to individual altruism, but individual altruism needs to be better recognised, praised and encouraged.

Question 14
Yes if the demand is legitimate – what sort of demand do you mean? A demand for human gametes for in vitro fertilisation is not a legitimate demand if those making the demand cannot accept the responsibility for caring for the child that would be produced. Of course some demands are more pressing than others. But raking them will always be very difficult.

Question 15
Recognition and praise, yes. Financial incentives are dubious.

Question 16
Of course some forms are unethical. Pointing a loaded gun at the head springs to mind. That example is at the extreme end of a spectrum of potential coercion and society has to decide with great care what level of persuasion is acceptable, probably on a case-by-case basis.

Question 17
Anything that suggested an inappropriate level of persuasion.

Question 18
Most forms of 'indirect compensation' have a measureable financial value, so the

difference is at best small. However, there is potentially a difference in relation to some forms of indirect compensation. For example, I personally believe that those who refuse an opportunity to donate organs for transplantation (without good justification – but what is good justification?) should have, to some extent, a lower priority for treatment if they themselves need a transplant. That represents an explicit link between rights and responsibilities and it does not have a financial equivalent.

Question 19
Yes. The former are easy to measure – ask for receipts. The second are not, so the value of the compensation is hard to decide and will inevitably arouse suspicion of 'payment for donation'.

Question 20
No.

Question 21
Of course. Pointing a loaded gun at the head springs to mind.

Question 22
Incredibly difficult! I am aware of examples where, after live organ donation, very considerable levels of coercion within the family were revealed. But none of us knew before the event.

Question 23
Yes. To demand entirely specific consent is to assume that for all the other myriad purposes to which human tissue may be put, there is refusal. Where there are special circumstances (e.g. research into contraception, research involving vivisection, as noted above) this may be appropriate and specific consent should be sought. If a proposed new use brings significant new risks to the donor, the donor needs to understand those risks so renewed consent is needed. But in general, consent to use a sample for a research projects suggests an individual who is favourably disposed towards research. It is best to check, if that is practicable; but if it is not, a presumption that such use is not permissible is very likely to be contrary to the individual's wishes. So general / broad consent should be accepted. See also my response to question 3; if a biological sample is otherwise to be destroyed as waste, the assumption ought to be that it should be made available for the good of mankind unless there is reason not to (such as a risk of any harm to the person whose body produced the tissue). As recommended by the Nuffield Council on Bioethics in 1995. In my opinion, to block such use is not ethically 'safe' or even 'neutral'; it's downright unethical because it unnecessarily blocks possible benefits for society.

Question 24

Yes, as considered in law. How do we decide what is 'best interests'?

Question 25
I believe that if a clear wish has been recorded before death, the situation should be entirely in parallel to disposal of the deceased estate. There may be certain circumstances where the will of the deceased may be challenged, but not many. By default, the wishes of the deceased should override those of the family, perhaps unless those wishes are obviously malevolent. If the wishes of the deceased are not known, the role of the family should be to try to indicate what the response of the deceased if asked before death. We should seek as far as possible to avoid asking the recently bereaved to make difficult decisions. It can add considerably to their distress. But that does not mean that we should allow an opportunity to help the living go to waste.

Question 26
Current law is appropriate.

Question 27
No.

Question 28
Current law is appropriate.

Question 29
They should be allowed to withdraw consent if they choose to take active steps to do so - unless it is impractical, such as an organ that has been transplanted or a research sample that has been irreversibly anonymised. But consent for tissue use should be regarded as 'durable' unless it is specifically revoked.

Question 30
As a general comment, I believe that in recent years this debate has been distorted by an emphasis on human rights. A right has no meaning unless someone or some organisation accepts responsibility for ensuring or delivering that right. In healthcare, 'rights' tend to be assigned to or claimed by individuals, whereas delivery is commonly assigned to organisations or governments. This generates two problems in the context of medicine and human biological samples. First, human biological samples can ultimately be provided only by individuals, not by organisations. If individuals do not accept that responsibility in sufficient numbers, the current system will fail. Second, the nature of the debate encourages selfishness. Individuals are usually happy to claim their rights. In doing so, they may not even consider the entailed responsibilities. If they do, to attribute responsibilities to a government or large organisation is to depersonalise them. It actively discourages those who claim rights from considering how they have a duty

to help deliver rights for others. If, as a result, the individuals who make up society become more selfish over time, the delivery of rights will become progressively more difficult. The first human tissue legislation in the UK was passed because society had a need for human bodies (to train doctors and advance medical science), but as a result of social attitudes and beliefs there were too few altruistic individuals to supply the need. The legislation stopped 'bodysnatching' not by prohibiting the removal of corpses from graves, but by providing a supply of corpses for the benefit of society. It did so by the ethically dubious method of permitting the dissection of the bodies of deceased paupers, without their consent. To me, this shows that having a population that is willing to volunteer for clinical trials and to donate tissue samples for the benefit of others is not a natural state. It cannot be assumed. It is a civilised state that must be nurtured. To emphasise individual rights and simultaneously to ignore individual duties does the opposite.