Miriam Pryke

**Question 1**

Any human tissue belongs to a person not as property belongs but as constitutive of the person. In principle, any bodily tissue therefore raises ethical concerns because a person is giving part of themself, not something they own. Because body material constitutes the person, only the person can say whether they are willing to donate any or all of it, while alive or after their death, and they must do so purely on the basis of the relevant issues and not under moral pressure or pressure of incentives. All types of tissue therefore raise concerns, though different concerns arise with different types and at different times.

**Question 2**

Each type of tissue is special - raises its own issues, and should be treated on its own merits.

**Question 2**

Valid consent is paramount, whatever is proposed to do with someone's bodily matter. Without the valid informed consent of the person whose body it is, to the proposed use, there can be no question of using their bodily material for anything. A human body is a human person, and should be regarded not as a resource, but as an individual: all research, all medicine, is practised in order to benefit the individual person who receives a treatment. If an individual is violated in the course of research to find better treatments, the point has been lost. Nobody, however sick, however doomed, wants to benefit from the violation of another human being. So, if human tissue is to be used, it must be used with due respect, and the valid consent of the person whose tissue it is. Respect for the person who donates must always trump any amount of perceived benefit to be gained from using their tissue for others. Different tissues and different uses raise different ethical issues; it cannot be assumed that what is permissible in connection with one type of tissue or one type of procedure, will necessarily apply to other tissues or procedures. Each must be considered on its own merits. And probably constantly reviewed as technology develops. The means used to procure the tissue is also relevant to the moral acceptability of any proposed use. Dead people are people who have died: they are not carrion, and should be treated with utmost respect. It is very important that this debate is conducted, and that the whole population participates, because there is a gulf between public understanding and the current state of medical possibilities which it is too late to start finding out when one, or someone close to one, gets a diagnosis for which interventions dependent on these procedures are needed. Nevertheless, the very fact of this debate worries me: I am frightened of the commodification and devaluation of the human body, and I am frightened of being regarded and treated by doctors and related workers as a case,

a recipient, material, a resource, rather than as a sensitive individual with a life, a unique set of circumstances, concerns and values who may or may not want to avail myself of something they have to offer. It should be remembered that everyone has things they would rather die than do, and these will be different for different people. What one person finds acceptable another will not, and the individual's viewpoint, as donor, as recipient, is paramount.

**Question 3**

There may be differences with respect to very particular issues, but the moral concerns do not cease to be operative after death, i.e. a dead person is a dead person, and not an object or a thing, and must be respected as a person. That they cannot express preferences, or even have them, after death, does not nullify any preferences they might have had before death, where the wishes of the dead person are concerned. But there are things other people may not do in relation to a dead person regardless of any preferences that person may or may not have had, or may or may not have expressed, in their lifetime or in a will. There are limits to what people may do, limits to what one person may do in relation to another, and that applies to dead people as well as living people. It is not always possible to specify in advance or in general terms what the limits of human behaviour are, or are going to be, in particular eventualities.

**Question 4**

My personal view is that a person, a human being, is their body, and that body is infinitely immeasurably precious, and the violation of its integrity is always a sad thing, even when done as a necessary evil, as with surgery to save the person's life with their consent at a cost they accept. The violation of that priceless thing must therefore be avoided wherever possible and only done with the consent of the person whose body it is, and not even then if it were immoral (some people consent to things which other people should not do to them). Some uses of bodily material provide a lease of life at a quality for another human being, while others offer uncertain prospects in terms of longevity and/or quality and are, or may appear, experimental. The full understanding of all involved of the nature of the undertaking must be assured before proceeding, since some people may object to being used as experimental subjects, because this is a violation of human dignity, and should not be done without informed consent. That is, in my view, use of bodily material is always a use of a person, and people should not be used; but there are times when people will consent to this, and provided they know and understand that this is what they are doing, and those who do it to them, and those for whom it is done, appreciate the nature of the deed that is being done, that a person is

**Question 5**

Costs of participating in first-in-human trial: will be whatever the harm of the things done to the person are, and all medical procedures or processes produce harm,

however small. Different individuals will evaluate the harms differently, and it is the one who sustains the harm whose view is paramount, whatever the perceived benefits. Therefore they must be fully informed of the costs they will incur. Benefits: given we are talking about trials which do not benefit the person, the benefit of this individual's participation in the trial is that something is learned from the trial that was not known before and is, we hope, pertinent. A person who is willing to participate in a trial may derive some measure of personal satisfaction from having made a contribution for the ultimate benefit of humanity: it is therefore important that this person understands lucidly exactly what the trial aims to achieve, and exactly what it has achieved, in order that the person has a true understanding of the worth of their contribution, and not one that is either inflated or an underestimate. People should not be induced to enter a trial on exaggerated claims about its potential benefits, nor allowed to participate unless it is clear to those conducting the trial that they understand its scope and limitations and will be informed, as far as possible, of its outcome. Risks: are whatever the risks are, insofar as they are understood, for the particular trial, and obviously the person should be fully informed. A person may need to have statistical risks explained to them and time should be taken to ensure they understand what the statistics mean, and that, given that the outcome is unknown, if there is, say, a 1 in n chance of some adverse consequence, the person should be made to understand that there is no way of predicting whether she will be the one, or one of the n, and that it is possible she will be the one, and possible she will be one of the n. Relatives and those close to the person may be affected if the person is affected. Given the time taken to develop treatments, they are unlikely to benefit from the trialled treatment, though it is possible; they are more likely to be affected by any harm the person sustains in the trial in having to cope with its effects.

**Question 7**

Blood is least problematic to me, because it regenerates rapidly and may be procured relatively simply, and because it can make the difference between death and normal life for another person. I would give blood if I could. I personally would never give away gametes or embryos because I want to know and raise my own offspring. I have missing family I have never met, as a result of war, and I long for them. I would never willingly place a potential individual in that position. Further, the procuring of eggs is non-trivial so could not be done purely for research. I have not had infertility treatment; if I had had it, and had spare eggs or embryos, I still could not give them away for the above reason. I have heard of a group of sisters who did this: because they are the same family and the offspring produced grew up within this extended family, I find this less problematic, though I would be interested to know the feelings of the offspring thus reared. I might allow spare eggs or embryos to be used for research, but would like to know as far as possible what sort of research. Aborted foetal material: hasn't arisen for me, but looking at it from here, I could not allow the use of this material because I could not bear the thought of the calculated destruction for scientific curiosity and public benevolence

of what to me is an individual, albeit dead and undeveloped. I know what sometimes happens in abortion; better it doesn't happen; tragedy when it has to; I blame no-one for that; my sensibility resists compounding the insult to the individual foetus by using it as a resource no matter for what benefit to others. Organs: I am frightened of being placed under moral pressure to donate and being judged by medics should I decline, because I am frightened that medics lose sight of the wood for the trees. That said, I guess I am now considering whether I would donate an organ to one of my children. If there was a good chance of it giving them a good lease of life of good quality, and depending on what loss of the organ would mean for me, I might. I would not do it if the procedure was experimental, or unlikely to succeed, or to give good quality of life, or would make me permanently ill. I would discuss it with the family. I am worried that it could give rise to unforeseen issues, resentments, etc ("I gave you my kidney and you treat me like this?" "If you had given me your kidney I wouldn't be suffering like this" "Were they telling the truth when they said your tissue didn't match or was that just an excuse?" "Doctor you never told me what these complications would be like" "Couldn't you have offered your kidney, why is it always me who makes the sacrifices?" and godknows what else) and thus create as many problems as it is meant to solve. Tissues or organs or body after death: My sensibility resists the plunder of corpses for bodyparts. This is not trivial. It does not entail that one might not decide to master one's feelings for the sake of a greater good, if it were a greater good. It does entail that those feelings should be respected, and I am frightened of them not being - either in the case of my own body, or the body of someone I love. I am frightened that the body would not be respected by the researchers who use it. How would I know that the research was genuinely for the public good and not merely idle curiosity, or worse, that it might be used for purposes I would find abhorrent? I find it easier to countenance the idea of donating, say, just corneas, or just an organ: provided that this is a generally successful procedure and would give sight to someone, or a genuine lease of good quality life, then it would be a good thing. I do not want my body parts used to prolong someone else's agony or give them false hope. I would not want my whole body, or my loved ones' whole bodies, to be destroyed. I would not accept a donated organ. I would have to accept that my time had come to die. If I was blind and a cornea transplant could restore sight, provided there are not downsides that I do not know about, I might want that, so I would have to be prepared to give my corneas. I would not be prepared to allow my tissue to be used in commercial transactions. If I give it, I give it freely and nobody else makes money out of it.

**Question 9**

Some people consider the human individual sacred. They need not be religious. It is a way of expressing the view that a human individual is unique, irreplaceable, and a limit to what others may do. This means the individual is an absolute limit on what may be done. This grounds the idea that the point of scientific endeavour, medical science, is to enhance the lot of the individual - not to maximize benefit overall.

The individual is often lost sight of in considering public health issues; but the health of the public is the health of the individual members who make up the public, and the good of one member of that collectivity may never be sacrificed for the sake of any or all other members of that collectivity. No matter how great the benefit to others, an individual may not be harmed for their sake. An individual may, if the stakes are sufficiently high, and only they can judge that, sacrifice herself, but may not be sacrificed. A measure which benefits many may harm some. No-one may benefit at the expense of another. People do not count equally - they count absolutely.

**Question 10**

The individual is paramount. The point of medicine is to benefit the individual. The point of research is to find better ways to help individuals. A doctor does not aim to maximize the public good. She aims to help each individual who seeks her help. If you harm someone here and now for the sake of finding better treatments for others in the future you have negated your aim: they are not more important than this one. Why seek better treatments to help future people if, when the future arrives, you are going to harm those people to help yet future people? If you do that, your aim is to test treatments, not to help people. If that is what you want, you had better inform people you recruit for research that that is what you are doing. You may not harm this one to help that one. You may not harm this one to help those millions. You may not harm this one to save the world from destruction. No-one wants to benefit at the expense of another person; no-one wants the medical and related professions to act on their behalf such that they benefit at the expense of another, especially if the beneficiary does not know that it has cost another for them to receive benefit. It compromises the beneficiary if they benefit at another's cost. They trust the medical and related workers not to compromise them in this way. They trust the medical and related workers to deal honestly and not to use them as a means to the end of satisfying medical curiosity or saving other people's lives. A person who wishes to contribute to the progress of medical science may freely choose to do so. They must be properly informed of the costs to them of so volunteering so that their consents to procedures are valid. They may do so out of self-interest, if they hope they or their loved ones may benefit from so doing; or out of generosity and compassion for the suffering of others; or out of recognition that they are part of a community with common ideals, values and vulnerabilities, though they cannot be required to give of themselves as a duty - allowing one's body to be made use of for medical purposes is above and beyond the call of duty; or out of a sense of indebtedness because they have received help from others, though they cannot be required to give back just because they have received, and what they have received ought to have been freely given.

**Question 11**

Repaying people for bodily material introduces issues other than moral ones into consideration. People then ask themselves not only whether it is right to do what

they propose, but whether it is in their interests. Anything can be made to be in someone's interests by pricing accordingly. Vulnerable people should not be induced to consider entering into medical processes with risks of harm because they hope to gain materially from so doing. Their consent would not be morally valid, whatever a court of law might say. No amount of perceived benefit to other people can justify placing pressure on autonomy and compromising a human individual in this way. Medical science should be free of any hint of such practices. Pragmatically, undertaking such practices will undermine trust in the medical profession because people will fear that priority is being given to securing participation over ensuring valid consent.

**Question 12**

No, never, under any circumstances whatever, never, not even if the continuation of the human race depended on it, and the human race would come to an end without it, not even then is there a moral duty to provide bodily material during life or after death. Each individual human being constitutes a limit to the actions of other individual human beings such that no human being may take what another human being does not freely give. This would be true even if that person ought to give it, which, if it ever is the case, is not the case here. No human being is ever under any circumstances whatever morally obliged to give up a part of themselves for another. No human being can ever under any circumstances whatever expect, require, demand or claim for themselves a part of another human being, living or dead. You get one life. When your body packs up, that's it. You can't take other people's. If they freely give, that is quite another matter. A world in which we take, we demand, from people what they do not freely give, is not a world worth living in.

**Question 13**

No, never, not ever, not under any circumstances, ever, whatever, never. Not to save the world from a pandemic. Not if the whole world is faced with certain death if you don't coerce people. There is no such moral duty. Moral duties cannot be created. What can be created are coercive laws. You can make coercive law if you want to, but would that be the kind of world you wanted to live in? You won't have to; people will volunteer - some will regard it as their duty under such exigent circumstances. Others will still not be under such moral obligation. People are differently placed. One size does not fit all. Let them decide; coercive law will pick the wrong people. Let it be.

**Question 14**

The commercial language of supply and demand is inappropriate and morally wrong in this context. Human beings and parts of human beings are not commodities for the use of other human beings. What is the case is that there are more cases of people who want bodily material from other people, or doctors who want to use it, than there are bodily materials made available by people for their use. No human

being can ever be in a moral position to expect, require, demand or claim for themselves part of another human being, living or dead. However, it is also true that some human beings are willing to give parts of themselves to others. It may also be true that others would be willing to do so if they were aware of and understood the issues. Currently there is a gulf of understanding between the medical profession which makes use of techniques involving donated human material and the general public who are not sufficiently aware of what and how things are done until they find themselves in a situation, which is too late to start finding out. It is not morally wrong, and is probably morally required, to inform, educate and debate with the general public about all of the issues related to donation, freely, openly, transparently, in a fair, balanced way, before a situation arises for them which places them on a steep learning curve and may place them under moral pressure, so that each member of society is prepared and equipped to take a view on whether they would wish to receive, or donate, their bodies or parts. There is no other ethical way to address the discrepancy, and if we arrived at a position where everyone was appropriately informed, and recorded their choices, yet there was still a shortfall of donors or in amount of donated material in relation to number of procedures which could be performed(which might not be the case), we would all have to accept that fact. We would have to devise the fairest possible system, within pragmatic and technical constraints, for allocating insufficient resources.

**Question 15**

Expenses are acceptable; loss of earnings could be problematic. compensation is different from incentive: compensation repays something that has been lost by the person

**Question 16**

An incentive is what it says it is. It will be effective. But no action which aims to influence the behaviour of some people by weighting it in favour of others in this sphere can be morally acceptable. Certainly not institutionalized actions. I have no interest in legislating for what private people may agree to amongst themselves. But such arrangements cannot be institutionalized, made standard professional practice, and remain within the morally acceptable. Practitioners will debase themselves, and respect for and trust in their profession, if they engage in practices which some private individuals may be willing to do and other private individuals have no right to comment on.

**Question 17**

An incentive is a bribe. To accept that incentive is to succumb to a bribe. Offering incentives to people to provide bodily material or participate in a trial morally compromises them, and thus degrades those who offer the incentive. An incentive is a temptation. It causes people to question moral boundaries and tempts them to

move them for other than moral reasons. Who knows what circumstances may arise which could make you do something which in other circumstances you would not do? In other countries people sell kidneys; how bad would things have to be for you to sell your kidney? Can you guarantee that things will never get that bad in this country? Only if we safeguard our values by refusing to commodify people's bodies. It should be no part of medical practice to tempt people into finding out what they will do when the circumstances press them; there are things people should not do, at any price, and it is wrong to tempt them. If medical science starts to do this it will have crossed a line, on the other side of which is a slippery slope.

**Question 21**

Anything that is an incentive invalidates consent automatically because it commodifies that which is not part of an economy, but belongs to a human being not as property but constitutively. Bodily material is not part of a person, it is constitutive of a person, and as such cannot be priced - cannot be converted into currency, which is what incentives do. To offer a person the opportunity to convert their bodily matter into currency is to place a temptation before them which constitutes a pressure to give which in its absence might alter the decision. Imagine offering a disincentive: instead of offering money or free medical treatment or whatever for bodily material, imagine charging people money for donating bodily material, or imposing fines or punishment on those who do. Clearly that would influence their decision: it would not be a decision made purely on the basis of the moral issues but would now be a matter of personal prudence - regardless of whether it would be right or wrong for them to donate material, it would now be unwise. If disincentives influence decisions in the wrong way, then equally incentives influence decisions in the wrong way: regardless of whether it would be right or wrong for a person to donate, it would now be in their personal interests. People should be making decisions to donate or not donate purely on reasons internal to the moral issue and their decisions should not be influenced either one way or the other by incentives or disincentives.