

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.

Question 3

Yes, because there may be risks to current or future health from providing organs or tissue during life. So although statistically, living kidney donors have above average life expectancy (because they need to be fit and healthy to donate), the operation carries risk, and if the donor goes on to develop kidney problems this could be life threatening or life limiting if they only have one kidney. Some tissue donation is painful (even sometimes giving blood samples). However, if you are alive you can give informed consent, which is what is important ethically. Once you are dead, tissue or organ donation isn't going to be any risk to your health.

Question 4

From personal experience there are considerable risks to live organ donation, my partner experienced a collapsed lung within a day of donating a kidney (to our son) and was unwell for several days, in pain and suffered acute upset stomach due to the anti-biotics. However, our son is well and thriving, so we would do it all over (and may have to in the future). My partner's employer agreed to paid leave, but did treat it as sickness (he was off work for 6 weeks) and did institute their sickness management procedure, which was unnecessary and stressful. However, my son and our entire family has benefited enormously, and also, my partner got himself very fit before the donation, and takes much more care of his health now.

Question 7

My only reservation about providing bodily material is if it was for commercial use or exploitation. So, I would be unlikely to volunteer for a drugs trial or donate bodily material to a commercial organisation, especially if not for a defined purpose. I don't object to people being paid to take part in drugs trials or to donate bodily material for research where a company may well end up making profits as a result. Likewise, if IVF and other fertility treatment is paid for by individuals, I see no reason why egg or sperm donors should not be paid for their bodily material. However, as we have a free at the point of use NHS, which carries out various treatments and procedures involving bodily material, I am not in favour of people being paid for this material. Separately, people should not necessarily experience a financial loss due to providing bodily material, so there should be provision to pay for lost pay or similar, or additional care needs, if someone donates bodily material within the context of procedures and treatment provided by the NHS, or for non-commercial medical research.

Question 8

I would probably consider participating in certain trials depending on the purpose of the medicine, and whether the medicine or treatment is likely to be used by the NHS. I'm not a big fan of some types of cosmetic surgery provided privately, but a

friend recently had a breast reduction on the NHS, so it is not always easy to be sure whether the research will be used on a not-for-profit basis or for purely commercial purposes. I would consider the likely uses of the treatment or medicine, although I accept that some medicines are developed for a particular use and end up being used for other purposes. As an individual, I not sure it is about prioritising purposes, although I would be generally more inclined to participate if there was likely to be a benefit to my family in terms of treating/managing conditions that affect us.

Question 14

I think it is right to try to meet demand for organ transplantation, as this can be life saving in an immediate sense and quality of life improving in the longer term (as well as generally saving money compared to long term management of a serious, chronic condition). If demand is met within the UK, there would be far less, if any, "tourism" for organs. I suppose the demand for bodily materials to develop treatments or cures for currently incurable conditions is important, and perhaps should take precedence over developing new treatments for curable or more easily managed conditions. But there is also a societal benefit to developing more cost effective treatments or treatments with very few side effects, especially for conditions that effect large numbers - statins are an example of this, or key-hole surgery. But how pressing is the need to develop treatments for a range of conditions that are irritating or have a minor impact on quality of life, but are not life threatening or life limiting. I was struck by the range of medications advertised and available in the USA for conditions such as "bladder urgency" - which have hardly been medicalised in this country. I do have a view that "big pharma" creates or medicalises conditions to stimulate demand for their products or to find uses for expensively developed drugs.

Question 16

I'm not sure how "benefit sharing" would work or if it would be desirable, for as long as demand, say for organs, exceeds supply, there has to be some form of prioritisation - in relation to possible outcomes, age/years of life added, family impact, compliance with post-transplant regime. This would open up prioritisation effectively on non-medical grounds, and is a potential reward.

Question 18

No, I don't think so, everything has a cost/price/value.

Question 19

In terms of live organ donation, I would like to avoid a situation where people can "make money" in some way from the donation, but I do think it may be worth considering a wider range of claimable expenses (for example, additional care or domestic help - my partner could do very little for a number of weeks after donating a kidney, I ended up with chronic back pain for two years due to the

additional strain of physically caring for our son post-transplant, because my partner couldn't help as much as he usually does, and my son's needs were greater than usual) arising from the impact of the donation. There should not be any situation where a friend or relative is worried that they can't afford to do.

Question 22

I think this is probably not possible, although in my personal experience there is a degree of rigour in ascertaining that the donor is comfortable with the decision. But family (or even peer) pressure, guilt, expectations can be very subtle and hard to disentangle. Some friends and colleagues said to us after the transplant that they thought we were very brave, that we had done a wonderful thing, that they don't know if they could do the same. I think that most people, given the chance to save a life of a child or partner or sibling, would do so willingly. I have a colleague whose mother needs a kidney transplant, is on dialysis, but is adamant that she won't accept a kidney from her son, because of the risks involved - so family pressure works the other way too!

Question 24

I think there is. I would not want my younger son to even consider live donation to his brother until he was an adult (over 18). However, if the situation arose where my older son needed another transplant, and my younger son was the only related donor in a position to do this, it would be a really difficult situation. I think once he was a teenager, he could probably give some form of informed consent, but it would be a really difficult situation - it would be so hard to make him believe that he was free not to donate, and we wouldn't in some way hold it against him.

Question 25

I don't think families should have a right of veto if the dead person's wishes are known e.g. donor card, and I would prefer a policy framework where family were informed, but their objections noted but not to come in the way of taking the organs or tissue. Where the wishes are unknown, I think families should be persuaded as much as possible, including hearing testimony from other families who have agreed to donation in these circumstances, but I think that they should be allowed to veto ultimately. If there was an "opt-out" policy, then as long as a dead person had not "opted-out", there should not be a family right of veto.