

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.

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Question 1

Ethical issues could surface when genetic studies are performed on the transplant donor. The scientific rationale for such work is not in question but have the potential consequences for the donor's living relatives been fully considered.

Question 2

No. All donated tissue/ organ is "special" and should be treated with respect.

Question 3

Potentially. The ramifications for both the donor and family should be considered in both settings. The onus of responsibility for the donation is shifted after death, this poses ethical concerns.

Question 4

It depends on the setting and the reason for providing the tissue. Psychological support may be paramount for some people if they enter into the transplant programme - success is the positive sign of the coin - failure is the cost. If it's a living donor, the feelings they will have to live with. Protection of an individual's confidentiality is paramount in the research setting as disclosure of certain findings could lead to discrimination - evidence-based medicine is the benefit.

Question 5

I can't comment using healthy volunteers but in the oncology setting this type of work allows the patient to come to terms with their prognosis in a time that is suitable for them. It also gives them a level of security because of the high level of care that is delivered for this type of work. If this work is performed properly the risks are reduced to a level that is usually acceptable to the patient and the patient's carers. There is also a benefit to society if the treatment ultimately results in an improvement in current care for that disease.

Question 6

Previously mentioned.

Question 7

Yes. It would depend on the reason - if it was a living donation I would definitely agree. However if it is for research purposes I would evaluate the scientific integrity of the research project being proposed to me. Donation for unspecified purpose is not acceptable to me as there have been so many projects that have

been ill-defined and are not properly performed with little value at the end result.

Question 8

I would find it more acceptable if I had the disease/condition for which the trial was evaluating the medicine, primarily because of the time factor. The trial design would also be a factor, is it being performed correctly, is the scientific evidence sound and do I have confidence in the research team looking after me, would be things that I would look for.

Question 9

Fair representation of values mentioned in within the document.

Question 10

I think dignity and justice should always prevail with solidarity being the last value. Solidarity can lead to a greater responsibility being placed on certain individuals with others not having to contribute at all.

Question 11

Not really. The motive to take part is more the issue.

Question 12

A parent may consider it a moral duty where genetic conditions are inherited. This may challenge the parent for him/herself but also if the material was to come from a sibling.

Question 13

Inherited diseases.

Question 14

I think it is right that we try and meet the demand, but realise that this is not always feasible. There is a moral issue providing organs for transplantation if the recipient has little intention of adopting a healthier lifestyle to facilitate the optimum chance of success. Unfortunately George Best and his surgeon was a prime example of the negative element of the transplant debate and lent itself to question whether the organ should have gone to a recipient with a greater need, not necessarily one who had fame and money.

Question 15

This can be helpful and a positive factor. Currently the different forms of compensation are adequate. Recognition of making a valid, worthwhile contribution to further advance medicine is generally well viewed.

Question 16

Huge sums of money. This could lead to bullying and/or coercion and if given by a relative could result in a division within the family if the outcome was considered detrimental.

Question 17

I would not like to be offered free treatment. I consider that here in the UK treatment should be given free of charge, and that if this was being used by researchers/my medical team as an incentive, it would make me question their integrity, reduce my respect for them and seek alternative care.

Question 18

Depends whether the environment is the private sector or an NHS setting and which type of compensation is offered. Free/reduced cost fertility treatment may be more appropriate and useful at a societal level rather than a straightforward financial reimbursement. In the oncology setting where patients are extremely vulnerable, it would be very easy to exploit the patient by offering financial inducements.

Question 19

Yes - compensation for economic losses is factual, other factors are a personal interpretation - who determines what is an inconvenience or a discomfort to any one individual.

Question 20

I don't envisage a time when the supply will outstrip the demand, newer technologies/therapeutics have led to increased numbers of patients being treated, and the associated supportive research programmes increase. Streamlining any of the processes may lead to more refined research, but this has usually resulted in an expansion of bodily material being requested - not less.

Question 21

Over-zealous positivity for the intervention by the researchers, such that the information imparted was not balanced.

Question 22

Very difficult. It may be easier to determine, if the family member is of the age where a level of consent can be expected. It would be useful if an independent third party could be present and be part of the process.

Question 23

Yes - those mentioned in the document.

Question 24

Yes, because there is a moral duty of care when making a decision on behalf of another person.

Question 25

Family members should respect the wishes of the deceased. If these are not known the spouse/parents should have final say on whether bodily material may be used.

Question 26

The position and role of the immediate family should be recognised.

Question 27

No - I think this may lead to unscrupulous behaviour from private harvesting companies.

Question 28

This would be difficult to monitor. It may be better to ensure that the research performed is of a high quality and is valid to ultimately benefit society as a whole. This would be far easier to manage through the regulatory frameworks in place.

Question 29

Consent is the issue. If researchers are aware that they will likely want to utilise already donated tissue, then it would be far better to say this on the original consent form, even if future projects are not identified. For bodily material requested after death - the role of the family needs to be considered and there are satisfactory processes in place to address this situation.

Question 30

No