



Nuffield Council on Bioethics: Human bodies in medicine and research

**Report of deliberative workshop on ethical
issues raised by the donation of bodily
material**

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1. Executive summary

1.1 Background

In 2009 Nuffield Council on Bioethics established a Working Party called 'Human bodies in medicine and research' to consider ethical issues raised by the provision of bodily material such as organs, blood, skin, bone, cornea, sperm, eggs, embryos, or even whole bodies, for medical treatment and research and participation in clinical trials. It is planned that a report outlining the group's findings, including recommendations for policy, will be published in autumn 2011.

The Working Party held a public consultation between April and July 2010 which was publicised as widely as possible and enabled anyone with an interest to submit their views. However, they also wanted to explore the views of those without any particular interest or previous experience in the subject matter.

To this end, the Nuffield Council and the research consultancy Opinion Leader jointly applied for a Wellcome Trust People Award to hold a deliberative workshop with recruited members of the public to explore their views on this topic. The grant was approved in April 2010. Following several months of planning, the workshop took place in Bristol on 26th July 2010, and was attended by 43 members of the public, recruited to be broadly representative of the UK population as a whole (a full sample structure is provided in section 2.4). The workshop was arranged and facilitated by Opinion Leader staff, with members of the Working Party taking part as speakers and observers. The workshop consisted of a mix of plenary sessions, presentations, breakout sessions and individual and group exercises (a full description of the method is provided in section 2.3).

This document provides a full narrative of the discussions that took place at the workshop. It was produced by Opinion Leader using data capture.

1.2 Pre-existing views on donation

Participants showed a good general knowledge of donation in table discussions, as described in section 3.1. They were familiar with the practice of donating a wide range of different bodily materials including blood, organs, tissue and gametes, and were aware that bodily material is taken from both live and deceased donors. They also knew of several different uses of donated bodily material including the preservation of life, improvement of quality of life and the creation of new life. However, they did not spontaneously consider research as a potential use of donated material.

When considering the importance of these different types of donation, participants tended to prioritise those which were most directly involved in the preservation of life, such as blood and organ

donation, followed by those that were involved in the improvement of quality of life; as highlighted in section 3.5. Research was seen as having potentially greater benefits than direct treatment, as it could lead to positive impacts for a great many people, and so for some was seen as important as donation for life saving treatments. However, overall it tended to be seen as less important as its outcomes were less tangible and certain. Donation for fertility treatment was seen to be of lowest importance. Despite participants seeing that it could be very important for those in need of donation, creating life was seen as of lower social importance than preserving and enhancing existing life.

As well as types of donation, section 3.3 shows how participants also had good general knowledge of the ethical issues relating to donation. They spontaneously raised issues relating to supply and demand such as a perceived deficit of blood and organs for donation, and even nuanced issues relating to shortages affecting particular ethnic groups. They also mentioned, without being prompted to consider them, issues relating to consent such as arguments for and against a move to an opt-out system of consent, and relating to incentives such as the prospect of payment for organ donation.

1.3 Issues of supply and demand

Participants said spontaneously that they saw meeting the demand for bodily material as important, and this sense was reinforced when they were provided with information relating to the current deficit of donor material in the UK. As highlighted in section 4.2, of particular concern was the number of people (1,000) who die each year awaiting a donor organ.

They perceived a moral imperative to meet this demand, and in principle endorsed efforts to attempt to increase supply to this end. However, they were immediately cautious of the methods that were used to increase supply, particularly the potential for an opt-out system of consent and the use of financial incentives.

Section 4.3 describes participants' discussion of the potential to increase supply through the adoption of an opt-out system of presumed consent. While some were supportive of this system, others felt that this system would take the decisions out of the hands of donors, which was seen as their proper place, and put them in the hands of the state. Incentives were also seen as a potential way of meeting demand, however on the whole participants were extremely cautious about the potential for donors to be coerced into donating bodily material. They felt that donations should be made if, and only if, the donor thought it was the right thing to do, not because of any external influence.

1.4 Issues of consent and control

Consent for donation was seen as being at the discretion of the donor in the first instance, and of relatives of people who die and leave no indication of their wishes. However, the case of a deceased donor who has made their wishes to donate clear, and whose wife is against the donation described in section 5.3.2, split the opinions of the participants. Some felt strongly that the donor's wishes should be followed and the donation be taken, and others felt that the wishes of the wife should trump those of the deceased as she may suffer emotional trauma if the donation were taken. It proved impossible to reach consensus on the right course of action in this case. However, it was seen by all participants as highlighting the need for families to discuss donation and their wishes relating to it openly in order to avoid this type of situation arising.

The only case where consent was not seen to sit either with the donor or their relatives was in the case of 'waste' bodily material following a medical procedure described in section 5.3.3. In this case participants unanimously agreed that consent could pass to healthcare professionals, as this type of donation was seen as having no scope to harm the donor in any way. However, participants felt this type of donation should be regulated, potentially through a team of healthcare professionals making decisions, or alternatively their actions being over seen by an ethics committee.

Whilst consent was seen as being predominantly in the hands of donors, this did not necessarily mean that healthcare professionals should be forced to accept donation. As highlighted in section 5.3.4 participants felt that it was right for healthcare professionals to be able to reject donations where they considered them not in the best medical interests of the donor. Again, it was felt best that these medical decisions should not be taken by a single doctor.

Control of donated material was seen as being mainly the responsibility of healthcare professionals, who participants felt should follow the principle of prioritising patient need. Overall, donors were seen as giving up control over their bodily material when they donate, although they thought that it was entirely at the discretion of the donor whether or not to give their bodily material under these conditions. An exception to this rule, described in section 5.1.2, were the donations of organs from one donor to another known specific individual e.g. a family member, because this decision to donate is predicated on the organ going to a particular individual. Also, a minority of participants felt that those donating gametes should be able to stipulate who it should or should not go to. However, on the whole participants felt that donors had no moral rights over the use of their donated material.

1.5 Issues of incentives and recognition

Altruism was seen as the main reason why people do, and should, donate bodily material. Participants tended to favour incentives and recognition if, and only if, they maintained altruism as the primary reason for donation; as shown in section 6.1.

Cash-based incentives were generally opposed for a two reasons. Mainly they were seen as potentially coercive, encouraging people to donate 'just for the money'. Section 6.3 describes how this was seen as a negative not only because it was seen as debasing the concept of donating for altruistic purposes, but also because it was seen as potentially promoting inequality because it was felt they would mostly appeal to less well-off people. Secondly, as described in section 6.2, cash incentives were not seen as particularly appealing by participants, who saw recognition and benefits in kind as more likely to sway people to donate. There were two main exceptions to this rule. Firstly, as highlighted in section 6.4.3, the offering of a contribution to funeral expenses as an incentive for donation of bodily material after death was seen as an appealing concept because it was aimed at helping the relatives of the deceased, rather than the donor themselves, and because it was seen as suitable recognition for the contribution of the donor after death. The other exception was payment for medical trials described in section 6.4.1, which was seen as fair compensation for the risks involved. For a few participants, payment for donations of gametes for private fertility treatment was also seen as a fair recognition of their contribution to a profit making process.

Benefits in kind, such as priority for an organ in future, free/reduced price fertility treatment etc, were seen as being, on the surface, highly appropriate. Initially, participants felt that recognising someone's contribution to a pool of donor material by allowing them preferential access to it was appropriate. However, after examining the potential consequences, participants tended to switch to opposing the use of this type of donation. This was because, as described in section 6.4.2, they did not want this type of benefit in kind to become a factor in medical decisions i.e. they did not want donors to be treated in preference to someone with a greater medical need. This was seen as unfair to healthcare professionals who may have to leave the sicker person untreated, and for people who may not have donated for reasons of ignorance of the system, or because of strong beliefs.

Recognition in the form of a thank you or a token e.g. a medal was seen as really the only appropriate thing someone donating could expect to receive. However, as shown in section 6.2, this was not seen particularly as a motivation to donate, but rather a just acknowledgement of that person's decision to donate.

1.6 Conclusions

Participants perceived a moral imperative for society to address any mismatch between supply and demand of bodily material. However, they were concerned that individual donation decisions be in the hands of the donors, with no intervention or coercion from outside parties. Relatives should make donation decisions on behalf of deceased people who had not made their wishes clear. Although consensus could not be reached on how to resolve conflicts between a deceased person who wants to donate and a relative who opposes donation, this was seen as indicating a need for families to discuss their wishes with one another beforehand.

Participants felt that control of donated materials should be in the hands of healthcare professionals under a transparent and fair system of allocation, with the exception of allowing a donor organ to be given directly from one person to another.

Cash incentives were seen as potentially coercive and unappealing, and were only suitable for recognising the risks involved in taking part in medical trials, or as a contribution to funeral expenses. Benefits in kind, such a priority for an organ in future, were seen as having potentially negative impacts on medical decision making and so were generally rejected. It was perceived that donations should be recognised through a thank you letter or a token. However, this was not seen as offering a reason to donate, rather an acknowledgement of that person's decision to donate.

2. Introduction

2.1 Background

2.1.1 The Nuffield Council on Bioethics

The Nuffield Council on Bioethics examines ethical issues raised by new developments in biology and medicine. Established by the Nuffield Foundation in 1991, the Council is an independent body, funded jointly by the Foundation, the Medical Research Council and the Wellcome Trust. The Council has achieved an international reputation for addressing public concerns, and providing independent advice to assist policy makers and stimulate debate in bioethics.

2.1.2 Working Party on human bodies in medicine and research

The Council established a Working Party called 'Human bodies in medicine and research' which met for the first time in January 2010. The Working Party is chaired by Professor Dame Marilyn Strathern and has members with expertise in clinical trials, health psychology, histopathology, transplantation services, medical law, medical ethics and anthropology.

The Working Party is considering the ethical issues raised by the provision of bodily material for medical treatment and research, and participation in clinical trials. 'Bodily material' includes organs, blood, skin, bone, cornea, sperm, eggs, embryos, or even whole bodies. Issues to be considered include incentivisation, altruism and forms of remuneration; control and consent; living and post-mortem provision; and the responsibilities of donors, recipients, healthcare professionals and the government. It is planned that a report outlining the group's findings, including recommendations for policy, will be published in autumn 2011.

Input from the wider community is integral to the Working Party's discussions. The group held a public consultation from April to July 2010 which enabled anyone with an interest to submit their views. A consultation website, with background information and questions, was publicised as widely as possible. However, the Working Party also agreed that finding out about the views of people without a particular personal or professional interest in the area – 'the man on the street' – would be extremely valuable to the project. Such people are the potential providers and recipients of bodily material, and their views and concerns are vital to the success of any government policies in this area.

To this end, the Nuffield Council and the research consultancy Opinion Leader, an independent research-based consultancy, jointly applied for a Wellcome Trust People Award to hold a deliberative

workshop with recruited members of the general public to find out their opinions about the donation and use of bodily materials in medicine and research. The grant was approved in April 2010,

2.2 Objectives

The key objectives of the exercise were to engage with 40 people, drawn from a cross-section of the UK community and who do not have a particular interest in the topic, on the provision of bodily material for medical treatment and research to:

- 1) find out their views and concerns on the topic and explore the extent to which these may differ from those who already have an interest in the area;
- 2) search for any new ethical issues related to the topic that the Working Party hasn't already thought of;
- 3) broaden the evidence base underpinning the Working Party's conclusions;
- 4) give participants the opportunity to learn about and discuss a live bioethics issue, feed their views into an inquiry of the Nuffield Council on Bioethics, and potentially influence policy.

2.3 Method

The use of bodily materials in medicine is a sensitive topic area about which many members of the general public may have little detailed knowledge. Furthermore, the ethical and human rights issues raised by considerations of donating bodily materials are complex and in many cases there are no easy answers. Traditional research, such as focus groups or surveys, which aim to gather views based on the participants current level of knowledge, would only tell the Working Party what people think given how little they may know. Therefore, a deliberative approach was chosen in order to enable people to develop an informed viewpoint and give greater credence to the overall conclusions of the final report. The deliberative method fosters in-depth discussion of complex issues, such as those surrounding bioethics.

A deliberative approach was chosen because it provides the opportunity to present people with new evidence and information as the day progresses. A variety of deliberative techniques enable the participant to understand and scrutinise information and start to understand some of the trade-offs that have to be considered in the use of bodily materials in medicine.

The workshop, held in Bristol, was attended by 43 participants and lasted for one day, which allowed sufficient time for participants to receive information and have discussions about the issues (see appendix for agenda and materials). The day was a mix of presentations from Working Party members and round table discussions. Participants sat at tables of 10 or 11 managed by a facilitator taking 'real-time' notes on a laptop whilst moderating discussions. Participants were given a variety

of stimuli throughout the day, designed to help them develop an understanding of the issues surrounding donation. The stimuli also helped participants to view donation from a variety of perspectives, including donors, recipient, healthcare professionals and the government. Stimuli included ranking cards, individual handouts, table handouts and scenarios.

Members of the Working Party presented at intervals throughout the day on topics including types of donation, supply and demand, consent and control, and incentives and recognition. After each presentation there was an opportunity for participants to ask questions to clarify any points they did not understand or to ask for further information. These presentations served to inform subsequent table discussions, after which a participant or the facilitator from each table presented back to the room. Participants were asked to fill in two questionnaires, one at the start of the day and another at the end of the event. This allowed us to capture both their uninformed awareness of the use of bodily materials in medicine and subsequently their informed opinions, to see how their responses changed over the course of the day. The end-of-day questionnaire was also used to ascertain participants' views on the format and organisation of the day and how they felt about taking part.

2.4 Sample

The workshop was attended by 43 participants. These participants were recruited to be broadly representative of the UK population. The number of people from ethnic minority groups was increased above the small number that would be representative according to census data, in order to ensure that there were at least 2 participants from ethnic minority groups at each table. The number of young people, and particularly students were also increased as these groups account for a disproportionately high proportion of donors.

People who had direct experience of donating or receiving bodily materials or those closely related to such people were, as far as possible, screened out as it was felt that these people's views were already being captured by the main consultation. It also enabled all participants to start from the same point, preventing those with more experience of the subject from dominating the discussion. However, this did not exclude people who had given blood or were on the organ donor register, since these people are prevalent throughout society and thus it would be misrepresentative to exclude them.

The demographics of the sample are detailed below (fig. 1):

Figure 1 – Demographic profile of respondents

Demographic	43 participants
Gender	
Male	19
Female	24
Age	
18 – 29	13
30 – 44	13
45 – 59	9
60+	8
Socio-economic group	
A/B	8
C1/C2	20
D/E	15
Ethnicity	
White	32
Black British ¹	3
Black Caribbean	7
Mixed	1
Area	
Urban	18
Suburban	15
Rural	10

2.5 About this report

This report, written by Opinion Leader, provides a full record of the responses from participants at the workshop, and draws out key themes and conclusions from these responses. The findings in the report are drawn from all of the data captured at the workshop including:

¹ Note – recruitment criteria specified a proportion of Black or Minority Ethnic (BME) respondents rather than setting quotas on specific ethnic groups. Due to the high Black population in the Bristol area, all but one of those filling the BME criteria at the workshop were Black. This means no other ethnic groups were represented at the workshop.

- Table facilitator pro-forma notes
- Flip charts
- Individual and group self completion document both quantitative and qualitative (see appendix for all self completion forms)

It should be noted that the quantitative information presented in this report are drawn from the participants' responses to pre and post workshop questionnaires (all 43 participants completed the pre workshop questionnaire, 29 completed the post workshop questionnaire), and the incentives self completion form (completed by all 43 participants). As such, this information is reflective only of the views of participants and should not be considered indicative of the population as a whole. It is used in the report only to provide a qualitative feel for the strength of feeling on particular issues, and to provide a feel for how, if at all, participants' views shifted over the course of the workshop.

Quotations in the report are taken from table facilitators notes, which were taken in shorthand, and have been expanded to make them complete sentences. As such they are representations of what participants said on the day rather than exact word-for-word verbatim quotes.

3. Initial perceptions of donation

The workshop began with an open discussion on donation, covering the participants' awareness of donation of bodily material and their initial views on the general pros and cons of donation. They were then given a short presentation outlining the different types of donation of bodily material that are possible and then discussed their relative perceived importance.

3.1 Spontaneous awareness of donation

3.1.1 Awareness of different bodily materials

Participants showed good overall awareness of different types of donation. When asked what types of donation they were aware of they tended to interpret this to mean the types of bodily material that can be donated. They did not immediately think in terms of the different uses that bodily material can have, or the distinction between live and deceased donors.

They showed a good general knowledge of the different types of bodily material that could be donated, mentioning (broadly in order of most well-known to least):

- Blood
- Organs
- Tissue
- Gametes

Participants tended to mention blood and organs first when asked what types of donation they had heard of, with blood donation tending to be slightly the more prominent of the two. This may be somewhat due to some of the participants being - or having previously been - blood donors themselves. By contrast, people who had been involved with donation of other types of bodily material were excluded from the workshop. However, blood donation was also the type of donation participants were most aware of in their day-to-day lives. They mentioned seeing advertisements for blood donation on the television and on posters, particularly in doctors' surgeries. Blood donation was also visible to participants through blood donation trailers which many participants were used to seeing in their local area. Others mentioned that blood donation trailers visit their workplace and so it is highly visible to them. They also perceived blood donation as being relatively prominent in the media which, in particular, covered stories relating to the shortage of blood. There was some more detailed knowledge of the donation of blood, with some participants also being aware that blood is used in constituent parts such as platelets.

"You see blood donation poster, telling you to give blood, and they advertise on the TV with all the celebrities. Everyone knows the symbol with the two hearts. Blood

donation is the most heard of but you always see the donor card in the surgeries. The blood lorry, sometimes see it parked up for sessions. You can just go in.”

Organ donation was also seen as highly prominent. Participants named a range of organs that could be donated to other people. Most commonly mentioned were kidneys, the heart, lungs and the liver. However, some participants also mentioned the pancreas and spleen as organs that could potentially be donated. As with blood, participants mentioned that organ donation is relatively high profile in the media; again they mentioned publicity around the shortage of organs for donation, particularly publicity concerning individual cases of people in need of a donor organ. However, organ donation is seen as less widely advertised than blood donation, with participants only mentioning the presence of leaflets in doctors’ surgeries and the opportunity to register when applying for driving licences as the places they had seen organ donation being encouraged.

Tissue donation tended to be mentioned after blood and organs. However, despite being less top of mind, participants were able to name a number of types of tissue which can be donated. The most commonly mentioned was bone marrow. However, participants also mentioned corneas, the placenta and umbilical cord, the face, hair, and stem cells as other types of donation they had heard of. One participant mentioned that he and his partner had consented, for the purpose of research, to donate their child’s umbilical cord after its birth. Others were aware that the placenta could also be donated for research purposes. Several mentions were made of face transplants and participants mentioned highly prominent stories of face transplants being reported in the media in recent years.

Participants were also generally well aware of the donation of gametes. These were always called ‘eggs’ and ‘sperm’ by participants. The donation of sperm was better known than the donation of eggs. Participants spontaneously mentioned the changes in legislation which have made it possible for the offspring of donor gametes to be able to identify their genetic parents at 18 years old.

Participants did not spontaneously mention the potential to donate complete bodies for medical research, either during life or after death, or the potential for a living donor to donate a partial organ

3.1.2 Awareness of different uses of bodily materials

Participants also showed good general knowledge of the potential purposes of donated bodily material including (broadly in order of the most well known to the least):

- Life saving
- Life extending
- Life creating
- Life improving
- Cosmetic

- Use during medical procedures

Participants tended to think first of life saving and life extending uses for donated bodily materials. Top of mind were transplants used to save or extend the life of the person e.g. a heart or liver transplant. Linked to these purposes of preserving life was the peripheral purpose of improving life. This was particularly the case where participants perceived that the recipient would be spared from treatment through donation, e.g. a kidney transplant removing the need for dialysis treatment. The goal of preserving human life was spontaneously seen as highly important.

“It’s quite important if it’s going to save someone’s life”

Participants were also aware of the use of donated gametes in fertility treatment. Some also mentioned the emergence of face transplants as a cosmetic procedure for those who had been severely disfigured. Again, this was linked to improving the quality of life for the recipient.

A few were also aware that blood, as well as being used for life preserving reasons for trauma patients, is also used during planned operations and other medical procedures that can involve blood loss.

Research was not mentioned spontaneously as a purpose for donated bodily material (besides the single mention of umbilical cord donation mentioned above. This was not raised again when purposes for donation were specifically probed on).

Participants showed good awareness of donations from both living and dead donors. Donations of organs were discussed spontaneously both in the context of a live donor, generally in the case of someone donating a kidney to a family member, and deceased donors.

Whilst they did not mention that gamete and blood donations from deceased donors are prohibited under current legislation, both of these types of donation were only mentioned spontaneously in the context of live donors.

“You don’t have to be dead to donate some of these things”

3.1.3 Awareness of legislation and regulation

Participants had limited knowledge of the current laws relating to the donation of bodily material and which bodies are in charge of regulating the processes involving donated material. They were most aware of legislation relating to the donation of organs and how these differed to laws in other countries. They were aware that the UK operates an opt-in system of donation, and that this differs

from some other countries which operate an opt-out system. There was also some knowledge that the UK does not allow payments for donations of bodily material.

However, beyond this there was no knowledge of the legislation governing other types of donation, and no participants were able to name the bodies that regulate donation or the use of donated material.

3.2 Profile of donation

Donation was perceived to have a relatively high public profile. As previously stated, participants showed a good awareness of donation types and this knowledge was generally gleaned from the appearance of stories in the media and advertising and registration materials relating to blood and organ donation. They also mentioned the appearance of storylines relating to donation in television dramas such as *Holby City* and *Grey's Anatomy*.

However, despite this relatively high public profile, participants said that donation was not a topic which they considered very often. They said that there were only a few circumstances in which they had or might consider donation:

- When encountering one of the true or fictional stories involving donation mentioned above
- When they were confronted with a situation where there was an opportunity to donate or register to donate
- If they were personally affected by a need for donated material

The appearance of donation in the media, whilst being a key driver of knowledge, did not make donation a topic of personal importance to participants. Participants said that they did consider the issue more deeply when they were in the position of deciding whether and what to donate. These situations were often enforced, e.g. where they had to complete the donation section on a driving licence application, or when blood donation was available at their workplace. However, these situations tended not to have any lasting impact.

Participants said that they thought people are most likely to consider donation when it becomes of personal importance to them, i.e. when they- or a close family member or friend - is in need of donated material.

“No really, you don't think about it until it affects you. Only when it is important to you and often that is too late”

Participants lamented this lack of general consideration, saying that people 'should' consider it before this point. This was seen as important for two key reasons. Firstly, people's perceived lack of

consideration was seen as a possible cause of the shortage of donors of all kinds. Secondly, the lack of discussion about donation among family members was perceived as potentially making donation decisions relating to deceased loved ones more difficult as people would not be aware of the deceased person's feelings about donation. They spontaneously called for greater education about donation, and perceived greater discussion of it as something which should be encouraged.

"If someone asked me about my mum then I wouldn't want them to touch her. But, if she had said yes, then I would respect her wishes. It should be talked about more in families, so it's not such a shock"

3.3 Pre-existing issues relating to donation

Participants were asked to think what issues there may be relating to donation from the point of view of:

- Donors and potential donors
- Relatives of deceased people
- Those in need of donor material or those who use it
- Regulators and healthcare professionals

Participants proved to be highly sensitive to the ethical issues surrounding donation and were able to talk at length about them with little prompting. They spontaneously raised most of the issues that were to be asked about later in the course of the workshop.

3.3.1 Issues for donors and potential donors

For donors and potential donors, issues primarily centred on decisions concerning whether or not to donate. They considered the issues that could potentially encourage or be a barrier to people donating bodily material. These included:

- Personal beliefs
- How donated material is used
- The implications of donation

One potential barrier to donation that participants perceived was the **personal beliefs** of some potential donors. Several participants mentioned that they thought some religions may oppose the donation of bodily material, and that this might make it difficult for followers of these religions to donate (and also potentially to receive donation themselves). Participants also thought that deciding what bodily material to donate might be difficult. Many participants mentioned that they would not want to donate their eyes after death due to this potentially affecting the appearance of their body, and because eyes were seen as being highly personal.

The issue of whether or not donors would know **where and how donated material is used** was also seen as potentially having an impact on decisions to donate. On the positive side, the desire to help other people was seen as a potent incentive to donate, so knowing where the donation was going might provide a compelling reason to donate. This was particularly the case where the recipient was known to the donor, but could also be compelling where there was no pre-existing relationship.

However, on the other hand, donors would want to be sure that donated material would not be wasted. For them, this meant both in terms of the material actually being used for the purpose for which it had been donated, but also - in some cases - more broadly in the sense of being used for someone who 'deserves' the donated material. Some thought that they might not want a donation they made to go to someone who had caused their need for donation, e.g. they needed a liver donation because of an alcohol-related disease. This was because they felt that the person may be less deserving of the donated material than someone else who had not caused their own need, and because the individual in question might 'waste' the donated organ by continuing the behaviour which had caused the need in the first instance.

"George Best, he went through two livers. Why did he get it?"

As well as donors wanting organs to go to good use, participants felt that the issue of control could extend to other judgements regarding potential recipients. This might include not wanting donor material to go to people of another race or religion. However, while participants thought that donors and potential donors might be concerned about what happens to donor material, they did not spontaneously consider that potential donors could or should have any control over what happens to it. Instead, they thought about whether or not potential donors would want to know how donated material is used. Participants said that it might be 'better not to know' where donated material was going, as it might make decisions to donate more difficult.

"There's the issue of who receives their donation. I think it's best not to know who it's going to. There are good and bad sides to knowing who it's going to"

Participants thought that there may be **implications for the donor** which might be a potential barrier to donation. Firstly there were health implications both from the perspective of the donors and the recipient's health. They said that donors may be put off where donation could have negative health implications. For example, they believed that kidney donation could have detrimental health impacts for donors.

The potential health benefits of donation for recipients were seen as a key concern for donors. Participants said that donors would want to feel that there was a good prospect of their donation having a positive health impact for recipients. Poor prospects of a positive improvement in the recipient's health were seen as a potential barrier to donation, especially where there are potential health implications for the recipient as well. These two sets of health impacts traded off against each other, whereby the risks to the donor have to be justified by the potential benefits for the recipient.

Participants also discussed potential implications for the personal life of the donor. In particular, they discussed the potential for children conceived from donated gametes to trace their genetic parents. Participants generally thought that this could act as a barrier to donating gametes as people may not want to put themselves in the position whereby their personal lives may be affected in the future by the sudden appearance of a child conceived through previously donated gametes. As mentioned, participants were not sure of the legal status of donor 'parents' and felt that they would not want to be put in a position of being emotionally or financially responsible for a child conceived from gametes they had donated.

3.3.2 Issues for relatives of deceased people

Relatives would also face similar issues around the decision to donate as those faced by live donors or those deciding on their own donation after death. However, participants said that relatives would face additional issues around:

- The emotional stress of the situation
- Finding comfort after death
- Potential conflicts with the deceased's wishes
- The shortness of the decision process

Participants saw decisions of whether or not to donate as being harder for the relatives of deceased people than for the individuals making decisions about their own bodily material. This is because the decision comes at a time when the relatives are already under a great deal of **emotional stress**, having just lost a loved one. They also said that they could see how decisions to allow bodily material to be removed from a loved one's body could be extremely difficult. Several said they would not want their relatives' bodies to be interfered with in this way, and many more said that they were not sure how they would respond under these circumstances.

The flip-side of these potential difficulties was the potential for relatives to **find comfort** after the death of a loved one. Participants said that they could see that using deceased relatives' bodily material to benefit others, especially where it may save the lives of others, could be seen as honouring the deceased, and could provide a measure of comfort to relatives that their loss had not been in vain, meaning that others might not have to suffer the same feelings.

“I had a friend who died at 45 and after the funeral they said that she had donated to 11 people and it was so many different things like glands and so on. I didn’t realise. The family came round and let everyone know. It made them feel better, that she had helped other people after she had passed. That is a lot of life”

These considerations were seen as difficult enough in isolation. However, they could add further pressure if the feelings of the relatives regarding the donation of bodily material were in **conflict with the deceased’s wishes**. Knowledge of the wishes of the deceased regarding donation could make decisions easier if the relatives either agreed with them, or where the relatives simply wanted to follow the deceased’s wishes. However, if relatives did not like the idea of bodily material being removed from the deceased’s body, and the deceased was also a registered organ donor, this was seen to make the situation much harder for the relatives. Participants generally felt that if they were in this situation they would not go against the wishes of the deceased, regardless of their own feelings. However, they sympathised with relatives and wanted to see their emotional well-being protected. These conflicts emerged as the area of greatest contention for participants, and they sometimes found it hard to come to a consensus on how they should be resolved. However, from this early stage of the debate they stressed the importance of families discussing their views on donation of bodily material in order to make decisions like this as easy as possible for family members.

“People want to fulfil the deceased persons’ wishes. If they respect their burial wishes, then they should respect their donation”

“The family should be able to overrule (the deceased person) because you can’t cope with it. If you lost your son the stress would be awful”

Another feature of these decisions which was seen as potentially exacerbating an already difficult situation was the **shortness of time** participants perceived relatives had to make up their mind. They wondered how long after death relatives would have to decide whether to allow the deceased’s bodily material to be donated, and, assuming that the time period would be relatively short, felt that it would not be long enough, given the difficulty of the decision.

3.3.3 Issues for recipients of donations

Participants said that recipients and users of bodily material would mostly be concerned with getting suitable donor material, and with the potential benefits this might have. They considered issues including:

- The availability of donor material

- The appropriateness of donor material
- The success of treatments using donated bodily material
- The psychological effect of receiving donated bodily material

The key perceived concern for recipients was the **availability of donor material**. Participants could see that the need for donor material would be acutely felt by those who were waiting for it. This was seen as being especially the case where the availability of donor material is 'life or death' for recipients. However, participants could also see that people in need of donor material for other purposes, e.g. fertility treatment, could also be emotionally affected by a lack of supply.

As well as being greatly needed by potential recipients, donor material was also perceived to be generally in short supply. As previously mentioned, the media coverage of donation that participants recalled often concentrated on shortages of donor material. The combination of an acute need and a lack of supply were seen to make the availability (or lack thereof) of donor material the key issue for potential recipients. Participants also felt that this perceived shortage would be more acute for particular minority groups. There was a perception that donation may be less common among certain ethnic groups due to religious or cultural aversion to it.

“Sometimes it can be the choice between life and death. You see regular appeals for donations, particularly aimed at ethnic groups”

“There are some religions which stop you donating. You would have to think that there are some people who wouldn't want to go against what you have been taught from childhood”

Participants also mentioned that as well as there being a ready supply of donor material, there were also issues surrounding the **appropriateness of this donor material**. Participants said that some types of donation needed to be specifically matched to the recipient, e.g. in terms of blood group. They thought that people who needed donor material of a relatively rare type, e.g. from a person with a rare blood group, might be particularly concerned about the supply of donor material. Participants saw this as linked to the issue above relating to the lack of donation from particular ethnic groups, who might be more likely to have characteristics that are rare in the population as a whole.

As well as being matched to the potential recipient, appropriateness also related to the perceived quality of donated material. Participants thought that potential recipients would want to know the history of the donated material coming to them, e.g. the age, health and background of the person donating their bodily material. This was linked to the potential **success of medical procedures** carried

out using the donor material, with the prospects for success seen as greater if the donor was young and healthy. Some participants spontaneously mentioned that some people might be excluded from donation if their bodily material was perceived as being of poor quality, e.g. an older person might not be able to donate. The success rate of these procedures was seen as a general issue, regardless of the quality of the donor material. Participants saw some of the medical procedures involving donor material as having a high chance of failure. In particular, they discussed the potential for transplanted donor organs to be rejected by a recipient's body. However, they also perceived improvements in medical techniques which might make the chances of success today greater than they had been previously. This in turn was seen as having a potential knock-on effect on the overall demand for donor material, as medical procedures involving donation became a possibility for a greater number of people.

Finally, participants mentioned the potential **psychological effect of receiving donor material**. Some perceived the concept of having another person's bodily material in your own body as being somewhat unnatural and so potentially troubling for participants. There was also a perception that some people might be averse to receiving donations from people who were not 'like them', e.g. of the same race or religion, and that some people might want to be able to reject donor material on this basis.

"It could affect them psychologically knowing someone else's body part is in them. Having received it they might not feel it is right to have a foreign body part inside them"

3.3.4 Issues for regulators and healthcare professionals

The issues around the health outcomes for both donor and recipients and around the effectiveness of treatments involving donor material were also seen as being key concerns for regulators and health care professionals. However, they were seen as being mostly concerned with maximising the potential benefits of the donor system, and with maintaining it in an ethical way. Taking their perspective, participants considered issues including:

- Minimising barriers to donation
- Encouraging donation
- Talking to bereaved relatives
- Deciding how to use donor material

Participants could see that, as well as preventing inappropriate or unethical donation behaviour, regulation has the potential to limit the possible level of donation. These limitations could be introduced firstly by disallowing some types of donation (which may prove positive if the banned donation is inappropriate in some way), or through bureaucracy. They thought that regulators would

be concerned to maximise the possible number of donations by **minimising barriers to donation** by ensuring the processes are as streamlined as possible. Participants also perceived that healthcare professionals would want to maximise the possible number of donations by ensuring the collection and distribution of donor material.

Participants felt that regulators and healthcare professionals would want to - and to a certain extent should, - have a role in **encouraging donation**. They thought that healthcare professionals could be a potential source of information on donation, and quite clearly have a role in **talking to bereaved relatives** about the potential for donation. This was seen as a difficult role, not only because of the potential emotional stress involved, but also because they would have to tread a fine line between on the one hand encouraging donation, and on the other of respecting the family's wishes. Regulators were also seen to have a role in encouraging donation. This was generally seen as a task of raising awareness of donation and providing information on its potential benefits. Participants saw this as important, but also were concerned that this encouragement should be kept relatively low key, ensuring that people were not pressured into donation by any means.

“Getting a culture of donation; not forcing people to donate.”

A key issue for regulators and healthcare professionals was seen to be **making decisions about how to use donor material**. This was seen as particularly difficult where there was a limited supply of donor material which is required by a large potential pool of recipients for life-saving treatments. These decisions involving life and death were seen as particularly hard ones, as much for those making the decisions as for those who were affected by them. Regulators and healthcare professionals were seen as being put in the position of ‘playing god’. For this reason the rules governing these decisions and the processes involved in making them were seen as key to ensure that they are made for the ‘right reasons’.

“They have to pick and choose who gets what, and take responsibility of who lives or dies”

3.4 Response to information on donation

Following this initial, open discussion relating to donation in general, participants were given a presentation by Keith Rigg (see appendix for the full presentation), a member of the Nuffield Council on Bioethics Working Party on human bodies in medicine and research. This presentation was aimed at providing participants with some introductory information about donation, including:

- What different types of bodily material can be donated
- What uses there are for these different types of bodily material

- The numbers of registered donors in the UK, the number of donations, and the numbers of different medical procedures carried out involving donor material

The purpose of this presentation was to try to ensure that all participants were aware of all that is referred to in the consultation as ‘donation of bodily material’.

Participants engaged in a brief discussion of these facts and figures following its conclusion. Participants were surprised by some of the things one can donate. As previously mentioned, there was already a reasonably good knowledge of the different types of bodily material that could be donated. However, many had not heard of partial organ donations from live donors. A few had heard of partial liver donations, but none were aware of partial lung donations.

“I was surprised about partial organ donation. Did not know you could do that with lungs. I know the liver regenerates”

Some were unaware that face transplants were possible. This led to some additional debate, and some expressed an aversion to face transplants as they felt this could be very difficult for the family members of the donor if the recipient bore a strong resemblance to the donor. They also felt that this may be taking an element of the donor’s identity from them. However, most felt that face transplants would offer those with severe disfigurement a greatly improved quality of life.

“I don’t really agree with face transplant. You are walking down the road in someone else’s skin. It’s an open casket – its stripping you of who you are, what you look like”

“If you have been in a fire then it could be a new lease of life”

Participants were surprised by the overall numbers involved, e.g. 17 million people on the organ donor register; 2,000 babies born each year from donor gametes as they felt that these were higher than they had expected. However, some felt that in comparison to the population as a whole these numbers could actually be seen as relatively low e.g. 1.4 million blood donors being “around 5% of people” (author’s note: this is actually closer to 2% of the population). This led some to question what drives donating behaviour among the public, and what could be done to encourage more people to donate. There was therefore a call for greater publicity around donation to encourage more people to donate. They pointed to other public health issues where they perceived communications to have had positive effects on awareness and said that it might be possible to replicate this effect for donations.

I would have thought blood donation was low, but it's down to awareness. I would only think of it when I see the lorries, it's not something you think about. Maybe if you were asked at the doctors more people would sign up. I have never been asked; if I was I would go away and think about it"

"I think the media could play a bigger role. They have these adverts for elections, after the news they could have a minute. I think most teenagers know about STDs (sexually transmitted diseases) so they should do it in the same way. Go into surgeries and schools and have 'blood donor day'"

Again this desire to encourage donation was tempered with a desire not to pressurise people. Participants said that donation was a personal decision and should be left to the conscience of the individual.

"It is up to the person donating themselves as to what happens to their body"

3.5 Relevant importance of different types of donation

3.5.1 Initial discussion of importance

Overall, the donation of bodily material was seen as highly important by participants. They could perceive a number of important benefits of donation, and found it very hard to identify any disadvantages, and so tended to be generally in favour of donation. This extended to being in principle in favour of efforts to maximise the donation of bodily materials, although participants wanted this done within certain moral limits which we will discuss later.

The overarching benefit of donation was seen to be that it 'helps people' in a variety of ways, and can help with the preservation and improvement of people's lives. This was seen as a general positive for those who were helped by receiving a donation, and for society as a whole. Although participants could identify a number of issues with the donation of bodily material - as described above - these were seen to be susceptible to a potential solution, and were not seen as general disadvantages of donation. The only type of donation that was seen negatively was the donation of gametes for fertility treatment. However, participants who potentially disapproved of this type of donation tended to disapprove of fertility treatment in general, and the negative view of gamete donation was peripheral to this broader point. It is also worth noting that this point of view tended to be relatively low key, rather than a strongly held aversion to fertility treatment. Generally, the disadvantage was one of a perceived misappropriation of public funding rather than any fundamental objection to fertility treatment. Participants saw fertility treatments as a lower priority than other treatments aimed at helping someone with a disease which was either potentially

limiting, or affecting the quality of their life. Only a small minority claimed to actively disapprove of fertility treatment because it could be seen to be contributing to overpopulation, or because it was to a certain extent playing god by allowing those who were 'not meant to have children' to conceive.

“There are some who cannot have children. They might not be supposed to have children... I think if you can't have children should pay yourself. The NHS should be for saving life”

These downsides of fertility treatment described above led to types of donation aimed at creating life being prioritised below other types of donation aimed at in some way improving the health of an individual, whether in a direct or indirect way, as will be addressed below.

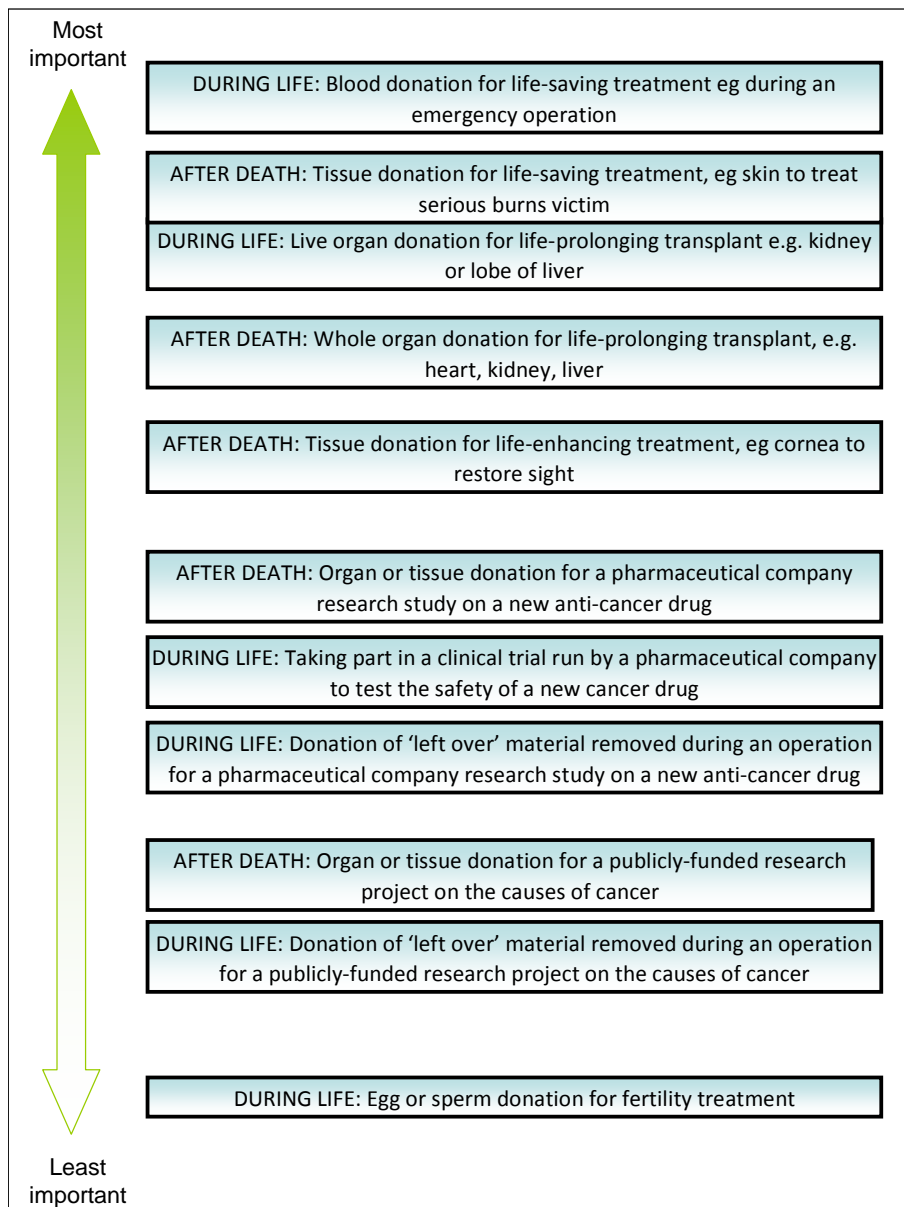
3.5.2 Prioritisation of different types of donation

Participants were provided with a series of cards with different types of donation written on them including:

- AFTER DEATH: Tissue donation for life-saving treatment, e.g. skin to treat serious burns victim
- AFTER DEATH: Whole organ donation for life-prolonging transplant, e.g. heart, kidney, liver
- AFTER DEATH: Tissue donation for life-enhancing treatment, e.g. cornea to restore sight
- AFTER DEATH: Organ or tissue donation for a publicly-funded research project on the causes of cancer
- AFTER DEATH: Organ or tissue donation for a pharmaceutical company research study on a new anti-cancer drug
- DURING LIFE: Donation of 'left over' material removed during an operation for a pharmaceutical company research study on a new anti-cancer drug
- DURING LIFE: Egg or sperm donation for fertility treatment
- DURING LIFE: Taking part in a clinical trial run by a pharmaceutical company to test the safety of a new cancer drug
- DURING LIFE: Blood donation for life-saving treatment e.g. during an emergency operation
- DURING LIFE: Live organ donation for life-prolonging transplant e.g. kidney or lobe of liver
- DURING LIFE: Donation of 'left over' material removed during an operation for a publicly-funded research project on the causes of cancer

Participants were then asked, as a group on each table, to rank these different types of donation from the most important to the least important. The overall prioritisation of these different types of donation is shown in the diagram below (fig. 2):

Figure 2 – diagram showing overall participant ranking of importance of different types of donation



The main differentiating factor between the different types of donation is the purpose. Priority increases as the immediate impact on the life of the individual increases. Therefore life-saving donations are more important than life-preserving, which are more important than life-enhancing. Despite being ranked lower, research potentially has more impact on life than life-enhancing treatments. Participants also saw it as an essential prelude to other immediate life-saving treatments and so for some could be ranked above them. However, its effects are seen as less immediate and less tangible than direct medical interventions, hence it tended to be ranked lower than them.

“Blood is important, without it you can’t survive, and it’s one of the easiest to donate”

Fertility treatment is afforded the lowest priority, as while it may improve the quality of life of the potential parents, it cannot be said to in any way 'save' their lives.

Blood donation was generally seen as the most important type of donation as it is something which is almost universally accessible to potential donors, and has a myriad of uses for life-saving treatments, as opposed to the narrow use of transplant surgery of tissue donation after death and organ donation during life.

In terms of research, developing a potential treatment was generally seen as more important than fundamental research. However, as previously stated participants recognised the life-cycle of treatments and so recognised that this ordering could be reversed.

"It's all part of a cycle. Research is needed to understand how organ donation and diseases actually work to be able to save lives"

This preference for treatment oriented uses of donation existed despite the examples of it being private sector and the fundamental research being public sector. Public sector uses of donor material were, on the whole, seen as more important than private sector. This was because as the sole beneficiary of public sector research was seen as being society, whereas private sector research, although it may have social benefits, can also contribute to the profits of the private companies. However this disadvantage was seen to be trumped by the overall benefits of the research itself, which is why they were ranked as more important.

4. Supply and demand

4.1 Initial views of supply and demand

The lack of donor material was perceived as a key issue for potential recipients and for those regulating and administering donation as discussed above (see chapter 3 - *Issues for recipients of donation*). However, although participants saw the lack of supply as important, as it could have dire consequences for those affected, it was not something of personal importance to them. It was not, therefore, something which moved them to any emotional response or to any personal action to help to meet this need (as we will discuss later in section 6.1, suggested reasons for donating were often nebulous and not necessarily linked to this perceived lack of donor material). Despite this lack of personal connection to the need for donor material, participants did see this as an issue that society has a role, and potentially a duty, to address.

“It is not serious until it's you needing it. None of us need anything, so we don't have an issue. Overall, it is big issue as a country. There are a lot of people dying because they are not getting what they need”

As mentioned above, participants perceived shortages of supply across a range of donated bodily material.

Blood was perceived to be in generally short supply. However, shortages were seen as being particularly acute for rare blood groups, and for blood that can be used regardless of the recipient's blood group. As already discussed, this perception was formed via media stories relating lack of supply of blood, and advertising encouraging people to donate which stressed its shortage and the continuous need for it for a range of medical treatments.

“If you have O negative blood then it can go to anyone. So that must be the one they are most in demand for”

Organs and tissue for life-saving and life-enhancing treatments were also seen as being in constant short supply. Participants had heard stories in the media discussing waiting lists for organs, and said that waiting lists imply that supply does not satisfy demand. Here again, the issue was seen as particularly a case of not just an insufficient number of organs, but not enough *suitable* organs which could be matched with the particular requirements of potential recipients. Participants saw the intensity of this need as being reflected in the emergence of 'transplant tourism', i.e. people in need of transplants travelling abroad to countries with greater supplies of donor material in order to receive a transplant, which some of them said they had heard of in the media.

“I would imagine there isn’t enough? There wouldn’t be a waiting list otherwise. It’s about suitability, you may have a lung but it might need to be compatible. Some people have rare blood types as well”

Sperm was perceived to also be in short supply. This was thought to be linked to changes to the law in the last few years which now make it possible for children from donor sperm to trace their genetic parents after they are 18 years old, which as previously mentioned, is perceived to have dissuaded men from donating sperm and so led to a lack of supply.

“The supply of sperm is gone down as anonymity has elapsed”

A minor point that was raised by some participants was that of problems that could arise from the oversupply of donor material. One participant mentioned that they had been turned away from a blood donation centre because the blood service had achieved its quota for his type of blood that day. This particular participant felt hurt by this rejection of his offer of donation at the time, and said the incident had made him think twice about donating in the future. Other participants also felt that it is wrong to reject a donation, even where this donation is surplus to requirements and may incur additional cost. Rejection was perceived as an affront to the donor. This was seen as not only emotionally damaging for the donor, but also seen as having potential to dissuade others from donating, either because they might not want to risk being rejected or because they might perceive the levels of supply to be sufficient without their donation.

“Mine (blood group) is common and they said they wouldn’t take it that day as they had too much of it already. I was disgusted because they refused to take it. That might make people less inclined to donate their blood”

Participants saw the issue of lack of supply of donated bodily material as potentially hard to address. Despite awareness of issues relating to supply and demand, participants said this may not translate into greater donation, even where donation might be quite simple e.g. blood donation. They perceived a moral imperative to attempt to meet the demand for donor material due to the potential benefits it can have, not least preserving life. Participants again said that greater efforts should be made to encourage donation, although again they applied the caveat that any promotion should be ‘appropriate’. What participants meant specifically by appropriate encouragement will be discussed later in this section.

4.2 Reactions to information on supply and demand

Participants were given a presentation by Naomi Pfeffer (see appendix for the full presentation), a member of the Nuffield Council on Bioethics Working Party overseeing this project, providing information on issues of supply and demand including:

- The level of demand for different types of material
- The reasons for the shortage of supply
- Current and potential ways of attempting to meet demand
- Potential queries around the necessity to meet demand

Participants were surprised by some of the facts and figures relating to supply and demand. They thought that the number of people on the organ waiting list (8,000) was very high, and were shocked at the numbers who die each year while on the list (1,000). They thought this was a very high proportion. Other elements of demand were also a surprise. None, for instance, were aware of the high demand for bodily material to be used in cosmetic or sports injury treatments. This demand was seen as less important than that of organ donors as the impacts of this type of donation were seen as trivial in comparison of transplant surgery. They therefore felt that meeting this need did not fall under the 'social obligation' to meet demand, however the information relating to the scarcity of organs for transplant, and the impact of this scarcity in terms of lives lost reinforced the perception that there is a need to actively attempt to increase levels of supply (and reduce demand if possible), ideally for all purposes.

Participants were interested by some of the procedural elements of donation which affect the level of supply. For instance, many commented on the very specific circumstances which need to pertain to allow for organ donation e.g. brain stem death. They asked many questions relating to the speed with which donor material needs to be removed after death for it to be viable.

Much discussion immediately following this presentation centred on the potential ways to increase supplies. Many picked up on mentions of a potential 'opt-out' system, where consent is presumed. This caused much debate on the tables as to where this system would be an improvement on the current 'opt-in' system, and whether it would be morally right to adopt it. Participants were initially split on whether it would be justifiable to bring in such a system. Some were strongly in favour of an opt-out system as they felt it would have a marked impact on the amount of available donated bodily material (a point, incidentally, which was not disputed by those who opposed an opt-out system). However, others were strongly opposed to an opt-out system as it was seen as taking control away from the individual and placing it ultimately in the hands of the state. Participants with this perspective tended to see donation decisions as highly individual, and not something which should be forced on people in any way. They saw bodily integrity as very important, and thought it was wrong to make assumptions about the way people would want their body treated. Those in

favour countered these arguments by saying that people would still be in control as they have the option to opt-out and that those with strong feelings about not donating would be most likely to feel moved to do so. However, this did not necessarily satisfy those who opposed the idea as they thought that some people might be less able to make the arrangements to opt-out and so some people might slip through the cracks of the system, i.e. not want to donate, but not have been able to opt-out.

This debate between pragmatic views of meeting demand and principles of an individual's rights over their body was played out later in the day during the discussion of consent and control (see chapter 5).

"You are an individual – we should have choice and shouldn't do anything that we don't want to do"

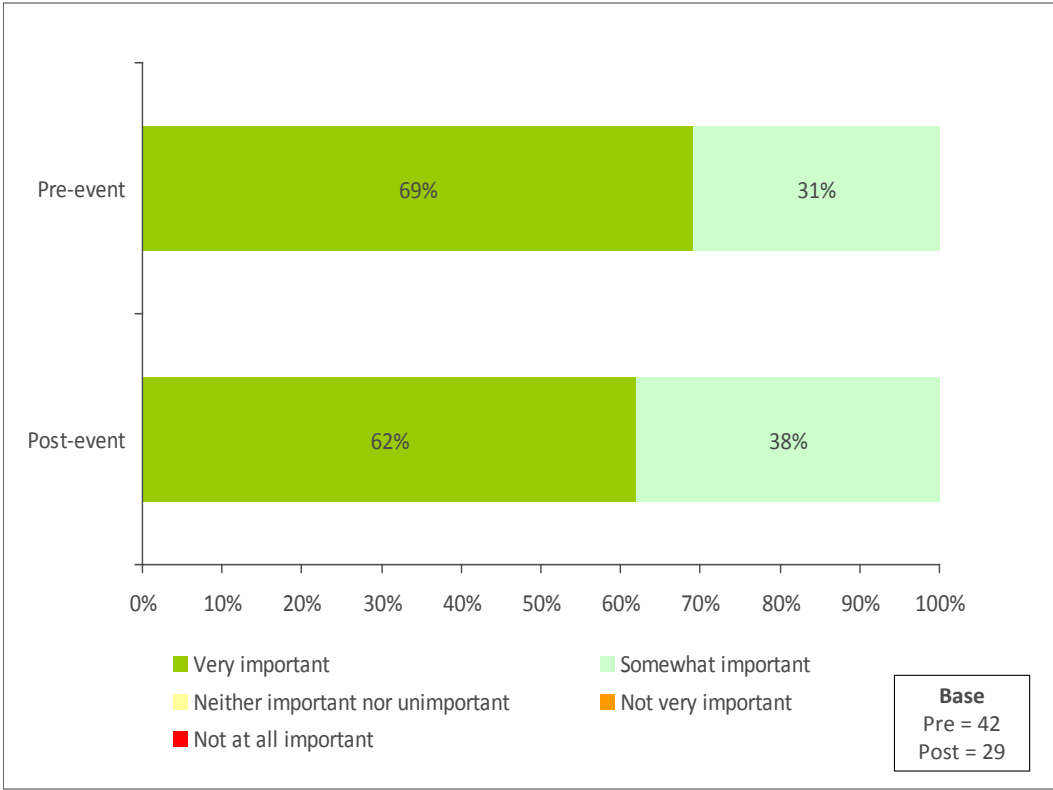
"It's a good idea for everyone to go on the register and then for people to opt-out. You would end up with more people on the register, to overcome the reticence issue"

People also picked up on the potential use of incentives mentioned in the presentation. This was seen as a potential necessity if demand is to be met. This idea again caused some initial debate; with some questioning who would fund incentives and how they would be operate.

4.3 Implications of attempting to meet demand

As already mentioned, participants were generally comfortable with the idea of encouraging people to donate. They saw meeting the demand for donated bodily material as important and thought that encouraging more people to donate was a good way to achieve this. Both before and after the event, all participants who responded to the pre and/or post questionnaire said that they thought that it was either important or very important to take steps to meet demand (fig. 3).

Figure 3 – pre/post questionnaire - Q3/Q1. How important do you think it is to take steps to increase the amount of donation to meet the demand for bodily materials?



The main perceived advantage of attempting to meet demand was in the reduction of suffering to people, both those in need of donation and their family. There was also perceived to be a potential monetary benefit to society as the use of donor treatment was often associated with a cure to an ongoing condition i.e. a kidney transplant negating the need for dialysis. Therefore more donor material would result in more of these types of procedures and hence a greater number of healthy people. This would have the dual benefits of not only reducing the need for ongoing treatments, reducing the burden on health services, but also making the recipient well enough to potentially re-enter the workplace and contribute to the economy through taxation.

However, they wanted encouragement of donation to take place within certain limits, including:

- Not encouraging people for whom donation goes against fundamental beliefs
- Not emotionally blackmailing people to donate
- Respecting the position of vulnerable people

The general principle for participants was that appropriate encouragement would persuade donations from people who had no aversion to donating but had just not considered it in the past, and should actively avoid persuading people who would not donate unless coerced in some way.

They therefore wanted any encouragement to specifically avoid targeting people whose beliefs put them explicitly in opposition to donation, e.g. people whose religion rules out donation. Even if these people could be persuaded, and their donations had a positive impact on recipients, this type of conversion was seen as wrong and the attempt to convert them as morally bad behaviour.

As already mentioned, participants thought there was a moral imperative to attempt to meet demand. However, importantly, the moral burden was seen as resting with society as a whole rather than with each individual. Most did not see each and every person as having an obligation to donate. They were therefore averse to encouragement which attempted to morally blackmail people into feeling bad for not donating. The individual decision to donate was seen as absolutely at the discretion of the individual.

Participants also felt that it was important not to encourage people who may be vulnerable to coercion. They mentioned people who were sick as potentially not in the right frame of mind to decide whether or not to donate. Equally they felt people who had been recently bereaved were in a vulnerable state and open to coercion. Monetary incentives could also be seen as potentially coercive to less well-off people who may be just 'doing it for the money'. Participants felt that any attempts to encourage people in potentially vulnerable states had to be managed with the utmost transparency and integrity.

"If they're on their death bed, it's putting them under pressure... you might be ill and put under pressure to say yes"

5. Consent and control

5.1 Initial perceptions of consent and control

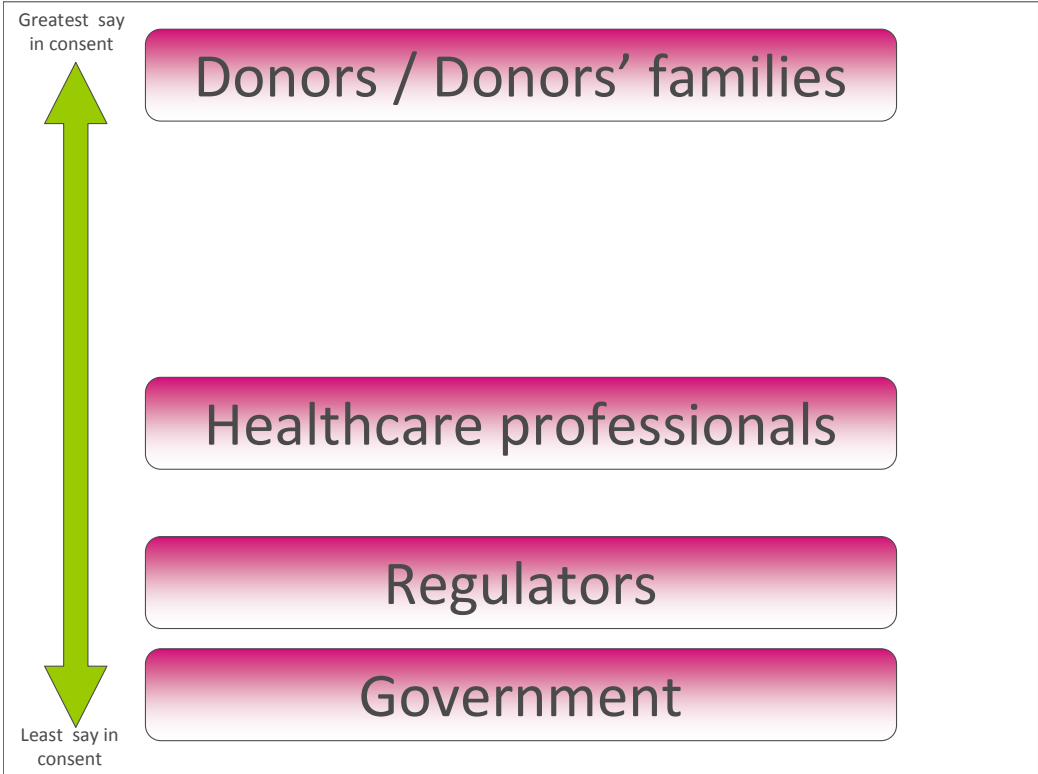
Participants were first asked who they thought does and should have the say over which bodily material is donated and how it is used. Unanimously, participants said that people own their own bodies, and most people thought the bodies of the deceased were owned by the next of kin.

On tables, participants were then asked to rank the following groups of people in order of who should have the greatest say in consent for donation, and then who should have the most control over how donations are used:

- Donors/donors' families
- The government
- Healthcare professionals
- Regulators

5.1.1 Who should give consent for a donation?

Figure 4 – ranking of amount of say in consent

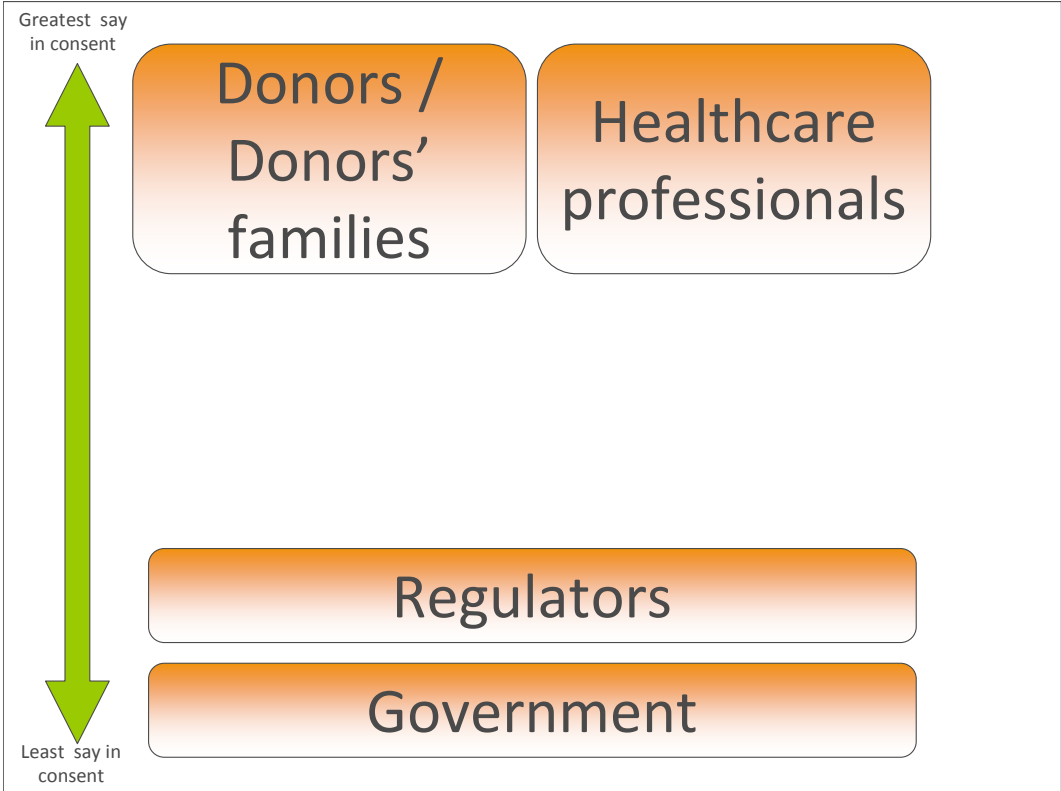


Participants felt that consent for donation should be the preserve of the donor if it is a live donation and the family of the donor if the donor is deceased. They generally saw no role for any of the parties mentioned. However, when pushed to put them in rank order they placed healthcare professionals above regulators and the government as they were seen as being the most impartial and trustworthy. Regulators were seen as somewhat more appropriate to make consent decisions than the government because they too were seen as more objective. The government was generally seen as acting politically, and it was felt they should not take any role in something as important or sensitive as decisions on donation (fig. 4).

“I would put the Government at the bottom. They are probably only interested in figures and whether they look good”

5.1.2 Who should have control over donation?

Figure 5 – ranking of amount of say in control



Control over donated bodily material was seen as being the preserve of healthcare professionals. Most participants said that - for most types of donation - healthcare professionals should take the decisions about how the bodily material is used.

The one unanimous exception to this rule offered by participants, were cases where a donor is making a donation specifically on the basis that the material goes to a recipient who is known to them, e.g. giving an organ or partial organ to a loved one with the aim of improving their health. This type of control, where someone known to the donor is the recipient, was seen as entirely appropriate.

However, participants were generally uncomfortable about donors exercising criteria based control of donation decisions, i.e. where they request donation to a recipient who has, or does not have, particular characteristics. This was felt to be inappropriate mainly because it was seen as pandering to the prejudices of individual donors. It was also seen as potentially corrupting medical practices. Participants said that donation decisions, as with any medical decision, should be made on the basis of prioritising medical need. Therefore the needs of recipients were seen as trumping the preferred criteria of donors.

Giving donors control over the use of donor material was also perceived as potentially undermining the value of donation. Participants expressed strong views that donations are a gift, and a contribution to society. Attaching conditions to that gift was perceived to make donation a less attractive concept. Participants said that, if a decision was made to donate, donors should accept that they are giving away that bodily material - and the responsibility for its use - to healthcare professionals who know how to get the best use from it.

“There should never be any types of control (by donors) over bodily materials, you can’t say “I want this to go someone who is...” you sign away the right to your parts when you agree to donate”

Additionally, participants thought that allowing donors to have control over the use of the bodily material they donate might make the system unworkable, as healthcare professionals would have to apply a unique set of criteria to each use of donor material (fig. 5).

“Donors shouldn’t have conditions as to where it goes – that would create a huge problem in deciding where donor material should go, which is where the healthcare professional comes into it. It’s not feasible (for donors) to attach conditions”

5.2 Reaction to information on consent and control

Participants were given a presentation by Bobbie Farsides (see appendix for the full presentation), a member of the Nuffield Council on Bioethics Working Party overseeing this project, providing information on issues of supply consent and control including:

- Current UK practices relating to consent and control

- How this is done differently in other countries

Participants were somewhat surprised by the way issues of consent and control are currently managed in the UK. They were unaware that human bodies cannot be owned, and found it hard to understand how they could not own their body. Many participants commented on the possibility for children to give consent depending on their level of maturity. Overall, participants were uncomfortable with children being able to give consent, seeing this as the role of the parents. They also questioned who would decide that a child was mature enough to offer consent.

Participants also mentioned that the role of donors and their families was greater than they expected. There were also several comments on the statistic that 40% of families do not give consent for donation for a relative who is on the organ donor register. Participants had differing views on whether this was a good or a bad thing. Some participants saw it as a positive sign that families' wishes were being respected, which - as mentioned - they felt was important to protect the emotional well-being of relatives. The system of not allowing families to have control, but generally following their wishes in any case, was seen as appealing as it was respectful of both the pre-eminence of the healthcare professional in decision making, and of the feeling of relatives. However, some saw it as wrong to go against the wishes of people who had actively opted in to donate. They saw respecting the wishes of families as potentially taking too great an account of people who are under stress and may not be thinking properly. They said that family members may live to regret their intervention.

"I like the fact family can't but that they don't anyway...It's not so much the family overriding the decision, they (the healthcare professionals) are just respecting their wishes.

"I can't see the sense in that – I (the donor who is on the organ donor register) have decided. At the moment they might not feel they are able to. But they might regret that later on"

5.3 Detailed discussion of issues

After this initial discussion, participants engaged in a series of discussions focusing on individual issues relating to consent and control, including:

- Control over donated gametes
- The role of donors and family members in donation after death
- Consent for use of 'left over' bodily material
- Consent for live donations of organs

These discussions were guided by the use of four scenarios involving sets of fictional characters in both fictional scenarios (which did not reflect current UK law) and true-to-life donation scenarios. These scenarios were developed to highlight various ethical issues, and were accompanied by a set of questions relating to them which were used to prompt the participants to consider the full range of issues (see appendix). Initially tables were split into 4 groups to think about these scenarios from one of four standpoints:

- Donors/Potential donors
- Recipients/potential recipients
- Health care professional/health institutions
- The public/government

They were then in these smaller groups asked to fill in a self completion form (see appendix) providing their feedback on the scenario from this perspective. The tables then came back together to discuss this scenario as a single group, comparing all these perceived points of view.

Through the rest of these chapters we will discuss the participants' responses to these scenarios and how they impacted on their views of issues of consent and control.

Although most participants felt that the potential egg donor's reason for not donating was prejudiced, they nevertheless felt that all prospective gamete donors should have the right to choose whether to donate or not, based on information provided by the clinic.

"It's a personal choice to donate; maybe it should be a personal choice to decide who the eggs go to."

A number of participants felt that education is important for two reasons. Firstly, education is a way of informing the donor about the risks and benefits of donating their bodily material, thus allowing them to make an informed choice. Secondly, education can serve to eliminate prejudices that may affect a donor's decision on whether to donate, such as in this scenario.

Participants felt that the potential same-sex recipients in this case would be psychologically affected if they knew about the donor's decision not to donate to ensure donor material did not go to a same-sex couple, and that this could exacerbate pre-existing insecurities about their sexuality. There was a universal feeling of sympathy with the same-sex couple; however participants generally felt that the right of the donor to choose not to donate overshadowed this.

"[It's] ethics versus choice, the donor has the choice but recipients are the ones in the ethical situation."

Participants also discussed the role of government in this case. It was felt that current laws were in place to prevent discrimination, and this was felt to be correct. However, there was an evident tension among participants in the knowledge that there was a potential egg that could have been available that was consequently not donated to a couple that were outside of the donor's stipulations, i.e. to a mixed-sex couple. A small proportion stated that the law could conceivably be changed to allow for donors to positively specify where their bodily material can go, however nobody supported this as a feasible alternative to the current anti-discriminatory system. Overall they thought the outcome of this scenario was correct as the healthcare professionals and regulators maintained control over use of donor material, although they lamented the loss of donor material this caused (fig. 6).

5.3.2 The role of donors and family members in donation after death (a true-to-life scenario)

In this scenario, an individual dies who is not on the organ donor register and, as no family member can be traced to make a decision on whether or not to donate her bodily material, the doctors do not take any bodily material from her. In the same hospital, another individual who is on the organ donor

“I think she should donate. The state would make the decision on what happens to her. There is no one there to be upset. Once she is gone she would make a difference”

Participants were discussing this in the context of an opt-in system. However, they felt that an opt-out system may not affect the morals of the situation, as you would still not be sure that someone had considered donation and decided **not** to opt-out unless you had made sure that each and every person had been asked whether or not they wanted to donate (in which case this would be an opt-in system). People who tended to be happy with the woman’s bodily material being taken also tended to support an opt-out system, and vice versa.

When considering the man who was registered to be an organ donor and his wife, participants’ views were split between thinking the man’s wishes should be honoured, and thinking that his wife’s wishes should trump them. However, the balance of opinion of this group of participants was slightly in favour of - with reservations - respecting the wife’s wishes, although some participants vehemently disagreed with this.

Some participants said that, as the husband had made his wishes clear, they should be respected. They felt that the potential for these wishes to be overridden made a mockery, to a certain extent, of the idea of having an organ donation register to which people decide to sign up.

“I just think what the point is (of an organ donor register) if you don’t respect people’s wishes”

Others, however, while respecting that the man had made his decision clear, felt that the views of the wife were more important because she would have to live with the emotional impact of her husband’s bodily material being taken against her wishes. They thought that her feelings must be very strong, as she was going against her husband’s wishes.

Overall, this scenario demonstrated the potential tension between the perceived weight of the individual will, and the importance of the feelings of relatives. These were, where they come into conflict, seen as extremely hard to resolve and consensus on what was the right course of action was impossible to achieve. However, it also reinforced the importance of planning ahead for this situation. Participants saw it as the responsibility of the donor, not only to register as an organ donor, but also to discuss this issue with their family and to smooth over any reservations on the part of their relatives before their death. They also saw healthcare professionals as having an important role in offering support to the relatives at this difficult time and provide them with information which

might help them make their decision, e.g. what condition the body would be left in, what effect the donated material might have (fig. 7).

5.3.3 Consent for use of ‘left over’ bodily material (a true-to-life scenario)

A patient has surgery to remove a cancerous tumour. A medical researcher would like to use some tumour cells for research into the mechanisms of cancer. The surgeon does not ask the patient for his permission because he does not want to bother him and consequently no tissue is used for research. The tumour is thrown away as clinical waste.

Figure 8 – word cloud of self completion responses to Consent for use of ‘left over’ bodily material scenario



Participants unanimously felt that the tissue from the patient’s tumour should have been used for research purposes once it had been removed from his body. The general sentiment was that if it is only going to be thrown away as waste, it might as well be used. ‘Left-over’ tissue should be monopolised for any possible benefit, such as research. This was not felt to raise any real ethical issues, since it was not seen to affect the patient in any way. Some participants expressed that the patient would be highly likely to want his tissue to be used for research into mechanisms of cancer, since it could potentially help others in his situation in the future.

“If it’s going to be thrown in the bin, use it.”

However, when considering the issues of consent and control, participants recognised there had to be rules and that tissue should not be used unconditionally. The ideas of consent and permission were felt to be important. A small but significant proportion of participants felt that the surgeon should have asked the patient for permission before the operation rather than insisting he should not be bothered. It was felt that if asked by the surgeon, the patient would have granted permission for his tissue to be used for research. It was also suggested by a small proportion of participants that an ethics committee could be put in place to decide whether the tissue could be used for research. This would take the responsibility away from the individual researcher and surgeon.

“Once the tumour has been removed Dwain would not worry about the use of his left-over tumour.”

However, the prevailing feeling was that the patient should not be bothered and that gaining consent was not paramount in this case. Rather, the tissue should be used for research regardless of the lack of consent, since it was felt that it would not affect the patient in any way. On balance, respondents felt that the benefits of using the tissue for medical research outweighed the costs of using the tissue without consent (fig. 8).

5.3.4 Consent for live donations of organs (a true-to-life scenario)

A father has two sons who both have an inherited kidney disease. When he found out about the elder son’s condition he donated one of his kidneys to him, and now he can live a normal life without the need for dialysis. After the younger son’s diagnosis, the father was identified as a suitable donor. The father made his wish clear that he wanted to donate his second kidney to his younger son with the consequence that the father would have no kidneys left and require dialysis for the rest of his life. The doctor refuses, since she will not carry out a transplant that will damage the health or endanger the life of the donor.

Participants agreed that the potential consequences for the father outweighed those of the child, since the child will remain on the register until a suitable donor is found. This could mean that he will not remain on dialysis for a long period of time; the father, conversely, would have to remain on dialysis for the rest of his life, with no kidneys at all. Also, the father risking his life to improve that of his son was felt to be indirectly detrimental to the life of his son, since he would decrease his lifespan and potentially not be around to help his children grow up, emotionally, socially and financially.

A small proportion of participants, however, felt that the doctor should not be allowed to make such a personal decision on behalf of somebody they do not know. Instead, the doctor should fully inform the father about all the risks and benefits regarding the transplant and allow him to make an informed decision. It was also mentioned that as a grown adult, the father can make decisions that should be respected, however this sentiment was secondary in this case due to the severity of the circumstance.

“Father should be given all the information by the doctor. It’s not the doctor’s decision to sentence someone to a lifetime of dialysis. Ultimately, it’s the father’s decision; the doctor should not be able to make this decision.”

The health of the second son could also make a difference. If he was close to death without the donation this was seen to make the donation more appropriate because his life was seen as potentially more valuable, because of his youth compared to the father. Also it was felt that if the son was likely to die soon, then the father might have a longer period of time after the donation was made to wait on the organ donor register for another donor kidney than the son would have, improving the chances of both being able to survive this situation.

“If he got really ill and might die then it could be reassessed. The father would still be healthy and able to survive on dialysis initially. You are prolonging it because the father might then have five years (on dialysis after the donation). He could then go on the list. He has lived longer and (his son’s) life would be more valuable it’s a newer life”

A prominent thread of conversation centred on the financial aspects of the potential donation. It was recognised that the cost of dialysis for the rest of one’s life would be very high. Therefore, participants questioned whether it would be in the government’s interests to allow the father to donate to his child if this would be more costly in the long-run.

“Overall, the government would want to save money; it would be pointless to take one person off dialysis and put another on.”

After considering the complex ethics of the emotional perspectives involved in this scenario, the prevailing feeling was that in the ideal situation the doctor would make the decision supported by an ethics committee, taking the entire scenario in context. It was felt that such an important and difficult decision should never be made by one person (fig. 9).

“It’s about level of control. Such a decision should never be down to one person; there should be a board to consult.”

6. Incentives and Recognition

6.1 Perceived reasons to donate

Participants could see a number of reasons to donate bodily material. In terms of which were most top-of-mind these reasons were:

- Altruism
- Shared benefits
- Recognition
- Monetary incentives
- Convenience

Participants saw the overwhelming reasons for donation as being centred on altruism, which could be manifested in several ways. Firstly they discussed open altruism, i.e. wanting to help others, with no knowledge of whoever this may be. This was seen as being driven by two main desires. Firstly they felt people might feel a civic duty to help other people. Secondly they said that this type of donation would make the donors feel good about themselves.

“The satisfaction of doing something good should be the most important, knowing you have helped someone, sense of humanity”

They also mentioned a more closed altruism, i.e. where they want to help a particular individual - usually a loved one. This was seen as being linked more directly to concern for the health and well being of the recipient.

However, participants also mentioned some reasons to donate based on self-interest. A few people mentioned the concept of shared benefits, whereby you donate because one day it may be you in need. They also discussed the potential for incentives and recognition to be a reason to donate.

Some participants mentioned current recognition schemes, such as the blood service giving out bronze, silver and gold badges to people who had achieved a certain number of donations. This was perceived very positively as it was seen as just recognition to people who had done something which had helped others. However, participants were less certain that these types of recognition provide a genuine reason for donating.

Monetary incentives were seen as having great potential to encourage people to donate. However, people were unsure whether this potential effectiveness meant that it was right to offer incentives, and many had a ‘knee-jerk’ aversion to incentives.

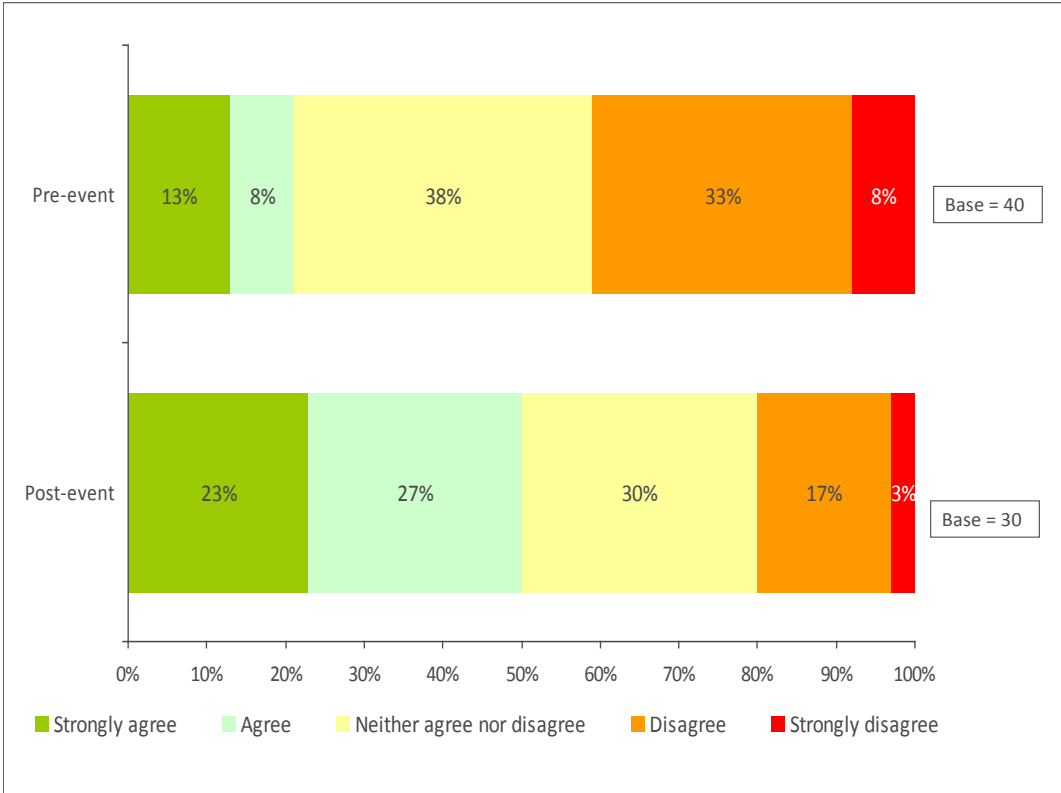
“It’s a dangerous line; using money could make people do it for the wrong reasons”

“It could be good, giving them something for their donation. It’s good to give incentive. If people are left to it then they won’t act, lots of things in life are related to rewards”

The final reason to donate, which was perceived as a fairly powerful one by some participants, was habit and convenience. Participants mentioned that some of their donation behaviour was learnt from family members, e.g. parents giving blood, and that they kept going back through habit rather than each time having a strong reason to go. Others mentioned that, if donation is made simple and convenient, e.g. through the use of mobile blood donation trailers, then there may be ‘no good reason not to’ donate. Forming these habits, and making it easy for people to donate were seen as a potentially a good way of trying to raise the level of donation.

Participants felt that altruism was the ideal motivation for donation. There was some disagreement of whether there was a moral duty on people to donate. Prior to the event, around 1 in 5 (21%) of those responding to the pre-questionnaire said they agreed that ‘people have a duty to donate their bodily material to help others’, with 2 in 5 (41%) disagreeing. By the end of the event the sense of duty had increased somewhat with half (50%) of those responding to the post-questionnaire now agreeing with this statement, and the proportion disagreeing dropping to around 1 in 5 (20%) (fig. 10). This increase in the sense of duty is likely to be based on the reinforcement of the perception that supply does not meet demand, and that this can have serious negative impacts for those in need, as these factors were seen as reinforcing the perceived importance of donation during group discussion. However, as mentioned previously, while participants recognised the moral value of donating, they questioned whether this equated to ‘duty’. Participants were in agreement that while there may or may not be a duty to donate; this duty was to do with an internal feeling of duty to others, rather than an external moral obligation from peers. They saw donation as a personal decision, and while they felt that donors were to an extent morally worthy, those who choose not to donate were not seen as morally deficient. They did not feel people should be condemned for not donating.

Figure 10 - pre/post questionnaire - Q5/Q3. d. People have a duty to donate their bodily material to help others



6.2 Spontaneous opinions of types of incentive and recognition

6.2.1 Appeal of incentives

Participants were given a grid, with different types of donation on the vertical axis and different types of incentive on the horizontal (see appendix). They were then asked to place blue and red stickers onto the grid to indicate:

- Red – This incentive would make you more likely to donate
- Blue – It would be acceptable to change the rules so this incentive was offered to everyone

When taking the results of this pattern as a whole, two interesting patterns emerge (fig. 11 and 12):

- Participants generally felt they did not require incentives to donate
- They perceived more incentives to be acceptable more widely than were seen as appealing to them individually, although ‘no incentives required’ was still often seen as one of the top few most acceptable ‘incentives’
- Donation of material for purposes with less of a benefit for society as a whole were seen as more in need, or deserving, of incentives

Participants selected 'no incentive required' most frequently in all but one case (*Taking part in a clinical trial run by a pharmaceutical company to test the safety of a new anti-cancer drug*), and was generally among the top few most picked responses, and the cases where it is not are highly instructive as were focused on types of donation seen as less socially worthy (see below). This reflects the dominant view that people do donate, and should donate, for generally altruistic reasons. This can also be seen in the types of incentives that were seen as appealing acceptable. A *benefit in kind*, e.g. *priority for an organ in future* and *A recognition of your contribution*, e.g. *letter of thanks* were seen as the most appealing and acceptable incentives, for types of donation both during life and after death. As mentioned above both of these types of donation reflect the social nature of donation. Recognition of contribution was seen as the proper credit for actions that benefit society as a whole. Donation for research were broadly seen as a gift to society as a whole, as they benefit no particular individual, but potentially go to improving the lives of many people through the development of new treatments. However, these social benefits could involve saving individual lives, which where many lives are saved are seen to have a positive effect on society by improving the lives of recipients and the well being of their relatives. A benefit in kind was also seen as appropriate as it was sharing the benefits of a donation system among people who contribute. However, on reflection participants actually saw this type of preferential treatment as inappropriate when considering it in context (see *Priority treatment for organ donors* below).

Although cash benefits were seen as least appealing for them, participants found substantial cash payments to be more appealing than charitable donations, with token cash payments the least appealing incentive overall (for some this ordering was reversed). This may have been simple recognition of the fact that they found a lot of money more appealing than a little money. However, substantial cash payments were most appealing for types of donation that were seen as less socially worthy, i.e. donation for fertility treatment and donation to aid private research. As we will discuss below, the transactional nature of these purposes was seen as making incentives a just pay off for the donor, as well as a potential incentive to donate (see *Priority treatment for organ donors* and *Incentivisation for research donations*).

Figure 11 – appeal of types of incentive and recognition self completion – during life

During life	A recognition of your contribution, e.g. letter of thanks		A donation to a charity of your choice		A benefit in kind, e.g. priority for an organ in future		Token cash payment, i.e. enough to buy yourself a small present		Substantial cash payment		No incentive required		Other	
	Them	Others	Them	Others	Them	Others	Them	Others	Them	Others	Them	Others	Them	Others
Blood donation for life saving treatment	13	15	1	5	7	5	1	9	4	2	24	12	0	0
Live organ donation for life-prolonging transplant	8	9	4	5	8	13	0	6	2	7	10	3	2	0
Egg or sperm donation for fertility treatment	6	7	3	4	7	7	6	11	6	7	10	3	0	0
Donation of 'left over' material removed during an operation for a publicly-funded research project on the causes of cancer	6	12	2	4	2	4	1	4	2	2	22	13	0	0
Donation of 'left over' material removed during an operation for a pharmaceutical company research study on a new anti-cancer drug	7	9	1	5	3	6	2	7	3	5	14	11	0	0
Taking part in a clinical trial run by a pharmaceutical company to test the safety of a new anti-cancer drug	2	8	5	3	4	5	1	6	8	10	4	4	0	0
Total	42	60	16	26	31	40	11	43	25	33	84	46	2	0

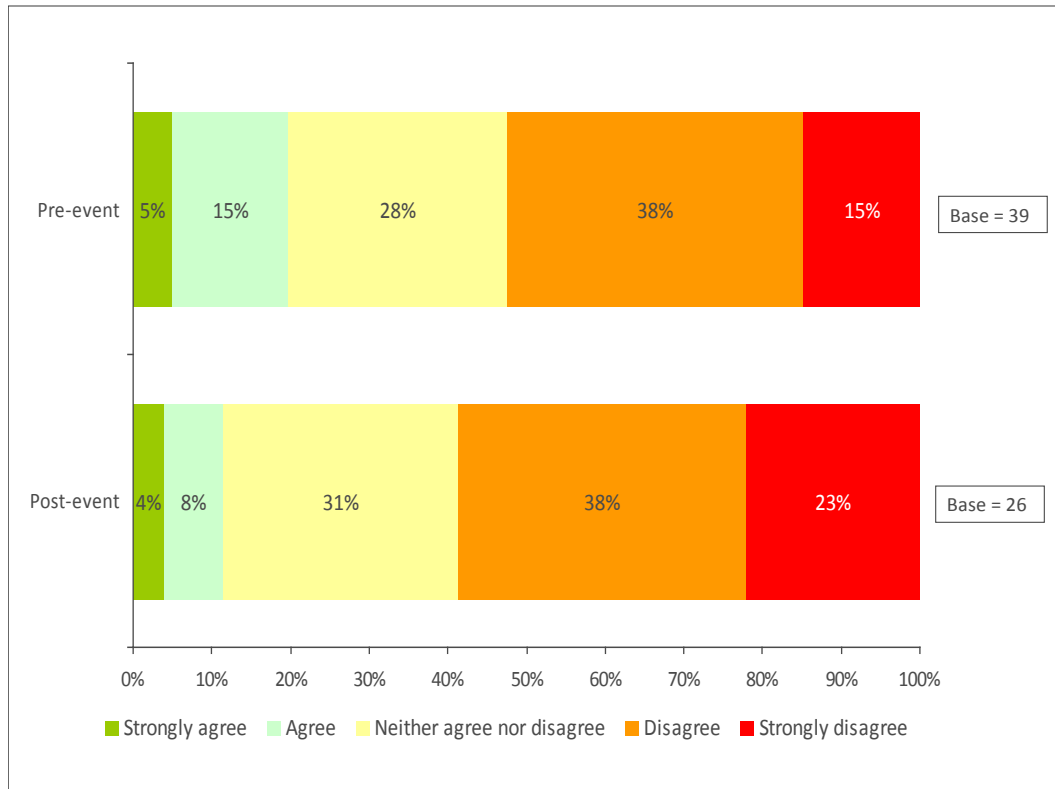
Figure 12 – appeal of types of incentive and recognition self completion – after death

After death	A recognition of your contribution, e.g. letter of thanks		A donation to a charity of your choice		A benefit in kind, e.g. priority for an organ in future		Token cash payment, i.e. enough to buy yourself a small present		Substantial cash payment		No incentive required		Other	
	Them	Others	Them	Others	Them	Others	Them	Others	Them	Others	Them	Others	Them	Others
Agree now to donate tissue after death for life saving treatment	10	14	5	8	12	15	1	8	4	4	21	11	1	0
Agree now to donate whole organ after death for life-prolonging transplant	11	8	3	8	12	16	0	5	5	5	16	9	1	0
Agree now to donate tissue after death for life enhancing treatment	5	8	2	5	11	16	0	3	4	3	15	7	0	0
Agree now to donate organ or tissue after death for a publicly-funded research project on the causes of cancer	5	9	3	6	11	13	2	5	4	3	17	9	0	0
Agree now to donate organ or tissue after death for a pharmaceutical company research study on a new anti-cancer drug	3	7	7	6	9	12	0	6	4	3	11	6	1	0
Total	34	46	20	33	55	72	3	27	21	18	80	42	3	0
Grand total	76	106	36	59	86	112	14	70	46	51	164	88	5	0

6.2.2 The appropriateness of incentives

The lack of appeal of monetary incentives was mirrored in their relative inappropriateness. At the beginning of the workshop over half (53%) of participants said that they disagreed that people should be paid cash to donate, with 1 in 5 (20%) agreeing. By the end of the workshop the proportion of participants disagreeing that they should be paid rising to around 3 in 5 (61%) and those agreeing falling to around 1 in 10 (fig. 13).

Figure 13 – pre/post questionnaire - Q5/Q3. a. People should be paid cash to donate their bodily material



Participants tended to agree more with more social incentives i.e. benefits in kind rather than cash. Over the course of the event the proportion of participants agreeing that people should receive extra benefits for donating rose from around 2 in 5 (43%) to just over half (51%)(fig. 14). Overall, the use of recognition was seen as more appropriate at the end of the workshop compared to the start. Although the proportion of participants agreeing that donors should receive some sort of recognition dropped slightly, the proportion agreeing strongly increased from 1 in 5 (20%) to nearly 2 in 5 (38%) and the proportion disagreeing dropped from 1 in 5 (20%) to 1 in 10 (10%) (fig. 15).

Figure 14 – pre/post questionnaire - Q5/Q3. b. People should receive extra benefits for donating their bodily material to help others

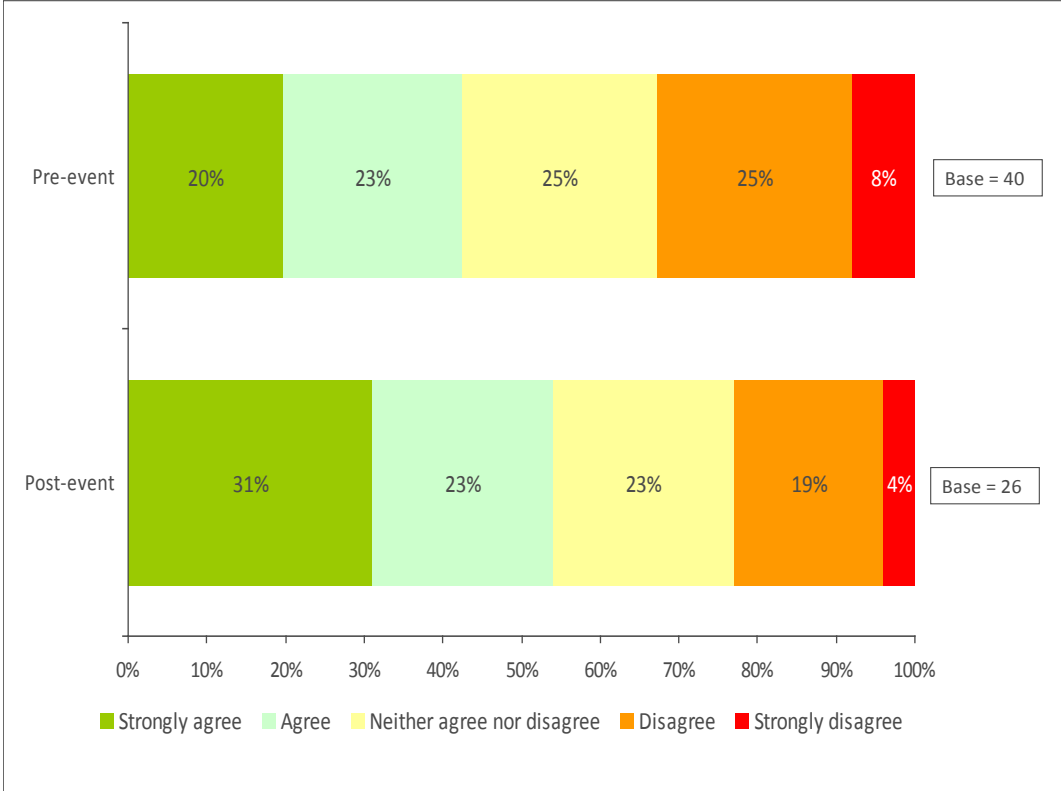
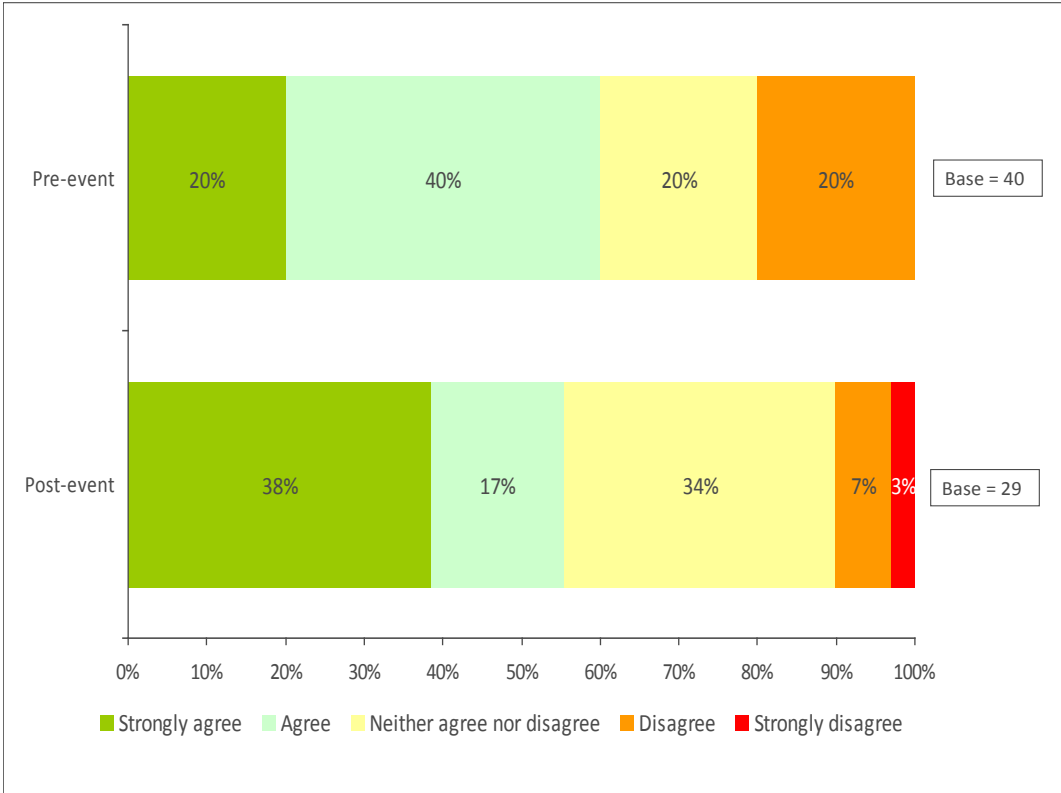


Figure 15 – pre/post questionnaire - Q5/Q3. c. People should receive some kind of recognition for donating their bodily material to others



6.3 Reaction to information on incentives and recognition

Participants were then given a presentation by Gillian Lockwood (see appendix for the full presentation), a member of the Nuffield Council on Bioethics Working Party overseeing this project. This aimed to provide some information on the use of incentives to encourage donation including:

- The current UK law on the use of incentives
- What other types of incentives and recognition could be used in the future
- The system in other countries
- Some initial arguments for and against the use of incentives

Some of the incentives mentioned caught the participants’ attention. The payment of funeral expenses for people donating bodily material after death was appealing to many. It seemed like a practical way of thanking that person for their donation, and assisted the family of the bereaved. It was seen as very different to monetary expenses paid during life as it was not going to the person donating, but was rather a way of that person assisting their family.

Participants again expressed nervousness regarding cash payments. They were seen as being potentially highly effective, but they worried about their capacity to coerce people into donating. For

this reason they felt it essential that cash incentives not be offered where there is an element of risk to the donor, as less well off people may put their health in jeopardy just for the money. They particularly worried about people in developing countries, who, they felt, may be particularly susceptible to this type of incentive.

“It’s not acceptable to attach that element of risk in terms of cash payment, but other forms of incentive would be more appropriate such as funeral expenses”

Some mentioned the possibility of a letter of thanks and felt this could be appealing especially if it explained how the donor material had been used and the impact it had.

Participants expressed surprise at the level of some cash incentives available for egg donors in the USA. They felt somewhat uneasy that this money depended on the education and looks of the donor.

6.4 Detailed discussion of issues

After this initial discussion participants engaged in a series of discussions focusing on individual issues relating to incentives and recognition including:

- Cash payments for sperm donation
- Priority treatment for organ donors
- Incentivisation for research participation

These discussions were guided by the use of four scenarios involving sets of fictional characters in both fictional scenarios (which did not reflect current UK law) and true to life donation scenarios. These scenarios were developed to highlight a range of ethical issues, and were accompanied by a set of questions relating to them which were used to prompt the participants to consider the full range of issues (see appendix). A self completion exercise identical to that used for the consent and control scenarios was also used here.

Through the rest of this chapter we will discuss the participants’ responses to these scenarios and how they impacted on their views of issues of incentives and recognition.

6.4.1 Cash payments for sperm donation (a fictional scenario)

A prospective sperm donor goes to an in-vitro fertilisation (IVF) clinic to find out about donating, since he wants to help people who are struggling to have children. He is informed there is an incentive of £100. The donor subsequently decides not to donate, since the idea of payment makes him think a lot of people donate, just for the money, and this puts him off.

Figure 16– word cloud of self completion responses to cash payments for sperm donation scenario



Discussions on this scenario largely focussed on financial concerns and their relationship with the moral aspects of donation.

Participants felt that the incentive of £100 in the scenario was reasonable, with many even feeling that it was too high and that £50 would suffice. Male participants concurred that £100 would make them more likely to donate their sperm. It was felt that this could appeal more strongly to younger individuals, who may have little to no income. Due to this, a proportion of participants felt it would be a good idea to offer counselling prior to donation so that prospective donors would be fully informed about the implications of the act.

“It sounds like a lot of money. I wouldn’t think many people will turn it away.”

There was concern that cash incentives for donating sperm would appeal more strongly to individuals from lower income backgrounds or to those in financial difficulty. It was mentioned, for instance, that such a system could attract ‘druggies’ or people just after the money. Concern would be much greater if cash incentives were offered for donating other bodily materials such as organs, since this could force individuals with little income to take risks with their health. However, in the case of sperm donation this was not felt to be an issue, since it is not detrimental to health. Moreover, participants felt that since there is a discrepancy between supply and demand for sperm donations, small cash incentives are an acceptable way of increasing the supply.

There was concern, however, that a cash incentive would mitigate the ‘feel good’ driver behind donating sperm, as in the scenario. The effect of money could be seen to remove the element of altruism, consequently deterring prospective donors from deciding to donate. More generally, a small proportion of participants inferred that cash incentives were emblematic of our increasingly money-oriented society. For some, payment nullified the status of the act as a donation. It was felt to be important that the act of giving one’s sperm was fundamentally an altruistic or ‘feel good’ action rather than a means to an end; that end being financial gain.

“The word donation means giving something for free.”

A potential way of resolving this problem was a system in which donors have the ability to give their incentive payment to a charity of their choice. This was a popular idea among some participants, since it would allow for, or potentially even embellish, the ‘feel good’ altruistic incentive to donate.

A minority thought incentives were more than just acceptable for sperm donations, but were more a just reflection of contribution to a money making enterprise. They commented that, as fertility treatment generates profits for some clinics, donors should be paid for their part in this process.

However, on balance, participants felt that cash incentives for sperm donations were acceptable as long as the prospective donor is fully briefed about the use of the sperm and contact rights of children *vis-à-vis* sperm donors in the future, and so on (fig. 16).

6.4.2 Priority treatment for organ donors (a fictional scenario)

An individual signed up to the organ donor register after seeing a poster stating he would be prioritised for a transplant over those not on the register if he ever needed one. He signed up. Another individual has liver disease and requires a transplant, but she is not on the register. Philip goes on to develop liver disease, but at a less advanced stage than the other individual. Due to being on the register, he is prioritised and receives the transplant.

Figure 17 – word cloud of self completion responses to priority treatment for organ donors scenario



The majority of participants felt that the outcome of this scenario was not fair. That the individual who joined the organ donor register would receive preferential treatment over somebody with a greater need for the same donated organ was felt to rely on many factors which were out of the control of the characters involved. For instance, the unregistered individual may simply be unaware of the organ donor register, having never seen the poster which informed the registered individual about the benefits of registering. Consequently, the registered individual would be more likely to survive a liver illness, as in the scenario. This could be due to pure luck, with no conscious choice or decision making involved.

“Due to an everyday occurrence – seeing a poster - [the registered individual] has a higher chance of surviving than another individual.”

“It’s a bit of a lottery that he saw the poster; it’s not fair that he receives preferential treatment.”

There was a strong moral feeling among participants that the defining factor in allocating organs for transplantation should be medical need. However, a small proportion noted that if the unregistered individual had not signed up to the organ donors’ register through laziness or complacency then they are partially to blame. Moreover, if the individual has consciously chosen not to register, for instance for ethical, religious or personal reasons, then the situation becomes even more difficult to disentangle morally.

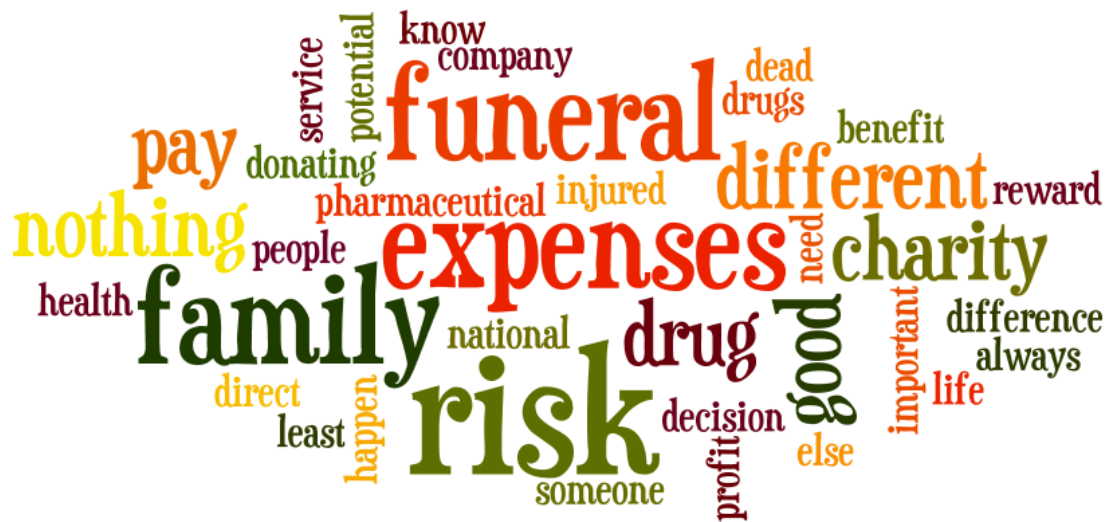
“It should be the moral situation that the most ‘needy’ person gets the treatment.”

Concerning the scenario, participants felt that no blame could be placed upon the liver specialist who had the final say in allocating the liver to the registered individual. Rather, the problem was perceived to be inherent in policy and thus the government were deemed to be ultimately responsible. Participants concluded that the problem of preferential treatment is inherent in an opt-in system. They felt that in an opt-out system, there will be less chance of a hierarchy of prioritisation developing due to unawareness among some individuals (fig. 17).

6.4.3 Incentivisation for research donations (a true-to-life scenario)

In this scenario, a lady donates her body to medical science as that she can help people when she is gone. She dies of bone cancer. A researcher uses some of the cells to help develop a new bone cancer drug. Several years later, the drug is used in ‘first in human’ trials. A volunteer gets paid £800 to test the drug. A third individual has bone cancer and could potentially benefit from the drug in the near future.

Figure 18 – word cloud of self completion responses to Incentivisation for research donations scenario



It was felt to be a noble and morally respectable decision on the part of the donor; an act that could be life-saving or life-enhancing for individuals in medical need. The researcher using the cancer cells from her body to aid the development of a new bone cancer drug was also felt to be performing an important and progressive job and, ultimately, one that contributes towards the ‘greater good’. Participants had no qualms about the ethics of this situation.

“The decision for her to do it for other people is more important than any reward.”

When informed that a volunteer is subsequently paid £800 to conduct a ‘first in human’ trial with the newly developed cancer drug, questions of justice in terms of payment arose among participants. They felt that the volunteer should be incentivised for risking his health and directly putting his body on the line by trialling the drug. This was felt to be relatively straightforward, since the volunteer makes the conscious choice to participate in the medical trial in the knowledge that he will get paid a certain amount for his risk. In the case of medical trails, financial reward is also seen as the only genuine incentive which would encourage people to take part i.e. they would not do it otherwise. Also the benefits of research, as described above, are not as clear cut as in the case of donating an organ/partial organ to a friend or relative. As there is no one in particular who they care about who would benefit from this type of donation, as there is with organ/partial organ to a friend or relative, there is much less potential for altruism to be either the most effective or most appropriate incentive. Hence a financial incentive is seen as both appropriate and necessary.

However, they also felt that although the volunteer should be incentivised, the original donor or her family should also receive some benefits for her part in the development of the drug. Since the pharmaceutical company is presumably going to make large profits from a drug developed in part by medical research on donated bodily materials, those donors should be rewarded, or at least compensated. Participants felt that one way in which this could be done would be to contribute towards the donor's funeral expenses.

"As the pharmaceutical company are benefitting, then [the deceased donor] should definitely get at least her funeral expenses paid."

Another suggestion was that a percentage of the profit from the drug could be donated to a charity of the donor's choice.

Overall, participants were heavily in favour of the use of donated bodily material in medical research, if the donation is consensual, since medical innovation can save innumerable lives (fig. 18).

"There is always a need for more drugs."

7. Conclusions

At the conclusion of the workshop, participants were asked to consider all they had discussed that day and to develop some recommendations outlining the key things they would want to happen, and the ethical principles they would want followed in the development of future policy on donation of bodily material. They did this under headings relating to the key topic areas of the workshop:

- Meeting demand
- Consent and control
- Incentives and recognition

This section draws together the participants' key points during this summing up session with other key findings developed throughout the day.

7.1 The prominence of donation

Participants demonstrated a good level of general knowledge regarding different types of donation and the potential issues there are for people involved with donation. However, they also felt these issues were not top-of-mind for the general public. Therefore there was a general call among participants for a broad awareness raising campaign to bring these issues to the fore. This was seen as key, as all of the methods they suggested involve a level of public cooperation and support to make them work.

7.2 An imperative to meet demand

Participants saw the issue of a lack of supply as being extremely important, and felt there was a moral imperative to attempt to meet demand. However, this was seen as a duty for society as a whole, rather than an obligation for each and every person to donate. Decisions on donation were seen as being at the discretion of the individual involved. However, it was perceived that there was allowable scope for the government to attempt to influence these decisions. In short, participants felt that informing and encouraging donation decisions is allowable, whereas any form of coercion was deemed to be not allowable. The way this was judged by participants is by looking at the motivation for donation so that people did not end up making decisions to donate for the 'wrong reasons' i.e. other than because they felt that it was the right thing to do. This was seen as limiting, but not entirely excluding, the acceptable use of incentives (of which more below). Mostly this was seen as a job of informing potential donors of the benefits and disadvantages. It was seen as appropriate that healthcare professionals take a leading role in informing donation decisions.

Participants wanted to see efforts to meet demand concentrated on more 'important' types of donation i.e. those that were aimed at saving or prolonging life, or materially improved the health of the recipient. This generally meant prioritising the demand for material used in direct medical

interventions, but participants saw research, with similar aims over the long term, as also being a priority.

7.3 Complexities of consent and control

Discussions around the ethics of consent and control proved the hardest on which to reach consensus. At the close of the day some participants recommended a shift to an opt-out system of donation, whereas other recommended an opt-in system. In both cases however, participants saw raising awareness and improving information on donation decisions mentioned above as essential, either to drive registration under an opt-in system, or to ensure people considered their options under an opt-out system.

Healthcare professionals, regulators and the government were seen as having no role in consent, with the sole exception of the use of 'waste' material in research. Here participants saw it as entirely appropriate for healthcare professionals to use this material without donor consent. Consent was seen as generally in the hands of the donor, except where a deceased person had left no indication of their wishes. There was little consensus as to how differences between the donor's and relative's wishes should be resolved. However, participants wished to minimise these conflicts by encouraging dialogue among families regarding their donation wishes.

Control over donated bodily material was seen sitting most appropriately in the hands of healthcare professionals, with the sole exception of organ donation from one individual to another. However, it was seen as important that these decisions are transparent and balanced, and so participants advocated the use of decision making panels, or the oversight of ethics committees, to ensure decisions are fair.

7.4 Use of incentives and recognition

Incentives were seen as having a potentially important role in meeting demands. However, participants had grave reservations over the use of some incentives, which overrode their potential to increase the supply of bodily material.

In general participants rejected the use of monetary incentives, in part due to their potential effectiveness. They were seen as having the potential to be coercive, encouraging people to make donation decisions against their better judgement, and as potentially preying on the financially needy. The only exceptions were payments for medical trials, which were seen as fair compensation for the risk involved, and for some payments for donation of gametes towards private fertility treatment, which were seen as fair profit sharing for the input of donors.

Benefits in kind were seen as more appropriate as they directly reflect the input of the donor. However, they were seen as having potentially negative consequences as honouring the benefit in kind may introduce an additional element into medical decision as doctors may have to treat the person who had donated, not the person who in greatest need, which was seen as unacceptable. Therefore they were not seen as appropriate for life saving donations such as organ donation. They were however appropriate in the context of fertility treatment e.g. free IVF in exchange for donor eggs.

Recognition was seen as important, both in terms of encouraging donation and honouring donors. For donations after death, contributions to funeral expenses were seen as the most appropriate way of honouring the donor, and were seen as potentially appealing to donors in a way that would not compromise their decision making because it is an incentive that only applies after death. For live donors recognition in the form of a thank you letter was seen as appropriate, although it was not seen particularly as a reason to donate. It was seen as appropriate that the main reason for people to donate be altruism and a personal feeling that it is the right thing to do.

8. Appendix – Workshop materials

The Appendix is available to download as a separate document at:

www.nuffieldbioethics.org/donation/donation-external-consultation