

Chapter 4

Debates over ethics

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Chapter overview

- Two unifying factors governing the bodily materials considered in this report are that they all come from persons, and that their intended use is to benefit others rather than the person who is the source of the material. These two aspects of the donation or volunteering of bodily material have generated a number of (sometimes competing) ethical concerns. Ethical values often invoked in response to such concerns include:
 - Altruism
 - Autonomy
 - Dignity
 - Justice
 - Maximising health and welfare
 - Reciprocity
 - Solidarity.
- Other pertinent values highlighted in response to our consultation included:
 - 'professional' values, such as respect, honesty, and the exercise of the duties of care and confidentiality; and
 - positive values inherent in interpersonal relations, including love, generosity, compassion and trust.
- Many of these ethical values may be interpreted in diverse and sometimes contradictory ways. This does not mean that they become redundant but rather that the way they are being used in particular circumstances needs to be made explicit and, where necessary, justified. For example, the traditional emphasis on the importance of the „gift“ has been criticised both because it may fail to prompt sufficient donors to meet demand, and because it may at times be used as a cover for coercive or exploitative relationships. However, it is clear that for many the notion of the gift elicits the sense of a supremely 'social' act in its orientation towards others. It also plays an important role in drawing attention to the person (the gift-giver) whose body is at issue. It epitomises the opposite of theft and seizure by force, and in so doing it points to the desirability of material properly given rather than improperly taken. We suggest that, only by 'unpacking' ethical claims made around donation practices in this way, can we hope to understand the context in which these values may be understood.
- Other concepts that generate strong, and sometimes conflicting, reactions are the notion of the „public“ and „private“ aspects of the donation of bodily material; and the meanings associated with money. In donation, public and private are understood in many different ways, and it may be more helpful to think of public and private as being complementary and overlapping rather than as in opposition. Money in turn may be conceptualised in many ways, including as 'cash' (negatively as 'naked cash' or positively as transferable currency that may be used for any purpose); as influence; as a pricing mechanism; and as a reward.
- Finally, this chapter touches on the psychological aspects of how individuals arrive at moral judgments. Certain kinds of transactions, for example the notion of attaching monetary value to things considered priceless such as organs, may be considered by many as 'taboo'. While some people will in practice be willing to change their view on taboo subjects (for example to achieve a valued end, such as saving lives), others will not, perceiving that it would violate deeply-held intuitions, or have an unacceptable long-term impact on societal values and functioning. Yet policy still has to be made in the context of such competing public views. We note how an awareness of these factors adds to the importance of seeking to find areas of mutual agreement and concern, where particular policies may be supported by diverse audiences for diverse reasons.

Ethical values

- 4.1 We highlighted in the Foreword that two unifying factors govern the bodily materials considered in this report: they all come from persons,⁴⁸⁴ and their intended use is to benefit others rather than the person who is the source of the material. These two aspects of the donation or volunteering of bodily material have generated a number of (sometimes competing) ethical concerns around consent, control, and ownership (See Box 4.1 opposite). In addition, the issue of 'shortage' has created its own area of concern, prompting the question: *How far should society go in attempting to encourage or facilitate the donation of bodily material?* Addressing the legitimate role of public and private bodies in responding to that shortage, the question becomes: *how far should public and private bodies go in encouraging, or even incentivising, people to provide their bodily material or to volunteer for a trial? and should they take action*

⁴⁸⁴ As we note earlier, we use the term 'person' to indicate a social being in relationships with other social beings.

themselves to facilitate donation? The aim of this chapter is to provide an overview of some of the ethical values widely considered to be at stake, before embarking on our own discussion of these issues in Chapter 5. It will also consider the importance of considering the *context* in which appeal is made to these values (see paragraph 4.6, and following sections).⁴⁸⁵

Box 4.1: Examples of ethical dilemmas arising in the context of donation

- Is it right always to try to meet demand? Are some needs or demands more pressing than others?
- How should bodily material be valued? Are some forms of material more valuable in themselves than others? Are some uses more valuable in themselves than others?
- Does the offer of any significant incentive – whether in the form of direct cash payment or indirect financial benefits such as free or reduced fees for IVF treatment – act as a form of „undue influence“ on the person concerned and compromise the voluntary nature of their consent?
- How can we guard against the risk of coercion in the family context – for example to donate bone marrow or a kidney as a living donor – where the „donor“ may not feel able to say no?
- What role should families play in deciding whether a deceased person’s bodily material should be used to benefit others?
- Should those who are prepared to donate bodily material be entitled to specify the recipient?
- Should the state intervene if one person is willing to sell a body part that another wishes to buy?

- 4.2 The consultation document published by the Working Party in April 2010⁴⁸⁶ pinpointed a number of ethical values that are often invoked when people in the UK consider the donation of human bodily material. We reproduce them in expanded form in Box 4.2 overleaf, illuminated by quotes from consultation respondents. The purpose of doing so is to highlight how controversies and disputes that arise in connection with the donation of bodily material are often not so much about the respective merits of particular values, but rather about the ethical dilemmas with which these values are associated, and the way in which values are invoked to make particular claims.

⁴⁸⁵ As Stephen Wilkinson succinctly puts it in relation to an argument about exploitation and instrumentalisation: "What does all the ethical work here is context": Wilkinson S (2003) *Bodies for sale: ethics and exploitation in the human body trade* (London: Routledge), p42.

⁴⁸⁶ Nuffield Council on Bioethics (2010) *Give and take? Human bodies in medicine and research*, available at: <http://www.nuffieldbioethics.org/sites/default/files/Human%20bodies%20in%20medicine%20and%20research%20consultation%20paper.pdf>.

Box 4.2: Ethical values cited in the Working Party's consultation document

“We think that the ‚gift relationship“ is of the essence when bodies and donations are under consideration.” - *Patricia Stoot, Convenor, Health and Bioethics Committee, National Board of Catholic Women*

“As an unfortunate fact of reality, altruism does not produce enough organs.” - *Jonathan Lee*

Altruism is widely understood as entailing a selfless gift to others without expectation of remuneration. For several decades, this understanding of altruism has been presented as the basis of blood and organ donation in the UK. Altruistic giving may be to strangers, or may take place within the context of family or other relationships. The widespread support for this model for donation is found both in the regulatory emphasis on voluntary and unpaid donation (see Box 2.1) and in common descriptions such as „giving the gift of life“. Such descriptions contrast with the not infrequent portrayal of those paid to participate in first-in-human clinical trials as „human guinea-pigs“.

Some argue, however, that a model of individual altruism no longer sits easily in the more commercial world of modern health care: why should those providing material be required to act on an altruistic basis when everyone else involved in the transaction is remunerated in some way? Others express concern that the traditional altruistic model can often be subject to hidden coercive pressures, as when patients on a transplant list might „expect“ a suitable relative to donate an organ to help them.

“Autonomy and the ability of an individual to give or decline consent should be paramount. Values should therefore be prioritised relating first to the individual and then society.” - *Royal College of General Practitioners*

“Autonomy is normally considered a priority, but should not necessarily always take precedence. An example might be when an emerging new infection threatens to become a serious public health issue, in which case testing samples in an existing tissue bank without donor consent could be justified.” - *The Medical Research Council*

Autonomy is often highlighted as the key value underpinning people's entitlement to control their own bodies, either because of the relationship of identity between a person and their body, or because bodies are regarded as „part of“ or as „belonging“ to the individual person. Respect for autonomy is shown primarily through the importance placed on consent: valid consent must be given before bodily material may be taken, and before a person participates in a first-in-human trial (although what constitutes 'valid' consent may differ depending on different conceptions of autonomy). Concerns about coercion and „undue inducement“ undermining valid consent similarly reflect the importance attached to ensuring that decisions about a person's body are freely and autonomously made by the person concerned.

More controversially, it may also be argued that respect for autonomy should entail permitting people to do what they wish with their own bodies, including selling their bodily material as a commercial transaction. Similarly, it may be thought desirable actively to encourage „autonomy“ by making people responsible for their own circumstances, as in the move away from what comes to seem medical paternalism.

“Dignity and justice should always prevail.” - *Jayne Doran*

“Concepts such as dignity and justice have proven ambiguous in practice and should be minimised.” - *Anonymous consultation respondent*

Dignity and concerns about 'commodification'. The concept of the inherent dignity, or special status, of the human body is often expressed in terms of Kantian concerns about using people purely as 'means' rather than as 'ends in themselves'. Bodies have a double position in health care: the body of a patient receiving medical treatment is a source of concern (an 'end in itself'), but when bodily material is being used to treat others, there is the risk that the material is viewed purely as a 'commodity', available as a 'means' to others' ends. Such concerns may be exacerbated if money enters the equation: in a Kantian view, dignity and price are essentially mutually incompatible. Putting a price on a human being, or on part of their body, may be seen as giving it a relative value, whereas human beings are of „incomparable ethical worth“.

For some, donation of bodily material can only respect human dignity if the donation is made with the primary aim of helping others: in such a way the donated material will not become purely a means to another end, but also an expression of the 'ends' of the person making the donation. Others argue that there is nothing inherently undignified in providing bodily material in return for a fee and that degradation depends on one's own perception of what is degrading.

“Equity must be a central component of every aspect of a scheme within which individuals donate any substance, whilst living or after death.” - *Graham Driver*

“Formal equality can be beneficial ... But always treating people the same may lead to other inequalities through failing to recognize their differences.” - *Dr Rachel Ariss*

Justice is concerned with a „fair“ distribution of benefits and burdens within or between societies. Issues of justice arise in at least two distinct contexts in donation and volunteering. On the one hand, concerns arise that those who are most likely to donate or volunteer may be the least likely to benefit from access to the services of which the donation/volunteering is part. Those volunteering for first-in-human trials, for example, may be those who have poor access to health care and are

unlikely to access the resulting benefits. Similarly, a key anxiety about any form of commercial market for bodily material is that it may induce primarily the poorest and most vulnerable members of society into becoming donors, with the main recipients being the better-off. This could occur both within individual countries (low, middle and high income countries alike) and also lead to inhabitants of lower income countries becoming the main source of organs and gametes – „donor nations“ – for the inhabitants of wealthier nations.

On the other hand, the question arises as to what constitutes „fair recompense“ to the donor or volunteer who in many cases may be the only person concerned *not* to receive any form of remuneration (contrast the salary paid to health care staff involved in the transaction) or direct benefit (as where a recipient derives health benefit from the donated material). Such questions arise especially where the intermediaries concerned in the transaction – for example some fertility clinics or pharmaceutical companies – operate on a commercial basis.

“Maximising health and welfare should be a major priority.” - Faculty of Pharmaceutical Medicine of the Royal Colleges of Physicians of the United Kingdom

“There is no doubt in my mind that the altruistic concepts of „maximising health and welfare“, reciprocity and solidarity are sadly missing from discussions in this area.” - Marlene Rose

Maximising health and welfare: An ethical approach that prioritises the achievement of the best possible outcome for the greatest number, minimising harm and maximising benefit overall. One argument that is sometimes made in favour of an „opt-out“ system (where organs are routinely taken after death unless the person has explicitly objected) is that the good to those able to benefit from treatment and research exceeds the harm of the interference with autonomy. A similar argument could be made for a moral duty to participate in research.

On the other hand, arguments based on the maximisation of health and welfare may be deployed against the use of commercial markets in bodily material and the use of payment in first-in-human trials because of concerns about the creation of an underground „shadow economy“ of exploited and vulnerable members of society.

“Reciprocity is an opportunistic „value“ that should be banned: what if I have nothing to „give“ and need to „take“?” - Haris E. Cazlaris

“... reciprocity is a positive concept if it connotes active cooperation among individuals and includes relationships of gratitude and just recompense.” - The Anscombe Bioethics Centre

Reciprocity: Reciprocal relationships involve a notion of exchange between two or more parties in the context of a mutually beneficial relationship. Such a relationship requires both that the parties to the relationship are jointly bound, and that there is some kind of equitable return between them. The value of reciprocity may be used to justify the practice of benefit-sharing or compensation in return for providing bodily material or participating in a first-in-human trial (see also **Justice**). It also underpins the idea of paired organ donation, with one donor/recipient „pair“ entering into a reciprocal arrangement with the other.

Thus, reciprocity may be evoked positively, where two parties perceive a sense of mutuality or common purpose, and acknowledge the value of „fair dealing“ between themselves; this may be projected on to unknown others, so that a person may act for public benefit in the conviction or hope of „do as you would be done by“. Reciprocity may also be invoked negatively, as in the argument that those who are not prepared to provide bodily material should not, were they to need it, be eligible to receive such material themselves.

“Solidarity is very important as „we are all in it together“ in the sense that disease is not chosen and does not strike in a moral way.” - Anonymous consultation respondent

“Solidarity recognises our interconnectedness, the natural compassion that everyone feels (or should feel) toward others in view of the hardships and misfortunes of those others, and it is in compliance with noble values of dignity, respect and mutual help. It emphasises community and mutual obligations.” - Shawn H. E. Harmon

Solidarity expresses the idea that „we“re all in this together“, with an implication of mutual obligations and mutual support within a definable community (based, for example, on geography or on shared interests). It links with values that are communal and collective in origin, encompassing ideas of a „shared humanity“ or a „shared life“ in which we can all both contribute and receive, and where those who are vulnerable should be given special protection. In the context of the donation of bodily materials, both donors and recipients could, in different ways and circumstances, potentially be „vulnerable“ and in need of such protection. „Altruism“ and „solidarity“ may, in many cases, be overlapping concepts: one may give blood, for example, out of a desire to help others – and also out of an awareness that anyone may, at any time, need blood themselves.

However, there are also degrees of solidarity depending on the narrowness or breadth of the community in question: indeed, by definition, a „community“ excludes those outside it. Solidarity can thus work to exclusionary effect, as when minority groups resist identification with the majority or are excluded by it.

- 4.3 In the responses to the consultation exercise, and in the course of our enquiries generally, it was suggested that further pertinent ethical values were:
- **Professional values:** these included ideas of 'doing no harm' (non-maleficence) and of actively seeking to do good ('beneficence'); of exercising a duty of care; of honesty towards, and respect for, patients, donors and research participants; of taking professional responsibility for one's actions; and ensuring respect for confidentiality and privacy. All these values emphasised the special role of the health professional in safeguarding and protecting those in their care, and in promoting practices that are beneficial to health and protect the rights and interests of individual patients.
 - **Values inherent in interpersonal relations:** positive values included love, generosity, compassion and trust. For some respondents, these more 'emotional' values were felt to be far more critical in determining how individuals came to make decisions about donation, and in safeguarding the process of donation, than the more 'abstract' ethical values set out in the consultation document (see Box 4.2).⁴⁸⁷ While in general these relational values were highlighted as being relevant to the behaviour and motivations of potential donors (particularly in the context of families), clearly they also have relevance to the way in which professionals see their role and exercise their professional responsibilities.
- 4.4 These ethical values have been used and combined in a variety of ways. They have been variously taken for granted, adhered to explicitly, and rendered controversial. They can be stretched ('autonomy' taken as a near-prohibition on intervening in others' personal decisions) or shrunk ('reciprocity' seen as no more than a matter of tit-for-tat). They can be appealed to in support of different sides of an argument ('autonomy' versus 'solidarity' say), prioritised (as in regulatory approaches based on the importance of 'autonomy' in giving consent) or superseded in certain contexts, such as by the familial values of 'love' or 'obligation', which may trump everything else (see paragraph 4.3). In what follows, we briefly consider four examples of the way people may be influenced in espousing and deploying these values: first with respect to notions of what is 'public' and what is 'private'; second in respect to understandings of moral obligation; third in respect to the idea of the gift relationship; and fourth with respect to the meanings accorded to money. In conclusion (paragraph 4.17), we offer a comment on an important implication of this pluralism.

The public and the private

- 4.5 The boundary between what is 'public' and what is 'private' emerged repeatedly during the Working Party's inquiry, and provides a very clear example of how particular concepts can be called upon in both positive and negative ways to give strength to a particular argument. We noted in Chapter 2, for example, that the HFEA drew to our attention one significant difference between the use of bodily material in fertility treatment and the use of bodily material in other forms of health care: fertility treatment takes place primarily within the private sector. This 'private' nature of much fertility treatment is used by some as an indication that such treatment is not a 'core' health service but rather a dispensable luxury. Others, by contrast, argue that this 'private' nature takes fertility treatment outside the legitimate scope of 'public' (e.g. state or other regulatory) concern: why should the state intervene in decisions made in the private sphere by autonomous patients and their doctors? We highlight in Box 4.3 some of the many tensions exemplified by the concepts of 'public' and 'private'.

⁴⁸⁷ Note that we do not distinguish between social and ethical values in the abstract: the distinction lies in the way these concepts are held or applied. So social values may be deployed as ethical principles to justify a set of guidelines or win a moral argument, and values stated in ethical contexts may thereby acquire a further aura of social legitimacy.

Box 4.3: Public and private

The Working Party met with a number of social scientists⁴⁸⁸ to discuss how ideas of what is „public“ and what is „private“ influence attitudes to and assumptions about the donation of bodily material. This box draws heavily on that discussion:

- Ideas of 'public' and 'private' are **heavily intertwined**: notions of marriage and family, for example, can be described as concerning both private relationships and publicly-acknowledged status. The 'public' NHS has many 'private' transactions, and the 'public' act of donating may lead to 'private' kinship-like relations, for example between the family of a deceased donor and the recipient. Charities, by definition, must offer 'public benefit', but are often contrasted with the 'public' (state) sector. What appears to be a 'private' decision to donate bodily material may in fact be heavily influenced by 'public' expectations. Doctors are often a 'public' third party in what would otherwise be a 'private' activity, such as conception.
- Donation is a **multi-layered process**, involving a range of individuals, institutions, stages and procedures, each of which may be characterised differently. For example, eggs may be donated for research (public gain), for a stranger's treatment (public gain), for a friend or relative's treatment (private gain), or in exchange for cheaper IVF (private gain). Levels of IVF funding could be characterised as a 'public' issue of health care provision or as a 'private' matter in connection with personal difficulty in conceiving. 'Private' concerns about the future existence of a genetically-related child may affect choices about donating eggs for the 'private' good of another individual. Similarly, a 'private' decision to donate an organ to a family member may affect that family member's autonomy: they may feel that a 'private' matter of how they treat their transplanted organ has acquired 'public' obligations.
- The terms 'public' and 'private' each has a **range of meanings**. 'Public' may refer to the common good (the NHS, public services); the generalised unknowable good (e.g. possible future research benefit); and also by contrast the market (to which all 'publicly' have access). The 'public' may be sub-divided, for example by region ("Scotland needs you to give blood"⁴⁸⁹) or by community (for example campaigns targeting particular ethnic groups). 'Private' may refer to notions of relationship, of exclusivity, and of money: for example informational privacy, personal relationships and personal control (eg over the destination of donated material); but also 'private' health-care where money exchanges hands. In terms of 'private' decisions, to what extent does anyone make decisions entirely on their own?
- The **purpose** of donation may affect our judgment as to the relative benefits of 'public' or 'private' action in particular circumstances: it is very inefficient to have one's own blood stored before an operation, instead of relying on adequate communal (ie 'public') resources - but it is clinically better to have a kidney transplant from a live donor (which will generally be a directed 'private' donation).
- **Interactions** between 'public' and 'private' forms of provision are key in making policy decisions that result in the promotion or regulation of particular forms of activity. As well as considering whether 'private' provision of material may undermine 'public' provision, we should consider the question in reverse, that is, does pressure to achieve goals that serve the public good undermine legitimate private interests? For example, might encouragement to the relatives of a deceased person to allow use of the organs as an act of „public“ spiritedness undermine their 'private' interest as guardians of the integrity of a body?
- When it comes to people's behaviour, are there situations where it is more helpful to think of 'public' and 'private' as **complementary and overlapping**, rather than in opposition? There is some evidence, for example, that those who provide eggs for 'public' research in order to fund their 'private' treatment would also do so for no personal gain once they have had their family, and that enhancing the 'private' needs of others to have a family may give the donor a general 'public' sense of 'doing good'.

- 4.6 The comments in Box 4.3 on ideas about public-private action demonstrate how the meanings of concepts may, at one time, appear to be in direct opposition to one another; and yet, at another time, occupy different points on a spectrum – or even appear to blur into one another. For example, 'private' sector research could be set up in opposition to a 'public' sector approach: the former seen as an activity concerned essentially with commercial gain and the latter with public good. However, commercial research and development may lead to medicines of widespread public benefit, while research originating in the public sector may itself lead to commercial success. Indeed where public sector tissue banks levy higher service charges for 'private' users than for 'public' ones, they could themselves be said to be acting as private bodies. Justification for the chosen meaning comes from the *purposes* for which these concepts are used.

⁴⁸⁸ In the Working Party's 'Opinion Forum' on 2 November 2010: see Appendix 1 for details.

⁴⁸⁹ YouTube (2007) *Scottish blood donation*, available at: <http://www.youtube.com/watch?v=NPvrQyo3VRY&feature=related>.

The question of obligation

- 4.7 The same is true of many other pairings of concepts. One example can be found in the responses we received to our consultation question about 'moral duty'. Those who thought that donation had (or should have) nothing to do with 'duty' or 'obligation' saw these concepts in stark opposition to the exercise of free will, individual choice, autonomy or altruism. This interpretation saw the notion of moral duty as involving coercion or compulsion from others, including from society or the state, which took away or diminished individual freedom of action.⁴⁹⁰ There were others who saw duty as entailing a much more benign sense of compulsion, especially if the impetus came from the self: that is, as an impetus to act according to cherished values, including altruism, or else in the interests of society at large.
- 4.8 Distinctions were also drawn between the concept of duties or obligations that should fall on the state (or on organisations associated with the state) and those that could legitimately be regarded as falling on individuals. Participants at the Working Party's 'deliberative event'⁴⁹¹ felt very strongly that there was a 'moral imperative' on society to meet potential demands for bodily material, but equally strongly that individuals should only donate if they personally thought it was 'the right thing to do', suggesting that such decisions were a matter of private morality, uninfluenced by social pressures.⁴⁹² Such a view chimes with the anxieties noted above, that any suggestion of a personal 'duty' might imply compulsion or coercion. We return in Chapter 7 to a discussion of what duties or obligations public agencies and organisations may reasonably be considered to have, given that, by definition, bodily material may only be sourced from the bodies of persons (see, for example, paragraphs 7.11 to 7.14).

The gift relationship

- 4.9 When, more than 30 years ago, Titmuss was searching for a title to his book comparing blood donation under paying and non-paying regimes, he chanced upon the phrase 'gift relationship'.⁴⁹³ The gift epitomised the benefits of a non-paying system of blood collection – practical and medical advantages came with voluntary and altruistic donations from people who wanted to contribute to the community pool, as part of their 'relationship' to society. Since then the notion has passed into general parlance, to be joined with any kind of donation, sometimes appearing even more persuasive when recipients can be identified (as in live organ transplants) and a relationship imagined with them.
- 4.10 The gift evokes two contrary sets of ideas about the relationship between donor and recipient. One is that of an absolute hand-over where the donor relinquishes any further interest in what is given.⁴⁹⁴ The second is that of the circulation of gifts in interpersonal relationships, where the acknowledgment of an obligation created by the gift, and the possibility of reciprocal return, plays a large part in maintaining those relationships. Where material is donated anonymously,

⁴⁹⁰ In such an interpretation, the separate notions of the existence of a duty, and the enforcement of that duty, have been conflated.

⁴⁹¹ 43 people, drawn from diverse social backgrounds, with no existing special interest in donation: see Appendix 1 for more details.

⁴⁹² Opinion Leader (2010) *Nuffield Council on Bioethics: human bodies in medicine and research - report of deliberative workshop on ethical issues raised by the donation of bodily material* (London: Opinion Leader), p5. This strongly expressed consensus that 'something should be done' to ensure supply was met but that no individual should feel compelled, contrasted with discussions later during the event on the possibility of moving to an 'opt-out' system of organ donation, where participants disagreed passionately with each other.

⁴⁹³ Oakley A and Ashton J, introduction to new edition of Titmuss: Titmuss R (1997) *The gift relationship: from human blood to social policy* (London: LSE Books), pp7-8. Titmuss examined the nature of the gift specifically in the context of blood donation as distinct from other forms of the gift in other contexts or other cultures.

⁴⁹⁴ For example as in the donor consent form for a blood sample collected as part of the Cambridge University SEARCH Breast Cancer study in 2010: "In a legal sense [your sample] will be treated as a 'gift' and you will have no claim over the sample should the results of this research lead to commercial development." Or as in: "to give something without expecting anything back", egg donor's idea of a gift, quoted by Konrad M (2005) *Nameless relations: anonymity, melanesia and reproductive gift exchanges between British ova donors and recipients* (New York: Berghahn Books), p67.

and hence direct reciprocity is impossible, recipients may thus wish to become donors themselves in order to "give to somebody else the opportunity that I've been able to have".⁴⁹⁵

- 4.11 We emphasise this point because the images through which people think about their situation or that they bring to an argument matter, and the gift is a powerful image in donation. Consider the ethical values set out at the beginning of this chapter. The gift contains the description of an act ('giving') that implies concern towards others, and may be invoked synonymously with altruism. It typifies voluntary donation (autonomy), gives dignity to the donor who is credited with selflessness, and acknowledges the unequal distribution of good health (justice). Gift-giving is an expressive as well as instrumental act, reflecting on the character of the gift-giver as well as achieving some aim, such as helping another. It may express a general desire to maximise health and welfare, possibly as some kind of return for the donor's own good fortune (reciprocity) or out of fellow feeling (solidarity).
- 4.12 By contrast, some of the dilemmas implicit in the quotations from consultation respondents in Box 4.2 point to more negative contexts of the gift: depending on altruistic gifts simply does not save enough lives; autonomy is compromised if the gift becomes coercive; and relying on gifts may in fact diminish the dignity and justice to be found in a proper system of recompense. It could be argued that the desire to allow people to express communal virtues should not get in the way of a realistic concern for maximising health and welfare; that one should not have to depend on people's feelings of solidarity to bring about equitable outcomes; and that any enforced requirement of reciprocity in gift-giving would be full of hazards and pitfalls, not least of bribery and corruption.
- 4.13 Moreover, it should be added that the notion of the gift is often used rhetorically in order to obtain material that then circulates on a commercial basis. This makes some cynical about its usage. Others foretell the 'end' of the gift as such, suggesting that the notion of the gift becomes redundant if it can be shown that the concern for others implicit in altruism can co-exist with monetary reward.⁴⁹⁶ This in turn supports arguments to the effect that a contrast between altruism and payment is not the stark 'trade-off' of incommensurables it once seemed.⁴⁹⁷ Or it may be pointed out that the very yielding-up of control involved in giving a gift sets up a contradiction with respect to material from the body, when the person is often regarded as having an interest in what happens to it in the future.
- 4.14 We would comment that, however cynically, or with diverse motives in mind, people appeal to 'the gift relationship', and however much it is seen to stand in the way of alternative approaches to maximising health and welfare, it is clear that for many it elicits the sense of a supremely 'social' act in its orientation towards others. It also plays an important role in drawing attention to the person (the gift-giver) whose body is at issue. Some would stress it keeps commodification at bay; no-one would deny it epitomises the opposite of theft and seizure by force. In so doing, it points to the desirability of material properly given rather than improperly taken.

⁴⁹⁵ Quotation from an egg recipient with regard to further donated eggs in storage: *Ibid*, p199.

⁴⁹⁶ Or the 'end' of any useful distinction between gift and commodity when donation is necessarily supported by a procurement industry, or when new forms of property are created, as in private blood banking, that fall into neither category (see Waldby C, and Mitchell R (2006) *Tissue economies: blood, organs and cell lines in late capitalism* (Durham, NC: Duke University Press); Healy K (2006) *Last best gifts: altruism and the market for human blood and organs* (Chicago: University of Chicago Press)).

⁴⁹⁷ The growing tolerance of commercial or semi-commercial arrangements over a spectrum of institutions, including the NHS, may be a factor here, but the specific point about the co-existence of altruism (the notion of altruism often being a shorthand for 'non-commercial') and monetary reward comes from people reflecting on the motivations of gamete donors or surrogate mothers in particular.

The role of money

- 4.15 We have chosen three sets of circumstances (public and private, the nature of obligation, and the gift relationship) in order to draw attention to the way in which values interact with one another. They are also examples of where the 'social' and the 'ethical' overlap. It is helpful to extend some of these reflections on shifting and overlapping meanings to an aspect of donation that often has a hugely over-determining effect: money. Money does not just evoke complex responses but, more often than not, very firmly-held ones. Indeed, when money appears, it can seem to drive everything else out of the picture.
- 4.16 Responses to our consultation document were illuminating here: they demonstrated a range of terms and attitudes associated with the word 'money', and these are summarised in Box 4.4.⁴⁹⁸ It should be noted that the focus is not on commerce, markets or payments, but on the image of 'money' itself, as a means of exchange. Such concerns may therefore also be just as applicable to 'reimbursement' and 'compensation' as to 'reward' and 'remuneration' (see paragraph 2.44 for definitions of these terms as used in this report).

Box 4.4: Some meanings of money (from consultation responses)

A. Money is cash (cash is cash)

Money shows its character as cash, which gives it image and substance. The few respondents who referred to 'cash' took it as a bottom line in several senses, with 'cash in hand' carrying the negative connotations of money grubbing. Cash may be regarded as a problem in itself ('naked cash'), leading people to make unwise decisions or to participate in harmful pursuits. At the other end of the spectrum it is suggested that *only* money is a suitable reward, for example because it gives people freedom to do what they liked with it or because it is the only transparent way of rewarding the donor.

Another bottom-line attitude is found in those who say that, when it gets down to it, there is no distinction between direct and indirect forms of compensation because it all has a financial value, it is all money in the end. In one case, reimbursement for expenses was included here too as an example of an inappropriate payment.

B. Money has influence

Money may be regarded as affecting things around it, usually negatively: having a contaminating effect. It may be seen not only as breaking down barriers between actions that should be held apart, but also as affecting people's thinking. So while incentives can take many forms, and appear as good or bad influences, monetary incentives can be portrayed as problematic in themselves. This is the sense in which people only have to use the word „payment“ to conjure up inappropriate inducements.

As a medium of exchange, money can render a whole range of things transferable, and convertible into other things. For some, this characteristic suggests that, left to itself, it cannot be contained: "Once money is exchanged for donated bodily material it will be very difficult to stop". The question therefore arises whether such 'containment' may be achieved by categorising money provided for different purposes in different ways. There was broad agreement between respondents that somehow the line can be held by a clear division between, on the one hand, monetary recompense for expenses (although opinions differed as to what should count as an expense), and, on the other, reward that leaves the donor significantly better off as a result of their donation.

Dividing money into 'large' and 'small' amounts does some of same work in judging whether money may provide an inappropriate incentive. Many responses commented on the importance of limiting the amount of money, keeping it to a minimum and so forth.

C. Money puts a price on everything

The fact that money is a standard of value (a pricing mechanism) may be a principal reason why the 'line' should be held against what are seen as inappropriate uses. Quantification leads to a single standard of measurement, rendering everything into its own coin (for example putting a value on „life“). Thus money may be seen to have a reductive effect, especially in this field where certain actions may be regarded as priceless. This common measurement also allows for the calculation of monetary gain. To make or seek monetary profit from the use of the body is seen by some as undignified, as showing lack of respect. Profit itself can be seen as a problem here. Another perceived problem with money is that its use may encourage financial comparisons between different forms of donation: for example between the respective value of donating an egg and donating a kidney.

The expressed fear of commodification relates both to 'money as influence' (the 'contaminating' effect of money), and 'money as price' (the fear that people themselves are being valued in monetary terms).

⁴⁹⁸ For more information, see summary of consultation responses: Nuffield Council on Bioethics (2011) *Human bodies: donation for medicine and research – summary of public consultation* (London: Nuffield Council on Bioethics).

D. Money rewards

Because of the questions being considered, money did not show much of its positive character. One response, however, saw recompense as the appropriate demonstration of care by a responsible society. Financial award was also advocated as part of a multiple reward system. For some, money is seen as a justifiable reward because it stores value, and can be used as a token of value: it may offer a recognition of worth without necessarily implying exchange or pricing.

Divisions similar to those summarised above under 'money as influence' also appeared when people thought about how to 'reward' donors. Here the main issue at stake was seen as the need to defend altruism. Altruism was brought in either to say that any reward would erode the altruistic act, or, by contrast, that altruism was a public virtue that required 'recognition'. Non-monetary recognition was seen as the safest form, but tokens of small financial value were regarded by some as a suitable „containment“ of money. A different tack was to point to advantages of systems that allow reward and non-reward to coexist. It was also argued that non-monetary forms of recognition may themselves be harmful, if they put social or psychological pressure on individuals to donate.

Making moral judgments

- 4.17 We noted earlier (see paragraph 1.41) the importance of accepting as a starting point the plurality of opinion within the UK regarding the meanings and significance of bodily material. To take the last of our examples, Box 4.4 above demonstrates a similar plurality of attitude with regard to the meanings to be attached to money. An important characteristic of social life is the way in which individuals reproduce this pluralism in their own decision-making. The fact that values can be opposed, combined, or seen to overlap with one another enables individuals to act in complex scenarios: they can take into account at one point these particular circumstances and at another point that set of interests; they can identify how particular actions arise out of varying degrees of concern for the self and for others; or they can deal with the contrasts between different forms of bodily material as noted in Chapter 1. However, when it comes to making judgments, other factors also move into view. We note here the importance of taking into account, not only the ethical arguments highlighted in this chapter surrounding the circumstances in which donation may take place, but also psychological research on *how* people make morally significant decisions.
- 4.18 The moral judgments people make can be based on rapid intuitions which are sometimes followed by slower moral reasoning, in which they make their values explicit.⁴⁹⁹ Such judgments are often brought to mind before any conscious processing has taken place. Moral reasoning can thus involve a retrospective search for evidence to support an intuition. That is the point at which ethical values may be articulated. This is not to suggest that some positions are not the result of moral reasoning but, rather, that on many positions moral judgments do not follow from conscious reasoning in advance. Indeed, they may be contained in 'scripts', that is responses made up of family, community or religious values, a kind of ready reference point to how someone in 'my situation' or 'from my milieu' (culture, class, ethnicity) ought to respond. The slower expression of explicit moral 'reasons' may or may not correspond with the script.
- 4.19 This perspective on moral judgment reflects observations that certain transactions are often simply considered taboo, as in attaching monetary value to things people prefer to think of as priceless: for example friendships, children or indeed the procurement of body material.⁵⁰⁰ Although they might not do so readily, some, however, *are* willing to attach monetary values to 'priceless' things such as organs if they believe that doing so will achieve an end that they value, such as saving lives. Such a willingness may, for example, emerge if the individual comes to realise that the taboo conflicts directly with other values that are equally, or more, important to them. For others, such a consideration does not alter their rejection of the use of money in this context, perceiving that it would violate deeply held intuitions about the integrity or sanctity of

⁴⁹⁹ Haidt J (2001) The emotional dog and its rational tail: a social intuitionist approach to moral judgment *Psychological review* **108**: 814.

⁵⁰⁰ Fiske AP, and Tetlock PE (1997) Taboo trade-offs: reactions to transactions that transgress the spheres of justice *Political Psychology* **18**: 255-97; Baron J, and Ritov I (2009) Protected values and omission bias as deontological judgments, in *Psychology of learning and motivation*, Bartels D, Bauman C, Skitka L, and Medin D (Editors) (Oxford: Elsevier).

certain forms of relationships, or have an unacceptable long-term impact on societal values and functioning.

4.20 Such views may not necessarily be shifted by new evidence: moral judgments may be rapid, strongly held and intractable. This can be problematic when it comes to several persons having to reach some kind of joint agreement, or indeed to making policy in the context of strongly competing public views. Solutions offered in this area may take as their starting point the importance of acknowledging the legitimacy of different views, along with a desire to make sure that the outcome is based on consideration of a wide range of evidence with the aim of achieving ultimate judgments that are reasoned rather than intuitive. Suggested approaches include:

- Encouraging groups made up of individuals who hold different views but who are committed to a common solution for a shared problem (such as seeking to increase the availability of bodily material) to devise, elaborate and defend different arguments, with the aim of finding solutions that reflect several perspectives.⁵⁰¹ Anthropologist Alan Fiske and psychologist Philip Tetlock, for instance, use the example of responding to the shortage of donor organs as an example of decision-making by a group searching for "some kind of shared and reflective equilibrium".⁵⁰² They conclude that there need be no single determinate solution; they also conclude that symbolism matters – that the same material transaction can take on very different meanings for different groups. Thus they describe hypothetical scenarios where organ selling might be permitted but with safeguards and concessions (with the aim of meeting some of the specific concerns of those intuitively opposed to a payment model), or where such markets were banned, but financial incentives permitted in the form of honorary awards for community spirit or as compensation for sacrifice.⁵⁰³
- Seeking ways of presenting evidence for and against competing positions in ways that would be likely to appeal to people with different sets of values (for example to those who tend to talk in individualistic terms and those who tend to talk in more egalitarian terms).⁵⁰⁴ Alternatively, evidence could be presented by a diverse range of experts. The aim, in approaching evidence in these ways, is not to persuade people to accept one position or another, but rather to consider all sides of an argument to avoid cultural polarisation.

4.21 While a closer analysis of psychological approaches to moral decision-making goes beyond the scope of this report, we note here the importance of this area of research, both for informing the ways in which organisations and intermediaries seek to approach potential donors, and in the broader realm of over-arching policy-making. In particular we note that one goal on the way to reaching a decision may be to find areas of overlapping consensus, even though particular policies may be supported by diverse audiences for diverse reasons.

⁵⁰¹ We here take up the argument expressed in Fiske AP, and Tetlock PE (1997) Taboo trade-offs: reactions to transactions that transgress the spheres of justice *Political Psychology* **18**: 255-97. Oriented to a complex situation in which a diversity of facts, procedures, values and opinions is evident, the paper combines Fiske's (1991) relational theory and Tetlock's (1986) value pluralism model. Four elementary models "give motivational and normative force to social relationships" (1997: 258). These work as four procedures or ways of weighing up arguments, positions, or circumstances. *Communal sharing* (CS) divides world into distinct classes, permitting differentiation but no numerical comparison, e.g. benefit-sharing where there is no metric for internal comparison. *Authority ranking* (AR) constructs an ordinal rank permitting priorities, e.g. privileged access for some. *Equality matching* (EM) defines socially meaningful scales that can be adjusted to make valid choices, e.g. equivalence in compensation. *Market pricing* (MP) makes ratios meaningful so one can combine quantities and values of diverse entities, as in a cost-benefit analysis, e.g. budget deficit as a percentage of GDP.

⁵⁰² Ibid, 294. We cite their example as a model of decision-making, not as a guide to our own arguments (it is not chosen to reflect the Working Party's view). The reference to shared reflective equilibrium is derived from Rawls J (1971) *A theory of justice* (Cambridge MA: Harvard University Press).

⁵⁰³ Ibid. 294.

⁵⁰⁴ Kahan D (2010) Fixing the communications failure *Nature* **463**: 296-7.