

This response was submitted to the consultation held by the Nuffield Council on Bioethics on Give and take? Human bodies in medicine and research between April 2010 and July 2010. The views expressed are solely those of the respondent(s) and not those of the Council.

### Responses to Question from the Nuffield Council on Bioethics

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*Nuffield: Should any particular type(s) of human bodily material be singled out as 'special' in some way?*

- Kidneys and partial livers are the only organs that can be most readily transplanted from living donors. The majority of transplant candidates – three quarters – need kidneys.<sup>1</sup> Also, kidney transplants save money compared to keeping patients on dialysis, adding a considerable cost-saving dimension to kidney-only systems of exchange.

*Are there significant differences between providing human bodily material during life and after death?*

- With respect to kidney donation, living donation offers a kidney with greater longevity and of better quality than deceased donation. Because kidneys from living donors survive twice as long as those from the deceased, their recipients are less likely to need another transplant or return to dialysis.<sup>2</sup> Further, the number of kidneys available for deceased donation is not sufficient to meet the demand, whereas the number of potential living donors with healthy kidneys is much greater. Only half of families give permission for their loved one's organs to be retrieved at death if they are unaware of his or her preferences. While maximizing deceased donation is certainly desirable, even presumed consent laws, which assume that all individuals consent to having their organs donated at death unless they state otherwise, cannot meet demand. Of the roughly 2 million Americans who die annually, relatively few possess organs healthy enough for transplanting. The number is estimated to range between 10,500 and 13,000, representing less than 1 percent of all deaths each year.<sup>3</sup>

*(Nuffield lists the following "ethical values at stake:" altruism, autonomy, dignity, justice, maximizing health and welfare, reciprocity, and solidarity). Are there any other values you think should be taken into consideration? How should these values be prioritized, or*

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<sup>1</sup> Organ Procurement and Transplantation Network, "Overall by Organ: Current U.S. Waiting List," <http://www.optn.org/data> (accessed April 2, 2008).

<sup>2</sup> Connie L. Davis and Francis L. Delmonico, "Living-Donor Kidney Transplantation: A Review of Current Practices for the Live Donor," *Journal of the American Society of Nephrology* 16, no. 7 (July 2005): 2098-2110.

<sup>3</sup> Ellen Sheehy, Suzanne L. Conrad, Lori E. Brigham, Richard Luskin, Phyllis Weber, Mark Eakin, Lawrence Schkade, and Lawrence Hunsicker, "Estimating the Number of Potential Organ Donors in the United States," *New England Journal of Medicine* 249, no. 7 (August 2003): 667-74.

*balanced against each other? Is there one value that should always take precedence over the others?*

- I have chosen to focus on altruism and the importance placed on this value by many in the transplant community as the only legitimate basis for living or deceased organ donation. While altruism is an admirable virtue, it has not produced nearly enough kidneys to meet demand. Some critics of non-altruism-based organ donation policies allege that increasing organ donation by way of non-altruistic motives “cheapens” the “gift” of giving an organ. But it is unlikely that the recipient of a life-saving kidney would agree. Further, we should not be concerned with the value of the “gift” to those individuals purporting to donate out of a sense of altruism since, by definition, a true altruist should not be concerned with getting anything in return.
- While some critics of incentive programs worry that such donations would crowd out altruistic donations, there is no reason to believe that both non-rewarded and rewarded systems could not exist alongside each other. Allowing such programs would merely increase the number of options available. Indeed, if such crowding out were to occur, one would have to ask whether those supplanted altruistic donations were truly driven by altruism in the first place. Further, if some people withheld voluntary action if remuneration were available to others, then a regime of donor compensation would give those remaining “altruistic” donors bragging rights: they would be the ones who acted out of generosity, not for material gain, a distinction that would allow them to retain and intensify the “warm glow” that comes from performing acts of charity. Given the importance of “social signaling” through gift-giving (“look at me, so generous, so civic-minded!”) the opportunity to accentuate the distinction should be most welcome.
- Finally, while some individuals might be willing to donate on the promise of receiving some form of reward, this does not mean that receiving compensation would be their only motivation. Financial and humanitarian motives do not reside in discrete realms. Moreover, it is unclear how their co-mingling is inherently harmful – the goodness of an act is not diminished because someone was paid to perform it. The great teachers who enlighten us and the doctors who heal us inspire no less gratitude because they are paid. A salaried firefighter who risks her life to save a child trapped in a burning building is no less heroic than a volunteer firefighter. Soldiers accept military pay while pursuing a patriotic desire to serve their country. As in the case of surrogate motherhood or egg or sperm donation, for which donors receive financial compensation, donors are also often motivated by the desire to help another person. The desire to do well by others while enriching oneself at the same time is as old as humankind. Indeed, the very fact that generosity and remuneration so often intertwine can be leveraged to good ends: to increase the pool of transplantable organs, for instance.

There is only a modest empirical literature on crowding out but here is a summary. In 1971, Richard M. Titmuss, a professor of social administration at the London School of Economics, published *The Gift Relationship: From Human Blood to Social Policy*, which laid the foundation for an empirical analysis of crowding. Examining blood procurement data from the 1960-70s in the United States, where various incentives for donation were offered, and the United Kingdom, which had an exclusively voluntary system, Titmuss concluded that incentives had crowded out altruistic donation because less than 10 percent of all procured blood in the U.S. was from truly voluntary donors, compared to 99 percent in the U.K.<sup>4</sup> Titmuss's analysis was methodologically flawed, at least in part due to his classification of "altruistic" motives for donation. At best, Titmuss's empirical work revealed that the internal motives of British blood providers in the 1960s were nuanced and complex, even when the opportunity to give blood was crowded in by laws requiring donation alone. In a different study, an analysis of an Israeli day care that switched from a no-late-pickup policy to a late fee system showed that when the late fee was in place, tardiness actually increased because parents interpreted the fee as a price for the service of chaperoning their children.<sup>5</sup> In surveys and social psychology experiments, researchers have found that subjects are less willing to participate, or participate as strenuously, in a task they had already agreed to perform for free if it is accompanied by an offer of money. But few real-world data exist to indicate whether the ability to purchase organs crowds out kidney donation from either living or deceased donors.

Presumably, the ability to obtain a kidney from a stranger eases the burden on ambivalent would-be family donors as well as on the patients themselves, especially older individuals who are reluctant to ask their children to sacrifice an organ for their sake. But if those organs are not immediately available, as would undoubtedly be the case in the early stages of a compensation system in this country, the sense of obligation to help loved ones would likely remain. Significantly, none of the psychological experiments by motivation-crowding theorists focuses on an activity like organ donation, in which the beneficial effects are immediate and the stakes are life and death. What's more, these experiments focus on the question of whether people who are prepared to perform an act voluntarily will be less willing to do so if they receive payment. They do not address the question at hand: whether those willing to donate their own or their loved ones' organs would become less willing if *others* had the option of getting paid. Also unaddressed is the question of whether an increase in living donation might curb deceased

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<sup>4</sup> Richard Titmuss, *The Gift Relationship: From Human Blood to Social Policy* (London: Allen & Unwin, 1971)

<sup>5</sup> Rothman and Rothman, "Hidden Cost of Organ Sale"; Uri Gneezy and Aldo Rustichini, "A Fine is a Price," *Journal of Legal Studies* 29, no.1. (2000): 1-17.

donation, given that the latter is significantly more complicated logistically. However, given that there would still be a need for hearts, livers, and lungs, which can be transplanted only from the deceased, it is reasonable to expect that a conceivable drop in deceased donation of kidneys would be tempered by the need for these organs; When families decide to allow their loved ones' organs to be retrieved, they know that all viable organs will be taken, not just kidneys. There would be no logic in withholding the organs of the deceased simply because the supply of *kidneys* was enhanced through compensating living donors.

*Do you think that it is in any way better, morally speaking, to provide human bodily material or volunteer for a first-in-human trial for free, rather than for some form of compensation? Does the type or purpose of bodily material or medicine being tested make a difference?*

- Organ donation policy, in my view, should be driven by utilitarian concerns. As long as the two parties involved in donation – the donor and the recipient – are sufficiently competent to make a decision in their best interest and have been provided all of the necessary information, it should not matter whether the motivation is altruistic or the desire to enrich one's self through some form of compensation. Too often, I have found, transplant professionals see altruistic giving as an ends – wrong, it is merely a means to the true end: saving lives and reducing suffering.
- It is all too easy to romanticize altruism or volunteer donation as opposed to compensated donation. Sociologist Amitai Etzioni urges the postponement of paying for organs in favor of what he calls a “communitarian” approach “so that members of a society will recognize that donating one's organs...is the moral (right) thing to do...it entails a moral dialogue, in which the public is engaged, leading to a change in what people expect from one another.” Thomas A. Shannon, a professor of religion and social ethics, writes “I would think it a tragedy if...we tried to solve the problem of the organ donor shortage by commodification rather than by the kindness of strangers who meet in the community and recognize and meet the needs of others in generosity.” To be sure, these skeptics have a right to their moral commitments, but their views must not determine binding policy in a morally pluralistic society. A donor compensation system operating in parallel with our established mechanism of altruistic procurement is the only way to accommodate us all.

*Is there a difference between indirect compensation (such as free treatment or funeral expenses) and direct financial compensation?*

- Although there is a compelling argument for a traditional market arrangement – needy patients who could afford it would remove themselves from the

pool, increasing the chances that others could receive an altruistically donated posthumous kidney – many people are understandably uneasy about offering lump-sum cash payments. Not only is a classic free-market unfair to those who could not purchase, the critics say, but cash is too much of a lure for the economically strapped. These are reasonable points. A solution is to provide in-kind rewards--such as a down payment on a house, a contribution to a retirement fund or lifetime health insurance - so that the program would not be attractive to people who might otherwise rush to donate on the promise of receiving a large sum of instant cash. It is important to note, however, that in the U.S., we offer direct financial compensation in a number of similar situations, such as surrogate motherhood or sperm and egg donation.

- Several countries have been innovative in the area of indirect compensation. Singapore, for example, has set aside \$7 million for a fund to cover lifetime health insurance costs for anyone who donates a kidney while alive. In Israel, citizens who register to become posthumous donors get slight priority if they ever need an organ. Also, Israeli families may now accept up to \$13,400 to “memorialize” the deceased donor with, for example, a scholarship in his name. Most controversially, Iran pays cash to kidney donors. It is the only country that has wiped out its waiting list.

*How can coercion within the family be distinguished from the voluntary acceptance of some form of duty to help another family member?*

- Such coercion within the family is what I refer to as the dark side of altruism. Our current transplant system makes every donation seem like a “loving, voluntary gift of organ donation.” But this is because there is no legal alternative. Pressure from family members or those with whom a person shares a close relationship to donate a kidney “altruistically” is indeed a form of coercion that exists because of the lack of alternatives to altruistic donation and the correspondingly low supply of available organs. Today, individuals who feel uncomfortable about donating a kidney to a relative or friend must live with the tremendous emotional burden of knowing that the life of their loved one is in their hands, which may compromise their “consent” if they ultimately decide to donate an organ. Sociologists have written about familial dynamics that involve guilt, overt pressure, and subtle threats. Consider the “black sheep donor,” a wayward relative who shows up to offer an organ as an act of redemption, hoping to reposition himself in the family’s good graces. Some donate as a way to elicit praise and social acceptance. For others, donation is a sullen fulfillment of familial duty, a way to avoid the shame and guilt of allowing a relative to suffer needlessly and perhaps even die. How can it be more ethical to accept a donation from an ambivalent relative than to reward a willing stranger who knows the risks, is

ensured follow-up care, and wants to use the compensation to enhance his own well being of himself or that of his family?