

# “Because you’re worth it?” The taking and selling of transplantable organs

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In the UK, the legal processes underpinning the procurement system for cadaveric organs for transplantation and research after death are under review. The review originated after media reports of hospitals, such as Alder Hey and Bristol, retaining organs after death without the full, informed consent of relatives. The organ procurement systems for research and transplantation are separate and distinct, but given that legal change will be applicable to both, some have argued now is the time to introduce alternative organ transplant procurement systems such as presumed consent or incentive based schemes (despite inconclusive British and American research on the status of public attitudes). Findings are reported in this paper from qualitative and quantitative research undertaken in Scotland in order to ascertain the public acceptability of different procurement systems. Nineteen in depth interviews carried out with donor families about their experiences of donating the organs of the deceased covered their views of organ retention, presumed consent, and financial incentives. This led onto a representative interview survey of 1009 members of the Scottish public. The originality of the triangulated qualitative and quantitative study offers exploration of alternative organ procurement systems from different “sides of the fence”. The findings suggest that the legal changes taking place are appropriate in clarifying the role of the family but can go further in strengthening the choice of the individual to donate.

Cadaveric organ donation in the UK is dependent on the willingness of individuals choosing to “opt in” and donate organs after suffering from brain stem death. Individuals can opt in via: signing a donor card; on their driving licence; when registering with a new general practitioner (GP), and on the National Health Service (NHS) Organ Donor Register. Survey trends show approximately 70% of the population are willing to donate their kidneys after death<sup>2–7</sup> although the UK organ donation rate is the lowest in Europe at 13.1 per million of the population. Although it is regarded as the individual’s own decision whether to “altruistically” donate organs, health professionals always approach the family first in order to ascertain a “lack of objection” (the wording in the previous 1961 Human Tissue Act) before the removal of organs can occur. Studies have found that if the family do not know the individual’s wishes, approximately 30% will refuse.<sup>8–10</sup> In 1994 the NHS Organ Donor Register was introduced in the hope that making information about the donor’s wishes available might reduce the number of relatives refusing donation, hence increasing the availability of organs.<sup>11</sup> Early indications are that this has had limited success.

Because of the continuing shortage of organs for transplantation in the UK, some individuals and organisations have become increasingly frustrated with the present voluntary gifting system.<sup>12–14</sup> Calls to change the system are becoming more vocal, with proposals to either introduce a European style presumed consent option (“opting out”) or to consider implementing financial incentives. I report on views from members of the general public who have generally not experienced an organ donation request, compared with the families who have been approached. The results demonstrate some similarity around opposition to a hard version of presumed consent, but differ on the acceptability of death grants given to the family. I speculate on the reasons for this and compare how the results of this research relate to the proposed changes in legislation about to take place around procuring organs in the UK.

## BACKGROUND

During 1999–2001, the media reported that certain hospitals in the UK, such as Alder Hey and Bristol, had retained organs after postmortem examination without the permission of the parents. Relatives have since successfully sued for legal damages: all of this raised issues of “informed consent” and increased public criticism of medical paternalism. Defenders of presumed consent argue that the issue is anything but “dead” since Alder Hey and that the public are discerning enough to be able to tell the difference between organ retention and donation.<sup>14</sup> Presumed consent is the preferred strategy of fourteen European countries that have an “opt out” law based on an assumption that individuals are willing to donate their organs unless they have registered an objection otherwise. There are two versions: a “strong” one, whereby health professionals ignore relatives’ objections and take the organs and a “soft” version whereby the family’s objection is taken into consideration.

In 1994, the World Medical Association banned incentive schemes because of reports of “transplant tourism”, and an unregulated organ market thriving in Third World countries.<sup>15</sup> Both the United Kingdom and United States legislation prohibits the offering of financial incentives (the 1989 Human Organ Transplant Act and 1984 Uniform Anatomical Gift Act/National Organ Transplant Act, respectively). Yet it was also in the late eighties that calls began in the United States for the introduction of incentives in order to increase the organ donation rate.<sup>1 16 17</sup> The schemes vary in form and content—that is, whether the incentive is given to the donor or the family or someone other, whether it is given before or after death, and whether it is given on consent or recovery of organs. Such proposals initially received widespread criticism and condemnation; however, recently they have attracted a growing number of supporters.<sup>12 18–23</sup> Authors justify the adoption of a market approach by citing the financial gain for all concerned in the transplant process (physicians, coordinators, surgeons, social workers, hospitals, etc) with the donor and family being the only participants not directly benefiting from the process.<sup>1</sup>

## PUBLIC(S) VIEW OF THE TAKING AND SELLING OF ORGANS

### Methods

We do not know much about public preferences for any of the incentive options or how they compare to versions of presumed consent; previous studies have proven to be inconclusive on this. Thus a random sample of 1009 Scottish adults, aged 16 years and over (TNS Social, February/March 2004) was undertaken (February to March 2004). After being piloted on 100 university students the questions were included as part of a monthly omnibus survey. Interviews were conducted at the home of the respondent by market researchers using computer assisted personal interviewing. Analysis was then conducted with SPSS v11.5 by the market researchers and the author. All relationships are significant at the 0.01 level unless otherwise stated.

Background characteristics were weighted to match the profile of the Scottish population (Table 1) and standard demographics collected such as age, social economic group, sex, household size, marital status, area, and presence of children.

This sample size allows a 3–4% margin of error and was considered appropriate in terms of the balance between representativeness and available resources; this does, however, have implications for examining relationships within this sample. Data on ethnicity—for example—was not included because of lack of available representative sample and an inability to reach significantly robust conclusions.

### Findings

In this sample, the majority said they would be willing to donate all their organs (69%), with 17% not willing to donate any, and 14% saying they were unsure. The “unwilling” tended to be male, from the least privileged socioeconomic group D/E, and aged over 65. There was no strong demographic association with the “unsures” although the younger cohort of 16–24 year olds (22%) made up a proportion of this group. The organs least likely to be donated were the eyes (18%). Respondents were asked which methods of organ donation registration they were aware of and with which (if any) they had registered. Of those who said they were aware (88%), the donor card was cited by the vast majority (86%), 27% were aware of the NHS Organ Donor Register; 19% that they could register via the UK driving licence and 9% when signing up for a Boots card. Twelve per cent were unaware of any of these options.

Like similar UK studies conducted in the 1990s, the translation of willingness to donate into behaviour was a tenuous one.<sup>2-7</sup> As Table 2 demonstrates, of the “willing”

**Table 2** Those willing to donate who had registered

Method of registration	% who said willing to donate (69%)
NHS Organ Donor Register (ODR)	3
Donor card	32
Donor registration through Boots Advantage card	1
Donor registration on a UK Driving Licence	5
Donor registration when joining a GP practice	2
Others	1
No	36
Don't know	26

(69%), over a third had not registered with any method and a further quarter did not know whether they had.

Strikingly, over two thirds of those “willing” were uncertain whether they had registered or had left no indication. Other results show that just under half of those willing to donate had not told their family despite the majority (74%) saying they were aware the next of kin would have the final decision. Two thirds of those who said they were unwilling to donate had not discussed this with their family, with half not knowing that their family would decide. It would seem that a wholesale lack of familial communication about organ donation persists.

Subsequent questions asked respondents to indicate whether any of the listed incentive schemes described to them would make them more or less likely to allow their organs to be used for transplantation (Table 3).

Offering a payment of £20 to register proved to be the least popular of all options. Approximately 40% of respondents reacted positively to the grants after death of a £2000 payment per organ to the family, to a favourite charity, or toward funeral costs. (We found certain groups to be more favourable toward incentives, especially the 16–24 age cohort and men.) The “living incentive” schemes had little effect; a cash payment of £20 to register on the NHS Organ Donor Register, followed by £2000 offer for a kidney while alive,<sup>12 13 20</sup> then life assurance reduction<sup>17</sup> was not popular (the highest socioeconomic group (A/B) seemed more predisposed to reductions in life insurance). Importantly, there is a prominent level of “would make no difference” response to all options—even the favoured “cash to relatives” option. Therefore, the overall reaction to any of the financial options was decidedly tepid. Table 4 below shows those unwilling to donate were even more likely to be against incentive proposals although the “unsures” seemed slightly more in tune with the overall response to the options: the “unwilling” and “unsure” said it makes no difference.

**Table 1** Background characteristics of respondents

Age:	%
16–24	14.5%
25–34	17%
35–44	18%
45–54	18%
55–64	13.5%
65 +	19%
*TOTAL:	100%
Sex:	%
Men	48%
Women	52%
TOTAL:	100%
SEG (CLASS):	%
AB	20%
C1	28%
C2	21%
DE	31%
TOTAL	100%

\*weighted figures

**Table 3** Likelihood of incentive options to positively affect donation

Incentive	% overall much/more likely	% overall makes no difference	% overall much/less likely
Cash payment of £20 to register	18	68	11
Cash payment of £2000 to donate kidney while alive	24	51	21
10% reduction in life assurance premiums	25	60	11
Cash payment of £2000 for funeral or crematorium costs	39	49	9
Cash payment of £2000 to a favourite charity after death	39	47	11
Cash payment of £2000 per organ to family	43	42	12

**PUBLIC(S) VIEWS OF ALTERNATIVE PROPOSALS**

We asked respondents whether they would be much more likely to agree or disagree (or neither) with the options shown in Table 5.

Only 21% said that cash or a reward should be introduced despite 70% saying it would encourage others to donate. Hence, our respondents recognise that cash incentives can motivate behaviour but, in the case of organ transplantation, it is normatively questionable to do so. (As one would expect, there was a higher level of agreement from the 16–24 age cohorts that cash awards both should and would be used.) As researchers, we attempted to describe a hard version of presumed consent with the statement: “Doctors should be automatically allowed to take organs for transplantation unless the deceased was against it”; this was opposed by 50% of the sample and 39% agreed. There appeared little to differentiate in gender and age attitudes toward versions of presumed consent. Surprisingly, the present findings show that the majority of support appeared to reside in a soft version of presumed consent (especially among the least privileged socioeconomic groups) or mandatory donation. Nearly three quarters of the sample said that either an individual should be made to choose or their relatives had to be consulted “Priority when receiving an organ” appears to be split, with 42% agreeing with this option whereas 43% said neither agree nor disagree; figures in tune with the death grants discussed earlier.

Table 6 shows the “unwilling” were more opposed to grants, and prioritised donation than the willing and unsures. Forty six per cent of the “unsures” agreed with prioritised donation although results elsewhere show an equal number that it made no difference. Those unwilling or unsure about organ donation are opposed to a hard version of presumed consent when compared to others in the sample but in favour of being made to make a decision—that is, of mandatory donation. Yet it was a soft presumed consent that gained the most support from the unwilling (the under 24s and lowest social economic group predominated in this and unsures). One is left to conclude that those not sure or unwilling are content for the final decision to be taken by their relatives. We now turn to the views of the donor families.

**DONOR RELATIVE VIEWS OF TAKING AND SELLING OF ORGANS**

**Methods**

In 2001 nineteen interviews were carried out with Scottish families who had agreed to donate the organs of their deceased next of kin. After approval from local research ethic committees (LRECs) was gained, forty six letters were sent to

**Table 4** Likelihood of incentive options to positively affect donation (by willingness to donate)

	All	Percentage of those much/more likely to donate (by willingness to donate)		
		Willing	Unwilling	Unsure
Cash payment of £20 to register	18	20	7	17
Cash payment of £2000 to donate kidney while alive	24	25	17	29
10% reduction in life assurance premiums	25	32	9	14
Cash payment of £2000 for funeral or crematorium costs	39	44	23	37
Cash payment of £2000 to a favourite charity after death	39	45	18	38
Cash payment of £2000 per organ to family	43	45	33	46

**Table 5** Agreement rate with alternative proposals

	% Overall much/more likely to agree	% Overall neither agree or disagree	% Overall Much/less likely to agree
People should be given a cash award for allowing organs to be used	21	19	60
A cash payment or reward would encourage more people to allow their organs to be used	70	11	17
Doctors should be automatically allowed to take organs for transplantation unless the deceased was against it	37	9	53
The wishes of relatives should be considered before doctors are automatically allowed to take organs for transplantation	74	8	16
Individuals should be made to choose while they are alive whether or not their organs can be taken	74	10	14
Priority if willing to donate	42	43	12

donor families. Twenty nine were returned, with nineteen donor families participating in interviews with the author. Interviews were conducted at a time and place that suited the respondent and lasted approximately one to three hours. As part of a more general open interview about their experiences, beliefs, and reasons for donation families were asked for their views on organ retention, presumed consent, and financial incentives. Permission was sought to tape the interview and reassurances about confidentiality given (pseudonyms are used in the following accounts). Interviews were transcribed verbatim and analysed before the next interviews were conducted. The text was imported into a computer aided qualitative data analysis package that aided the management of data (QSR NUD\*IST 4) and a constant comparative method used.

**Table 6** Agreement with alternative proposals (by willingness to donate)

	Overall	% Much more/more agree (by willingness to donate)		
		Willing	Unwilling	Unsure
People should be given a cash award for allowing organs to be used	21	20	21	21
A cash payment/reward would encourage more people to allow organs used	70	72	61	76
Doctors automatically allowed to take organs unless the deceased was against it	37	45	23	16
Relatives’ wishes considered before doctors automatically allowed to take organs	74	71	80	86
Individuals made to choose while they are alive whether or not their organs can be taken	74	77	69	68
Priority given to individual if willing to donate	42	46	22	46

## Findings

The donor families did not equate their own experiences with those of the families involved with the organ retention affair:

If it was to help somebody else that wouldn't have worried me to be honest, but I think it was the fact that so many weren't used for anything. I think that is hard to take [Mrs Roberts, donor mother].

People just whipping things out and then putting them in jars for no apparent reason. That builds up the fear of people. Let's face it, if everybody got all their organs taken out when they died, they would have big warehouses, it would be like the food mountains, the wheat piles. Big warehouses filled with body parts [Mr Davidson, donor husband].

I put the following to respondents: "There are proposals to introduce other systems because the present system is failing to meet the demand for organs. One such system is called presumed consent or opting out where, unless a person has recorded their objections the hospital is allowed to take the organs. Would you support or be against the introduction of this system?" As in the public survey, reactions were mixed, with ten respondents supportive of a soft presumed consent and the rest opposed. Most of those who were for presumed consent leaned toward the softer version, adding that the objection of the "closest relative" should be taken into account. Views about presumed consent were related to whether the family had refused to donate certain organs. A third of the sample that had refused to donate the eyes was also against presumed consent. The donor family respondents that rejected presumed consent had strong beliefs about the importance of the "right to give". In contrast to the presumed consent discussion the reaction to the general issue of financial incentives was unambiguous: sixteen of seventeen donor relatives asked were opposed. Others suggested that the introduction of financial incentives would produce the effect of non-donation. Given the choice between financial incentives and presumed consent, the latter was generally viewed as more preferable. Hence, some support was found for a softer version of presumed consent in this sample. However, the reasons offered by those respondents who were hostile to its introduction rooted their objections in the emotive language of the "right to give" and "stealing". The response to financial incentives was it was "immoral".

## CONCLUDING REMARKS

The present survey findings are generally consistent with previous UK and US studies that found certain groups to be more favourable toward incentives, especially the 16–24 age cohort and men.<sup>7, 24–28</sup> No association was found, however, with the lower socioeconomic group—the same finding as in one or two British and American surveys.<sup>8, 29</sup> The relationship between youth, gender, and the acceptability of incentives is an intriguing finding common to all such research and I am at a loss to explain and am reluctant to offer an explanation that suggests a reductionist, instrumental value approach. The younger age cohorts could be less likely to think seriously about their mortality (this might also explain why the younger age groups seemed so more unsure about organ donation when compared to other age cohorts). One might speculate that favouring incentives is a generational issue common to this age cohort that changes with ageing. Repeating this type of research on a longitudinal basis would offer more satisfactory conclusions.

There was an overall lack of support for any of the "incentives to the living individual"; although the cynics (or ethicists) among us might suggest that £20 to register or

£2000 to donate was not enough. Further research might investigate variable and higher amounts of compensation to ascertain whether this is the case. The preference this sample demonstrated for grants after death arguably shows that one does not want to directly benefit from organ transplantation but rather wants any benefit to go to charity, to helping with funeral costs, or to go to the family. In fact, a certain level of sympathy and empathy is being directed toward the plight of the bereaved, of the family left behind. Asking these same donor families about how they would feel about such a proposal provokes strong, negative reactions of it being "immoral". The findings from the donor families suggested a mixed reaction to a soft version of presumed consent. However, in the survey more than three quarters of the sample suggested they supported soft presumed consent. Strikingly, those not sure about donation and unwilling to donate also appeared to be generally supportive of soft presumed consent. But (and this is an important but) in the survey, was this option taken in its entirety—that is, as a soft version of presumed consent, or was the emphasis on "relatives' wishes should be considered before organs can be taken"? Despite the "unsures" and the "unwilling" leaning toward mandatory donation, the emphasis appears to be on asking the family for consent before automatically taking organs.

This research has obvious implications regarding current policy and legislative changes. In the UK, legal change to The Human Tissue Act (1961) and that the law be changed so there is positive agreement to, or "authorisation" of, postmortem examinations and organ transplantation, as opposed to the absence of refusal.<sup>29</sup> The findings from the current research support this but also the option of mandatory donation. The "obligation to choose" is in the spirit of the proposed legal changes but also strengthens the choice and role of the individual.

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