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Do Incentives Matter? Providing Benefits to Families of Organ Donors

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Whether the number of organs available for transplant would be positively or negatively affected by providing benefits to families of organ donors has been debated by policymakers, ethicists and the transplant community at large. We designed a telephone survey to measure public opinion regarding the use of benefits in general and of five types in particular: funeral benefits, charitable contributions, travel/lodging expenses, direct payments and medical expenses. Of the 971 adults who completed the survey (response rate = 69%), all were from Pennsylvania households, 45.6% were registered organ donors, and 51.7% were nonwhite. Although 59% of respondents favored the general idea of incentives, support for specific incentives ranged from 53% (direct payment) to 84% (medical expenses). Among those registered as donors, more nonwhites than whites supported funeral benefits (88%) vs. 81%; p = 0.038), direct payment (63% vs. 41%; p < 0.001) and medical expenses (92% vs. 84%; p =0.013). Among those not registered as donors, more nonwhites supported direct payment (64% vs. 46%; p = 0.001). Most respondents believed that benefits would not influence their own behavior concerning donation but would influence the behavior of others. While benefits appear to be favored, their true impact can only be assessed through pilot programs.

Key words: Benefit programs, financial incentives, organ donation

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Introduction

The shortage of donor organs is well documented. As transplant technology improves, more medical conditions are treated through transplantation and, in turn, more people are added to candidate waiting lists. Strides to increase organ supply include technological advances (split or partial organ transplants, artificial organs), use of living donors, expansion of the donor criteria and educational programs that encourage people to register as donors (1–4). Unfortunately, these initiatives have been unable to close the gap between need and supply.

Benefits or incentives for family members who consent to donation are among the more controversial (and as yet untested) strategies for increasing organ supply. Opponents argue that incentives are coercive to the poor and dehumanize society by commodifying human bodies, while proponents argue that individuals should be allowed to act autonomously, consistent with their self-interests (5–9).

Even if one agrees that incentives are ethically acceptable, the empirical question is whether they would increase donation rates (10,11). Prior surveys report levels of support ranging from 12% to 52% for incentive-based programs (12–14). Some research indicates that incentives have the potential to increase donations (15), whereas others conclude that incentives would not influence donation decisions or that they would lead to possible backlash and the falling of donation rates (12,14).

Part of the reason that findings are inconsistent is that some studies ask about incentives generally while others describe specific programs. The public tends to oppose "financial incentives" but to support directed benefits, such as funeral expenses, life insurance or preferred donor status (13,16–18). Methodological differences in sampling frames also lead to differences. Previous polls found greater support for benefits among respondents who were younger, were nonwhite or had higher incomes (13,19).

Prior studies have overlooked several pertinent issues. They have not gauged opinion regarding the amount of money that should be offered to families, nor have they examined differences in the levels considered appropriate based on ethnicity or income. These issues are particularly important given disparities in transplant rates among

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minorities and given ethical concerns regarding exploitation. Even in studies in which demographics have been examined, support has not been assessed for a wide variety of benefits.

Our study was designed to survey a random sample of Pennsylvania households about issues related to incentives and benefits. We expected many households to be knowledgeable about donor benefits because of two events that occurred shortly before our survey took place. First, the Pennsylvania Department of Health (in conjunction with the state's organ procurement organizations) developed a pilot program to contribute \$300 toward the funeral expenses of each organ donor (20). This was the first program in the United States allowing donors or their families to receive benefits, and it received substantial coverage from the news media (21-23). Second, the pilot program was halted because of concerns that the provision of funeral benefits violated federal law (24). Our decision to focus on Pennsylvania residents was therefore motivated both by the desire to explore the issues of incentives and by the hope that our study might provide important insights and enable the Department of Health to move forward with its pilot program.

Our study explored whether respondents supported donor benefits as a matter of policy and whether they thought that benefits would affect donation rates. The study's primary goal was to examine how public opinion varied with the types of benefits offered and with the sociodemographic characteristics of respondents (particularly their ethnicity and whether or not they were registered as donors). The secondary goal was to collect information about the amount of the incentive that respondents considered permissible and examine whether the amount varied with types of benefits.

Methods

Between November 2000 and February 2001, we developed an 84-item survey in conjunction with the Survey Research Program at the University Center for Social and Urban Research. The survey was pre-tested (n = 24) and modified. Between March 2001 and August 2001, we administered the final version by telephone to a random sample of Pennsylvania households, with oversampling of African American households. Unlike many surveys, ours first asked about "incentives" generally and then inquired about specific types of benefits. Our study received approval from the University of Pittsburgh Institutional Review Board.

Survey content

The focus of the survey was to describe several types of donor benefits and ask respondents about providing such benefits to relatives of organ donors through a state-run program.

First, we asked respondents whether they agreed or disagreed with the following general statement: "The state should offer incentives or benefits that encourage eligible families to donate a loved one's organs." Answers

were ranked on a five-point scale ranging from strongly agree to strongly disagree (or were recorded as "does not know" or "refuses to answer").

Second, we described five benefits that could potentially be offered to donor families: funeral benefits for the organ donor, charitable contributions made in the name of the organ donor, reimbursement of travel and lodging expenses incurred by the family in conjunction with the organ donor's death, direct cash payments, and help with medical expenses incurred by the organ donor. While these are not the only benefits that might be offered, we chose them because they have been discussed in the literature and have an inherent economic value. We randomized the order in which benefits were presented to respondents. For each benefit, we asked the following: (i) whether the respondent would favor or oppose a state program offering such a benefit to eligible families; (ii) how the program would affect the respondent's own willingness to give consent and donate on behalf of a family member; (iii) how the program would affect the respondent's own willingness to become (or remain) a registered organ donor and (iv) how the respondent expected the program to affect the willingness of other people to consent and donate organs on behalf of a family member.

Next, we asked respondents to estimate how much of a benefit (monetary value) would be appropriate. We initially asked about a \$300 funeral benefit, to be consistent with Pennsylvania's pilot program ("If the state went ahead and offered a benefit, say funeral expenses, as a 'thank you' to families who donated, do you think that an amount of \$300 is too little, too much or approximately the right amount to offer?"). If respondents did not agree with the \$300 value, we asked them to specify an amount they considered appropriate. Likewise, we asked if all types of benefits should have the same value. If not, we again asked respondents to specify suitable amounts for the other benefits.

The survey also included general attitudinal questions about organ transplantation and donation based on prior work by two of our investigators (25). We asked knowledge-based questions about Pennsylvania's pilot program and collected demographic data, including information about gender, age, race, education, religion, occupation and income. Finally, we recorded whether the respondent was a registered organ donor and whether he or she personally knew anyone involved in the transplantation process (e.g. candidates, recipients, donors, donor families).

Sampling frame and sample size calculations

Pennsylvania residents who were 18 years or older, spoke English and lived in residential households with a telephone were eligible for our survey. A random sample of households provided by a commercial sampling firm served as our final sampling frame. Using census data on the proportion of African American households, we mapped each three-digit telephone exchange into "high-density" and "low-density" areas, and we oversampled from high-density areas. To compute a 95% confidence interval around the estimated approval rating (i.e. the proportion of households in favor of benefits) with 4% precision, we needed a total of 925 respondents, including at least 385 African Americans.

When interviewers contacted a household, they asked to interview the head of the family. If unavailable, they asked to speak with any available household member over 18 years old.

Statistical analysis

We examined the proportion of respondents who knew of Pennsylvania's proposed funeral benefits program and determined how they learned of the program (e.g. newspapers, television, friends). We then asked about other potential donor programs. Because we wanted to know whether support differed depending on whether we used generic terminology

("incentives") or described specific programs, we first computed the percentage of respondents who favored the general idea of a state-sponsored benefit program. We then computed the level of support for the five programs considered in the survey. Next, we examined the likely impact of benefits on respondents' own willingness to donate organs of a family member, respondents' own willingness to register as an organ donor and respondents' beliefs about the willingness of other people to donate organs of a family member.

We were interested in the effect of respondent characteristics, especially current donor status (to test whether incentives might decrease donation rates among registered donors) and ethnicity (to address concerns that incentive programs target minority donors). Because these covariates are not independent (chi square = 49.6, p = 0.001), we used proportional z-tests to determine if there were differences in the proportion of favorable responses by ethnicity within donor status categories.

In multivariable analyses, we included ethnicity, donor status and their interaction as covariates. We additionally adjusted for age, gender, education (college graduate or not), household income, religion (Christianity, Judaism, other, none), whether the respondent knew someone involved in the transplant process and whether the respondent ever worked in a health-related setting. To estimate overall support for donor benefits, we used logistic regression and defined the outcome as "in favor" or "not in favor." For the "willingness" questions, which have three possible outcomes ("more willing," "no effect" and "less willing"), we used multinomial logistic regression. For brevity, we discuss findings from the multivariable analyses but do not provide coefficient estimates (available by request). Analyses were completed using SAS (Cary, NC).

Finally, we summarized data regarding the appropriate monetary value of donor benefits. When asked to provide specific amounts, respondents answered in variable ways, with some stating exact dollar amounts and others providing ranges or giving qualitative responses (e.g. "it depends on the family's needs," "no amount is too much to offer"). We therefore focused our analysis on questions specific to the proposed value of \$300 and examined whether respondents considered this to be too little, too much or approximately the right amount to offer. We used chi square tests to determine if there were differences based on donor status and ethnicity.

Results

Sociodemographic characteristics

The survey was completed by 971 respondents (Table 1), representing 69% of the eligible households we contacted. The average age of respondents was 44 years (range: 18–91 years). Most (65%) were female, and 41% were African American (including 9 persons of mixed ethnicity). More than 30% graduated from college, and 56% reported household incomes of \$30 000 or more.

Of the respondents, 45.6% (n = 443) said they had a signed organ donor card or a donor designation on their driver's license. This percentage is slightly higher than the statewide average of 42.3% (26). Donor status varied by ethnicity, with 57% of white respondents and 35% of nonwhite respondents indicating that they were registered donors. Half of the respondents (n = 479) said they personally knew someone involved in the organ transplantation process, and one-third (n = 340) worked at some point in a health-related occupation or setting.

Table 1: Characteristics of study respondents

	Study
Characteristics	respondents (n = 971)
Mean age in years (SD)*	44.0 (16.7)
Female (%)	65.2
Race/ethnicity (%)	
White	48.3 (16.7)
Black	41.4 (16.7)
Other race/ethnicity	9.1 (16.7)
Refused to answer	1.2 (16.7)
College graduate (%)	30.8 (16.7)
Income at least \$30 000 (%)	56.0 (16.7)
Religion (%)	
Christian	78.7 (16.7)
Jewish	3.1 (16.7)
Other	5.1 (16.7)
None	11.8 (16.7)
Do not know, refused to answer	1.2 (16.7)
Registered organ donor (%)	45.6 (16.7)
Personally knew someone involved in the transplant process (%) [†]	49.3 (16.7)
Worked in a health-related occupation or setting (%)	35.0 (16.7)

^{*}SD indicates standard deviation.

†Based on personally knowing any of the following: a transplant candidate, a transplant recipient, an organ donor or a family member who was asked to consent and donate the organs of a loved one.

Of the 80 respondents (8.2%) who said they heard of a benefits program in Pennsylvania, only 13 (1.3% of the total sample) recalled specific details about the program (data not shown). Ten (1.0%) learned about the program through the media. In comparison with our overall sample, this group was slightly younger (mean age: 41.5 years; range: 24–60 years), and 9 (0.9%) worked in healthcare settings.

Overall findings

We found moderate support for donor benefits as a general policy, with 59% of respondents agreeing that "the state should offer incentives or benefits that encourage eligible families to donate a loved one's organs."

As shown in Table 2, level of support was substantially higher when we asked specifically about funeral benefits, charitable contributions, travel/lodging expenses and medical expenses (which were supported by 81%, 73%, 78% and 84% of respondents, respectively), and it was lower when we asked specifically about direct payment (which was supported by only 53% of respondents).

When we asked respondents how specific benefit programs would affect their own willingness to donate organs on behalf of a family member, between 71% and 76% (depending on the benefit) said that benefits would have no effect. Among those for whom a benefit would have an impact, most reported that the benefit would make them

Table 2: Respondents' reaction to donor benefits

	Overall support for benefits programs (%)*		Percentage indicating an effect on own willingness to consent/donate [†]		Percentage indicating an effect on own willingness to register as a donor [†]		Percentage who anticipated an effect on willingness of others to donate [‡]	
Type of benefit	Favor	Oppose	More likely	Less likely	More likely	Less likely	More likely	Less likely
Funeral benefits	81	17	23	3	22	5	68	5
Charitable contributions	73	25	21	5	18	8	51	8
Travel/lodging expenses	78	19	22	2	20	4	64	5
Direct payment	53	42	17	8	16	9	59	5
Medical expenses	84	13	26	3	24	5	70	4

^{*}Percentage who did not know or refused to answer is not shown (range: 2-5%).

more willing to donate. Net gains in willingness (defined as the percentage that would be "more willing" minus the percentage that would be "less willing") were positive for all five benefits but were largest for medical expenses (23%) and smallest for direct payment (9%).

When we asked respondents how specific benefits would affect their own willingness to register as an organ donor if they were not currently registered or to remain registered if they were currently registered, from 71% to 76% (depending on benefit) again said that donor benefits would have no effect (Table 2). Net gains in willingness were again positive for all five benefits but were largest for medical expenses (19%) and smallest for direct payment (7%).

Unlike the expectation that they themselves would be unaffected, when we asked respondents to predict the effect of donor benefits on other people's actions, most believed that donor benefits would encourage others to donate organs (Table 2). The respondents predicted that net gains in other people's willingness to donate would be positive for all five benefits but would be largest for medical expenses (66%) and smallest for charitable contributions (43%).

When we asked respondents whether a benefit worth \$300 was too little, too much or approximately the right amount, many were uncertain (Figure 1). The proportion who were unsure or refused to answer ranged from 3% (n = 33, funeral benefits) to 14% (n = 137, medical expenses). Of the remainder, most believed that \$300 was too little. The majority of respondents who believed that \$300 was too much were those who opposed benefits entirely.

Support for benefits based on donor status and ethnicity

We found no evidence to suggest that the group of respondents who were registered as organ donors (group 1) were

more opposed to benefit programs as a general policy than the group of respondents who were not registered as organ donors (group 2). On the contrary, group 1 was highly committed to the organ donation process and showed a level of support that was equal to or greater than that of group 2 (results available by request). Only direct payment, which received the lowest level of support in both groups, was significantly less popular in group 1 (50% vs. 56%, p = 0.004). Within each group, however, overall support for specific benefits varied by ethnicity, with greater support from nonwhite respondents. As shown in Table 3, ethnicityrelated differences were significant for the three benefits (funeral benefits, direct payment and medical expenses) among respondents in group 1 and were significant for the one benefit (direct payment) among respondents in group 2. In the adjusted models, nonwhite respondents were still twice as likely to support direct payment as white respondents.

With respect to their own decisions, results by donor status and ethnicity did not differ substantially from our overall findings. When asked how specific benefits would affect their own willingness to donate organs on behalf of a family member, the only significant difference between group 1 and group 2 was that group 1 appeared more supportive of direct payment. Within group 1, there were no differences between white and nonwhite respondents (Table 4). Within group 2, support for charitable contributions and medical expenses was higher among whites than nonwhites (Table 4). In multivariable analyses, group 1 remained more supportive of direct payments than did group 2, and support for charitable contributions remained significantly higher in whites than in nonwhites.

When we asked respondents how specific benefits would affect their group membership, we found that the proportion who were already in group 1 and were willing to remain there (i.e. continue being registered donors) was higher than the proportion who were currently in group 2 and were willing to join group 1 (i.e. become registered donors). This finding persisted in the multinomial regressions after adjusting for other covariates. Within group 1, nonwhite

[†]Percentage reporting no effect, did not know or refused to answer is not shown (range: 71–76%).

[‡]Percentage reporting no effect, did not know or refused to answer is not shown (range: 26–41%).

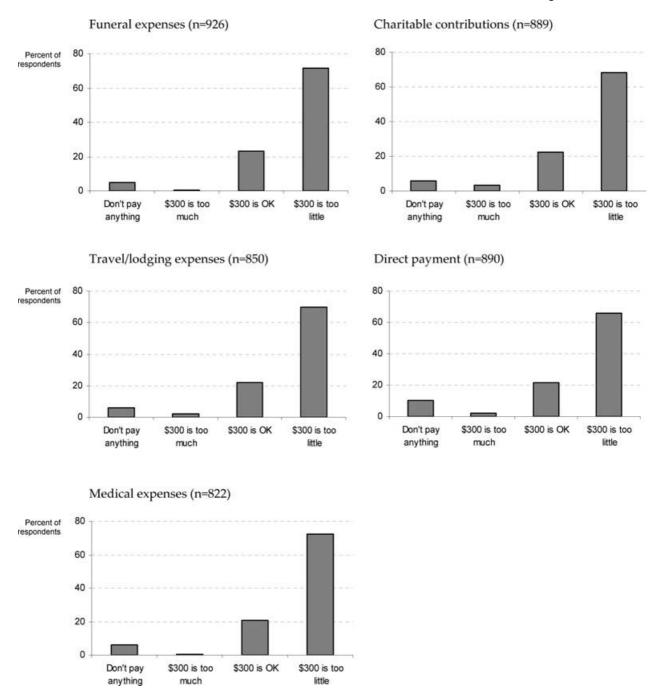


Figure 1: Appropriateness of a \$300 benefit. For all of the proposed benefits, most respondents felt that \$300 was too little to offer donor families. Sample sizes varied across benefits because we excluded respondents who either did not know or refused to answer. We also excluded 12 respondents who did not provide race information.

donors demonstrated more willingness to remain registered than white donors, but the difference was only significant for funeral benefits and medical expenses (Table 5). Within group 2, net gains in willingness to become registered ranged from 0% to 21% across benefits, with no significant differences by ethnicity (Table 5).

When we asked respondents to predict the effect of donor benefits on other people's actions, we found that those in group 1 anticipated higher net gains than those in group 2 (Table 6). Overall, those who were in group 2 and were nonwhite predicted the smallest net gains across all types of benefits.

Table 3: Respondents' overall support for specific benefits, by ethnicity within donor status*

Type of benefit	Percentage in favor of benefit program								
	Total sample (n = 971)	Registered as organ donor			Not registered as organ donor				
		White (n = 268)	Nonwhite (n = 169)	p-values	White (n = 201)	Nonwhite (n = 321)	p-values		
Funeral benefits	81	81	88	0.038	77	80	0.397		
Charitable contributions	73	76	78	0.738	71	68	0.438		
Travel/lodging expenses	78	75	79	0.345	75	81	0.133		
Direct payment	53	41	63	< 0.001	46	64	0.001		
Medical expenses	84	84	92	0.013	84	81	0.420		

^{*}Respondents were divided into two groups based on their donor status. Proportional z-tests were used to compare differences in the responses of whites and nonwhites within each group. The 12 respondents who refused to provide race information are not included in the results.

Table 4: Net effect of benefits on respondents' willingness to donate organs of a loved one, by ethnicity within donor status*

Type of benefit	Net percentage [†] who would be more willing to provide consent and donate								
		Registered as organ donor			Not registered as organ donor				
	Total sample (n = 971)	White (n = 268)	Nonwhite (n = 169)	p-values	White (n = 201)	Nonwhite (n = 321)	p-values		
Funeral benefits	20	21	21	0.966	20	19	0.747		
Charitable contributions	16	19	15	0.361	19	10	0.049		
Travel/lodging expenses	20	20	22	0.755	20	17	0.461		
Direct payment	9	10	16	0.157	4	9	0.301		
Medical expenses	23	24	26	0.761	28	16	0.007		

^{*}The p-value indicates the significance level of white versus nonwhite, within donor status using a proportional z-test. A total of 12 respondents refused to provide race information.

Table 5: Net effect of benefits on respondents' willingness to become (or remain) a registered organ donor, by ethnicity within donor status*

Type of benefit	Net percentage [†] who would be more willing to sign/renew a donor card								
		Registered as organ donor			Not registered as organ donor				
	Total sample (n = 971)	White (n = 268)	Nonwhite (n = 169)	p-values	White (n = 201)	Nonwhite $(n = 321)$	p-values		
Funeral benefits	17	16	26	0.026	18	12	0.164		
Charitable contributions	10	16	15	0.880	11	3	0.093		
Travel/lodging expenses	16	16	22	0.104	17	13	0.366		
Direct payment	7	9	14	0.267	0	7	0.183		
Medical expenses	19	18	28	0.012	21	15	0.212		

^{*}The p-value indicates the significance level of white versus nonwhite, within donor status using a proportional z-test. A total of 12 respondents refused to provide race information.

When we asked respondents about the appropriateness of a \$300 benefit, trends for white and nonwhite respondents (Figure 2) were similar to those in the overall sample (Figure 1), but white respondents were more likely to rate \$300 as appropriate and also more likely to oppose benefits of any kind, whereas the nonwhite respondents were more likely to view \$300 as too little (p = 0.001 for each benefit).

Discussion

There are several concerns regarding the generalizability of our findings. First, because Pennsylvania has several large transplant hospitals and two organ procurement organizations actively involved in educational programs, residents might be more receptive than the general population to efforts promoting organ donation. The media

 $^{^{\}dagger}$ Net percentage = (percentage "more willing") – (percentage "less willing").

[†]Net percentage = (percentage "more willing") – (percentage "less willing").

Table 6: Net perceived effect of benefits on others' willingness to donate organs of a loved one, by ethnicity within donor status*

	Net percentage [†] who said others would be more willing to consent and donate								
Type of benefit		Registered as organ donor			Not registered as organ donor				
	Total sample (n = 971)	White (n = 268)	Nonwhite (n = 169)	p-values	White (n = 201)	Nonwhite (n = 321)	p-values		
Funeral benefits	63	68	72	0.453	67	53	0.010		
Charitable contributions	43	49	38	0.073	46	38	0.156		
Travel/lodging expenses	59	68	60	0.114	69	45	0.001		
Direct payment	64	70	70	0.993	68	56	0.032		
Medical expenses	66	71	73	0.670	75	55	0.001		

^{*}The p-value indicates the significance level of white versus nonwhite, within donor status using a proportional z-test. A total of 12 respondents refused to provide race information.

coverage when Pennsylvania's pilot program was proposed (and again when it was canceled) might also affect respondents' receptiveness, but the fact that only 1% of our sample demonstrated any familiarity with details of the program suggests that this was not the case. Second, the proportion of respondents who indicated that they were registered organ donors (45.6%) may appear to be high, but it is indeed similar to the statewide estimate for adults over 18 years old (42.3%) (26). The proportion of respondents who reported knowing someone involved in the transplantation process (49.3%) was also high, and unfortunately there is no statewide estimate to use for comparison. Third, as with other surveys, ours can be criticized on the grounds that the data cannot be verified and that self-reported beliefs may differ from actual behavior when confronted with a donation decision (18).

Despite these limitations, our study offers several useful insights. Unlike earlier studies, we framed the issue of incentives in a manner that allowed respondents to explore and express their beliefs from a number of angles. It asked respondents to consider the concept of incentives in terms of the general idea and specific examples of the idea. It also asked them to consider the effects of incentives on their own actions and on the actions of others. All of these considerations come into play both in individual decision making and in public policymaking.

Most respondents favored the idea of providing donor benefits as a matter of policy and also believed that benefits would have a positive effect on overall organ donation rates. At the same time, however, respondents generally believed that their own decisions regarding donation would not be influenced by the offer of benefits. Beliefs about the appropriate value for donor benefits were less clear, but virtually no one, in favor of donor benefits, felt that an initial program offering \$300 was inappropriate.

Concerns that the offer of benefits would have different effects based on donor status or ethnicity of respondents were not substantiated in our study, since

the similarities between groups generally outweighed the differences. We did not find that currently registered donors would oppose benefits and reconsider their decision to donate, thereby leading to an overall decrease in the supply of transplantable organs. On the contrary, registered donors appeared highly committed to their donation decision and expressed strong support for benefit programs. The number of respondents opposed to benefits was small, and most were not registered donors.

Within the group of respondents who were already registered as organ donors, nonwhite respondents were more positive about donor benefits as a general concept, but whites and nonwhites held similar beliefs about how the offer of benefits would affect their own actions and the actions of others. Within the group of respondents who were not registered as organ donors, whites were more optimistic that donor benefits would increase overall donation rates. In general, nonwhite respondents were more likely to consider a \$300 benefit to be too little.

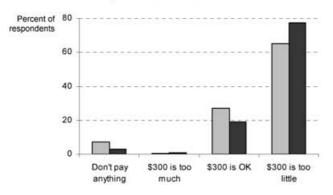
Although our findings suggest that donor benefits hold promise, they also suggest that direct payment is not the place to start. Of the five types of benefits included in our survey (funeral benefits, charitable contributions, travel/lodging expenses, direct payment and medical expenses), direct payment received the lowest level of support both in the overall survey sample and when the sample was stratified according to respondents' donor status. Moreover, direct payment was the most polarizing type of benefit, resulting in the largest differences between ethnic groups. For efforts to be effective and to avoid ethical concerns about targeting minorities, our data suggest that offering one of the other types of benefits might be a more useful place to start.

Unfortunately, the first opportunity to systematically evaluate the effects of donor benefits on donation rates was lost when the Pennsylvania Department of Health canceled its pilot program before the U.S. Department of Justice

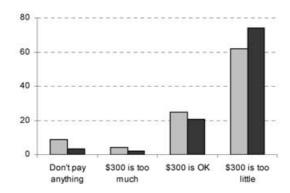
[†]Net percentage = (percentage "more willing") - (percentage "less willing").

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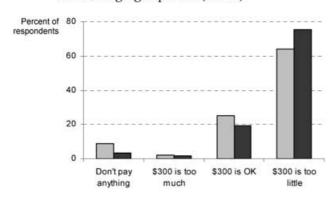
Funeral expenses (n=926)



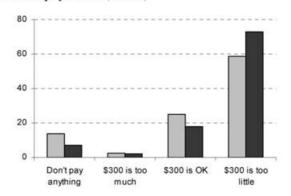
Charitable contributions (n=889)



Travel/lodging expenses (n=850)



Direct payments (n=890)



Medical expenses (n=822)

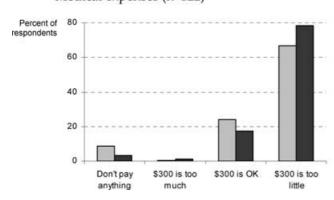




Figure 2: Appropriateness of a \$300 benefit, by ethnicity. Nonwhite respondents were more likely to consider \$300 to be "too little" for donor benefits, while white respondents were more likely to oppose any payment at all (p-value = 0.001 for all benefits). Sample sizes varied across benefits because we excluded respondents who either did not know or refused to answer. We also excluded 12 respondents who did not provide race information.

could issue an opinion about its compliance with federal law (24,27,28). Funds that were earmarked for the pilot program have been used to offset donation-related travel and lodging expenses. Most requests for such reimbursement have come from living donors and not families of deceased

donors (27). National support for similar programs was approved in the U.S. House of Representatives in 2003 (29) and in both the House and Senate in 2004 (30), and several state laws provide tax deductions for living donors up to \$10 000 as well (31–33).

Because federal law allows for remuneration for expenses incurred as part of the donation process, these programs for living donors are viewed as "reimbursements" rather than as "incentives." In contrast, programs for deceased donors or their families continue to face opposition and have yet to marshal the support needed to successfully navigate the political process. However, lack of Congressional action for broader exploration of donor benefits does not mean that they are not a viable option. The American Medical Association's Council on Ethical and Judicial Affairs (34,35) supports pilot programs to evaluate donor benefits, and the Organ Donation and Recovery Improvement Act provides that "the Secretary of Health and Human Services, in consultation with appropriate entities, including advocacy groups representing those populations that are likely to be disproportionately affected by proposals to increase cadaveric donation, shall submit to the appropriate committees of Congress a report that evaluates the ethical implications of such proposals" (30). In response, the Institute of Medicine is currently working with a panel of experts to study various options for increasing organ donation rates, including the use of financial incentives for both living and deceased donors (36).

We believe that the results of our study are policy-relevant and suggest that donor benefit programs offer one viable option for improving donation rates. We hope that our findings will provide the impetus needed both to inform policy and to encourage studies to test the effects of donor benefits for all types of donors.

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