

BRIEF COMMUNICATION**Public attitudes toward contemporary issues in liver allocation**

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Allocation of scarce livers for transplantation seeks to balance competing ethical principles of autonomy, utility, and justice. Given the history and ongoing dependence of transplantation on public support for funding and organs, understanding and incorporating public attitudes into allocation decisions seems appropriate. In the context of the current controversy around liver allocation, we sought to determine public preferences about issues relevant to the debate. We performed multiple surveys of attitudes around donation and evaluated these using conjoint analysis and clarifying follow-up questions. We found little public support that allocation decisions should be based solely on risk of waiting-list mortality. Strong public sentiment supported maximizing outcomes after transplantation, prioritizing US citizens or residents, keeping organs local, and considering cost in allocation decisions. We then present a methodology for incorporating these preferences into the Model for End-Stage Liver Disease (or MELD) priority score. Taken together, these findings suggest that current allocation schemes do not accurately reflect public preferences and suggest a framework to better align allocation with the values of the public.

KEYWORDS

ethics and public policy, health services and outcomes research, organ procurement and allocation, social sciences, survey, United Network for Organ Sharing (UNOS)

1 | INTRODUCTION

Embodied in the National Organ Transplant Act (NOTA) and the Final Rule, ethical principles guiding allocation of organs include autonomy, utility, and justice.¹ In 2017, approximately 2500 patients died or were deemed too sick for transplantation on the liver transplant waitlist,² demonstrating the significance of allocation policy as a matter of life and death. Waiting list priorities are the operational balance of ethical and moral principles that are sometimes in conflict. Reasonable people can disagree on how to weight these various factors and arrive at different allocation decisions. Some may favor priority to children, others those at highest risk of death over a certain period, and still others might favor those predicted to live longest after transplantation.

Autonomy plays a central role in our transplant system. The Final Rule permits directed donation of an organ to a named recipient,¹ and individuals determine whether to donate.^{1,3} For these reasons, public attitudes regarding how organs are prioritized should be an important consideration in designing policy.

Neuberger and Ubel explore this concept of autonomy and argue for the importance of public opinion in allocation decisions. Support for this position arises from the facts that transplantation (a) is a public good, (b) depends on public funds for research and development, and (c) in most cases is paid for by public funds. They further recognize that transplantation depends on the willingness of the population to donate, and that an unjust allocation system may adversely affect this decision. Other investigations show that the public is capable of flexible and thoughtful approaches to transplant priorities.⁴ It can also be argued that consideration of public perceptions is in The Final Rule in mandating the "best use of organs," a functionally inert requirement that depends on societal input to operationalize.¹

Abbreviations: HRSA, United States Department of Health and Human Services, Health Resources and Services Administration; NOTA, National Organ Transplant Act; UNOS, United Network for Organ Sharing.

Previous investigation into public opinion regarding organ allocation policy addressed general questions about public attitudes toward donation. A survey conducted in 2012 by The U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA) queried more than 3200 adults. This report included attitudes and behaviors related to donation.⁵ A few questions concerned organ allocation priorities, with a single question forming the basis for much of the current debate. Respondents preferred an organ to go to the patient with the most medical need, regardless of location, with 81.7% agreeing with this statement. The survey did not define “medical need,” or the complexities and difficulties of this nuanced question.

Other literature regarding organ allocation is fairly general, with small sample sizes or questions of limited relevance to contemporary allocation.⁶⁻⁸ For example, in a discrete choice experiment about renal transplantation, respondents preferred policies that recognized the importance of recipient age, societal responsibilities, time on the waitlist, life expectancy, and posttransplant quality of life.^{9,10} Another study of priorities for patients with renal failure in receiving kidneys identified preferences for “enhancing life, medical priority, recipient valuation, and deservingness.”¹¹ In some cases, public opinion conflicts with generally accepted medical ethics, for example, when a surveyed population felt that allocation should depend on whether patients caused their own disease.^{12,13} Based on these findings, public preferences seem generally but not completely consistent with current medical ethics. Most of these studies were conducted in the 1990s or deal directly with children, thereby limiting generalizability.

Given the current debate on organ allocation policies, we sought to better define public preferences with respect to the competing ethical priorities that are part of contemporary debate. Specifically, we were interested in understanding the relative importance of posttransplant survival; waitlist mortality; nonresident, noncitizen status; and local vs nonlocal organ allocation to better inform allocation policy. These topics have been recently debated in the governing bodies that regulate transplantation and have been extensively debated.¹⁴

2 | MATERIALS AND METHODS

We conducted 2 independent surveys to examine public preferences for liver allocation priorities. The first survey provided the basis for a conjoint analysis and was administered to 100 respondents via the conjoint.ly online platform. We chose to survey 100 respondents based on a power calculation, which suggested 88 respondents would be sufficient according to the conjoint.ly platform. Respondents had previously signed up with the survey company conjoint.ly to agree to take surveys and were paid \$5.00 for successful completion of the survey. Respondents were from all over the United States. Conjoint surveys offer a method of analyzing individual preferences that allows researchers to estimate the importance and relative influence of different attributes on a specific choice.

In this survey, respondents were asked which hypothetical patient among 3 should receive a liver for transplantation. Each patient was defined by the same 4 attributes—residence, functional status, survival, and waitlist mortality—but each attribute varied. Respondents were instructed to examine the levels of each of the 4 attributes and choose the patient who should receive the liver. Demographic information about the respondents was recorded.

The residence attribute included 3 levels: (a) the patient lives in your state or (b) the patient lives in another state, or (c) the patient does not live in the United States and comes only to receive a transplant. Functional status included 2 levels: (a) the patient feels very sick and is unable to carry on normal activities or work or (b) the patient feels okay and can carry on normal activities or work. Survival included the following: (a) the patient will live 5 years after the transplant or (b) the patient will live 10 years after the transplant. Finally, waitlist mortality included the following levels: (a) a 15% chance of dying in the next 3 months without a transplant or (b) a 30% chance of dying in the next 3 months without a transplant. Respondents chose among the 3 hypothetical patients 10 separate times, and each time, the 3 patients varied in the levels of each attribute.

In analyzing the data generated through the conjoint surveys, we followed the outline of Hainmueller et al, who provide an approach to identify the causal effects of different components.¹⁵ We estimate a linear regression in which each observation is a hypothetical patient presented to a participant. The regression model takes the following form.

$$\begin{aligned}
 I(Y) = & \beta_1 I(\text{lives in another state}) \\
 & + \beta_2 I(\text{Does not lives in the U.S.}) \\
 & + \beta_3 I(\text{Patient feels okay}) \\
 & + \beta_4 I(\text{Will live 10 years after transplant}) \\
 & + \beta_5 I(\text{30\% chance of dying in the next 3 months}) + \epsilon
 \end{aligned}$$

The dependent variable, $I(Y)$, is an indicator variable for which the patient was chosen, and the independent variables indicate different levels of each of the 4 attributes. For the residence attribute, an indicator variable equaled one when the hypothetical patient lives in another state, and a separate indicator variable equaled one when the hypothetical patient does not live in the United States. For all other attributes, a single indicator variable was included that equaled one when the attribute took the value labeled above. Based on the form of the regression model, the coefficient on each indicator represents the average effect from going from the reference level (the level labeled as above) to the level represented by the specific indicator variable. Standard errors are clustered by individual respondent.

Following the initial conjoint survey and attendant data analysis, we conducted a second (nonconjoint) survey of approximately 500 respondents to clarify effects observed in the conjoint analysis. We conducted this second survey through the online platform provided by Qualtrics. Again, participants had previously agreed to take surveys and were paid \$5.00 for successful completion of the

studies. Participants lived throughout the United States. Questions explored public attitudes on citizens vs noncitizens, local allocation, and the importance of waiting list mortality, posttransplant outcomes, and cost of allocation decisions. The survey instrument was administered online and is included in the Appendix S1. Statistical analysis was performed using *t* tests with the null hypothesis of a mean of zero. All statistical analysis was completed in STATA MP, version 15.1 (StataCorp, College Station, TX). Demographic data were determined using longitude and latitude information from the respondents. The Google (Mountain View, CA) Maps API was used. A get request to the server was made with the latitude and longitude values and the returned zip codes were written into an output file and matched to the respondents.

3 | RESULTS

3.1 | Conjoint survey

The conjoint survey and analysis were conducted with 102 participants evaluating the relative importance of place of residence, functional status, survival benefit, and risk of waitlist mortality. Demographic information is provided in Tables 1 and 2. The results of a linear regression examining the importance of different attributes are reported in Figure 1. Each point represents the marginal effect of a particular level of a given attribute (with the accompanying 95% confidence interval) relative to the baseline level for that attribute, which is always the first level listed within each attribute and is by definition zero. Each effect represents the average consequence from going from the baseline level to a different level.

Respondents were 11% less likely to choose an otherwise identical individual to receive a liver who “lives in another state” relative to someone who “lives in your state” ($P < .001$). Similarly, respondents were 31% less likely to choose an individual who “does not live in the US” relative to someone who “lives in your state” ($P < .001$). Respondents were 10% less likely to choose a patient who “feels okay” to receive a liver relative to a patient who “feels very sick,” other things being equal ($P < .001$), and respondents were 21% more likely to choose a patient who “will live 10 years after the transplant” relative to a patient who will only live 5 ($P < .001$). Finally, patients

TABLE 1 Distribution of area of residence for conjoint respondents

Population density	N (%)
Urban population of 2500 to 19 999	3 (2.9)
Urban population of 20 000 or more	3 (2.9)
Counties in metro areas of fewer than 250 000	8 (7.8)
Counties in metro areas of 250 000 to 1 million	10 (9.8)
Counties in metro areas of 1 million or more	72 (70.6)
Missing data	6 (5.9)
Total respondents	102

TABLE 2 Distribution of age for conjoint respondents

Age range	N (%)
18-24 y	11 (10.8)
25-34 y	21 (20.6)
35-44 y	26 (25.5)
45-54 y	20 (19.6)
55-64 y	3 (2.9)
65+ y	21 (20.6)
Total respondents	102

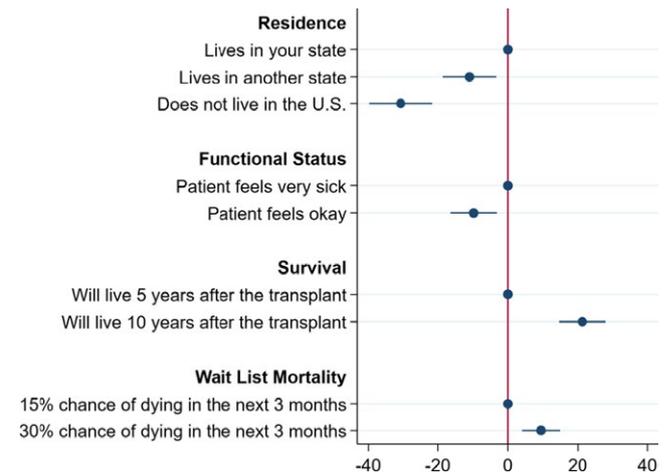


FIGURE 1 Conjoint analysis assessing relative importance of residence, functional status, posttransplant survival, and waitlist mortality in allocation decisions. In order of highest impact were residence, posttransplant survival, waiting list mortality, and functional status

with a 30% chance of death in the next 3 months were 10% more likely to be chosen than patients who have only a 15% chance ($P < .001$).

Because this survey was a conjoint survey, meaning respondents weighed different levels of different attributes against one another when deciding who should receive the liver, the estimated average effects can be directly compared to one another. Place of residence is the most important determinant of liver allocation, with those that live in the United States taking precedence over nonresidents who travel to the United States only for transplantation. To place this effect in context, priority for a nonresident who only comes to the United States for transplantation would only supersede a US resident if all of the other 3 criteria were unfavorable for the US resident. The least important determinants for priority were functional status and waiting list mortality.

3.2 | Follow-up survey results

Five hundred twelve people responded to the follow-up survey, which was then closed to new participants. The demographics of these respondents are provided in Tables 3 and 4.

TABLE 3 Distribution of area of residence for follow-up survey respondents

Population density	N (%)
Completely rural or less than 2500 urban population	3 (0.6)
Urban population of 2500 to 19 999	20 (3.8)
Urban population of 20 000 or more	35 (6.7)
Counties in metro areas of fewer than 250 000	44 (8.5)
Counties in metro areas of 250 000 to 1 million	105 (20)
Counties in metro areas of 1 million or more	311 (60)
Missing data	2 (0.4)
Total respondents	520

TABLE 4 Distribution of age for follow-up survey respondents

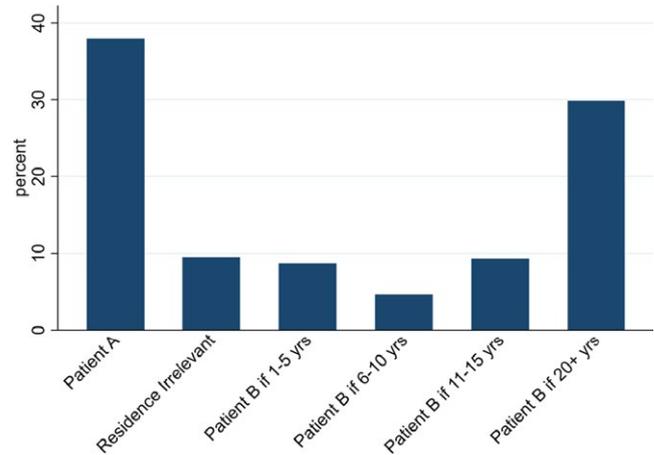
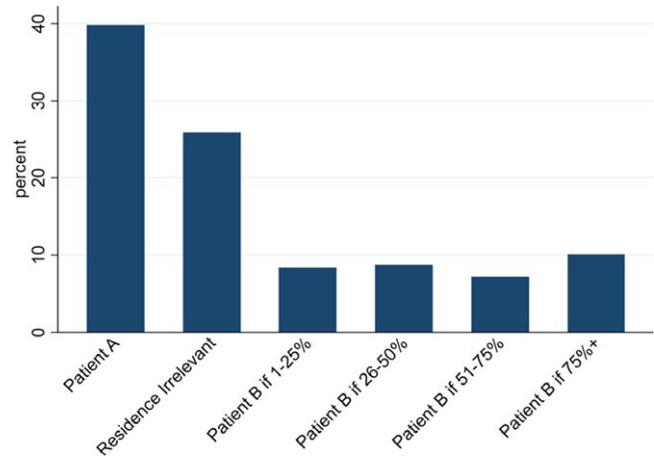
Age range	N (%)
18-24 y	44 (8.5)
25-34 y	111 (21.3)
35-44 y	95 (18.3)
45-54 y	95 (18.3)
55-64 y	98 (18.8)
65+ y	77 (14.8)
Total respondents	520

3.2.1 | Transplantation of foreign nationals

As it pertained to transplanting foreign nationals who travel to the United States only for transplantation, 55.7% ($P < .001$) of respondents thought an available organ should go to a patient who lives in the United States in every case. To further understand this finding, we asked it in a different context to see if the answer was sensitive to a specific posttransplant survival. We found the result was sensitive to the expected posttransplant survival of the recipient (Figure 2): 38.0% ($P < .001$) felt the organ should always go to the US resident, while 29.8% ($P < .001$) felt that more than 16 years of posttransplant survival would be needed to justify giving higher priority to the foreign national.

We asked a similar question to determine how consideration of priority for foreign nationals was influenced by expected waitlist survival and found results similar to that for posttransplant survival (Figure 3): 39.8% of respondents felt the organ should always go to the US citizen, in contrast to 25.8% who felt that citizenship should play no role in the decision. Among the rest, 8.3% felt that allocating to the non-US citizen would require an additional 3-month mortality risk of 1%-25%, 8.7% felt it would require a 26%-50% additional mortality risk, 7.2% felt this would require a 51%-75% increased mortality risk, and 10% felt this would require more than a 75% increased mortality risk. Similar to the previous findings, these results suggest that most respondents felt that being a US citizen should be a strong determinant of organ allocation.

Based on the result of the conjoint analysis, we learned that respondents valued both posttransplant survival and risk of waiting list mortality. To better understand the relative weights of these factors, we sought to determine the relative equivalence of an

**FIGURE 2** Weighting of residence vs posttransplant survival. Patient A represents a US resident and patient B a nonresident, noncitizen. A plurality of respondents felt that the organ should always go to the US resident. The next most common response was that the organ should only go to the nonresident if that person would gain 20 or more years of posttransplant survival**FIGURE 3** Weighting of residence vs mortality risk. Patient A represents a US resident and patient B a nonresident, noncitizen. A plurality of respondents felt that the organ should always go to the US resident. The next most common response was that residence was irrelevant to the discussion

additional 5 years of life expectancy with pretransplant mortality risk. Results show that 18.5% ($P < .001$) felt that the organ should always go to the patient with the higher posttransplant survival, whereas 38% ($P < .001$) felt the organ should always go to the person with the higher waiting list mortality; 12.3% ($P < .001$) felt an additional 5 years of posttransplant survival were worth a 1%-20% increased risk of waiting list mortality, 11.9% ($P < .001$) felt that it was worth 21%-40% increased risk, and 19.3% felt this was worth more than a 40% increased mortality risk. Overall, 62% ($P < .001$) felt that posttransplant survival should be considered in allocation decisions. Another way to look at these results is that about 50% of the respondents felt that 5 years increased life was valued at less than 20% decreased mortality, and 50% felt the 5 years increased life was valued at more than 20% decreased mortality. We

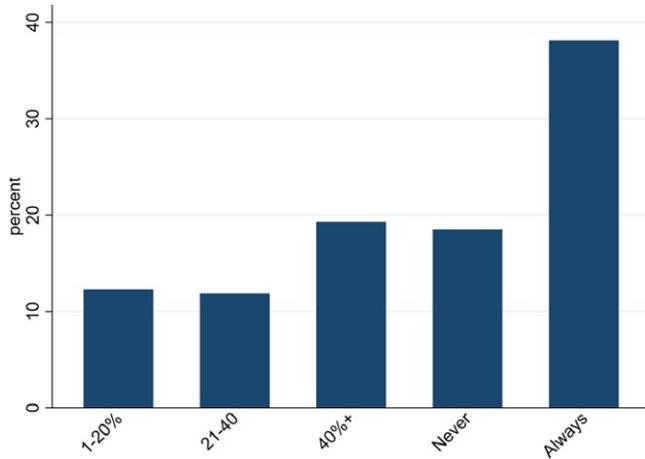


FIGURE 4 Weighting of 5-year additional survival vs mortality risk. A plurality of respondents felt that the liver should always go to the patient most likely to die in the next 3 months while waiting for a transplant. Half of the respondents felt the liver should go to the person who derived an additional 5 years of life if the waiting list mortality difference was at least 20%

therefore conclude that 5 years of increased life is approximately equally valued with 20% decreased mortality. The results are displayed in Figure 4.

3.2.2 | Prioritizing local patients

In the context of aviation costs, 46.9% ($P < .001$) of respondents agreed that some degree of cost should be considered in the context of local vs nonlocal prioritization, while 28.4% ($P < .001$) felt that costs should not be considered. When queried about the importance of allowing areas with higher donation rates to keep organs within the community, 48.6% ($P < .001$) felt that local efforts should be rewarded to some degree, whereas 24.9% ($P < .001$) disagreed to some degree with this statement. Similar results were obtained regarding whether local donation should be prioritized to support local transplant centers: 54.6% ($P < .001$) of respondents agreed with this statement to some degree, whereas 19.7% ($P < .001$) disagreed with this statement.

In the context of questions about organ redistribution/broader sharing, 34.9% ($P < .001$) of respondents felt the organ should always stay in its community, 23.4% ($P < .001$) felt a minimal survival benefit was sufficient for nonlocal allocation, whereas 15.9% ($P < .001$) felt the survival benefit would need to be dramatic (greater than 16 years) to justify nonlocal allocation (Figure 5). Furthermore, 31.1% ($P < .001$) felt that organs should stay local irrespective of the survival benefit of nonlocal allocation, 26.9% ($P < .001$) felt that a minimal survival benefit would justify nonlocal allocation, and 23.4% ($P < .001$) felt that a survival benefit of more than 11 years was necessary to justify nonlocal allocation.

3.2.3 | Waiting time vs waitlist mortality

A total of 70.4% ($P < .001$) of respondents agreed to some degree that waiting list mortality was more important than time spent on the waiting list, whereas only 6.4% ($P < .001$) disagreed.

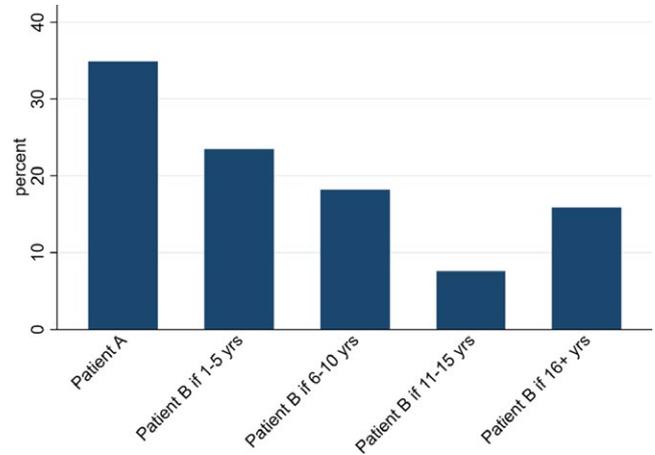


FIGURE 5 Weighting of place of residence vs posttransplant survival. A plurality of respondents felt that the liver should always stay in the community, and the second most common response required at least a minimal survival benefit to remain in the community. Overall, half of the respondents felt the liver should stay within the community either in all circumstances or in the setting of a modest survival benefit

4 | DISCUSSION

Decisions around organ allocation depend on simultaneous consideration of multiple ethical and moral principles including justice, utility, and autonomy. Our principal findings are that the public feels that posttransplant outcomes, citizenship/resident status, and functional status should be considered in allocation decisions, as should local allocation and cost. We conclude that public preferences differ significantly from current practice.

Our results are valuable in identifying this difference, and also for producing a methodology for translating public sentiments into relative value and even MELD points. For example, our findings allow us to place a discrete value on MELD points in terms of pretransplant survival: According to United Network for Organ Sharing (UNOS) data, the 90-day mortality for nonexception patients with a MELD of 25-29 is 13% (died or too sick for transplant), vs 29% for patients with a MELD of 35-40, a 16% difference. Using the mean of these ranges, this increased mortality is approximately 10 MELD points. In other words, a 16% increase in mortality equates to 10 MELD points. Combined with our findings that approximately 50% of respondents felt that for allocation priority 5 years additional survival equates to less than 20% increase in survival and 50% felt that for allocation priority 5 years equated to more than a 20% increase in survival, we conclude that 5 additional years of survival is worth approximately 10 MELD points. Similar calculations could be done for place of residency and degree of sickness.

Our findings conflict with the UNOS survey, which argues that the public favors allocation to the person most in need.⁵ Our results suggest that “the person most in need” is complicated and nuanced. In fact, we find that the public feels that a balance of competing moral and ethical principles is essential.

In this framework, we note that some feel the public should not be making allocation decisions due to a divergence of public opinion

from accepted medical practice. The public tends to penalize potential recipients thought to have caused their own disease, for example, in intravenous drug users who contract hepatitis C, or those with a history of alcohol abuse.^{16,17} Current medical practice, however, does not recognize these considerations. We feel that is the responsibility of experts to define reasonable boundaries of this discussion. We are in agreement with Ubel that among accepted moral principles, public perceptions are valuable as a guide to allocation decisions.¹² We further agree with Neuberger and Ubel that public preferences are not accurately represented by committee membership due to lack of a democratic election process.¹⁸ Therefore, it is essential to seek public preferences directly.

Current organ allocation almost exclusively prioritizes risk of waiting list death without clear ethical justification. Although used as a surrogate for fairness, in excluding those that never make it to the waiting list due to socioeconomic concerns, rural residence, or young people who are denied a transplant in favor of an older person (the fair innings argument),¹⁹ this is at best an imperfect measure.

As Lynch et al note, we live in diverse communities with different access to health care and consequences of health care decisions.²⁰ We found significant evidence that the public places priority on local donation and argue this needs to be incorporated into allocation decisions.

There are numerous limitations of our results. It is difficult to design surveys that respect the complexity of the decision-making in an easily understandable and unbiased fashion. This is evident in variation within our own survey. When asked whether respondents would favor a US citizen in every case, 55.7% agreed. When the question was modified to include posttransplant survival, only 38% chose this option. Presumably, some respondents felt in the context of a much greater survival of one recipient that transplantation of a noncitizen, nonresident would be more reasonable. We chose to compare 15% vs 30% mortality and 5-year survival vs 10-year survival but could have chosen other comparisons. We therefore do not claim that this is the definitive work on how to balance ethical principles. On the other hand, our results challenge prioritization of waiting list mortality over all other considerations, placing nonresident, noncitizens on equal priority with citizens, and the current movement toward national sharing without ethical or public justification. Modification of the current system to better incorporate public preferences is both possible and necessary.

DISCLOSURE

The authors of this manuscript have no conflicts of interest to disclose as described by the *American Journal of Transplantation*.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

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