

# Disparities in Deceased Organ Donor Research Authorization: Experience at One Organ Procurement Organization and Call for National Conversations



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**Introduction:** Research with deceased donor organs can provide an important platform for studying interventions to improve organ use and outcomes after authorization from the next-of-kin (NOK) or before death by the decedent (i.e., first-person authorization [FPA]). To date, information on authorization rates across donor subgroups is lacking.

**Methods:** We performed a retrospective chart review of all 690 deceased organ donors from January 2017 to December 2019 at a midsized Midwestern organ procurement organization (OPO). Multivariable logistic regression was used to assess associations between donor factors and research decline (adjusted odds ratio [aOR], 95% confidence interval [CI]).

**Results:** Electronic records for all 690 deceased donors were reviewed. Of these, 659 (95.5%) yielded at least one transplanted organ. Overall, research was declined in 10.8% of donations. Compared to White donors, research decline was higher for Black (16.0% vs. 8.9%; aOR, 1.87; 95% CI, 1.03-3.40;  $P = 0.04$ ) and other non-White donors (24.0% vs. 8.9%; aOR, 4.21; 95% CI, 1.02-17.39;  $P = 0.05$ ). Unadjusted research decline trended higher for Hispanic donors versus non-Hispanic donors (23.1% vs. 10.5%;  $P = 0.14$ ). Compared to donors age <40 years, research decline trended higher for donors age  $\geq 65$  years (16.7% vs. 11.8%; aOR, 4.87; 95% CI, 1.12-21.05;  $P = 0.03$ ), whereas research decline was 55% lower when donors provided FPA (7.3% vs 15.0%; aOR, 0.45; 95% CI, 0.27-0.76;  $P = 0.003$ ).

**Conclusions:** Deceased donor research authorization decline is higher for Black, other non-White, and older donors, but lower when the decedent provides FPA. Identification of disparities in research authorization may stimulate educational strategies to reduce barriers to scientific investigations directed at optimizing the outcomes of organ donation.

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**KEYWORDS:** deceased donor organ transplantation; disparities in research; next-of-kin authorization; organ procurement organization; research authorization; transplantation

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The number of patients with end-stage organ failure in need of transplantation in the United States has increased over time, with more than 100,000 patients currently on national waiting lists,<sup>1</sup> many of whom may die or become too sick for transplantation before an organ

becomes available.<sup>2</sup> There are significant discrepancies between allograft supply and demand, and a median wait time in the United States currently exceeds 4 years for a kidney transplantation.<sup>3-6</sup> In addition, the efficacy of transplantation is impacted by early and late complications including risk of graft dysfunction and failure, some of which may be mitigated by optimizing donor management and tailoring donor selection for the most suitable recipients.<sup>7,8</sup> With the high demand for deceased donor organs to serve patients in need, donor oriented research has become an important avenue of investigation to increase opportunities for successful organ use and to improve waitlist mortality and post-transplantation outcomes.<sup>7</sup>

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Three broad types of deceased donor research may be conducted. Donor management research takes place on a donor's organs before those organs are transplanted. The goal of donor management research is to maximize the number and function of transplantable organs.<sup>9</sup> Research may also be conducted on organs that are not transplantable or other tissues such as lymph nodes or spleen, seeking to improve understanding of the human body, including novel treatments outside of transplantation.<sup>10</sup> Despite the common intention to improve donor organ function, some research may involve interventions on the organ that may compromise transplantability or alter post-transplantation outcomes, and potentially run counter to the wishes of donors and donor families. In addition, there may be studies that investigate familial health risks, such as studies of genetic risk markers,<sup>11</sup> and the results of the research could have health implications for the donor's family. These concerns have led to authorization for deceased donor participation in donor-oriented research.<sup>12,13</sup>

In the United States, research on the deceased donor's body and/or organs is permitted without additional next-of-kin (NOK) authorization under the Uniform Anatomical Gift Act<sup>14</sup> if the decedent previously authorized such research through first-person authorization (FPA). In the absence of the deceased donor's documented decision, authorization for research using a donor's organs, tissues, or specimens requires consent from the NOK.<sup>15</sup> Across organ procurement organizations (OPOs), the agencies responsible for obtaining authorization and donor management, practices when a NOK opposes donor-provided FPA are variable. As a result, some OPOs honor the wishes of the donor in all instances, whereas others accept NOK refusal of authorization.<sup>16</sup> Anecdotal discussions and experience suggest that research authorization varies with donor and family characteristics, education, and OPO processes, but these experiences are not well described.

Deceased donor-oriented studies are unique in that impact may extend beyond donors themselves to organ recipients and to NOK.<sup>17</sup> To improve understanding of deceased donor research authorization rates and potential disparities, we performed a retrospective study of data from one intermediate-sized OPO. Our goals were to quantify rates of research authorization and to examine associations of research decline with relationship of the authorizing NOK and donor characteristics.

## METHODS

Study data were obtained through retrospective review of electronic health records for all deceased donors

(January 2017–December 2019) consented for organ procurement at one Midwestern, intermediate-sized OPO. Variables abstracted for each donor included age, sex, race, and ethnicity. Donor type included donation after cardiac death. The OPO electronic health record also classifies all brain-dead donors based on the standard criteria donor and expanded criteria donor definitions previously used in kidney allocation policy defined by age, cause of death, serum creatinine, and hypertension.<sup>18</sup> Since 2015, this use is not for organ allocation, but rather for internal review, including quality assessment and performance improvement. Donor race and ethnicity were recorded by the donor coordinator who interviews the deceased donor's authorizing NOK or agent. We classified race as White, Black, or Others (Asian, Native Hawaiian or Pacific Islander, Middle-Eastern or Other). Ethnic background was categorized as Hispanic or Non-Hispanic.

Using consent documentation from the donor's electronic health records, FPA status, decision-maker relationship to the donor, and status of research authorization were extracted, along with year of donation and final organ disposition. In the state of Missouri, FPA includes consent for research on donated organs. The OPO uses one consent form that includes consent for donation of gifts, organ and tissue exclusions, and research related to donor management, bi-specimens, and nontransplantable organs and tissues. The OPO also discusses research with all donors' NOK and honors objections, even if the decedent had provided FPA, as a local practice. Thus, if NOK objects to FPA authorization for research, final research authorization is recorded as declined.

Rates of research authorization decline were examined according to donor demographic traits, FPA status, NOK/decision-maker relationship, donor type, and year of donation. We compared trait distributions according to research authorization status by the Chi-square test. We assessed the association (odds ratio [OR], 95% CI) between donor factors and research authorization decline using unadjusted logistic regression analysis, and estimated adjusted associations (aOR, 95% CI) with multivariable logistic regression. We also examined possible interactions between donor factors and research authorization decline. Statistical significance was considered as  $P < 0.05$ .

## RESULTS

Electronic records for all 690 deceased donors in the study period were reviewed. Of these, 659 (95.5%) of donations yielded at least one transplanted organ. The donor cohort comprised 279 (40.4%) men and 411 (59.6%) women (Table 1). Racial distribution of the

**Table 1.** Associations of donor traits and donation-related factors with research authorization decline among deceased donors at one organ procurement organization, 2017–2019 (N = 690)

Donor Traits/Donation-Related Factors	Authorization Declined (n = 74) (%) <sup>a</sup>	Authorization Provided (n = 616) (%) <sup>a</sup>	Unadjusted Odds Ratio for Research Decline (95% CI)	Adjusted Odds Ratio for Research Decline (95% CI)
Age, yrs				
≤40 (n = 373)	59.5	53.4	Reference	Reference
41 to 54 (n = 175)	27.0	25.2	0.97 (0.55-1.69)	1.04 (0.50-2.13)
55 to 64 (n = 100)	4.1	15.8	0.24 (0.07-0.83) <sup>c</sup>	0.17 (0.04-0.67) <sup>c</sup>
≥65 (n = 42)	9.5	5.7	6.47 (1.58-26.40) <sup>c</sup>	4.87 (1.12-21.05) <sup>c</sup>
Sex				
Male (n = 279)	47.3	39.6	1.37 (0.84-2.22)	1.21 (0.65-2.26)
Female (n = 411)	52.7	60.4	Reference	Reference
Race				
White (n = 540)	64.9	79.9	Reference	Reference
Black (n = 125)	27.0	17.1	1.95 (1.11-3.43) <sup>c</sup>	1.87 (1.03-3.40) <sup>c</sup>
Other (n = 25) <sup>d</sup>	8.1	3.1	3.24 (1.23-8.49) <sup>c</sup>	4.21 (1.02-17.39) <sup>c</sup>
Ethnicity				
Hispanic (n = 13)	4.1	1.6	2.56 (0.69-9.52)	0.60 (0.09-4.10)
Non-Hispanic (n = 677)	96.0	98.4	Reference	Reference
FPA				
Yes (n = 384)	37.8	57.8	0.45 (0.27-0.73) <sup>c</sup>	0.45 (0.27-0.76) <sup>c</sup>
No (n = 306)	62.2	42.2	Reference	Reference
Decision-maker relationship to donor				
Parents (n = 323)	52.7	46.1	Reference	Reference
Adult children (n = 87)	8.1	13.2	0.54 (0.22-1.32)	0.52 (0.17-1.56)
Adult siblings (n = 73)	8.1	10.9	0.65 (0.27-1.60)	0.65 (0.24-1.74)
Spouse/partner (n = 154)	21.6	22.4	0.84 (0.46-1.56)	1.03 (0.49-2.20)
Power of attorney (n = 23)	5.4	3.1	1.53 (0.50-4.74)	1.56 (0.44-5.52)
Other (n = 30) <sup>e</sup>	4.1	4.4	0.81 (0.23-2.79)	0.92 (0.25-3.38)
Donor type				
DCD (n = 160)	18.9	23.7	0.93 (0.49-1.75)	0.69 (0.35-1.34)
ECD (n = 130)	18.9	18.8	0.74 (0.39-1.38)	1.80 (0.63-5.14)
SCD (n = 400)	62.2	57.5	Reference	Reference
Year of donation				
2017 (n = 223)	28.4	32.8	Reference	Reference
2018 (n = 196)	25.7	28.7	1.03 (0.54-1.98)	1.07 (0.48-2.39)
2019 (n = 271)	46.0	38.5	1.38 (0.78-2.45)	1.43 (0.69-2.96)

<sup>a</sup>Data represent column percentages (trait/factor distributions according to research authorization status). Deceased donor research authorization decline rates by donor traits are shown in Figure 1.

<sup>b</sup> $P < 0.05$  for difference in distribution of donor traits/donation-related factors (column percentages) according to research authorization status.

<sup>c</sup> $P < 0.05$  for association of indicated factor level (vs. reference level) with research authorization decline.

<sup>d</sup>Other Race includes Hispanic, Asian, Native Hawaiian or Pacific Islander, Middle-Eastern, Other.

<sup>e</sup>Other relationship to donor includes: adult grandchildren, grandparents, close friend, guardian of the person of the descendant, person acting as the guardian at time of death, person authorized to dispose of the body, guardian of the descendant's estate, or adult who exhibited special concern for donor.

CI, confidence interval; DCD, donation after circulatory death; ECD, expanded-criteria donor; FPA, first-person authorization for donation; SCD, standard criteria donor.

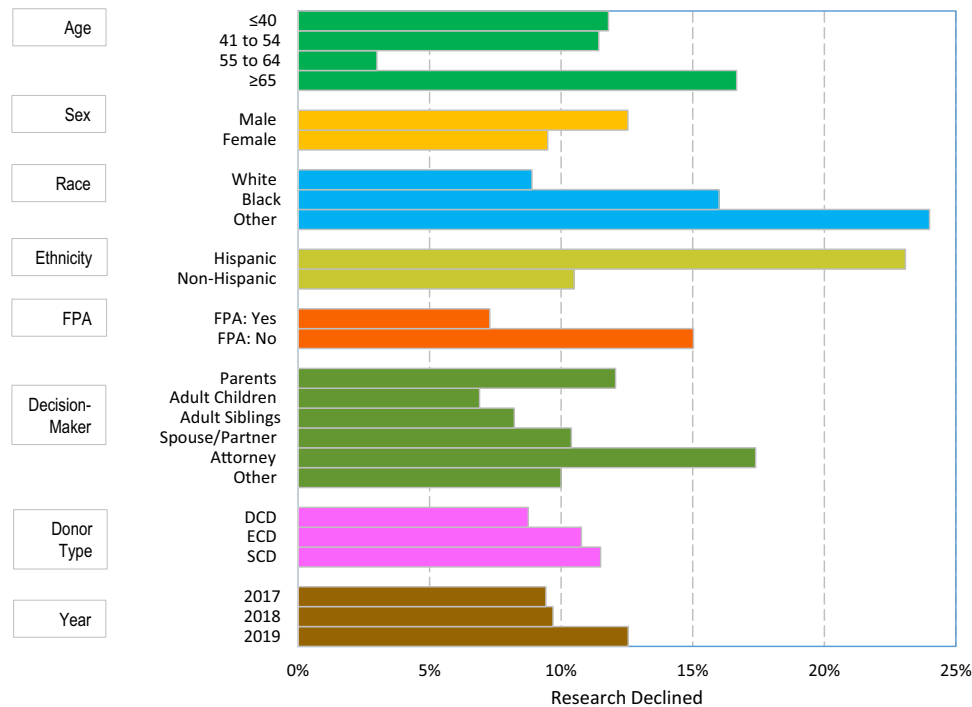
cohort included 540 (78.3%) White, 125 (18.1%) Black, and 25 (3.6%) other races; only 13 (1.9%) donors were Hispanic. Of the cohort, 373 (54.1%) were aged ≤40 years old, 175 (25.3%) were 41 to 54 years old, 100 (14.5%) were 55 to 64 years old, and 42 (6.1%) were 65 years and older. Among the cohort, 384 (55.7%) of donors had provided FPA; decision-makers were most commonly parents (323; 46.8%) and spouses/partners (154; 22.3%).

Overall, research authorization was provided for 616 (89.2%) of organ donors and declined for 74 (10.8%) of donors. Organ transplantation rates did not differ by research authorization status, except that the 15.4% of hearts used for research when the organ was *not*

*transplantable* and authorization was provided correlated with a lower relative proportion of hearts transplanted in the presence (vs. absence) of research authorization (Figure S1). Considered by research authorization status, 142 of 616 (23.1%) hearts were transplanted when research authorization was present, versus 27 of 74 (36.5%) hearts when research was declined ( $P = 0.03$ ). The hearts used for research only would not have been recovered (i.e., contributed to the denominator) if not for research, and there were no heart discards.

Compared to White donors, research decline was higher for Black (16.0% vs. 8.9%; aOR, 1.87; 95% CI, 1.03-3.40;  $P = 0.04$ ) and other non-White donors

## Research Authorization Decline Rate by Donor Traits and Decision-Maker



**Figure 1.** Deceased donor research authorization decline rates by donor traits at one organ procurement organization, 2017–2019. DCD, donation after cardiac death; ECD, expanded criteria donor; FPA, first-person authorization for donation; SCD, standard criteria donor.

(24.0% vs. 8.9%; aOR, 4.21; 95% CI, 1.02–17.39;  $P = 0.05$ ) (Figure 1, Table 1). There was no significant change in the proportion of non-White donors during the study period ( $P$  for trend = 0.64). Unadjusted research decline was higher for Hispanic donors versus non-Hispanic donors (23.1% vs. 10.5%,  $P = 0.14$ ), but decline in this small subgroup was not significantly different after adjustment. Compared to donors aged  $\leq 40$  years, research decline was lower for donors aged 55 to 64 years (3.0% vs. 11.8%; aOR, 0.17; 95% CI, 0.04–0.67;  $P = 0.01$ ), but higher for donors aged 65 years and older (16.7% vs. 11.8%; aOR, 4.87; 95% CI, 1.12–21.05;  $P = 0.03$ ). Research decline was lower when the donor had provided FPA (7.3% vs. 15.0%; aOR, 0.45; 95% CI, 0.27–0.76;  $P = 0.003$ ). There was no significant association of research authorization with NOK/decision-maker relationship to donor, donor sex, donor type, or year of donation. There was no significant interaction between age and race (interaction  $P = 0.37$ ), or age and FPA status (interaction  $P = 0.22$ ) on research authorization decline.

## DISCUSSION

Because of the “opt-in” nature of deceased organ donation, NOK are often relied upon as authorizing agents for organ procurement in many countries

worldwide.<sup>19</sup> In the United States, the organ donation system operates under an “opt-in” model in which the individual while alive (or the NOK after the individual’s death) must explicitly choose to donate organs.<sup>8</sup> For research studies of deceased organs, in the absence of the deceased donor’s documented decision, authorization requires additional consent from the NOK or surrogate decision-maker.<sup>8</sup> Thus, NOK research authorization has consistently been a requirement in published research protocols for studies of organ donor management and nontransplantable organs and tissues in the United States.

Barriers to large-scale analysis of the epidemiology of deceased donor research authorization in the United States include lack of documentation of research authorization as a defined field in DonorNet®. Authorization is collected by OPOs on a variety of local documents using specific language that is inconsistent across OPOs. Although scanned authorization forms are uploaded to DonorNet®, attachment labeling conventions vary, and documents must be individually downloaded and reviewed to determine authorization status. Lower rates of consent from decision-makers including NOK for certain donor groups, including racial/ethnic minorities, can translate into less opportunity for research to advance donation and transplantation in

these populations.<sup>15</sup> Inclusion of underrepresented racial/ethnic groups has lagged in many research domains, including studies in donation and transplantation. Reasons for these disparities include a lack of awareness of clinical research, distrust in medical experimentation, and religious-, cultural-, and knowledge-based beliefs.<sup>20-22</sup> Recently, because of the low participation among persons of color in clinical trials, the US Food and Drug Administration emphasized the importance of inclusiveness and a need to encourage more patients of different races and ethnic groups to participate in clinical trials and studies.<sup>23</sup>

The gap between allograft supply and the need for organ transplants in the United States has grown over time,<sup>6</sup> and donor-oriented research is an important strategy for improving the quantity and quality of organs available for transplantation, reducing waitlist mortality, and improving transplant outcomes.<sup>7,17</sup> In our current study examining experience at an intermediate-sized Midwestern OPO between 2017 and 2019, the overall research authorization rate was nearly 90%, a rate higher than anecdotal and published reports at many other OPOs.<sup>24,25</sup> However, despite general high performance in obtaining research authorization, we observed a trend towards more research authorization decline in recent years, supporting the need to monitor authorization processes, donor family education, educational barriers, and NOK concerns to help sustain authorization rates.

In our donor cohort, Black race was associated with nearly twice the adjusted likelihood of deceased donor research decline (aOR, 1.87). Ortigosa-Goggins *et al.* recently observed a similar association of Black donor race with research decline in a preliminary examination of data for 297 deceased donors, yielding 401 kidneys transplanted at one center in southeastern Florida (March 2019–October 2019).<sup>24,25</sup> The study design differed based on sampling from a transplant center (rather than OPO) perspective, and 71% of organs were imported after procurement at 47 OPOs across the United States, but patterns of racial disparity were similar despite the different designs. Black persons represent the largest group of persons of color on transplantation waiting lists; nearly one-third of waiting candidates are Black, whereas 15.1% of all deceased organ donors in 2019 were Black.<sup>26</sup> In the United States, there have been efforts to reduce organ donation disparities in the Black community, including multimedia campaigns to improve community perceptions related to organ donation.<sup>27,28</sup> In this context, the total number of Black deceased kidney donors increased modestly over the years 2016 to 2019 (n = 1319, 1349,

1486, and 1561, respectively<sup>26</sup>), but the percentage of deceased kidney donors from Black persons was relatively unchanged (14.5%, 14.3%, 15.1%, and 14.0%, respectively<sup>26</sup>).

Notably, kidney allografts from Black donors are classified by the US Kidney Allocation System to have approximately 20% higher expected risk of 5-year graft loss compared to organs from non-Black donors (aHR, 1.196), as parameterized in the Kidney Donor Risk Index score.<sup>29</sup> Higher KDPI score is correlated with increased risk of organ discard,<sup>7,30</sup> and distinguishing the biological/genetic contributions to risk of allograft failure from race as a social construct is a topic of active interest and investigation.<sup>11,31</sup> Disparities in donor research authorization in the Black community can pose barriers to studies that seek to improve allograft quality scoring and organ use, and to improve the outcomes of the community in need of transplants. Research authorization decline was also higher for other non-White donors in our cohort. Although we observed a trend toward higher research authorization decline for Hispanic donors, this association was not statistically significant; however, as <2% of donors were Hispanic, statistical power to detect an association was limited.

Recently, Ortigosa-Goggins *et al.* identified associations of donor age younger than 35 years with research authorization decline in their preliminary report of a sample of kidneys transplanted at one center in Florida.<sup>24,25</sup> By comparison, research authorization decline in our study of experience at one OPO (not limited to transplanted organs or by organ type) was highest for donors age  $\geq 65$  years (16.7% vs. 11.8% for donors <40; aOR, 4.87,  $P = 0.03$ ). This difference might reflect differences in donor race/ethnicity between the studies, as a much larger proportion (16.8%) of donors in study by Ortigosa-Goggins *et al.* were Hispanic,<sup>24,25</sup> as well as differences in the study designs and sampling approaches. Donor management research including older deceased donors is particularly important in the context of efforts to effectively use and achieve adequate outcomes of organs from older individuals, as part of initiatives to expand the availability of transplantation.<sup>7,17</sup> Collectively, these findings support the need for educational interventions including OPO and donor hospital staff, families, and the community to improve donor research authorization rates and increase research involvement opportunities for vulnerable groups, including those of diverse racial and ethnic backgrounds and of younger and older age. Processes for obtaining consent for donation should include attention to research authorization and be tailored for differences in religious-, cultural-, and knowledge-based beliefs.



Designated research authorization requestors (i.e., donor coordinators) generally work for the local OPO in remote hospitals, or the requestors may be trained by the OPO but not be employed by the OPO.<sup>9</sup> Requestors may use different styles and formats during discussions of research authorization with NOK, depending on the specific circumstances surrounding an individual donor, which may lead to provision of heterogeneous information to NOK.<sup>9</sup> The discussion of research authorization usually occurs at a time when the NOK's cognitive capabilities are stressed by the loss of a loved one. Standardized materials for the requestor to discuss inclusion of research as part of the request for donation may help reduce NOK's concerns in considering research authorization. Furthermore, OPOs could track and review research authorization rates as part of quality assessment/program improvement processes. However, national assessments are limited as research authorization status is not field-defined in the national DonorNet® database maintained by the United Network for Organ Sharing (UNOS), but rather is uploaded as scanned attachments.<sup>32</sup> Reprogramming of DonorNet® to include field-defined capture of donor research authorization would support systematic assessment of research authorization at a national level, and also support efficient access to authorization status information during the conduct of approved studies.

This study has limitations. First, this study captured experience at one OPO in the Midwest, and practices for donor research authorization may vary from state to state, and from OPO to OPO.<sup>16</sup> The small number of events in some subgroups limits statistical power and the precision of estimates. Studies with larger numbers of donors from diverse racial and ethnic minority groups and greater decline rates may identify other patterns and possibly even greater disparities in research authorization. Second, we did not have access to data on specific education or approaches used by staff in different cases, or on staff training and characteristics, and some of the observed variation could reflect variation across requestors in discussing donor research with NOK. The impact of donor family-requester race concordance has also been raised.<sup>33,34</sup>

In addition, we lacked information on other factors that may have influenced rates of donor research authorization in our study such as changes in staff or the number of research studies that the coordinators participated in during the study period. Third, it is important to consider the limitation of varying consent forms and authorization processes across OPOs, often as a result of varying state policies regarding research on donor gifts. Future studies of best practices in the approach to request for both donation and research authorization are needed with a focus on health literacy

and cultural sensitivity. Further, although the OPO did not require additional research consent forms for specific studies, some OPOs and state laws require study-specific consents such as for genetic testing, which could pose additional barriers to authorization.

In summary, in this study of one midsized OPO, we found that deceased donor research authorization decline is higher for Black, other non-White, and older donors. In contrast, research authorization is higher when the descendent provides FPA. These findings highlight the need for granular, process-level studies to identify barriers to donation research authorization across communities. Incorporation of field-defined research authorization status in the national donor registry would facilitate broader study and assessment of factors associated with research authorization across OPOs and donor subgroups. Ongoing work engaging OPOs, donor hospitals, and public health education systems is needed to address potential barriers to research authorization, including community education, sensitivity to cultural beliefs and perceptions, and staff training and processes. These efforts are vitally needed to help advance opportunities for clinical research in organ donation and transplantation, and improve the potential benefits of the gift of life for patients across the country.

## DISCLOSURE

The authors declared no competing interests.

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## DATA AVAILABILITY STATEMENT

Data availability is limited to summary form due to data use agreements.

## SUPPLEMENTARY MATERIAL

[Supplementary File \(PDF\)](#)

**Figure S1.** Organ disposition according to research authorization status.  $P < 0.05$  only for heart disposition according to research authorization status: 15.4% of hearts were used for research when the organ was *not* transplantable, correlating with a lower relative proportion

of hearts transplanted in the presence (versus absence) of research authorization (23.1% vs. 36.5%;  $P = 0.03$ ).

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