

Contents lists available at ScienceDirect

# American Journal of Transplantation

journal homepage: www.amjtransplant.org



Personal Viewpoint

Time to discard the term "discard"



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ARTICLE INFO

## ABSTRACT

*Keywords:* Discard Deceased organ donation The 2022 Scientific Registry of Transplant Recipients Consensus Conference "People Driven Transplant Metrics" offered an opportunity for a diverse group of stakeholders in the solid organ transplant community to exchange ideas about what information and metrics are important to different stakeholders. Participating patients and family members called on the transplant community to cease using the term "discards" to refer to donated organs that are not transplanted.

The 2022 Scientific Registry of Transplant Recipients Consensus Conference "People Driven Transplant Metrics" offered an opportunity for a diverse group of stakeholders in the solid organ transplant community to exchange ideas about what information and metrics are important. The conference was uniquely strengthened by the robust involvement of patients, family members, living donors, and deceased donors' family members, representing 24% of the 258 conference participants. Patients, living donors, deceased donors' families, and caregivers were recruited through social media platforms and collaborations between Scientific Registry of Transplant Recipients and various patient advocacy organizations. Participants represented diversity in geography, sex, race, ethnicity, age, and organ types. This event presented an important opportunity for these critical stakeholders to let transplant professionals, payers, and regulators know what was important to them.

Although much of the feedback from the conference will be synthesized and prioritized over the coming months to years, one resounding result of the conference can, and should be, implemented by the transplant community immediately. Much of the conference focus was on the use of data to drive improved access to transplant. Conference participants reported a need for data or metrics to drive policies intended to minimize the inappropriate nonuse of donated organs. As is common, most in attendance referred to the nonuse of recovered organs as "discards." Participating patients and family members called on the community to cease using the term "discards" to refer to donated organs that are not transplanted (Table 1).

The potential for moral injury to deceased donors' families who hear this term in reference to their loved one's gift is significant. The term evokes imagery of a donated organ being thrown into a trash can. Although there is broad consensus in the transplant community that avoidable or inappropriate nonuse of a deceased donor's organ is an event that should be minimized,<sup>1-4</sup> the nonuse of an organ is at times an appropriate clinical decision that must not minimize the value and significance of the deceased donor's gift. For example, nonuse of organs recovered from a donor who is subsequently found to have a malignancy in the procured lungs is an appropriate clinical decision. Because potential deceased donors become older and have more comorbidities, these situations will likely become more frequent. Although we owe it to deceased donors, donors' families, and transplant candidates to work toward a system in which every organ that could potentially benefit a patient is transplanted, a 0% nonuse rate is likely not a realistic goal because it may lead to missed opportunities to expand the donor pool through broader and more complex donor acceptance. In addition, an

https://doi.org/10.1016/j.ajt.2023.01.018

Received 22 September 2022; Received in revised form 10 November 2022; Accepted 25 January 2023 Available online 3 February 2023 1600-6135/© 2023 American Society of Transplantation & American Society of Transplant Surgeons. Published by Elsevier Inc. All rights reserved.

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#### Table 1

#### Illustrative quotations.

- "And then donor discard... This is not a term that our patient group liked. They do not like that term. They want to call this something else. It's offensive and they want to think about, maybe it's organs not placed..."—Moderator reporting deceased donor's family member's perspective from breakout group
- "The other thing I wanted to talk about is the sensitivity in our data collection and our language. And I found myself reflecting...this morning on the session when she used the term "donor discard rate." And to me, that's akin to the offensive term that we've tried to eliminate, ...like organ harvest."—Transplant recipient
- "As far as a donor's family, I think organ discard rate is just as offensive as saying organ harvest. And it kind of conjures images of just throwing it away. And what language, how we choose to frame it, I'm not here to suggest what that answer is. I just think we need to as a community consider... how it may actually be offensive to them and/or off-putting to the transplant recipient in the same regard."—Transplant recipient

organ that is donated but not transplanted can still be a great gift to the scientific community for purposes such as the use of donated organs to create a molecular atlas of the human transcriptome and the development and evaluation of new organ preservation technology.<sup>5,6</sup>

Transplant professionals accustomed to using the term "discard" are appropriately focused on the potential for harm resulting from a high proportion of nonuse (15% across organ types in 2020 and 21.2% for kidneys<sup>7</sup>), particularly when nonuse is inappropriate.<sup>3,7</sup> However, these

are not the only harms to consider, and the language used by professionals should also be responsive to the needs of the patient and family stakeholders. More granular data on the reasons for organ nonuse are needed to fully characterize the issue, and emerging research is better elucidating the impact of the recent change in organ refusal reason codes.<sup>8</sup>

Medical journals can accelerate the change in terminology by requesting that authors use an alternative to the term "discard." The best term to describe nonuse in different situations is not yet clear; options such as "nonuse" (as used herein), "nonutilization," "organs donated not transplanted," "organs not placed," or other terms can all be explored. Notably, the recent report by the National Academies of Sciences, Engineering, and Medicine, "Realizing the Promise of Equity in the Organ Transplantation System," also showed a preference for the term nonuse: organ nonuse rate: This term is used to refer to the proportion of organs that are donated and procured but ultimately not transplanted. The nonuse rate is commonly referred to as the discard rate. However, the committee finds the term "discard" less than ideal and possibly offensive to some deceased organ donors and their families, as well as individuals waiting for an organ transplant.<sup>9</sup>

In addition, preferred terms may be organ specific to account for the different sequences for recovery and allocation across organ types; for

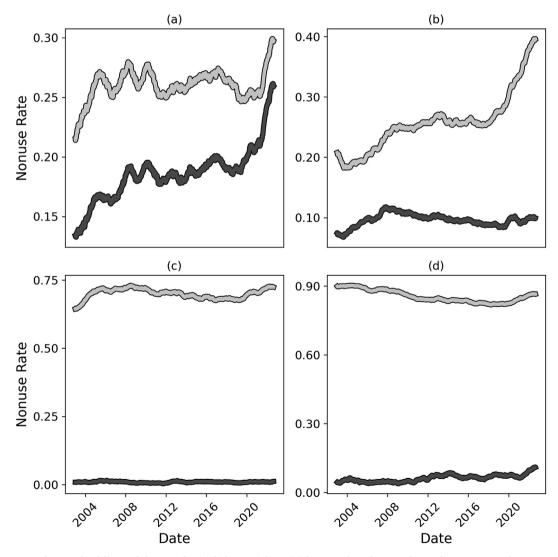


Figure 1. Nonuse rates of organs by different definitions for (A) kidney, (B) liver, (C) heart, and (D) lung. Dark gray lines represent the proportion of organ type recovered for transplant but not transplanted (currently referred to as the "discard rate"). Light gray lines represent the proportion of organs from all donors that were not transplanted, where a donor was defined as a person with at least 1 organ of any type recovered for transplant but in whom that organ itself was not necessarily recovered (sometimes referred to as the "nonutilization rate").

example, thoracic organs, unlike kidneys, are typically not recovered until a recipient is located, thus necessitating a different definition of "nonuse" that encompasses organs that were never recovered (Fig. 1). Regardless, robust engagement with our patient and family member communities is critical for finding a term that does not contribute to additional pain for families who will never stop grieving their loved ones. With family engagement, we can ensure that although we double down on our work to minimize inappropriate nonuse of deceased donors' organs, we do so with an ongoing commitment to honoring the gift of life provided by these patients and families.

# Acknowledgments

This work was conducted under the auspices of the Hennepin Healthcare Research Institute (HHRI), contractor for the Scientific Registry of Transplant Recipients (SRTR), as a deliverable under contract no. 75R60220C00011 (US Department of Health and Human Services, Health Resources and Services Administration, Healthcare Systems Bureau, Division of Transplantation). The US Government (and others acting on its behalf) retains a paid-up, nonexclusive, irrevocable, worldwide license for all works produced under the SRTR contract and to reproduce them, prepare derivative works, distribute copies to the public, and perform publicly and display publicly, by or on behalf of the Government. The data reported here have been supplied by HHRI as the contractor for SRTR. The interpretation and reporting of these data are the responsibility of the author(s) and in no way should be seen as an official policy of or interpretation by SRTR or the US Government. The authors thank SRTR colleague Anna Gillette for manuscript editing.

## 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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