



September 28, 2022

OPTN Proposal: Transparency in Program Selection

The National Kidney Foundation (NKF) thanks the Organ Procurement and Transplant Network (OPTN) for the opportunity to offer commentary on the white paper, *Transparency in Program Selection*. We appreciate the Ethics Committee's research and thoughtful analysis of transparency through the principles of autonomy, procedural justice, ethics, and utility.

Patients are at the heart of NKF's mission, and we firmly believe they deserve to participate actively in their healthcare. Shared decision-making requires transparency and patient-centricity, values we strongly support. As OPTN proceeds with this work, we must highlight the crucial need to collect national data on referrals, evaluations, and waitlisting, stratified by demographics that include race, ethnicity, age, and zip code, to truly promote transparency in the transplantation process and improve equitable access. We also recommend OPTN policies address the following patient priorities:

- Clear communication from transplant centers to patients regarding waitlist criteria
- Honest transplant center communications to patients and their referring provider about their waitlist status, including information about organ offers declined on their behalf
- Equitable access to the transplant waitlist and removing barriers that disproportionately affect patients from diverse and underserved communities
- Comprehensible and accessible transplant data and education for all health literacy levels

Waitlist Criteria

There is an urgent need to collect national referral and evaluation data from all transplant centers to increase transparency throughout the transplant process for patients to choose the transplant center waitlist that best suits their needs. Many patients can only get insurance to cover one transplant evaluation; they must go where they have the best chance of being listed. That can only happen if waitlist criteria are made available. Given the wide variation of transplant evaluation, waitlist management, and risk aversion practices across transplant programs, clear communication between the center and its patient population is imperative.¹ As patients decide where to pursue transplants, information about pre-listing measures such as body mass index, age, and length of substance cessation are especially relevant. We urge OPTN to facilitate measurable kidney transplant program outreach and education to nephrologists and dialysis centers so patients can select the transplant center best suited to their needs. Kidney transplant program information must also be readily

¹ <https://doi.org/10.1111/ajt.12195>

available to referring providers for efficient dissemination to patients and to guide appropriate referrals.

Waitlist Status and Organ Offers

NKF is troubled that organs are declined on a patient's behalf, often without their knowledge. Transplant centers must regularly communicate with patients to ensure their readiness for transplant. Remaining active on the list, knowing their activation status, and their time on the waitlist are essential priorities for patients. Patients should also be provided regular updates about when an organ is offered and declined on their behalf (e.g., quarterly updates). Allowing patients to have insight into the types of organs available will ensure they are consulted and have a say in the kind of care they receive. We would also note the need for seamless communication between referring providers and transplant programs regarding waitlist management, such as why referrals may be declined, or the evaluation process ended so that referrals can be expedited to other transplant programs.

Equity in Transplantation

NKF applauds the Ethics Committee for viewing transparency through the lens of equity, another value we passionately uphold. Lack of knowledge, trust, and communication are patient barriers that contribute to inequitable transplant access, particularly among marginalized populations.² Patients from disenfranchised communities are often misinformed about kidney transplantation and have little knowledge of its benefits.³ Those fortunate enough to learn about transplants are often unfamiliar with the waitlisting process and unsure of the qualifying criteria that influence their access to the waitlist.³ Lack of insurance coverage and inadequate access to a geographically convenient transplant center are also barriers to transplant for many underserved populations. We encourage OPTN to conduct community-engaged research to improve equity in accessing the transplant waitlist and obstacles to transplantation. We also reiterate the importance of collecting national data from transplant centers on every step of the transplant process to make this possible.

Health Literacy

Health literacy is a vital component that must be considered with transparency in sharing program selection criteria to ensure patients of different cognitive and education levels can acquire and sufficiently understand transplant data to make appropriate healthcare choices.⁴ According to patient feedback, kidney transplant program-specific reports (PSR) shared by the Scientific Registry for Transplant Recipients (SRTR) are not easily comprehended. During the 2022 SRTR Consensus Conference, transplant center staff and patients revealed they did not know PSRs existed.

² <https://doi.org/10.1186/s12939-021-01616-x>

³ <https://doi.org/10.1093/ndt/gfu188>.

⁴ <https://doi.org/10.1111/ajt.14994>



Transparency should extend beyond the creation of information and ensure that patients and their healthcare teams realize it exists and finds ways to ensure it is understood. We would also advise OPTN to explore different strategies to provide transplant education, realizing that not all patients have access to digital information.

The National Kidney Foundation (NKF) truly appreciates OPTN for highlighting the need for transparency and striving to make the transplant patient experience more accessible and understandable. Please get in touch with Morgan Reid, Director of Transplant Policy and Strategy (morgan.reid@kidney.org), if there are opportunities for NKF to support this initiative further.

Sincerely,

A handwritten signature in black ink, appearing to be "K. Longino".

Kevin Longino
CEO and Transplant Patient

A handwritten signature in black ink, appearing to be "Paul Palevsky, MD".

Paul Palevsky, MD
President