



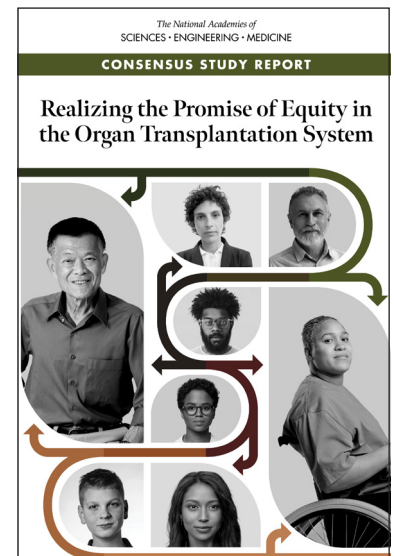
Realizing the Promise of Equity in the Organ Transplantation System

While the U.S. deceased donor organ transplantation system has seen significant growth in the number of transplants performed, the number of individuals waiting for a transplant continues to outpace the number of transplants performed. Despite the many individual successes of organ procurement and transplantation in the United States, the components of the system suffer from significant variations in performance, creating an inefficient and inequitable system. An individual's chance of being referred for a transplant evaluation, being added to the waiting list, and then receiving a transplant varies greatly based on race and ethnicity, gender, geographic location, socioeconomic status (SES), disability status, and immigration status.

The U.S. Congress requested that the National Institutes of Health sponsor this study to examine the fairness, equity, transparency, and cost-effectiveness of the deceased donor organ procurement, allocation, and distribution system. To accomplish the task, the National Academies of Sciences, Engineering, and Medicine empaneled a committee of 17 members with expertise in bioethics, health equity, biostatistics, economics, law and regulation, transplant surgery, nephrology, epidemiology, organ procurement, management science, and quality improvement. To address its broad charge, the committee focused on three key issues and areas of opportunity for improvement in deceased donor organ procurement, allocation, and distribution—challenges of inequity in access, variation and inefficiency in system performance, and underuse of donated organs.

CHALLENGES OF INEQUITY IN ACCESS

It is well established that inequities arise in access to referrals, evaluation, and the waiting list for organ transplant, yet little is known where along the trajectory in that process disparities are most likely to arise, especially for vulnerable populations. The purview of the Organ Procurement and Transplantation Network (OPTN) begins when an individual patient is added to the waiting list for a deceased donor organ. The committee finds that this gap in oversight presents a significant challenge to ensuring fairness and equity in the organ transplantation system and that federal oversight should expand to begin when an individual is diagnosed with end-stage organ failure and include the steps involved in identifying patients as needing a transplant before patients are added to the



waiting list. Certain groups of patients (e.g., patients of color, lower SES, female gender) receive organ transplants at a disproportionately lower rate and after longer waiting times than other patients with comparable medical need. These inequities undermine the trust necessary for the organ transplantation system to function optimally.

Justice, Fairness, Equity, and Transparency: Foundations for a Trustworthy System

Even when policies are premised on all people being treated alike, measurable—often large—disparities exist that are not explained by medical differences but rather arise from historical patterns of discrimination. Historical patterns of discrimination are embedded in social institutions (including health care) and are perpetuated by conscious prejudices and unexamined practices. Disparities in the ways that certain historically disadvantaged groups are treated or in the outcomes that the transplantation system produces for them are signals that injustice exists. To the extent that such disparities are avoidable, an equitable system will take the steps necessary to eliminate them.

Transparency is an instrumental value in shaping public beliefs and attitudes about the trustworthiness of the organ transplantation system. Individual and societal trust in the organ transplantation system depends on health care professionals fulfilling their ethical duties to do good and not harm, to respect the patients’ autonomy, and to strive for justice and utility in organ allocation decisions. Additionally, such trust is contingent on other institutions—the organ procurement organizations (OPOs),¹ OPTN, and federal government agencies—upholding these same values.

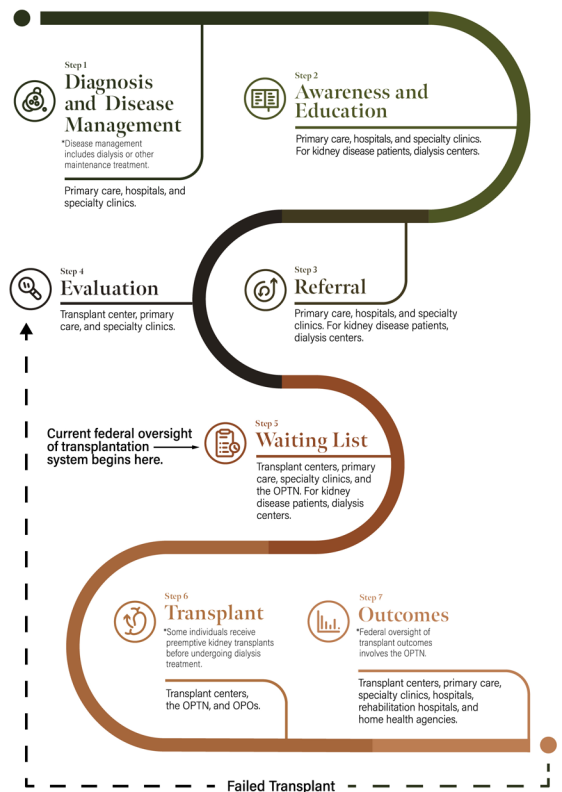


FIGURE 1 Transplant patient journey showing each step in the journey and the institutions responsible for creating the resources, setting the policies, or providing patients with the services that are relevant to that step.

VARIATION AND INEFFICIENCY IN SYSTEM PERFORMANCE

Marked variations in performance exist across the organ transplantation system. In particular, the committee identified five-fold variation among OPOs in their procurement of organs from donation after circulatory determination of death (DCDD) organ donors.² Across transplant centers, the committee found significant variation in the rate at which a center accepts the deceased donor organs offered to individual patients on the waiting list. In both cases, accountability currently does not exist for OPO performance in procuring DCDD organs and transplant center willingness to accept organs suitable for a patient. Each source of variation decreases the reliability and functionality of the system and directly affects equity in patient care. If an individual happens to join the waiting list at a transplant center with poor organ offer acceptance rates, or in an area where the OPO does not procure as many donated organs as it could, that individual is less likely to receive access to a transplant. While the behaviors of OPOs and transplant centers can vary significantly across the United States, the policy development process governing how deceased donor organs are allocated to individuals on the waiting list is the purview of the OPTN. The OPTN policy-making process for organ allocation includes extensive committee reviews that aim to involve all stakeholders, but the nature of the reviews contributes to variability in the policy development processes and a general slowness in policy development and implementation.

UNDERUSE OF DONATED ORGANS

The committee also identified the significant issue of organ nonuse (i.e., organs procured for transplantation but not transplanted). While the waiting list remains long and individuals waiting for an organ transplant die every day, too many donated organs are procured and not used. The proportion of kidneys from deceased donors

¹ Organ procurement organizations are not-for-profit organizations responsible for identifying potential organ donors, working directly with a decedent’s family about potential donation, receiving authorization for organ donation, obtaining organs from donors, and properly preserving these organs for quick delivery to a suitable recipient waiting for a transplant.

² DCDD organs are one type of medically complex organ.

that were recovered for transplant but ultimately not transplanted in 2019 was approximately 20 percent (Israni et al., 2021), with a projected 2021 kidney nonuse rate of 23 percent. The rate at which kidneys go unused in the United States is much higher than other developed countries (Mohan et al., 2018; Stewart et al., 2017). For example, the U.S. rate of nonuse for procured organs is nearly double the rate in France (Aubert et al., 2019). Approximately 62 percent of kidneys not used in the United States would likely have been successfully transplanted in France (Aubert et al., 2019).

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