

Realizing the Promise of Equity in the Organ Transplantation System

Recommendations for the Organ Procurement and Transplantation Network

Organ allocation systems determine how patients on transplant waiting lists are prioritized to receive offers of deceased donor organs. In the United States, each organ type has its own allocation system. All organ allocation systems are overseen by the Organ Procurement and Transplantation Network (OPTN), an independent entity created by the National Organ Transplant Act. The OPTN contract is overseen by the Health Resources and Services Administration, within the Department of Health and Human Services (HHS).

Organ allocation is complicated by the fact that some organs will be incompatible with certain transplant candidates due to blood type, organ size, other medical issues, or travel time from the donor hospital to the transplant candidate. When an organ becomes available, the United Network for Organ Sharing (UNOS)—a private, nonprofit organization administering the OPTN contract—conducts a process called a match run to generate a ranked list of transplant candidates for that specific organ.

Kidneys are by far the most transplanted organ, with large transplant programs reporting waiting lists of 1,000 kidney patients or more. The difficulties in managing lists of this size complicate the organ allocation process; for instance in the years 2008 through 2015, between

14 and 20 percent of deceased donor kidneys that were eventually transplanted were first offered to one or more persons who had already died but had not yet been removed from the transplant waiting list.

RECOMMENDED ACTIONS

Allocate kidneys based on time spent on dialysis.

Currently, the OPTN allocates kidneys to candidates who have spent the longest amount of time on the transplant waiting list; this results in inequality because White, wealthy, and abled patients have greater access to regular medical testing that can be used to place them on a waiting list sooner.

Action: The OPTN should change the kidney allocation system to only count waiting time after a patient initiates dialysis when determining their priority for transplant. Exceptions should be made for special cases, such as pediatric patients.

Allocate kidneys based on survival benefit.

The kidney allocation system also attempts to match transplant candidates with the greatest chances of long-term survival with the highest-quality donated organs. In theory, this policy maximizes the amount of time patients will have before needing another transplant. However, it may lower the total number of lives saved

because it allocates medically complex organs to sicker transplant patients. It also disproportionately allocates high-quality organs to White, wealthy, and abled patients, because these patients are generally healthier when they join the transplant list and so have a higher estimated long-term survival rate. Finally, even relatively healthy patients may derive greater benefit from receiving a medically complex organ immediately rather than waiting for a high-quality organ.

Action: The OPTN should study the effect of potentially changing the kidney allocation system to allocate kidneys based on survival benefit—the difference between a patient’s estimated odds of survival with and without transplantation. This will take into account the fact that medically urgent candidates can derive more benefit from a transplant than healthier candidates. Survival benefit calculations should take into consideration detailed information about transplant candidates and donor organs. Proposed calculations for survival benefit should be studied carefully to identify and eliminate unintended consequences both before and after implementation of an allocation policy change.

Finalize continuous distribution processes for all organs.

Continuous distribution is a framework for organ allocation and distribution that creates a composite score of multiple patient and donor attributes rather than considering each attribute in sequence. This can prevent a single metric, such as proximity to the donor hospital, from overriding considerations of medical necessity.

Action: The OPTN should accelerate its plans to finalize continuous distribution processes for all organs, with a goal of implementing continuous distribution frameworks for all organs by December 31, 2024.

Evaluate the use of race as a weighting factor in clinical equations.

Several clinical equations used in the organ transplantation process, such as the Estimated Glomerular Filtration Rate (eGFR) and Kidney Donor Profile Index (KDPI), include race as a weighting factor. This can lead to racial inequities in transplant waiting times and organ allocation, and ultimately to poorer

health outcomes and increased death rates for people of color who suffer from organ failure. The United Network for Organ Sharing recently approved the removal of race from the eGFR equation.

Action: HHS should require the OPTN to review all clinical equations that include race as a weighting factor and consider alternate equations that do not include race as a weighting factor.

Update algorithms used in organ matching.

To match donated organs with transplant candidates, the OPTN relies on algorithms that predict how urgent each candidate’s disease is and how long each organ is likely to function after transplant. Despite the important role these algorithms play in organ allocation, many of them are now outdated and have not been updated. For example, the current KDPI model is derived from deceased donor kidney transplants from 1995 to 2005. Even when it is clear an update is necessary, there are multiple-year delays. For instance, it was shown in 2008 that including sodium test results significantly improved the accuracy of one algorithm, but the algorithm was not updated to include this variable until 2016.

Action: HHS should require the OPTN to update its prediction models using the most recent data no less frequently than every 5 years. During the update period, the models themselves should be reconsidered by adding or removing predictors that will either improve predictive accuracy or increase equity.

Gather more data on factors leading to disparities in organ transplantation.

The full range of socioeconomic factors that lead to inequity in kidney disease progression and in access to the transplant system, and their specific impacts on transplant patients, are not known.

Action: Continue to gather data on factors that may result in disparities in access to, and outcomes of, organ transplantation (e.g., socioeconomic status, place of residence, access to health care, race and ethnicity, presence in patient or family of stressors caused by

racism) and use such data to determine whether faster progression to end-stage kidney disease is experienced by patients with any particular factor or combination of factors, and if so whether this evidence should be used to establish a new threshold for listing on the transplant list and for allocation of an organ for transplantation.

Incorporate Cystatin C testing into kidney disease evaluation.

The eGFR equation is used to determine the seriousness of individual patients' kidney disease and whether they are eligible for transplant. For individuals at high risk of

kidney disease, the National Institutes of Diabetes and Digestive and Kidney Diseases (NIDDK) recommended that the results of Cystatin C tests be incorporated into the eGFR equation.

Action: Incorporate Cystatin C testing into eGFR scores for individuals at high risk of kidney disease. Require the OPTN to ensure that all laboratories in the transplantation system become capable of conducting validated Cystatin C tests within 12 months.

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FOR MORE INFORMATION

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