Realizing the Promise of Equity in the Organ Transplantation System

Recommendations for Federal Policy Makers

The current organ transplant system is unduly fragmented and inefficient. The system is split into several different parts: clinicians caring for patients approaching or already diagnosed with organ failure, donor hospitals, organ procurement organizations (OPOs), the Organ Procurement and Transportation Network (OPTN), transplant centers, the Scientific Registry of Transplant Recipients, the Centers for Medicare & Medicaid Services (CMS), and other payers. These components operate largely independently of one another, and there is no organization or entity responsible for overseeing the performance of the organ transplant system as a whole. If the different entities in the organ transplant system operated in a more coordinated fashion with common goals and unified policies and processes, it could save additional lives and be more equitable. The organ transplant system is overseen by several government agencies such as CMS and the Department of Health and Human Services (HHS), which are ideally positioned to take actions that will increase the coordination, efficiency, and equity of the transplantation system.

RECOMMENDED ACTIONS

Achieve equity in the transplantation system within the next 5 years.

While equity in access and allocation has been a proclaimed principle of the organ transplantation system for decades, and appears in federal regulations directing allocation policy, the organ transplantation system remains demonstrably inequitable. Certain groups of patients (racial and ethnic minority populations, patients of lower socioeconomic status, female patients, older patients, patients with intellectual and developmental disabilities, and patients with inheritable diseases) receive organ transplants at a disproportionately lower rate and in some cases after longer wait times than other patients with comparable need.

Action: Under the direction and oversight of Congress, HHS should be held accountable for achieving equity in the transplantation system within the next 5 years. HHS's regulatory oversight of the organ transplant system should be extended to begin at the time a patient reaches end-stage organ failure and end beyond 1 year after transplant. Within the next 1–2 years, HHS should identify and publish a strategy with specific proposed requirements, regulations, payment structures, and other changes to eliminate disparities.

Set goals for the transplant system.

HHS should set goals for the transplant system as a whole based on the performance of its best performing donor hospitals, OPOs, and transplant centers in equity, organ donation rates, procurement, and transplantation of organs from donors after circulatory determination

of death (DCDD), acceptance of offered organs, and low rates of nonuse of donated organs. These goals can inform quality improvement programs, payment policies, regulations, technical assistance, and public education campaigns to increase the performance of all donor hospitals, OPOs, and transplant centers to ideal levels, improving performance and equity.

Action: HHS and CMS should build on the initial CMS goals established in the kidney transplant collaborative, and establish a national goal for all transplant centers to reduce donated kidney nonuse rates to 5 percent or less. They should establish new national goals to:

- Improve donation and transplantation rates among minority populations and disadvantaged populations based on the proven practices of donor hospitals, OPOs, and transplant centers that are most successful in these areas.
- Increase the number of organs procured from medically complex donors, including DCDD donors.
- Improve offer acceptance levels for each organ type to those achieved by the 5–10 percent highest performing transplant centers for that organ type nationally.
- Increase the number of transplants to at least 50,000 annually by 2026.

Develop a more expedient and responsive policy-making process.

The OPTN policy-making process includes extensive committee reviews that aim to involve all stakeholders, but the reviews also make policy development and implementation slow and somewhat unreliable. The OPTN has made some progress in decreasing the time for policy approval by the OPTN Board of Directors, but opportunities for further improvement exist.

Action: HHS should direct the OPTN and the Health Resources and Services Administration to develop a more expedient and responsive policy-making process. The OPTN should be required to ensure that this process represents all populations facing disparities, including persons with disabilities.

Create standardized metrics to measure equity in the transplantation process.

The OPTN collects an impressive amount of data about the transplant process, but challenges remain in translating these data to positive patient outcomes. Of more than 300 transplant quality metrics reported in the literature, many were poorly or inconsistently defined, and very few focus on equity, patient-reported experience, or other quality domains.

Action: HHS should create an integrated dashboard of standardized metrics that cover the full organ transplantation process, and are meaningful to stakeholders, including donor families, individuals who are or could be transplant candidates, and individuals on the waiting list. The metrics should be used for quality improvement and, once they are deemed valid and reliable, for regulatory purposes. All data points collected should reflect demographics including race, ethnicity, language, socioeconomic factors, disability status, and a social deprivation index based on geography.

Incentivize improvements in transplant system performance and equity.

The behavior of OPOs, transplant centers, and other actors in the transplant space is determined largely by CMS's reimbursement policies. CMS can alter these reimbursement policies to incentivize behavior that improves the number of organs transplanted and promotes equity in the transplant system.

Action: CMS should adopt payment policies that incentivize all providers to improve equity in access to care and outcomes for patients. CMS should make other adjustments to payment structures to incentivize better use of donated organs, such as eliminating disincentives for transplant centers to transfer donors to an OPO donor care unit, increasing reimbursement for referral for transplant evaluation for all organ types—and in the case of kidneys, before dialysis begins, incentivizing hospitals to smooth surgical scheduling to ensure the capacity to

recover and transplant donated organs, and incentivizing organ procurement from DCDD donors.

Evaluate and improve the transplant system's information technology infrastructure.

Coordinating an organ transplantation system requires a large and complex information technology (IT) system to coordinate the actions of donors, transplant centers, payers, and other stakeholders. Since 1986, a single nonprofit organization, the United Network for Organ Sharing, has been the sole administrator of this IT system.

Action: HHS should evaluate the IT infrastructure and data collection for deceased donor organ allocation, identify needed improvements, and assess the pros and cons of various alternative contracting approaches to maintain and improve the IT infrastructure.

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[1] As of February 1, 2022, Dr. Segev is at New York University.

FOR MORE INFORMATION

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