

Actions to strengthen the U.S. organ donation and transplant system

In brief

In order to best serve all patients in the U.S. who need or will need a life-saving organ transplant, United Network for Organ Sharing (UNOS) is recommending changes to bolster and streamline the U.S. organ donation and transplant system. Below, we have identified eight opportunities for system improvements, which are summarized along with proposed actions. These include actions that UNOS currently has the capability and authority to make as well as actions that will require modifications to the Organ Procurement and Transplantation Network (OPTN) contract.

Increase direct services, tools and resources to patients, donors, caregivers and their families.

Require the OPTN to provide expanded tools and resources to further inform and empower patients and families. These offerings should be detailed within the stipulations of the OPTN contract and include tools for patients to navigate the process from initial referral to post-transplant care.

Improve equity in access to the transplant healthcare system for patients with end stage organ failure.

The OPTN develops and maintains equitable organ allocation policies for patients who have been added to the national waitlist by their transplant hospital. The OPTN must be granted authority to collect demographic and socioeconomic data on patients much earlier in the transplant journey in order to investigate obstacles to equitable access to the waitlist.

Improve OPO performance measures by utilizing data reported directly from hospital electronic health records (EHRs).

Regulation of OPOs is conducted through CDC data that is insufficiently detailed and not released for two years after collection. Electronically reporting data on ventilated deaths, already collected via hospital EHRs, to CMS and/or the OPTN would enable offer near real-time performance reviews of organ procurement organizations.

Increase transparency of OPO, hospital and system performance by making more comparative performance data available publicly.

UNOS will publish new public-facing reports with comparative performance data on OPOs, transplant programs, and the system as a whole. Following implementation of the new continuous distribution framework, all organ allocation policy monitoring will be available via public dashboard.

Reduce risk of organ delay, damage or loss in transport.

UNOS seeks federal support in streamlining airline travel for unaccompanied deceased donor organs, currently designated as "cargo." Further, UNOS recommends requiring the OPTN to

develop a centralized tracking system, policies and protocols for unaccompanied deceased donor organs utilizing physical trackers.

Maintain safe, modern and reliable OPTN IT systems and infrastructure.

UNOS is committed to maintaining a safe, modern and reliable IT system to serve the system. In addition to annual contractually-mandated IT audits, UNOS and is seeking enhanced assessments from the U.S. Digital Service, as well as a third party assessment partner.

Enhance OPTN Membership and Professional Standards Committee (MPSC) oversight and increase transparency in the process.

UNOS seeks to establish formal ongoing communications and coordination with CMS to help streamline and align their respective efforts in performance improvement and regulation. Further, UNOS will create a new public page on the OPTN website to increase transparency on MPSC performance improvement and compliance review activities.

Make the OPTN an organization independent of the OPTN contractor.

UNOS has sought HRSA engagement to create an OPTN board of directors separate and distinct from the OPTN contractor's board of directors, to include the creation of a new, nonprofit corporate entity to be the OPTN as specified in NOTA.

Maintain OPTN registration Fee paid by transplant hospitals commensurate with reasonable costs to operate the OPTN.

Ensuring costs billed to Medicare are reasonable and allowable is essential. We strive to ensure that the OPTN Registration Fee meets these same standards, regardless of the source of payment, and the government exercises several oversight mechanisms over the development and approval of OPTN Registration Fee. We are eager to discuss any further measures that can be taken to ensure these fees remain reasonable.