

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

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## Introduction

The United Network for Organ Sharing (UNOS) has proposed and is working with Congress, the administration and the donation and transplant community to implement reforms that will improve the U.S. organ donation and transplant system. Our recommendations include changes to the Organ Procurement and Transplantation Network (OPTN) contract that we believe will hold all parts of the system accountable to better serve the patients who rely on it every day.

Below, we have detailed:

- Actions we are taking now and will take soon, as they are currently within UNOS' capabilities and/or within the authority of the current OPTN contract.
- Tasks UNOS recommends are added to and funded within future OPTN contracts.

The following actions and recommendations are intended to reflect the needs of the broader donation and transplant community.

## **Patient empowerment**

*Increase direct service, tools, and resources to patients, donors, caregivers, and their families*

The current contract obligates the OPTN contractor to provide web-based patient education materials on the OPTN website, which provide information about how organ allocation works, what to expect during the transplant process, the wait list, resources by organ, and more.

UNOS currently enhances these offerings with expanded resources.

### **UNOS Action**

UNOS is advocating that HRSA require the OPTN to offer more expansive consumer empowerment tools with the next OPTN contract. These empowerment tools will enable patients to make choices regarding their care. They will also provide education and resources for patients, donors, caregivers, parents and their families.

## Equity

### *Improve equity in access to the transplant healthcare system*

The OPTN is currently charged with developing and maintaining equitable organ allocation policies that apply to waitlisted patients, but true access to transplant — not just the waitlist — cannot be measured without understanding the national disease burden. We must take action to seek broader equity in access to transplant health care. The OPTN has been able to continually monitor and adjust organ allocation policies to improve equity in access among these waitlisted patients. The OPTN maintains an [Equity in Access Dashboard](#) to enable public research and review of these ongoing efforts, and publishes organ allocation policy monitoring reports for the public, which include data on key equity indicators.<sup>1,2,3</sup>

#### **UNOS Action**

In February 2024, the Secretary of Health & Human Services (HHS) issued a directive that authorizes the OPTN to collect pre-waitlist data. The transplant community has been requesting this authority since 2021.

The directive will require transplant centers to share information with the OPTN contractor when a patient is referred to them for an organ transplant. It'll also require organ procurement organizations (OPO) to provide the OPTN contractor with information on all ventilated patients referred to them from hospitals in their donation service area.

Access to this information will help increase equity in access to transplant. Additionally, access to baseline data on people most likely to qualify as organ donors can help better estimate donor potential and conversion.

UNOS, as the OPTN contractor, will continue working with the administration, Congress and the donation and transplant community to implement this directive and improve the system for patients.

## Data Collection

*Enable the OPTN to collect donor potential data directly from hospitals to drive more improvement in organ procurement organizations and diversify the pool of donors*

Greater access to accurate information and data on potential donors will help the OPTN's work with the transplant community to increase efficiency to strengthen the system.

### **UNOS Action**

In February 2024, the Secretary of HHS issued a directive that authorizes the OPTN to collect pre-waitlist data. UNOS, as the OPTN contractor, will continue working with the administration, Congress and the donation and transplant community to implement this directive.

Additionally, UNOS is working with Congress on legislation that would enable improved data collection on potential organ donors. This would require hospitals to disseminate data they currently collect on potential organ donors to the Centers for Medicare & Medicaid Services (CMS), and then to the OPTN. Access to this information will inform OPO performance monitoring and improvement and could increase accurate donor referrals. It would also direct CMS to study the current, voluntary use of automated donor referral notifications and develop recommendations to promote broader adoption.

## Transparency

*Increase transparency in OPO, hospital, and system performance by making more comparative data available publicly*

Increased transparency is critical to drive greater public and community trust in the nation's organ donation and transplant system.

### **UNOS Action**

As the OPTN contractor, UNOS developed and published the [Lung Monitor Dashboard](#) – a first of its kind organ-specific monitoring dashboard that was previously only available to transplant professionals and not the public. The dashboard reports data on key equity in allocation measures. It can also monitor the impact of policy changes based on the geography of where transplant hospitals are located and if they are in rural or urban areas. It serves as an important complement to the static monitoring reports for continuous distribution of lungs.

The dashboard became publicly available in November 2023 following HRSA approval.

Additionally, UNOS, as the OPTN contractor, developed interactive OPO organ recovery and usage maps, which display both OPO and hospital-level recovery transplant information. This information is based on donor characteristics selected by the user, as well as an organ usage map that displays which programs are transplanting the organs from those same donors. UNOS is advocating that HRSA make additional dashboards available to deliver at-a-glance information to the public, patients and policymakers.

## Transportation

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

Addressing concerns about organ tracking and transportation requires a system-wide, multi-pronged approach. UNOS has taken action as a private entity in developing and launching its own organ tracking solution, currently in use by 16 OPOs.<sup>4</sup> However, both the federal government and the OPTN must require, develop and enact a solution for national, system-wide tracking and efficient air transit.

### **UNOS Action**

Due to federal protocol changes following the September 11 attacks, unaccompanied organs were relegated to cargo and are still transported that way today. Cargo procedures are time-insensitive and can cause logistical problems, such as delays, when transporting time-sensitive organs intended for transplant.

UNOS supports the House (Section 834) and Senate (Section 737) Federal Aviation Administration (FAA) reauthorization legislation, which each include an organ transportation provision. We [join more than 20 industry organizations](#) in urging Congress that any final FAA reauthorization legislation include a provision that requires federal rulemaking to enable the transportation of a donated organ in the passenger cabin instead of in the cargo hold of a commercial airplane. UNOS will continue to work with Congress to include this transportation provision in the legislation and get it signed into law.

Additionally, UNOS is advocating for HRSA to include the following in the next OPTN contract:

- Mandate physical trackers for unaccompanied deceased donor organs.
- Develop a centralized organ tracking system.
- Publicly report on data related to tracking.
- Review all cases of a lost organ.

## **IT improvement**

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

Having a secure, reliable and efficient IT system for patients, donors and the transplant community is a top priority for UNOS as the OPTN contractor.

### **UNOS Action**

UNOS is updating its systems' user interface to make it easier for donation and transplant professionals to make and evaluate offers. We are leveraging internal and external experts in human-centered design, as well as engaging members of the community throughout the design process.

UNOS has hired additional IT and information security leaders to improve OPTN IT systems and infrastructure and is continuing to build application programming interfaces (APIs) with third-party experts. APIs support automated data transfer by enabling different computer systems to interact. They also decrease the amount of manual data entries OPTN members must complete, which will improve the efficiency of the system and increase patient safety overall.



## Oversight

*Enhance oversight and increase transparency in the peer review process*

UNOS closely coordinates and communicates with HRSA and CMS to ensure that quality of care and patient safety is enhanced, and the system is held accountable.

### **UNOS Action**

UNOS, as the OPTN contractor, created [a new public page](#) on the OPTN website to increase transparency. The page provides updates and information regarding the OPTN Membership and Professional Standards Committee (MPSC) performance improvement and compliance review activities.

## **Governance**

*Make the OPTN an organization independent of the OPTN contractor*

For almost 40 years, the governing boards of UNOS and of the OPTN have been the same. This has been due to a provision in the OPTN contract UNOS has held with the federal government to manage the nation's organ donation and transplant system.

### **UNOS Action**

In alignment with HRSA's Modernization Initiative, UNOS has taken steps to establish a governance structure for UNOS that is independent of the OPTN board of directors. In December 2023, the UNOS board of directors voted to eliminate the overlap of board membership, and in February 2024, UNOS members voted to ratify that decision. Having two independent boards will increase accountability, transparency and good governance, leading to greater public trust in the national system.

Starting March 30, 2024, UNOS will have a separate seven-member board that is independent from the OPTN 42-member board.

UNOS is committed to working with HRSA, under HRSA's direction, to ensure the successful and timely implementation of any OPTN governance restructuring plan by March 30, 2024.

## Conclusion

All stakeholders, including UNOS, share a common goal: Get as many usable transplant organs as possible to patients who need them, fairly, equitably, and efficiently. We must hold all parts of the system accountable for making sure that this happens. It is important that the next contract holds the OPTN to providing the highest level of service to patients and the greatest level of transparency to the public who has charged it with this lifesaving work.

## Notes

- <sup>1</sup> OPTN Equity in Access dashboard. <https://optn.transplant.hrsa.gov/data/visual-dashboards/equity-in-access/>.
- <sup>2</sup> “OPTN resource pages by organ.” <https://optn.transplant.hrsa.gov/professionals/by-organ/>.
- <sup>3</sup> “One year monitoring report shows increase in kidney transplant following policy changes.” <https://optn.transplant.hrsa.gov/news/one-year-monitoring-report-shows-increase-in-kidney-transplants-following-policy-changes/>. 1 July 2022.
- <sup>4</sup> “7,000 organs tracked with UNOS organ tracking service.” <https://unos.org/news/in-focus/7000-organs-tracked-with-unos-organ-tracking-service/>. 14 Dec. 2022.