

UNDERSTANDING THE OPTN MODERNIZATION INITIATIVE & IMPLICATIONS FOR CAREGIVERS

Family Caregivers & Transplant Care

Family caregivers are crucial to the U.S. healthcare system, particularly in the transplant sector where they provide essential, often round-the-clock support for patients. Due to these intense demands, caregivers face heightened risks for physical, mental, and financial hardship, including anxiety, depression, and financial strain.

To address this gap the National Alliance for Caregiving's (NAC) Transplant Caregiving Collaborative, seeks to recognize and uplift transplant caregivers through research and advocacy. Its first report: "Transplant Caregiving in the U.S: A Call for System Change," highlighted transplant caregivers' vital role and existing knowledge gaps. Its second report, "Gaps and Opportunities: Family Caregiver Programs in U.S. Transplant Centers," revealed limitations in standardized and coordinated practices that contribute to inconsistent support and disparities for caregivers. Findings from NAC's latest brief "The Family Caregiver Gap: Disparities and Missed Opportunities in Support Services Across U.S. Transplant Centers" further revealed inequities in the way family caregivers are supported across the transplant system.

What is the Organ Procurement and Transportation Network (OPTN) Modernization Initiative?

The Organ Procurement and Transplantation Network (OPTN), created under the 1984 National Organ Transplant Act and operated via federal contract, is undergoing a modernization initiative led by the Health Resources & Services Administration (HRSA).

The modernization initiative was launched in 2023 under the Biden Administration following long-standing scrutiny of the original OPTN. The Trump Administration has continued the modernization effort, investigating concerns about patient safety delays in organ assignment, reduced availability of donated organs, and declining trust in the OPTN.

To address these concerns, improvement efforts target

technology, data transparency, governance, operations, and quality/innovation, such as:

- Creating a real-time data dashboard on transplant centers and outcomes.
- Implementing major IT infrastructure upgrades to enable data processing.
- Fostering competitive rebidding for OPTN's management contract to increase accountability and independence.
- Increasing funding requests and removal of appropriations caps to expand eligible contractors.

Congress supported these reforms through the U.S. Organ Procurement and Transplantation Network Act of 2023 (P.L. 118-14). Feedback is being collected continuously via the HRSA OPTN Modernization site rather than through a single formal rulemaking process.



What is the Organ Procurement and Transportation Network (OPTN) Modernization Initiative?

Increase Public Trust

- Discuss the rights of donors and organ recipients
- Reassure families and loved ones that donation is not the cause of death
- Remove barriers to transplant due to inequity

Address Donor Organ Shortages

- Prevent organ waste after donation and expedite delivery to patients
- Expand existing criteria of death beyond brain death to circulatory or neurological processes

Improve Organ Donation Systems

- Migrate information systems from regional networks to national, cloud-based networks
- Improve IT infrastructure to provide real-time updates to patients and families, track organs in transit

Adapted from Adashi, E. Y., & Bayliss, G. (2023). HRSA Pushes OPTN Reforms as Criticism of US Organ Transplantation System Increases. *Clinical Journal of the American Society of Nephrology: CJASN*, 18(12), 1626-1627. <https://doi.org/10.2215/CJN.0000000000000270>.

Beyond the Patient: The Caregiver's Role in Transplant

For patients undergoing transplants or advanced therapies like CAR T-cell treatment, caregiver involvement is both intensive and non-negotiable. Many centers require 24/7 caregiver presence for extended recovery periods – often 30 to 100 days – plus transportation for follow-up care. Without a caregiver, patients can be deemed ineligible for a potentially life-saving procedure.

While caregivers are already treated as essential in transplant care (many centers require them as a precondition for patient eligibility), NAC's research reveals how caregiver support gaps are systemic:

- ~30% of transplant centers lack caregiver support programs.
- More than 40% of transplant centers either lacked written procedures for assessing caregiver support needs or were unaware of such documentation processes
- Only 3% of centers regularly assess caregiver needs- with most interventions triggered by crises- making it difficult to identify and provide support needed.
- While 58% of centers offer some form of caregiver-specific education and training, there is variability in the type, timing of the training offered, and delivery mode (e.g., on-site, in-system referral, or third party).
- Nearly half of centers (48%) cite limited awareness of caregiver support needs as their top challenge.

These deficits place heavy burdens on caregivers, who often perform complex medical tasks under isolating, emotionally taxing conditions. Cancer patients undergoing transplants face particularly prolonged and intense caregiving demands. Additionally, the practice of outsourcing caregiver services creates barriers to access, leaving caregivers unprepared and directly impacting the quality of patient care.

National Alliance for Caregiving: Six Priority Areas for OPTN modernization

1. Standardized screening during referral/waitlist phases to identify needs early and reduce bias, with caregiver inclusion in eligibility evaluations, potentially supported by new CPT codes.
2. Standardized caregiver data collection across centers for better coordination, continuity of care, and research.
3. Integration of caregiver coordinators in transplant teams to support caregivers across the transplant journey.
4. Comprehensive, continuous caregiver support programs spanning pre-transplant through long-term care.
5. Expand research into the diverse needs of transplant caregivers across different demographic and socioeconomic backgrounds to address existing health inequities.
6. Expansion of Medicare caregiver training services (CTS) billing codes across all transplant centers to improve caregiver access to essential training and support.

Additional aligned priorities include reducing AOOS allocations, transparent communication with patients/donors, and robust data collection for quality improvement. Some recommendations (e.g., calls for increased research on varying needs of transplant caregivers based on differing demographic data) fall outside OPTN's direct scope; alignment with related federal programs is encouraged.

Opportunities to Provide Feedback on OPTN Modernization

The primary way for caregivers, advocates, and organizations to provide comments on the Modernization Initiative is to submit public comments through the HRSA website, <https://www.hrsa.gov/optn-modernization/contact>. See template language below.

Other methods to influence the modernization effort include:

- Apply for volunteer roles, including OPTN Board or committee positions, to ensure caregiver perspectives are integrated: <https://optn.transplant.hrsa.gov/about/how-to-get-involved/>.
- Submit public comments at an OPTN regional meetings (online or in person), which usually take place twice a year: <https://optn.transplant.hrsa.gov/about/regions/regional-meetings/>.
- Participate in twice-yearly formal comment periods for policy/bylaw changes: <https://optn.transplant.hrsa.gov/policies-bylaws/public-comment/>.
- Use OPTN's critical comments portal to raise urgent safety or misconduct concerns: <https://optn.transplant.hrsa.gov/policies-bylaws/optn-critical-comments-and-directives/>.

Template Comment Language

As the OPTN modernization initiative progresses, I urge HRSA to prioritize the critical role of family caregivers in transplant success. The National Alliance for Caregiving's research reveals alarming gaps: 30% of transplant centers lack caregiver support programs, and only 3% regularly assess caregiver needs, despite caregivers being mandatory for patient eligibility.

- We strongly support adopting the following recommendations from the National Alliance for Caregiving:
- Standardize caregiver screening during referral and waitlist phases to identify needs early and reduce bias in eligibility evaluations
- Implement standardized caregiver data collection across all centers for improved coordination and research
- Integrate dedicated caregiver coordinators within transplant teams
- Establish comprehensive caregiver support programs spanning pre-transplant through long-term care
- Expand research on diverse caregiver needs to address health inequities
- Expand Medicare caregiver training services billing codes across all transplant centers

Family caregivers provide 24/7 support before, during, and after transplantation, often performing complex medical tasks under emotionally taxing conditions. Their support directly impacts patient outcomes and transplant success rates. Without systemic caregiver support, we risk perpetuating disparities that undermine the modernization initiative's goals of fairness and improved outcomes.

HRSA has the opportunity to ensure that OPTN modernization addresses the complete transplant ecosystem – patients and their essential caregivers alike. We urge immediate action to integrate these recommendations into modernization planning.

About the National Alliance

The National Alliance for Caregiving (NAC) is a catalyst for change, transforming how the United States recognizes, supports, and values its more than 63 million family caregivers providing complex care for older adults, people with a serious illness, or a disability. Through their nationally recognized caregiving research and advocacy, NAC drives policy, system, and culture change to elevate family caregivers as a national priority. NAC fosters partnerships across aging, disability, healthcare, philanthropy, and the private sector with the goal of making family caregiving more sustainable, equitable, and dignified.

