Changing Lives Through Transplant in Missouri—Leadership Summit

EXECUTIVE SUMMARY

NATIONAL KIDNEY FOUNDATION®

Overview

The goal of the National Kidney Foundation's (NKF) Changing Lives Through Transplant (CLTx) initiative is to drive a culture shift within transplant toward increasing equity and access through meaningful collaboration.

Using the Collective Impact model[i] as a framework, the NKF and stakeholder partners from across transplant, the health care delivery system, and communities across the state convened to develop and advance equitable strategies to improve transplant access, healthcare quality, and drive system level change across the region.

Through a series of Learning and Action Working Group (LAWG) discussions, stakeholders identified barriers and solutions to improve transplant referral, improve care coordination for patients, and identified the need for increased data collection and cross sector collaboration among stakeholder groups in Missouri. **57 stakeholders representing 23 organizations across the region participated in the LAWG discussions.**

In June 2025, NKF hosted a virtual summit to present the statewide roadmap to engage partners in joining this Collective Impact initiative. **Nearly 80 key healthcare and transplant stakeholders participated in the convening.** Of the 11 recommendations presented at the meeting, **nearly one third** of attendees made commitments to advance one or more recommendations of the roadmap at varying levels of support.

Transplant in Missouri

- **13,860** people have kidney failure (ESRD).
- **1,621** individuals are on the waiting list, but only **54%** are active.
- **16** people die on the Missouri kidney transplant waiting list each month. Nationally, **17** people die each day on the waiting list.
- The rate of kidney transplant among patients receiving dialysis in the state is **3.6**. The national average is **3.1.**[ii]

Methods

The National Kidney Foundation convened four LAWG with transplant, nephrology, health system leaders, public health professionals, and community stakeholders.

- **The Recipient Journey**
  Goal: Address key challenges in the kidney transplant process, from referral to post transplant care, with a focus on health equity and improving patient outcomes.

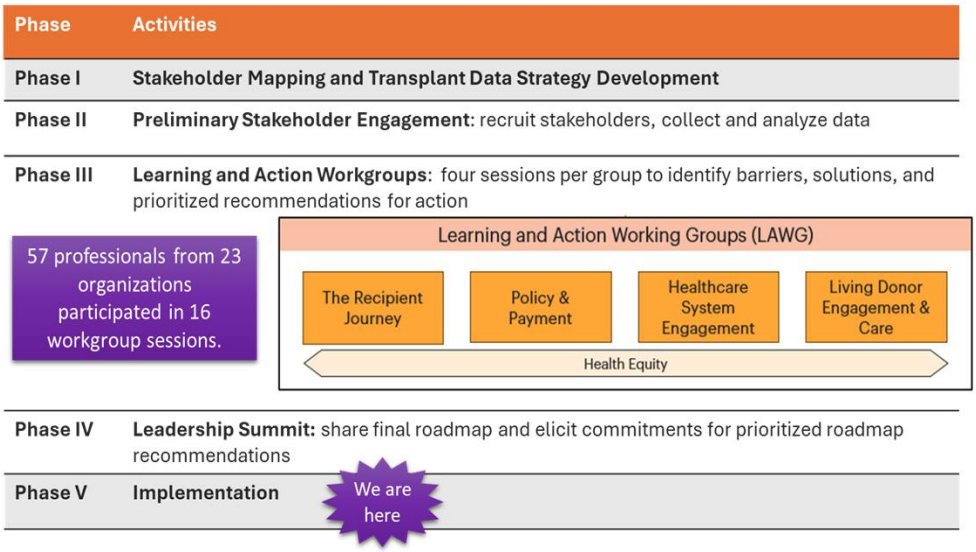
- **Living Donor Engagement and Care**
  Goal: To enhance living donor education, support, and long-term care, while addressing challenges that may discourage potential donors from diverse backgrounds.

- **Policy and Payment**
  Goal: To address policy and payment challenges hindering access to kidney transplantation, with a focus on state and institutional level barriers.

- **Healthcare System Engagement**
  Goal: Improve coordination and communication between healthcare institutions involved in the transplant process, addressing resource challenges and social determinants of health (SDOH).

Results of the Discussions

In total, 16 hours of facilitated discussions were held with stakeholders across the state. Numerous barriers to transplant access, including timely referal, targeted patient education, SDOH, and institutional challenges were identified. Consensus was reached around a series of solutions denoted below.



Statewide Barriers to Transplant Access

Recipient Patient Barriers: Across the workgroups, there were discussions on the factors that compounded challenges for patients accessing transplant, including timeliness of the initial referral to transplant, receiving accurate information about transplant referral, fears of not being placed on the waitlist after emotional investment of time and energy placed in the process, understanding the referral and transplant process, and complexity of navigating the transplant system once placed on the waitlist. Discussions on systemic barriers for patients also included how SDOH challenges further complicate transplant access. SDOH patient barriers discussed included access to insurance and coverage for transplant, access to dental care, access to consistent transportation, health literacy, and food insecurity.

These socio-contextual factors including low income and limited social support make navigating the complex transplant system particularly difficult for underserved communities (see Figure 1) [iii]. In Missouri, these disparities are especially pronounced. Rural areas face higher poverty

(16.5%) and uninsurance (14.6%) rates than state averages (12.3%, 11.9%), and Black Missourians experience higher poverty rates (29.8%) and uninsurance rates (13.6%) compared to White counterparts. Lack of insurance and financial resources severely limit access to kidney care and transplantation, widening the state's health equity gap[iv].

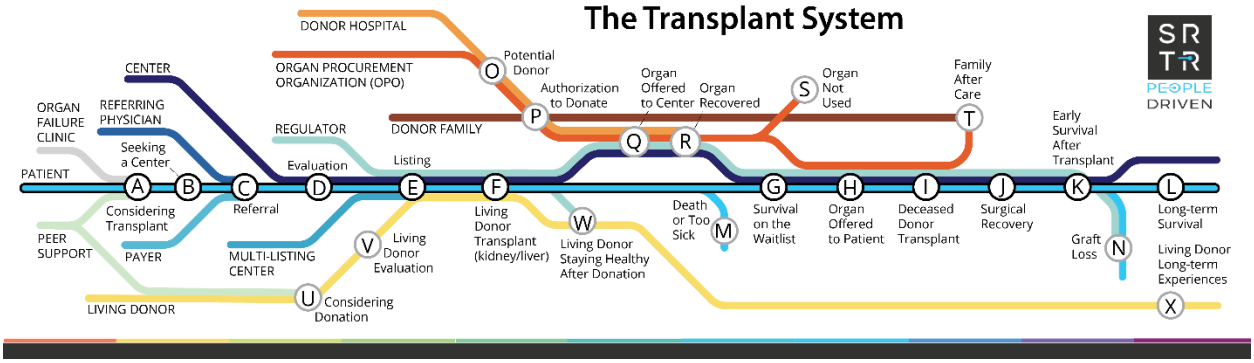


Figure 1. Multi-organ transplant system map, Scientific Registry of Transplant Recipients[iii]

Living Donor Patient Barriers: Living donation offers the best outcomes for patients, reducing wait times and providing better long-term survival rates, but awareness about living donation remains low. [v] Living donation also reduces healthcare costs associated with long-term dialysis and improves recipients' quality of life and the ability to remain productive members of our community. [vi] However, many potential donors face significant barriers-including system, clinical, policy, and psychosocial barriers that make the decision to become a living donor difficult. [vii] Moreover, in 2024, there were 6,419 living donor transplants. A combination of increased awareness about living donation and addressing system barriers to living donation can help increase the number of living donors and improve access to kidney transplants. [viii]

Barriers for potential living donors discussed during the workgroup meetings include financial barriers, lack of insurance to donate, and provider concerns regarding the long-term health of the potential donor. In some cases, donors may also be a caretaker for the potential recipient, contributing to distress as the potential donor tries to navigate the evaluation process for both them and the patient. Existing but unknown medical conditions, such as cancer or other chronic illness, prohibits donors from moving forward in the process, which can further complicate the psycho-social aspect of living donations because the potential donors' health status differs from what was expected, and they may not be able to donate. Additionally, policy barriers, such as paid time off from work, can impact an individual's ability to donate.

Healthcare Provider/Clinician Barriers: During the workgroup discussions, there were robust conversations about provider level barriers that made transplant referral challenging. These barriers include the volume of time and data management required to successfully get a patient from initial referral to waitlist, gaps in provider education about transplant as a treatment option, lack of understanding the referral and eligibility criteria (including opportunity for pre-emptive transplant), administrative challenges in sending referrals and overall care coordination, and

time constraints to comprehensively educate patients so they understand the "why" behind requirements and recommendations.

Health System Barriers: At the health system level, there were both internal and external factors raised during workgroup discussions. Barriers included technology, time, and resources (including staffing and other resources needed to optimize efficient transplant referral and patient waitlisting). Additionally, there was discussion on the disconnect between the referring providers' perception of patient readiness, i.e. patients may not be ready or interested in starting the evaluation process or a lack of understanding that they were referred for transplant. This breakdown in communication is a challenge not just at the point of referral to transplant but throughout the patient journey. Lastly, barriers related to SDOH, lack of patient social support, and resource availability hinder efficient and effective engagement of patients, donors, and healthcare professionals.

Solutions: A Roadmap for Change

Missouri Strategies: There was consensus across stakeholders that the following strategies, driven by motivated partners in a collective impact approach, could be implemented to advance systems change. Implementation will begin in Fall 2025, leveraging the expertise of individual stakeholders and stakeholder groups across the Missouri transplant, healthcare delivery, and public health systems.

Learning and Action Workgroup (LAWG) Recommendations - 2025

Employ a systems change approach to increase transplantation and donation.
- Execute quality improvement projects from CKD diagnosis and management through evaluation, including embedded education and referral processes
- Identify and build new organ donor registration opportunities outside the DMV, including patient portal implementation
- Convene a workgroup to develop a pilot to identify CKD patients for transplant referral, in collaboration with health plans

Improve preemptive transplant rates across Missouri and increase access to preemptive transplant
- Identify, develop, and pilot educational models for CKD3b-4 patients with a focus on preemptive transplant and living donation
- Research perceived barriers among MO general nephrologists to referring CKD patients for preemptive transplant and build solutions to address key challenges

Increase statewide collaboration on practices and tools to improve transplant and donation system capacity
- Create and institute a statewide shared learning network to foster peer-to-peer learning of best practices
- Pilot and evaluate the impact of a business case toolkit for transplant program growth to increase living donation
- Convene a workgroup to define, design, and implement a shared transplant patient referral form, including basic critical information and SDOH assessment

Improve navigation and support to reduce barriers for CKD patients and potential living donors
- Launch a pilot using Community Health Workers to provide navigation services in a transplant setting, including addressing community and social support needs
- Engage the MO employer community to identify state policy strategy around removing barriers for living donors

National Recommendation
- Advocate for expanding eligibility for National Living Donor Assistance Center (NLDAC) to provide more extensive support

Funding

The statewide Leadership Summit work was funded by the Missouri Foundation for Health, Mid-America Transplant Services, the Missouri Kidney Program, and Midwest Transplant Network.

[i]Kania J, Kramer M. Collective Impact. Stanford Social Innovation Review. 2011;9(1):36-41. doi:10.48558/5900-KN19
[ii] State Data. Organ Procurement and Transplantation Network. Accessed August 15th, 2024. https://optn.transplant.hrsa.gov/data/view-data-reports/state-data/#
[iii] Snyder JJ, Schaffhausen CR, Hart A, et al. Stakeholders' perspectives on transplant metrics: the 2022 Scientific Registry of Transplant Recipients' consensus conference. *Am J Transplant*. Jul 2023;23(7):875-890. doi:10.1016/j.ajt.2023.03.012
[iv]Davenport S, Brendel B, Jones A, et al. *Health in Rural Missouri*. 2020:1-89. Accessed August 15th, 2024. https://health.mo.gov/living/families/ruralhealth/pdf/biennial2020.pdf
[v] Axelrod DA, Schnitzler MA, Xiao H, et al. The economic benefits of kidney transplantation compared with dialysis. Transplantation. 2008;86(5):675-682. doi:10.1097/TP.0b013e318185eea4
[vi] Scientific Registry of Transplant Recipients (SRTR). Living Donor Chapter, 2020 Annual Data Report. SRTR website. https://srtr.transplant.hrsa.gov/ADR/Chapter?name=LivingDonor&year=2020.. Accessed September 5, 2025
[vii] Basiri A, Taheri M, Khoshdel A, et al. Living or deceased-donor kidney transplant: the role of psycho-socioeconomic factors and outcomes associated with each type of transplant. *Int J Equity Health*. Jun 01 2020;19(1):79. doi:10.1186/s12939-020-01200-9
[viii] United Network for Organ Sharing (UNOS). Data Reports: Transplant Trends. UNOS website. https://unos.org/data/.. Accessed September 5, 2025.

For more information about this initiative, please contact:

National Kidney Foundation
Haley Jensen, Sr. Director Transplant Programs
Hayley.jensen@kidney.org

National Kidney Foundation
Alexandra Garrick, Collective Impact Director
Alexandra.garrick@kidney.org

KIDNEY.ORG