Early Access to Kidney Transplantation: Key Insights from the 2026 E-STAR Annual Data Report

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E-STAR
Early Steps to Transplant Access Registry

Contents

Executive Summary

We are pleased to announce the release of the 2026 Early Steps to Transplant Access Registry (E-STAR) Annual Data Report, an interactive resource that offers novel insights into the earliest steps of the kidney transplant access pathway. While national reporting has historically focused on waitlisting and post-transplant outcomes, growing evidence highlights the need to look upstream in the pathway to understand barriers and opportunities to improve transplant access. Using data captured within the E-STAR, the only multi-regional registry capturing data on early transplant access steps for >260,000 patients across 37 transplant centers within four US regions, this report provides insights into the "black box" of the steps of referral and evaluation, while also highlighting experiences and perspectives shared by patients on their personal experience in the transplant process. This white paper summarizes the contributions of the E-STAR Annual Data Report, highlights key insights revealed through the report, and outlines implications and recommendations for transplant centers, dialysis organizations, kidney advocacy organizations, payers, and policymakers. Together, findings from this report underscore that early access to kidney transplantation is measurable, variable, and actionable. Data on these early steps can support quality improvement and advance national goals to improve access and accountability within the transplant system.

Key Highlights from the 2026 E-STAR Annual Data Report:

- **Referral rates improved over the past decade**, with the percentage of incident dialysis patients referred within one year increasing from 24.3% in 2015 to 33.4% in 2023.
- **Timely evaluation initiation (within 3 months of referral) declined**, falling from approximately 42% during 2015-2018 to 24.3% in 2024, suggesting growing challenges after referral.
- **Substantial variation exists across dialysis facilities and transplant centers**, creating opportunities for benchmarking, shared learning, and quality improvement.

- **Patient stories provide critical context** by illustrating the emotional, logistical, and informational barriers encountered during the transplant process and highlighting opportunities for clearer communication and stronger support throughout the process
- **Early transplant access is measurable and actionable**, highlighting opportunities to improve care delivery, accountability, and transparency across the kidney disease community.

Introduction

Why Early Transplant Access Matters and Why This Report Is Needed

Kidney transplantation remains the preferred treatment for many patients with kidney failure, which is the most severe stage of kidney disease. Individuals who undergo a transplant tend to live longer than similar patients who remain on dialysis. They also experience a higher quality of life, with more energy, fewer restrictions on food and fluids, and easier daily functioning. Over time, transplants can also be more cost-effective compared to dialysis for patients and the health system (Axelrod et al., 2018; Tonelli et al., 2011; United States Renal Data System; Wolfe et al., 1999). Yet, access to transplantation involves a complex, multi-step process that begins well before a patient is added to the deceased donor waitlist. These early steps include transplant education, referral for evaluation, attending educational sessions and medical appointments, completing the evaluation process, and determination of transplant eligibility. Progress through these stages is essential for accessing transplantation, but delays or drop-off at any point can prevent patients from ever reaching the waitlist.

Despite its benefits, most people with kidney failure receive dialysis rather than a transplant. While organ availability remains a critical constraint (Cron et al., 2025; "U.S. surpasses 49,000 organ transplants while deceased organ donations dip," 2026), many patients also encounter substantial barriers earlier in the transplant process.(Harding et al., 2021) People from underrepresented groups, such as those with lower incomes or living in rural or low-education areas, often face additional challenges at each step (Axelrod et al., 2010; Davis et al., 2014; Harding et al., 2021). These differences lead to ongoing gaps in who can receive a kidney transplant.

Historically, these early steps in the process have been poorly measured. This data has largely been confined to individual transplant center electronic medical records and has not been systematically tracked or reported at a national level. As a result, there has been limited

visibility into where delays occur, how access varies across patient populations and regions, or whether efforts over the past decade to improve transplant access have translated into meaningful change. The newly released 2026 Early Steps to Transplant Access Registry (E-STAR) Annual Data Report addresses this gap. By providing information on pre-waitlisting access in an interactive, accessible format, the Annual Data Report offers a new lens for examining, discussing, and improving early steps in the transplant process.

Overview of the E-STAR Registry

The Early Steps to Transplant Access Registry (E-STAR) is a multicenter initiative designed to gather standardized data on early kidney transplant processes, such as referrals and evaluation (Early Steps to Transplant Access Registry, 2023). Though these initial steps are crucial, national systems such as the USRDS and SRTR do not currently track or report detailed information about these early stages (Scientific Registry of Transplant Recipients, 2025; United States Renal Data System). This data gap limits the ability to develop quality metrics, identify barriers, and inform policy decisions for better transplant access. Unlike registries focusing on waitlisted candidates and recipients, E-STAR captures data on patients earlier in their transplant journey, including those who may never reach the waitlist. Created to support quality improvement, equity, and shared learning, it is the only multi-region source of pre-waitlisting data in the U.S., covering over 260,000 patients across 13 states and four ESRD networks. When linked with USRDS and SRTR data (Lentine et al., 2025; Scientific Registry of Transplant Recipients, 2025; United States Renal Data System), this registry uniquely captures data on referral and evaluation rates, preemptive referrals among CKD patients, and health system quality. Importantly, E-STAR is a collaborative resource for generating high-quality reports and tools that provide actionable insights for clinical teams, administrators, and other stakeholders.

What Is New About the E-STAR Annual Data Report

The E-STAR Annual Data Report (ADR) is a public-facing synthesis of data from the Early Steps to Transplant Access Registry, linked with USRDS and SRTR data, delivered through an interactive, web-based report. Unlike other reports, like the E-STAR dashboard (Kelty et al., 2025), the Annual Data Report offers a curated, interpretive view of the data, bringing together key findings, trends, and context in a single annual product for a broader audience. Rather than focusing on facility-level performance alone, the ADR emphasizes shared learning and system-level insights into early transplant access. This recently published report enables users to examine 1) key early access milestones such as referral and evaluation initiation; 2) variations among centers and regions, indicating where experiences differ; 3) trends over time, showing how early transplant access has changed over the past decade; 4) differences across patient subgroups, including race, ethnicity, age, sex, and insurance coverage; and 5) patient stories that highlight emotional, logistical, and social obstacles encountered during the transplant process. By making early access data visible and navigable, the Annual Data Report supports reflection, dialogue, and action among members of the kidney disease community.

Key Insights from the Newly Released E-STAR Annual Data Report

Although specific estimates vary across centers and regions, several consistent insights emerge from the newly released E-STAR Annual Data Report (ADR). Together, these findings highlight progress in early referral, growing delays later in the process, and persistent barriers to access that begin well before waitlisting.

Referral Has Improved, but Evaluation Timeliness Has Declined

The ADR shows improvement in timely referral for kidney transplant evaluation over the past decade. Across the four E-STAR regions, the proportion of new dialysis patients referred for transplant within one year of dialysis initiation increased from 24.3% in 2015 to 33.4% in

2023, reflecting a stronger emphasis on earlier referral practices and improvements in access, a result of increases in incentives for nephrologists and dialysis facilities to promote transplant access ("ESRD Treatment Choices (ETC) Model | CMS," ; Hippen et al., 2020; Services, 2019).

However, these gains have not consistently translated into improvements in timely evaluation start. The percentage of patients who begin transplant evaluation within recommended timeframes has declined over time, falling to 24.3% in 2024, compared with approximately 42% between 2015 and 2018. This growing gap between referral and evaluation start suggests emerging bottlenecks after referral, likely driven by increasing referrals that strain clinician staffing and availability (Bicki et al., 2024; Crenesse-Cozien et al., 2019; Nishio Lucar et al., 2024; Plantinga et al., 2024).

Delays and Disparities Emerge Early in the Transplant Pathway

The report's metrics on time between steps, both overall and broken down by region and by select patient demographics, show where delays most often happen along the early transplant pathway. Specifically, the longest delays most often occur between dialysis start and referral, while the shortest are between referral and evaluation initiation. These intervals vary significantly by region and patient subgroup. For some groups, the median time from dialysis start to referral exceeds several months, whereas others have shorter timelines. For instance, the median interval is about 6 months for patients aged 18-29 years at dialysis start, but longer for those aged 30-64 at around 8 months.

Additional report features also reveal differences in timely referral, evaluation start, and waitlisting rates by region and patient groups. For example, younger patients (ages 18–29) generally have higher rates of timely evaluation start, while older patients, especially those aged 65–80 years, have lower percentages starting the evaluation within three months. Patients with public insurance, such as Medicaid and Medicare, or no insurance, tend to have lower rates of timely evaluation start compared to those with employer-based insurance. These differences

highlight that barriers occur early in the transplant process, affecting some groups more than others. They can serve as a reference for targeted improvements to reduce disparities in access.

Wide Variation Across Dialysis Facilities and Transplant Centers

The figures in the Annual Data Report reveal significant variation in dialysis and transplant centers, both across and within regions. Within the same region, some dialysis facilities have 0% of patients starting evaluation within three months of referral, while others reach 100%. Similarly, at the transplant center level, percentages range from 1.6% to 76.6%, indicating variation in access depending on where a patient is referred. This variation demonstrates that access is influenced not only by patient characteristics but also by the organization and support systems for the referral-to-evaluation process. Findings underscore the potential for collaborative learning, the dissemination of best practices, and the need for enhancements in operational capacity.

Patient Experience Data Adds Essential Context

Insights from eight virtual focus groups with 47 patients from New England, New York, the Southeast, and the Ohio River Valley provide important context for understanding what it is like to move through the kidney transplant process. These insights highlight how the journey can be confusing, emotional, and full of barriers, yet it can also be strengthened by community support and personal resilience. These reported experiences help explain some of what we are seeing in E-STAR data (e.g., observed delays and drop-off of patients in early steps) by revealing common barriers patients face before placement on the waitlist. By integrating patient voices with quantitative metrics, the ADR offers a more complete, human-centered picture of early transplant access.

Implications and Recommendations Across the Kidney Disease Community

The E-STAR Annual Data Report (ADR) highlights that delays and disparities in transplant access emerge well before waitlisting, pointing to opportunities for improvement across the entire kidney disease system. The following implications and recommendations outline how different stakeholder groups can use early access data to support timely access, while emphasizing patient-centered transplant care.

Transplant Centers Benchmarking to Improve Access

For transplant centers, the ADR offers new insight into parts of the transplant process that have traditionally been hard to measure, beyond their electronic medical records and within E-STAR Reports. By tracking where patients encounter delays between referral, evaluation, and waitlisting, and observing how these patterns differ across centers, regions, patient subgroups, and over time, the report identifies opportunities to improve intake workflows, scheduling, and patient navigation before waitlisting decisions are made.

Early-access metrics from the report can be integrated into center discussions and used to inform routine quality improvement efforts, enabling transplant centers to work upstream to improve access. Used in this way, the ADR can inform staffing and capacity planning, support refinements to referral triage and evaluation processes, and identify patients who may need targeted follow-up or navigation. Importantly, the report's anonymized comparisons, used alongside your center's data and data reports within the E-STAR dashboard for E-STAR participating centers, support quality improvement and benchmarking to improve the transplant experience for patients and staff and reduce strain on the health system.

Dialysis Organization Benchmarking and Patient Insights to Improve Access

For dialysis organizations, the ADR highlights that although referral rates have improved over the past decade, strong referral performance alone does not guarantee timely access to subsequent steps in the process, and that access is not available at all facilities. The variation in

performance across facilities and regions provides an important benchmarking opportunity, helping organizations identify opportunities for improvement and monitor transplant access over time through performance measurement. This data, combined with insights from patient narratives reported in the ADR, underscores the important role of dialysis facilities in strengthening education, documentation, and follow-up after referral. Dialysis organizations can use ADR data to examine variability across facilities, identify patient groups more likely to experience delays after referral, and focus improvement efforts on communication, preparedness, and coordination with transplant partners.

Strengthening Advocacy Through Evidence

For patients and advocacy organizations, the ADR provides evidence that many barriers to transplant access arise after referral, during a period patients often describe as confusing, stressful, and opaque. By pairing quantitative data with patient-reported experiences, the report validates patient narratives and situates them within a broader system context.

Advocacy organizations can use ADR findings to support patient and caregiver education about what access looks like and timing expectations and to elevate early access as a priority for policy and practice change. The data help shift the conversation away from individual “readiness” toward the structural drivers of delays and toward strengthening advocacy efforts aimed at transparency, navigation support, and equity earlier in the transplant journey.

Data-Driven Insights to Advance Policy, Payment, and Performance Measurement

For policymakers and payers, the ADR demonstrates that early transplant access is measurable and that current national data systems leave critical gaps, shining a light on opportunities to improve the transplant system’s functioning through policy changes and system-level interventions. Although federal kidney policy has increasingly emphasized expanding access to transplantation, the absence of standardized pre-waitlisting data has limited the ability to assess system performance, identify barriers, and guide improvement

efforts across dialysis and transplant settings. The ADR shows that delays and disparities emerge in these early steps, well before patients appear in traditional waitlist-based metrics. As a result, payment models and accountability frameworks focused exclusively on waitlisting or transplantation, overlooking the stages where access is most constrained and where disparities first arise. By making these early steps visible, the ADR underscores the need for policy attention to extend upstream, capturing the full transplant access pathway rather than only downstream outcomes.

Given the forthcoming national data collection by the Organ Procurement and Transplantation Network (OPTN) ("HRSA directive to expand OPTN data collection," 2024; Patzer et al., 2025), data captured within the ADR can serve as an important precursor and complement. The ADR offers practical insight into how early access measures can be defined, operationalized, and interpreted, helping to inform measure development, identify implementation challenges, and establish baseline expectations for early transplant access before national reporting begins. In doing so, it supports thoughtful, phased integration of early access metrics into future OPTN data systems.

Together, these findings can support efforts to align payment and accountability models to promote timely and fair progression through early transplant steps, including changes in care coordination, patient navigation, and evaluation infrastructure. More broadly, the ADR demonstrates the feasibility and value of standardized pre-waitlisting data reporting, offering a tested framework to inform future national reporting efforts.

Research and Learning Health System Implications

Finally, the ADR serves as a platform for understanding health-system strategies related to transplant access. By documenting variation across centers, facilities, regions, and patient groups, the report highlights the importance of identifying best practices, implementing, and evaluating interventions and quality improvement initiatives aimed at enhancing access to these

vital steps. Researchers and health systems can utilize the data from this report and future iterations, along with similar data from their own EMRs and other data sources, to analyze how operational changes, policy modifications, and patient support strategies impact patient progression over time.

Conclusion

The newly released E-STAR Annual Data Report marks an important step toward transparency and accessibility in data on early transplantation steps. By illuminating the earliest steps toward transplantation, the ADR provides a clearer, more detailed picture of how patients move from dialysis to transplant evaluation and where delays, gaps, or disparities may occur. Used thoughtfully, these data can support quality improvement, strengthen advocacy, inform policy, and ultimately enhance access to kidney transplantation.

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