

February 9, 2026

The Honorable Mehmet Oz, M.D.
Centers for Medicare & Medicaid Services
U.S. Department of Health and Human Services

RE: File Code CMS-5544-P, Proposed Rule - Medicare Program; Alternative Payment Model Updates and the Increasing Organ Transplant Access (IOTA) Model for Performance Year (PY) 2

Dear Administrator Oz:

On behalf of the National Alliance for Caregiving (“NAC”), we appreciate the opportunity to provide public comments on the Proposed Rule for the Increasing Organ Transplant Access (IOTA) Model in its second performance year (“Proposed Rule”).¹

We represent the voice of 63 million family caregivers who support a friend or family member with disability, aging, or other healthcare needs. **Caregivers play a central role in the transplant patient’s experience, as most patients are not eligible for transplant without a caregiver to support them and agree to all caregiver responsibilities.**²

To understand the experience and need of this community, we have published three national reports, including primary and secondary research, on family caregiving and solid organ, blood, and stem cell transplantation. Additionally, we convene the [Transplant Caregiving Collaborative](#), a network representing stakeholders across the organ transplant and caregiving communities.

With this background in mind, we offer the following comments:

- I. **CMS’s commitment to quality, transparency, and public reporting supports a family-centered model of organ transplantation.**
- II. **CMS can improve the efficiency of the IOTA alternative payment model by leveraging caregiver training, maintaining data collection, and including family caregivers in care coordination processes.**
 - a. **The IOTA Model should leverage existing Medicare reimbursement for caregiver training services (CTS).**
 - b. **CMS should retain voluntary health equity plan submissions to support economic analysis of the IOTA Model program.**

¹ Centers for Medicare & Medicaid Services (CMS). Medicare Program; Alternative Payment Model Updates and the Increasing Organ Transplant Access (IOTA) Model, 2025-22543 (90 FR 57598). Published December 11, 2025. Accessed January 28, 2026. <https://www.govinfo.gov/content/pkg/FR-2025-12-11/pdf/2025-22543.pdf>

² Caregiver Responsibilities. American Society of Transplantation. Published 2025. <https://www.myast.org/caregiver-responsibilities-2>

c. **The IOTA Model should acknowledge the role of family caregivers in the organ transplant process.**

I. **CMS's commitment to quality, transparency, and public reporting supports a family-centered model of organ transplantation.**

We commend CMS for grounding the IOTA Model in quality measurement, transparency, and public reporting. These commitments are foundational to family-centered organ transplantation. Quality metrics create accountability for patient and caregiver experiences during the transplant process. Transparency enables families to make informed decisions when selecting transplant centers. Public reporting allows advocates to identify gaps and drive improvement.

These goals align with those described in the Proposed Rule,³ which states that the IOTA Model aims to “incentivize transplant hospitals to overcome system-level barriers to kidney transplantation.” Traditional barriers include quality-of-care issues that drive healthcare costs, such as a shortage of kidney donors and overreliance on kidney dialysis. We would like to call attention to an additional, existing barrier: **many transplant centers require a caregiver for post-discharge recovery, and the lack of a caregiver alone can be grounds for denying an organ transplant to a patient in need.**

In a nationally representative study, NAC and AARP found that of the 63 million Americans who provide care to a friend or family member, tens of millions support loved ones with conditions that can lead to kidney disease, such as aging (13%), diabetes (4%), and heart disease (4%).⁴

Caregivers play a role in healthcare and systems before, during, and after a patient's diagnosis and potential need for a transplant. Yet additional findings in our survey of transplant centers across the nation reveal significant gaps that underscore the need for transparency and public reporting to achieve quality aims:

- **30% of centers lack caregiver support programs.** Without public reporting, families cannot identify which centers will support them.
- **Only 3% of centers perform regular caregiver reviews.** Quality metrics could incentivize systematic assessment.
- **40% of centers lack or are unaware of processes for documenting caregiver needs.** Standardized reporting would create accountability.

Information and training present a twofold concern for transplant centers, as caregivers must be part of ongoing support throughout the transplant process. A comprehensive literature review notes

³ <https://www.federalregister.gov/d/2025-22543/p-56>.

⁴ National Alliance for Caregiving (NAC), AARP. *Caregiving in the US 2025*; 2025:20. Accessed January 28, 2026. <https://www.caregiving.org/research/caregiving-in-the-us/>.

that many caregivers lack information in an appropriate language or at an appropriate literacy level, making it difficult to follow tasks such as hospital discharge instructions.⁵

As one caregiver explained, many caregivers partner with transplant patients to make medical decisions.

He found he often lacked the information he needed when caring for his sister during the kidney transplant process:⁶

“A lot of times people just need a sounding board, you know, ‘What do you think of this? What do you think of that?’ And [my role is] trying to say, ‘Okay, this is what I think you should do, and this is why I think you should do it. I think that’s one of the things that’s really helpful... My only frustration, ever, was with information. You can’t make a really informed decision if you don’t have all the pieces.”

In addition to information gaps, many transplant centers lack staff to educate and train caregivers and lack tools and processes to evaluate the mandated caregiver role.⁷ This is especially true when patients and families are trying to understand the waitlist process.

One caregiver explained that his wife was repeatedly removed from the kidney transplant waitlist after medical complications like falls and mini-strokes. Each time, he worked to restore her health so she could be re-listed, often with little guidance from the transplant team and learning critical caregiving skills only in crisis moments.⁸ The yo-yo of organ offers and failure to match created financial burden for his family, as they had to frequently travel to evaluate the organ offers. In his words:

“We probably had 10 – 15 calls that were no-go’s, and we made the trip out there numerous times... We started targeting flights that were available, thinking about different seasons and different locations and how we would get there... I was living with a duffel bag under my desk.”

By including caregiver-related metrics in the IOTA Model's quality measures and public reporting, CMS can help families navigate the transplant system and incentivize centers to invest in caregiver support.

II. CMS can improve the efficiency of the IOTA alternative payment model by leveraging caregiver training, maintaining data collection, and including family caregivers in care coordination processes.

⁵ Cothran F, Mitchell HR, Montoya Y, Tokarewich L. *Transplant Caregiving in the U.S.: A Call for System Change*. National Alliance for Caregiving; 2023. Accessed January 28, 2026. https://www.caregiving.org/wp-content/uploads/2023/11/NAC_TransplantCaregiversReport-FINAL.pdf.

⁶ National Alliance for Caregiving. Care Stories: Jesus. *National Alliance for Caregiving*. Published online November 16, 2023. Accessed January 28, 2026. https://www.caregiving.org/care_stories/jesus/.

⁷ Guillory Reid K, Mitchell HR. *Gaps and Opportunities: Family Caregiver Programs in U.S. Transplant Centers*. National Alliance for Caregiving; 2024. Accessed January 28, 2026. https://www.caregiving.org/wp-content/uploads/2024/11/NAC_TransplantGapsReport_FINAL_11.05.2024.pdf.

⁸ National Alliance for Caregiving. Care Stories: Brian. *National Alliance for Caregiving*. Published online November 16, 2023. Accessed January 28, 2026. https://www.caregiving.org/care_stories/brian/.

a. The IOTA Model should leverage existing Medicare reimbursement for caregiver training services (CTS) regarding waitlist and offer decisions.

We applaud CMS's leadership in the 2024 rule requiring IOTA participants to review organ offer acceptance criteria with Medicare patients currently on the kidney transplant waitlist. This rule required a review at least every six months. The current Proposed Rule defines "transplant organ offer acceptance criteria" to focus on individualized patient acceptance parameters, suggesting that transplant centers will be required to have a detailed, nuanced conversation with the patient about the waitlist at least twice a year.⁹

The current incentive in the Proposed Rule is well-intended but may not be sufficient to change transplant centers' behavior. For example, the Proposed Rule estimates a minor burden on kidney transplant hospitals to conduct comprehensive and meaningful patient education and training.¹⁰ The current incentive to explain the waitlist process and acceptance criteria supports conversations with patients totaling no more than 15 minutes. Averaging roughly seven minutes every six months, this incentive may not provide enough support for transplant centers to help patients and caregivers understand the waitlist process and how health behaviors may shape their place in line.

Based on our understanding of the transplant process, we believe family caregivers should be included in these conversations and encourage CMS to encourage IOTA Model participants to leverage existing payment incentives under the Medicare program.

Transplant centers concerned about administrative costs or time spent communicating with caregivers should be made aware of Medicare billing codes that reimburse for family education and caregiver training services.¹¹ These codes allow providers to offer training and education to the caregivers of Medicare beneficiaries (see attached Appendix A). This existing reimbursement may mitigate the challenges facing organ transplant centers in the IOTA program that need additional time to provide waitlist education.

In our survey of organ transplant centers across the nation, many reported that the lack of resources available to them prevented support to the family caregiver.¹² Notably, of the centers that did have caregiver support programs, the most requested supports were group psycho-social programs and peer-mentoring. This aligns with existing billing codes which provide for reimbursement for individual and family counseling related to caregiving, in addition to training on activities of care.

Innovative organ transplant centers have an opportunity to create a more effective, meaningful process to educate patients and their families on the waitlist process and the healthcare behaviors that may drive eligibility. Using existing incentives in the program would also provide Medicare with additional data on the feasibility of scaling the IOTA Model at the end of the program.

⁹ <https://www.federalregister.gov/d/2025-22543/p-42>

¹⁰ <https://www.federalregister.gov/d/2025-22543/p-473>.

¹¹ Whiting CG, Anglim T, Mariani D, Montoya Y. *Trends in Innovation: Implementing and Refining Caregiving Training Services in Medicare*. NAC Cancer Caregiving Collaborative; 2025. Accessed January 28, 2026.

https://www.caregiving.org/wp-content/uploads/2025/07/NAC_CancerCollab_CTS-Medicare_v4.pdf

¹² *The Family Caregiver Gap: Disparities and Missed Opportunities in Support Services across U.S. Transplant Centers*. National Alliance for Caregiving; 2025. Accessed January 28, 2026. https://www.caregiving.org/wp-content/uploads/2025/12/NA_Transplant-Disparities-Report_082625.pdf

b. CMS should retain voluntary health equity plan submissions to support economic analysis of the IOTA Model program.

The current Proposed Rule would remove all health equity plan submissions and related terminology from the IOTA Model program.¹³ The removal of this information may undermine other program goals aimed at improving efficiency and lowering costs. Increased transparency around topics such as the waitlist will inevitably expose disparities in access, particularly in rural and underserved communities.¹⁴ When this happens, CMS will not be able to benefit from the insights offered by voluntary health equity plan participants. This will make it more difficult for analysts to determine which factors affect the upstream drivers of health that increase health system costs.

Existing research has shown that many rural and underserved families receive less support during the transplant process, which puts pressure on the healthcare system in other benefit programs. For example, in our analysis of disparities in transplant centers, those serving mostly Black/African American patients offer significantly fewer support programs for the patient's family caregiver compared to other centers (21–28% compared to ~33% at centers overall). Centers serving exclusively low-income patients are the least likely to offer financial counseling (22% vs. 31% overall), which increases the likelihood that transplant patients may be unable to pay for services or manage medical debt.

Removing references to health equity, especially at this stage of the program, will undermine efforts by researchers and analysts to understand how upstream drivers of health can affect the overall effectiveness and cost of this program. We encourage CMS to retain this voluntary requirement to better understand how social determinants of health can affect the IOTA Model's success and long-term cost savings.

c. The IOTA Model should acknowledge the role of family caregivers in the organ transplant process.

From the beginning of the organ transplant process through the end, the caregiver is a critical partner who should be included in the process. As described above, many organ transplant centers require the presence of a family caregiver for a patient to qualify for the waitlist. As the process continues, caregivers assist with everything from coordinating organ offers, supporting medical decision-making, and other skills, and with the physical, hands-on work of providing care.

As the IOTA program continues, acknowledging the role of family caregivers is increasingly important. For some kidney transplant patients, long waiting lists and a lack of available donor organs may mean that patients progress into hospice and palliative care. Including family caregivers in end-of-life discussions can be an effective way to avoid higher costs as kidney disease advances.

The National Kidney Foundation and the Coalition to Transform Advanced Care have recognized that caregivers of kidney disease patients play a role in medical decision-making.¹⁵ For example, patients who may require dialysis while waiting for an organ transplant can benefit from palliative care approaches, which are shown to reduce costs overall (estimated 14% for inpatient settings;

¹³ <https://www.federalregister.gov/d/2025-22543/p-44>.

¹⁴ See Soliman KM, Anand PM, Perry A, et al. *Inside-Out Overview of the Increasing Organ Transplant Access Model: Bridging the Gap between Stakeholders, Providers, Patients, and Donors*. *Kidney360*. 2025;6(5):857-860. doi:10.34067/KID.0000000780, <https://pmc.ncbi.nlm.nih.gov/articles/PMC12136648/>.

¹⁵ Center to Advance Palliative Care (CAPC), National Kidney Foundation (NKF). *The Case for Palliative Care in Kidney Care*; 2025. Accessed January 28, 2026. <https://www.capc.org/documents/download/1239/>

reduced cost and utilization in VA settings). Caregivers need information about how palliative care works and its benefits, to avoid driving up unnecessary spending due to fear about their loved one's condition.

The Proposed Rule¹⁶ likewise recognizes that kidney transplant hospitals often assess caregiver readiness throughout the transplant process. Acknowledging and supporting the caregiver during the process, using existing tools in the Medicare program, can support this work.

III. Recommendations

To meaningfully acknowledge and support family caregivers' role within the IOTA model's aims at improving outcomes and efficiencies, we recommend that CMS consider how it might incentivize the following specific actions drawn from NAC's national research on transplant caregiver support:

a. Implement standardized caregiver screening during the waitlist period.

NAC's survey of 114 transplant centers found that only 3% conduct regular reviews of family caregiver support needs. Most assessments only occur reactively, often triggered by crises or adverse medical events. CMS could encourage IOTA participants to adopt standardized caregiver screening protocols, which would complement the waitlist education conversations already required under the model.

b. Encourage standardized data collection on caregiver needs.

Nearly 40% of transplant centers either lack procedures or are unaware of documentation processes for assessing caregiver needs. This gap limits care coordination and prevents outcomes-based research on how caregiver support affects transplant success. CMS should encourage IOTA participants to document caregiver needs using consistent methods. Standardized data collection would support continuity of care, inform program quality evaluation, and help identify which caregiver interventions most effectively improve patient outcomes and reduce costs.

c. Ensure caregiver support services are available on-site, not only by referral.

NAC's survey found heavy reliance on external referrals for critical caregiver services: 66–70% of centers refer caregivers elsewhere for financial counseling, 52–70% for distress screening, and 57–70% for medical education. This creates delays and access barriers for caregivers managing time-sensitive responsibilities. Referral services also make it more difficult for CMS and the IOTA Model to ensure quality and transparency across providers. CMS should encourage IOTA participants to integrate essential caregiver services, particularly distress screening and medical/nursing education, into onsite programming to better control outcomes.

These recommendations align with the IOTA Model's goals of improving efficiency and reducing costs. By shifting from reactive to proactive caregiver support, transplant centers can identify

¹⁶ <https://www.federalregister.gov/d/2025-22543/p-64>

needs earlier, prevent crises, and ensure that the family members essential to transplant success are equipped to provide effective care.

Thank You and Contact Information

Thank you again for the opportunity to provide feedback on the Proposed Rule. Should you have any questions about our comments or need additional information, you can reach us at Yadira Montoya, M.S.P.H, Programs Director, at yadira@caregiving.org or (202) 918-1038.

Sincerely,

Center to Advance Palliative Care

Hawaii Family Caregiver Coalition

IgA Nephropathy Foundation

National Alliance for Caregiving

Transplant Families

Appendix A: Medicare CTS Billing Codes

For additional information, please view the full report, Trends in Innovation: Implementing and Refining Caregiving Training Services in Medicare. NAC Cancer Caregiving Collaborative; 2025. at https://www.caregiving.org/wp-content/uploads/2025/07/NAC_CancerCollab_CTS-Medicare_v4.pdf.

Code	Definition	Services	Time
G0539	Caregiver training in behavior management/modification for caregiver(s) of patients with a mental or physical health diagnosis, administered by physician or other qualified health care professional (without the patient present)	Individual Behavior Management / Modification Training	Initial 30 minutes
G0540	Caregiver training in behavior management/modification for parent(s)/ guardian(s)/caregiver(s) of patients with a mental or physical health diagnosis, administered by physician or other qualified health care professional (without the patient present)	Individual Behavior Management / Modification Training	Each additional 15 minutes
G0541	Caregiver training in direct care strategies and techniques to support care for patients with an ongoing condition or illness and to reduce complications (including, but not limited to, techniques to prevent decubitus ulcer formation, wound care, and infection control) (without the patient present)	Individual Direct Care Training Services	Initial 30 minutes
G0542	Caregiver training in direct care strategies and techniques to support care for patients with an ongoing condition or illness and to reduce complications (including, but not limited to, techniques to prevent decubitus ulcer formation, wound care, and infection control) (without the patient present)	Individual Direct Care Services Training	Each additional 15 minutes
G0543	Group caregiver training in direct care strategies and techniques to support care for patients with an ongoing condition or illness and to reduce complications (including, but not limited to, techniques to prevent decubitus ulcer formation, wound care, and infection control) (without the patient present)	Group Direct Care Services Training	Not Timed
96202	Multiple-family group behavior management/modification training for parents(s)/guardian(s)/caregiver(s) of patients with a mental or physical health diagnosis, administered by physician or other qualified health care professional (without the patient present)	Group Behavior Management / Modification Training	Initial 60 minutes
96203	Multiple-family group behavior management/modification training for parents(s)/guardian(s)/caregiver(s) of patients with a mental or physical health diagnosis, administered by physician or other qualified health care professional (without the patient present)	Group Behavior Management / Modification Training	Each additional 15 minutes

Code	Definition	Services	Time
97550	Individual Caregiver training in strategies and techniques to facilitate the patient's functional performance in the home or community (e.g., activities of daily living [ADLs], instrumental ADLs [IADLs], transfers, mobility, communication, swallowing, feeding, problem solving, safety practices) (without the patient present)	Individual Functional Performance Training	Initial 30 minutes
97551	Individual Caregiver training in strategies and techniques to facilitate the patient's functional performance in the home or community (e.g., activities of daily living [ADLs], instrumental ADLs [IADLs], transfers, mobility, communication, swallowing, feeding, problem solving, safety practices) (without the patient present)	Individual Functional Performance Training	Each additional 15 minutes
97552	Group caregiver training in strategies and techniques to facilitate the patient's functional performance in the home or community (e.g., activities of daily living [ADLs], instrumental ADLs [IADLs], transfers, mobility, communication, swallowing, feeding, problem solving, safety practices) (without the patient present)	Group Functional Performance Training	Not timed