



July 16, 2024

The Honorable Chiquita Brooks-LaSure
Administrator
Centers for Medicare & Medicaid Services,
Department of Health and Human Services,
Attention: CMS-5535-P,
P.O. Box 8013, Baltimore, MD 21244-8013.

Submitted electronically via regulations.gov

Re: CMS-5535-P: Medicare Program; Alternative Payment Model Updates and the Increasing Organ Transplant Access (IOTA) Model

Dear Administrator LaSure:

As a leading national, non-partisan voice for health care consumers, Families USA appreciates the opportunity to respond to the *Medicare Program; Alternative Payment Model Updates and the Increasing Organ Transplant Access (IOTA) Model*. Central to Families USA's mission is a commitment to improve health outcomes by changing payment incentives to improve health, reduce inequities, and prioritize the delivery of high-value health care services that meet the whole-person health needs of Medicare beneficiaries and their families. With more than three-quarters of people with end-stage renal disease (ESRD) covered by Medicare, CMS' work to establish the new IOTA Model is a promising step toward increasing access to transplantation services for people living with ESRD across the country.¹

We share CMS' concern that too many people are dying while waiting for kidney transplants, and agree that emerging academic research demonstrates that currently discarded kidneys could be a lifeline for many patients if they and their health care providers were given access to those kidneys. We also agree with CMS that there are significant racial and socio-economic disparities between those living with ESRD who receive transplants and those that do not. These are problems that must be addressed.

Families USA therefore strongly supports the adoption of the IOTA Model as a mandatory model for qualifying hospitals to change financial incentives within the kidney transplant ecosystem in order to increase access to kidneys for those who are waiting for transplants, advance health equity, and ensure patients are involved in key decision-making that could change the trajectory of their health and lives.

It is important to note that while we strongly support the overarching goals of the model, we **have serious concerns about CMS' proposed approach and offer specific recommendations**

CMS should consider to strengthen this proposed model. Our comments are focused on the following sections of the proposed model:

- Overall Support for Goals of Model and Proposed Mandatory Structure
- Comments on Proposed Rulemaking
 - III. C. 5. c. (3) Health Equity Performance Adjustment
 - III. C. 5. e. (2) Quality Measure Set
 - III. C. 8. a. Transparency Requirements

Overall Support for Goals of Model and Proposed Mandatory Structure

Families USA strongly supports the work of CMMI to explore and implement promising new payment models, and applauds the design of the IOTA Model as a *mandatory* model for qualifying hospitals.

Families USA strongly believes that it is essential that our health system move away from fee-for-service (FFS) economics and toward the creation of new financial incentives through population-based payments that reward health care providers for delivering care that makes people healthier.² Fee-for-service payment incentivizes health care providers to make money by performing more high-profit or high-margin procedures, rather than by allowing providers to generate a profit or margin based on keeping people healthy and reducing disparities.³ Additionally, researchers have well established that 80% to 90% of what drives variations in peoples' health is determined by the health-related socioeconomic and environmental factors in their lives, yet fee-for-service payment — the predominant model for how health care is paid for in the United States — offers no payment for addressing the social drivers of health.⁴ By definition, FFS provider payments provide a very narrow view of health and health care by signaling to providers that they can only be reimbursed for delivering the clinical care that drives 10% to 20% of health.⁵ By offering no payment for services to address social drivers of health and paying so much for hospital admissions and procedures, the economic incentives of FFS work against the professional responsibilities and desires of providers to improve health and reduce disparities. The Center for Medicare and Medicaid Innovation (CMMI) is working to change that.

Under the Affordable Care Act, CMMI is granted statutory authority to design and test alternative payment models, including the scope and scale of such models.⁶ While CMMI has tested more than 50 payment models over the past decade, the vast majority of these models opt for voluntary provider participation.⁷ Voluntary payment models allow providers to self-select into a model and can lead to “selection bias” where providers participate in models that are most lucrative to them, rather than ones that are best for patients or ones that generate Medicare savings.⁸ Mandatory payment models remove the risk of selection bias, and are more likely to achieve results that could be scalable across the health care system and thereby maximize the potential to increase Medicare savings.^{9,10} To achieve CMS' goal of having all fee-

for-service beneficiaries in accountable care relationships with their providers by 2030, it is essential to increase the number of mandatory models in which providers participate. This approach will help to scale provider participation in alternative payment models (APMs) across the country.¹¹ **Families USA strongly supports CMS's efforts to implement additional mandatory payment models including the proposed mandatory IOTA Model.**

Comments on Proposed Rulemaking

III. C. 5. c. (3) Health Equity Performance Adjustment

Families USA applauds CMS for prioritizing health equity in model design, however we have significant concerns about the potential unintended consequences of the proposed approach and recommend CMS take a different course to reduce inequities in the kidney transplant ecosystem.

The evidence is clear: end-stage renal disease (ESRD) disproportionately affects Black Americans, Native Americans, Asian Americans and Americans of Hispanic origin compared to White Americans.¹² Despite Black Americans being three times more likely to suffer from kidney failure compared to their White counterparts, Black Americans are underrepresented on transplant waitlists.¹³ Adding to these disparities, when Black patients do receive a kidney transplant, on average the transplanted kidney is of lower quality (presenting with a higher Kidney Donor Profile Index, as discussed below in section III. C. 8. a. Transparency Requirements) than White patients.¹⁴ Furthermore, the kidney transplant waitlist not only includes a higher number of White patients, but those patients also receive a disproportionate share of transplants.¹⁵

Historically, transplant programs calculated estimated kidney function using a set of health-based variables that they then used to determine the severity of kidney failure for a patient and level of priority to be placed on the transplant waitlist. However, one of the variables used in the calculation was a crude measure of race: either Black or non-black and importantly, no other race or ethnicity factors were considered. In doing so, Black patients' kidney function was overestimated, making it appear as though their kidneys were functioning at a higher level than was accurate. The result of this overestimation of kidney function was that Black patients were less likely to be placed on the transplant waitlist, and when they were, they were placed at a lower priority, creating a significant disparity in access to kidney transplants for Black patients.¹⁶ To address this egregious disparity, in 2022 the Organ Procurement and Transplantation Network (OPTN) required the removal of race as a variable when calculating kidney function.¹⁷ However, it was not until January of 2023 that OPTN approved a process to update the kidney transplant wait list and make needed adjustments to the wait-times for Black kidney transplant candidates.¹⁸ While steps have been taken to address this barrier in access to kidneys for Black patients, other barriers also exist including data that suggests socioeconomic factors such as

income and education have historically impacted the ability of Black patients to be placed on the transplant list.¹⁹

Moreover, hospitals often evaluate patient eligibility for transplant by performing what is commonly referred to as a “wallet biopsy,” where patients must demonstrate their ability to cover post-transplant medication costs, even if they are fully covered by health insurance, as co-pays for lifelong post-transplant medications can be expensive.²⁰ This “wallet biopsy” is a significant barrier for patients with lower incomes, which disproportionately include people of color, to be placed on the kidney transplant waitlist.²¹

To address these issues, CMS proposes testing a new payment model with a pay-for-performance financial incentive aimed at reducing racial and ethnic disparities in kidney transplant procedures and outcomes. Under this proposal, hospitals that participate in the IOTA Model will be evaluated on three domains: Achievement, Efficiency, and Quality.²² As part of the Achievement Domain, which constitutes 60% of the total hospital evaluation score, CMS will assess hospitals based on the volume of kidney transplants performed. As part of this measure, CMS proposes to apply a “health equity performance adjustment” that increases the Achievement Domain score for each kidney transplant performed on a low-income patient. This adjustment aims to incentivize access to kidney transplants for lower-income populations and reduce health inequities.²³

Families USA strongly agrees with CMS’ intended goal of financially incentivizing participating hospitals to improve health equity and decrease disparities in the overall transplant rate for patients with lower incomes. However, we have significant concerns about the potential unintended consequences of this design. Specifically, financially incentivizing the use of lower quality kidneys for patients while simultaneously financially incentivizing transplants for lower income patients could inadvertently link these factors and entrench a two-tiered system in which lower income patients are offered lower quality kidneys, exacerbating health disparities among transplant recipients.²⁴ Additionally, we are concerned that while the proposed model will boost transplantation rates for those already on the waitlist, it overlooks the broader barriers in health care access that keep low income patients from being placed on the transplant waitlist in the first place. To authentically address health equity, we must confront these systemic issues and ensure fair and equitable access to transplant waitlists for all eligible patients, regardless of income, race, or ethnicity.

As such, Families USA recommends an alternative approach. **We recommend that CMMI remove the health equity performance adjustment from the Achievement Domain.** Instead, participating hospitals should directly address the barriers to equity within the transplant process. To that end, **we propose increasing upside payments for high-performing hospitals and directing a portion of those upside payments into a specialized fund to support interventions aimed at overcoming socioeconomic barriers faced by kidney transplant candidates.** By removing financial barriers to transplant, CMS can take a meaningful step

toward rectifying the disparities in kidney transplant rates and promoting health equity among all socioeconomic and racial groups.

Finally, it is not sufficient to solely address access to the kidney transplant procedure. Participating hospitals must also continue to manage transplant recipients' health needs throughout their lifespan to ensure proper graft function and survival.²⁵ Low-income patients may face additional challenges or barriers to post-operative maintenance of the transplanted organ.²⁶ As such, **Families USA recommends that CMS adopt additional measures in the Quality Domain to ensure that patients receive high quality maintenance care that addresses their whole-person health needs far beyond the initial transplant operation.**

Such measures should include measurements of survival rate and assessments of the social drivers of health (SDOH) performed at the 365-day and 3-year post-transplant marks. Survival rate would be measured alongside graft survival rate to ensure the continued health and wellbeing of the patient at 90 days and 365 days. These time intervals are based on current standards of care for effective treatment and management of post-transplant care.²⁷ SDOH assessments center health equity and should prompt hospitals to evaluate and manage transplant patients' unmet needs to improve overall health. Families USA specifically recommends SDOH screening at the 3-year mark, as ESRD patients lose Medicare coverage 36 months after kidney transplant.²⁸ Given that the loss of insurance coverage has significant impact on health and access to health, an SDOH screening at that time should include tools to assist patients with obtaining alternative sources of health insurance coverage, as needed.²⁹

Taken altogether, Families USA makes the following recommendations:

- 1) Remove the health equity performance adjustment from the Achievement Domain.**
- 2) Adopt additional measures in the Quality Domain. Additional measures recommended for the Quality Domain include both a 90- and 365-day survival rate and SDOH assessments conducted for patients at the 365-day and 3-year marks.**
- 3) Increase upside payments under the pay-for-performance bonuses for participating hospitals and direct a defined percentage into the creation of a new SDOH fund. This new SDOH fund should be used by participating providers to screen and meet the SDOH needs of patients. Specifically, the funds should be allocated to patients attributed to the IOTA Model transplant waitlist or patients who are being considered for the kidney transplant waitlist with the goal of eliminating financial and socioeconomic barriers to transplantation.**

III. C. 5. e. (2) Quality Measure Set

CMS proposes four metrics as part of the Quality Domain. The Quality Domain comprises 20% of the total score used to determine bonus payments or penalties for participating hospitals through a pay-for-performance system. One of the four metrics included in the Quality Domain is the "CollaboRATE Shared Decision-Making Score Tool," used to determine whether patients were informed and involved in the decision-making process for their procedures. **While**

Families USA strongly agrees with CMS’ recognition of the importance of measuring shared decision-making within the Quality Domain, we have significant concerns about the appropriateness of the specific measurement tool CMS proposes to use.

A systematic review of academic research encompassing 30 papers to assess the validity of shared decision-making tools found that the CollaboRATE measure does not address all essential and ideal elements of shared-decision-making.³⁰ For example, CollaboRATE does not require the presentation of different care options or the discussion of pros and cons of care options, nor does the tool require that the provider and patient come to mutual agreement on a course of care.³¹ Additionally, the American College of Physicians does not support the CollaboRATE tool due to concerns about its validity and the tool’s applicability to internal medicine.³² The CollaboRATE tool does not ensure that patients and providers have discussed the specific nuances and tradeoffs of kidney transplantation for the use of kidneys with a higher Kidney Donor Profile Index (KDPI) in comparison to remaining on dialysis. Given this evidence, we are concerned about the use of the CollaboRATE tool in the IOTA Model.

As a result, Families USA makes the following recommendation:

- 1) Consider the use of an alternative instrument to measure shared decision-making, or consider measuring shared decision-making in a different way. For example, CMS could consider using an approach that establishes a target percentage of documented conversations between patients and palliative care providers or other qualified personnel to encourage increased access to advance care planning for kidney transplant candidates.** This concept will be explained in greater detail below, in section III. C. 8.a. Transparency Requirements.

III. C. 8.a. Transparency Requirements

As stated above, **Families USA strongly supports CMS’ goal of promoting shared decision-making in this proposed payment model; however, we recommend a more explicit approach to measuring shared decision-making.**

Under the proposed model design, participating hospitals would be required to notify patients (either face-to-face, over the phone, or through e-mail) about key information related to the kidney transplant waitlist — including the number of times organs were declined on the patients’ behalf, as well as the reason the organs were declined. CMS states that this requirement “would encourage conversations between patients and their providers regarding a patient’s preferences for transplant and facilitate better shared decision-making.”³³ We agree with CMS’ justification to improve shared decision-making but are deeply concerned that a passive notice to encourage conversation between providers and patients is not sufficient to ensure patients have been adequately notified. Given the provision in the 21st Century Cures Act that requires health care facilities to notify patients of test results, we are concerned that facilities will use the same electronic notification through patients’ portals for the proposed notifications. This could result in an automated notification being sent to patients rather than

incentivizing the level of quality and meaningful conversation between providers and patients that is required to provide adequate care management in these difficult situations. **Families USA therefore recommends that CMS strengthen this requirement to explicitly require providers to engage in a verbal conversation to notify and discuss patient preferences for transplant and shared decision-making about a treatment plan, and specifically prohibits the use of automated notifications for this purpose.**

In 2014, the United Network for Organ Sharing (UNOS) implemented the Kidney Allocation System (KAS) which included a method to quantify the quality of donor kidneys called the Kidney Donor Profile Index (KDPI). The larger the KDPI value, the shorter the time that kidney is expected to function following transplantation.³⁴ Donor kidneys with a KDPI value greater than 85% are routinely discarded instead of being used for transplantation due to higher risk of graft failure and poorer functioning.³⁵ However, emerging clinical evidence demonstrates that these kidneys could in fact be safely transplanted, thereby removing the need for long-term dialysis in those patients.³⁶ The use of long-term dialysis has not only been shown to increase risk of cardiovascular disease and infections,³⁷ but also is costly to the patient and the broader health care system.³⁸ Given that approximately 5,000 people die annually while waiting for a kidney transplant, increasing the number of available kidneys for transplant could reduce the number of patients who have to rely on long-term dialysis, and could reduce the number of patients who die while waiting for transplantation.³⁹

It is critical to acknowledge that while these previously-discarded organs may constitute an improvement over long-term dialysis, allowing patients to have a better quality of life, higher KDPI kidneys do come with inherent risks.⁴⁰ Higher KDPI kidneys are associated with worse health outcomes as compared to lower KDPI kidneys, including declines in survival rate, higher rates of delayed graft function, rejections in the first year following transplantation, and worse estimated glomerular filtration rate (eGFR), a marker for kidney function.⁴¹ A patient who receives a kidney with a KDPI greater than 85% is expected to need a new kidney again after an average of 5.5 years.⁴² This is a significant challenge for patients who end up on the transplant list again, as prior transplantation narrows the pool of potential donor kidney matches which can lead to increased wait times.⁴³ Additionally, further investigations should be done into the economic impact of re-transplantation, as most studies do not account for this set of circumstances. As a result of these kinds of complex tradeoffs, patients on the transplant waitlist will have differing risk tolerance levels for accepting a potential donor kidney with a sub-optimal KDPI value.

The choice to remain on the transplant list or accept a higher KDPI kidney is deeply personal and life-altering. Empowering patients to partake in shared decision-making is a crucial patient protection, recommended in clinical practice guidelines for the end-stage renal disease population.⁴⁴ To ensure that patients can make informed decisions about which options are desirable and acceptable to them, they must have comprehensive conversations with the

appropriate trained provider(s) about all the known tradeoffs and potential impacts of each care option. Yet only 29% of physicians report having formal training related to serious illness conversations, and even when they understand and agree with the importance of having these conversations, they report lacking the necessary time or feeling uncomfortable conducting them.⁴⁵

As a result, Families USA strongly recommends that CMS require hospitals participating in the IOTA Model to facilitate and document conversations about serious illness, including the patients' values and goals, between all patients who are listed for kidney transplant and appropriately trained providers and personnel such as palliative care physicians, transplant nephrologists, transplant psychiatrists, and social workers.

To further improve shared decision-making between providers and patients, CMS should provide participating hospitals with guidance on how to engage in these conversations.

Within the proposed IOTA Model, providers are measured on shared decision-making metrics (as discussed above, under III. C. 5. E. (2) Quality Measure Set), but are not provided with guidance on what elements should be included in these important conversations. Given that physicians report a lack of training in this area, we strongly encourage CMS to develop and disseminate such guidance. For example, CMS could leverage and adapt existing tools, like the Serious Illness Conversations Program (SICP), to facilitate these conversations.⁴⁶

The SICP guide has been shown to improve provider-patient conversations about patients' values, goals and treatment preferences as well as helping providers gather information for advanced care planning (ACP).^{47,48} Research shows that patient engagement in ACP with a palliative care provider supports patients' understanding of their priorities for living with serious illness and enables patients to plan for future health care decisions.⁴⁹ However, access to ACP has been limited for kidney transplant candidates and racial and ethnic disparities exist – with 24.4% of White candidates engaging in ACP, compared to just 19.1% of Black candidates and 15% of Hispanic candidates.⁵⁰ Requiring palliative care providers to engage with patients through serious illness conversations could close this gap. SICP, or a similar tool, could be tailored to kidney transplant discussions and utilized to improve shared decision-making. This approach gives structure and support for hospitals and clinicians to engage and inform patients of the risks and benefits of higher KDPI kidneys, supporting CMS' goal of improving shared decision-making. In a time of unprecedented clinician burn out and patient distrust in the medical system, CMS has the opportunity to combat both using these evidence-based interventions.^{51,52}

Families USA applauds CMS for elevating the importance of shared decision-making and strongly recommends these conversations be explicitly required and documented. As such, we make the following recommendations:

- 1) Require participating hospitals to facilitate and document serious illness conversations between all patients on the waitlist for kidney transplant and a palliative care**

provider or other trained provider (including transplant psychiatrist, transplant nephrologist, or social worker).

- 2) Provide participating hospitals with guidance on how to have these conversations by leveraging and adapting evidence-based tools, such as the Serious Illness Conversations guide.**

Families USA thanks CMS for the opportunity to comment on this proposed IOTA Model. We are encouraged by the work to move away from fee-for-service incentives and toward mandatory models that create a foundation for the proliferation of meaningful value-based care, all while addressing critical health inequities for patients with end stage renal disease. If there are any further questions, please contact Naomi Fener, Director of Population Health at Families USA, at nfener@familieusa.org.

Sincerely,



Sophia Tripoli
Senior Director of Health Policy
Families USA

¹ “9: Healthcare Expenditures for Persons with ESRD,” Annual Data Report, End Stage Renal Disease. National Institute of Health.

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