UWHealth | Transplant Center

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Response to HRSA Information Collection Request

Attention: HRSA Information Collection Clearance Officer

From: UWH Transplant Center, Madison, Wisconsin (UNOS Code WIUW)

Re: Information Collection Request Title: Process Data for Organ Procurement and Transplantation Network, OMB No. 0906-xxxx—New

ICR Reference Number: 202507-0906-001
Related Federal Register Notice: 90 FR 28754, published July 1, 2025

The UW Health Transplant Center appreciates the opportunity to provide continued feedback on the proposed data collection requirements. We support efforts to improve transparency and enhance the public's understanding of transplant center performance; however, we remain gravely concerned that the proposal significantly underestimates the scope, burden, and systemic impacts this data collection would entail.

This proposal, while well-intentioned, requires far more than the submission of data. In its current state, it presumes a level of infrastructure and readiness that does not exist in most centers. The actual work would involve major updates to our electronic medical record (EMR) systems to support accurate, structured data capture. Without native EMR integration or automated data capture mechanisms, transplant programs will be forced into unsustainable manual data abstraction and entry processes. This is particularly concerning as it appears HRSA has not fully factored in the timeline, cost, or feasibility of implementation at the center level.

The data elements proposed include information that is not routinely or consistently captured at the point of referral or even during evaluation. While obtaining information directly from patients may be straightforward, a large portion of the data will require outreach to dialysis centers, referring providers, and outside institutions. These efforts are highly labor-intensive and not always successful. This layer of work will consume valuable clinical and administrative time—resources that are already strained within the transplant ecosystem.

Equally troubling is the absence of clarity around enforcement or accountability. The proposal does not address what the consequences will be for programs that cannot provide all the requested data. Will incomplete data submissions be met with punitive actions? Who will be the enforcing authority—HRSA, UNOS, or CMS? Without clear guidance or policy guardrails, this introduces uncertainty and risk to transplant centers already operating under significant regulatory scrutiny.

Finally, this proposal appears to be a reactionary measure—perhaps spurred by public requests for information and recent media reports. While we understand the need for responsive policymaking, we caution against implementing data mandates as a reflex to incomplete or inaccurate narratives. Many recent critiques of the transplant system in the media have lacked proper context or factual grounding. Rushing to legislate or regulate based on those stories may result in unintended consequences that harm the very patients this system is meant to serve.

We urge HRSA to pause and engage in deeper dialogue with transplant centers and stakeholders. Implementation of any new data collection requirement must be preceded by a thoughtful impact analysis, infrastructure planning, and a realistic phased timeline. Without this, the proposed initiative risks redirecting resources away from patient care and toward bureaucratic processes that offer little clinical value.

We remain committed to data-driven improvement and accountability but ask HRSA to consider the operational realities of transplant programs and the long-term viability of our shared goals.

Respectfully,

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