

January 3, 2025

Ms. Joella Roland
HRSA Information Collection Clearance Officer
Health Resources and Services Administration
5600 Fishers Lane
Room 14NWH04
Rockville, MD 20857

Submitted Electronically: paperwork@hrsa.gov

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

Dear Ms. Roland,

We appreciate the opportunity to provide information related to the Health Resources and Services Administration (HRSA)'s Information Collection Request (ICR) related to "Process Data for Organ Procurement and Transplantation Network, OMB No. 0906-xxxx-New" on behalf of CommonSpirit - St. Joseph's Hospital and Medical Center - Transplant Center.

We are a multi-organ transplant center located in Arizona. Our transplant programs not only serve the local community but we provide transplant care to the surrounding states, and to patients throughout the United States. We care for approximately 2,000 transplant patients in all phases of transplant, and have one of the busiest and most successful lung transplant programs in the country.

The data directive would task transplant centers with collecting information related to referrals, evaluation results, and selection as a transplant candidate to expand the current OPTN data collection. The goal is to gain insight into who gets referred, who is referring, who gets evaluated for transplant services, and who gets placed onto transplant waitlists. Ultimately, the goal is to address disparities, improve access to organ transplantation, and evaluate the overall performance of transplantation. HRSA has requested feedback related to the necessity and utility of the proposed information collection, accuracy of the estimated burden, and ways to enhance the quality, utility, and clarity of the information being collected.

The pre-waitlist data collection will involve the gathering of referral and evaluation event data. Collectively, these two components will require an additional fifty-nine (59) data points, although some of this information is already captured on the transplant candidate registration form. However, the utility of this data in reducing disparities in access to transplantation appears to be misguided. The responsibility for referring patients for transplant services rests with referring physicians and dialysis centers, not transplant centers. Consequently, transplant centers have limited influence over who is referred and when, raising concerns about their accountability for the referral event data collection and

the accuracy of the information gathered. Furthermore, the sensitive nature of the information collected during the referral process is typically shared by patients only when necessary, such as at the time of listing. Requesting such private information prior to establishing a relationship with the patient could be perceived as intrusive, potentially undermining trust and contradicting the goal of reducing barriers to transplantation.

The additional workload created by the proposed data collection could place further strain on an already overburdened system, potentially proving counterproductive. The estimated time burden assumes that the necessary information is readily available, without accounting for the increasing volume of transplant cases. The proposed data collection process could delay or discourage access to transplant services by adding an extra layer of work upstream. While data collection throughout the transplant process is encouraged and supported, exploring opportunities within our community partners, electronic health record systems, and third-party technologies may provide a more sustainable and effective approach to achieving this goal.

The proposed data collection may inadvertently hinder the achievement of key goals, such as increasing access to transplantation, maximizing the number of organs transplanted, and reducing the non-use of available organs. The transplant community is well aware of the disparities in transplantation, which exist across geographic regions, ethnic groups, and socioeconomic statuses. These disparities are largely driven by factors such as limited resources, healthcare literacy, insurance coverage, and social vulnerabilities. Addressing inequities in transplantation must start with foundational programs focused on chronic disease management and education for both community healthcare providers and patients. Additionally, fostering dialogue and enacting changes within the insurance sector to improve transplant coverage is essential for reducing disparities nationwide.

We appreciate the opportunity to provide feedback, and would welcome future opportunities to collaborate with HRSA, CMS, and others toward the shared goal of improving care within the transplant community and for those that depend on it. If you have any questions, please contact us at 602-406-8000.

Thank you.

Sincerely,



Rajat Walia, MD, FCCP
OPTN Representative
Section Chief, Pulmonary Medicine
Medical Director, Lung Transplant
Norton Thoracic Institute
St. Joseph's Hospital & Medical Center