

**From:** [Alvarez RN, Kara](#)  
**To:** [HRSA Paperwork](#)  
**Subject:** [EXTERNAL] RE: Comment: Information Collection Request Title: Process Data for Organ Procurement and Transplantation Network, OMB No. 0906-xxxx—New  
**Date:** Tuesday, January 7, 2025 3:15:30 PM

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**From:** Alvarez RN, Kara  
**Sent:** Monday, December 23, 2024 3:11 PM  
**To:** paperwork@hrsa.gov  
**Subject:** Comment: Information Collection Request Title: Process Data for Organ Procurement and Transplantation Network, OMB No. 0906-xxxx—New

Good afternoon,

We appreciate HRSA's initiative to enhance the data collection regarding patients referred for organ transplant prior to their listing. These efforts are critical to improving transplant system efficiency and equity. However, we believe several concerns could be addressed to ensure the success and utility of the data collection:

1. There is a need for clear and consistent definitions of key data points. For example, "Referral Date," does this indicate the date the patient was referred from an outside provider to the transplant program regardless of reason? Or is this the date that the patient was referred for a transplant evaluation? Another unclear term, "Referral Closure Reason," is a referral considered closed if the patient is not a transplant candidate but continues to be a patient of the Transplant Center's disease management or specialty clinics? It also should be clarified if the intent is to capture outpatient community referrals only or if this will also include inpatient consults to the transplant providers. Standardizing these definitions across all programs is essential to ensure the data collected is consistent, comparable, and meaningful.
2. The proposed data collection focuses on patients referred for transplant evaluation, but many transplant centers also manage patients in specialty clinics for advance diseases or organ specific conditions who may never be listed as transplant candidates or are not a candidate at the time of the referral. Many of these patients who otherwise may not be transplant candidates are managed in these clinics in an attempt to optimize them for transplant. Our Transplant Center serves as a resource to our community where patients can receive specialized care, regardless of if they are a transplant candidate or not. The number of referrals to these clinics would

create a large burden on these types of programs, our center alone has received 4386 outpatient referrals and 2496 inpatient consults year to date.

3. We also ask that due to the volume of referrals and evaluations, the data is batch reported on a set cadence.

Thank you for the opportunity to provide feedback on this important initiative.

**Kara Alvarez, RN, BSN, CCTC**

AdventHealth Orlando

Transplant Data & Outcomes Nurse Manager| Transplant Institute

O: 407-303-2474

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