

From: [Cyr, Pamela](#)
To: [HRSA Paperwork](#)
Subject: [EXTERNAL] Public Comment: Agency Information Collection Activities
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Attachments: [image002.png](#)

Eliminating barriers to transplantation is among the most important topics in our field, and long overdue. It is something that our team considers hundreds of times per year as we make difficult candidacy decisions, and hundreds more times as we work to collaborate with referring providers and the general community. The collection of pre-waitlisting data does serve a function in determining glaring themes in barriers to transplantation candidacy, patient-related, system-related, and center-related themes and barriers to transplantation. It does not, however, capture the harm that occurs upstream, long before patients reach the referral stage for transplant. It is frequently the upstream barriers that have compounded by the time a patient reaches the point of referral for an organ transplant.

To fully capture the whole picture of equity/disparities in access to transplantation, one would have to have real-time state- or nation-wide chronic kidney disease, heart failure, cirrhosis, etc. registries that would help better portray the overall incidence of organ failure and referral to specialist practices in the community. Transplant programs are really only a piece of this puzzle. That is not to say we should not endeavor to eliminate as many barriers as we can, but that real and lasting equity in access to transplant will only come from collaboration between transplant centers, community providers, and agencies that are able to provide transportation and social supports to patients who lack those resources.

The estimated burden as laid out in the notice is significantly lower than the actual burden would be to complete the additional OPTN forms should they mirror a similar data collection process other OPTN forms require. I would suggest another secure method of collecting this information in quarterly or biannually in batches of information. The time it requires to completely and accurately fill out OPTN TIEDI forms is already a barely manageable task for our current staff, and this is including the use of Application Programming Interface (API) between our electronic health record and the UNet website.

I would recommend that prior to going live with any required data collection, HRSA engage transplant center and OPO information security and electronic health record teams to get an automated process for data extraction in place. This has the potential to be a model for other similar clinical inquiries in the future if done well.

Thank you for your consideration.

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