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To: [HRSA Paperwork](#)
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Subject: [EXTERNAL] HRSA data directive published for comment
Date: Friday, January 3, 2025 9:16:16 AM

This E-mail is my comment as an affected member of the public on Published Document: 2024-25522 (89 FR 87592), proposed by HRSA on 4 November 2024 regarding additional data collection by the OPTN.

Transplant programs must work to eliminate barriers to transplant. Addressing obstacles, collaborating with referring providers, and assessing patient overall health is done daily as transplant centers educate their patients and community, evaluate new patients, and have multidisciplinary team discussions related to care and candidacy. The collection of pre-waitlisting data does serve a function in determining patient-related, system-related, and center-related themes regarding the barriers to transplantation candidacy. It does not, however, capture issues that occur upstream, long before patients reach the referral stage for transplant. It is frequently these complications that compound into significant health care issues before any referral for organ transplant.

Transplant programs are one piece of a complex patient care puzzle. To fully capture the whole picture of equity/disparities in access to transplantation, one would have to have real-time state- or nation-wide registries for all chronic diseases (ESRD, COPD, CAD, ELSD) that would help better portray the overall incidence of organ failure and assess the timely referrals to specialized providers. Transplant programs cannot bear the burden of reporting and caring for patients who are not referred in timely fashion and those who have not had the primary care support of ongoing health maintenance.

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. Neither the cost nor the responsibility of the care for patients outside of transplant should be applied to transplant programs.

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. Time estimates are based on a document that indicates that many patient referral data information “cascades from the waitlist”. However, this will only address the patient who moves to waitlist. The HRSA announcement states that “data collection from the point of referral” to “provide insight into who gets referred and by whom, who gets evaluated, and who gets placed on the organ transplant waiting list”. This indicates that ALL referrals must be data collected, a much larger number than previously suggested. This alone guarantees a significant difference in work time needed. The transplant programs

tasked to ensure complete, accurate, and timely OPTN TIEDI forms. The current process is time consuming even when making use of Application Programming Interface (API) interfaces for data upload.

While the intentions of HRSA in putting this forward are good, the transplant community would like to endeavor to work together on more appropriate efforts regarding future policy. The Paperwork Reduction Act contains explicit requirements for the government both to justify the specific purpose of proposed new burden, and to take steps (including the use of technology) to minimize that burden where possible. It is our opinion that this submission fails on both counts, and as such must be withdrawn by HRSA or denied by OMB.

The HHS OIG data previously requested already should be published and discussed first. Only after this is complete then should further data collection be proposed. If and when it is, it should adhere to minimum necessary burden requirements, which would in this case be achieved by periodic report submission rather than patient-by-patient form-filling.

We thank you for your time and attention to this matter,

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