From: <u>Katie Dokus</u>
To: <u>HRSA Paperwork</u>

Subject: [EXTERNAL] Comment on Information Collection Request Title: Process Data for Organ Procurement and

Transplantation Network, OMB No. 0906-xxxx-New

**Date:** Friday, January 3, 2025 4:30:38 PM

Dear Deputy Director, Executive Secretariat McNaulty,

Please find below my comments on Information Collection Request Title: Process Data for Organ Procurement and Transplantation Network, OMB No. 0906–xxxx—New. This comment is submitted on behalf of myself as a career transplant professional, not on behalf of any institution or organization.

Eliminating disparities in access to transplantation is paramount; it is something that our team considers daily as we make difficult candidacy decisions and assist transplant patients in addressing social determinants of health. We support national efforts to improve systemic inequities. The proposal refers to facilitating the OPTN's ability to address disparities in processes of care and improving access without a plan for how this may be accomplished. The uncertainty of how the data will be used is concerning from a center perspective and likely to referred patients whose private information (including social security number) we would be required to submit.

The OIG compelled transplant centers to submit similar information on kidney patients less than a year ago. Before any further data collection is required, the OIG study results should be shared as well as the anticipated use of collected data to justify the considerable public burden being suggested here.

The method of collection proposed is unnecessarily burdensome on transplant centers. Validation of individual forms is cumbersome, as reflected in the burden hours. Our center would need to hire a part time data analyst just to complete these forms as proposed. This could be eased by removing the request to submit hundreds of thousands of individual forms and replacing it with regular submission (ex. semiannually) of a single spreadsheet with standardized data fields. This method was used by the OIG in its recent request to look at related data.

Form specific feedback: Candidacy decisions are rarely unifactorial; programs should have the option to select more than one reason for referral or evaluation closure. Phone number is not collected on candidate and recipient forms now, it is unclear why this should be added. Secondary insurance is also not currently collected and would be an appropriate addition to the TRR form.

Thank you, Katie Dokus

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