



American Society of Pediatric Nephrology

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January 3, 2025

Carole Johnson
Administrator
Health Resources and Services Administration
5600 Fishers Lane
Rockville, MD 20857
Submitted electronically to paperwork@hrsa.gov

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

Dear Administrator Johnson:

The American Society of Pediatric Nephrology (ASPN) appreciates the opportunity to comment on the Information Collection Request related to Process Data for Organ Procurement and Transplantation Network. Founded in 1969, ASPN is a professional society composed of pediatric nephrologists whose goal is to promote optimal care for children with kidney disease and to disseminate advances in the clinical practice and basic science of pediatric nephrology. ASPN currently has over 700 members, making it the primary representative of the Pediatric Nephrology community in North America.

Due to the significant advantages of transplantation over dialysis in a child, dialysis is a bridge to transplant for the vast majority of children with end-stage renal disease (ESRD), and transplant referral is critical for optimal pediatric ESRD care. Efforts to strengthen the accountability and transparency of the transplant system have the potential to improve the health of this vulnerable patient population.

ASPN believes that the collection of pre-waitlisting data is critical to improving access to kidney transplantation and we support the concept; however, we request that HRSA disclose the proposed form contents so that we can more accurately address whether the proposed additional data collection is appropriate, adequate, and not overly burdensome. We also recommend that HRSA collect information about the medical severity at the time of referral, in addition to demographic information. If only demographic information is collected, it will be impossible to identify disparities in timing of and access to referral for transplant.

Thank you again for the opportunity to provide comments on this information collection request. We look forward to continuing to work with HRSA to ensure that the needs of pediatric patients and their families are considered during this process. Please reach out to Stefanie Rinehart, ASPN's Washington representative, at srinehart@dc-crd.com with any questions.

Sincerely,

Meredith Atkinson