



Pediatric Transplant Center

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1/2/2025

RE: Agency Information Collection Activities: Proposed Collection: Public Comment Request; Information Collection Request Title: Process Data for Organ Procurement and Transplantation Network

To Whom it May Concern,

Our multidisciplinary Pediatric Transplant Center at Boston Children's Hospital (BCH) appreciates the opportunity to provide our collective commentary with regards to the HRSA directive for the OPTN to collect additional data on patients prior to waitlist registration.

As a comprehensive Pediatric Transplant Center supporting heart, lung, kidney, liver, and intestine transplant, providing equitable access to high quality transplant care is at the forefront of everything we do. Much like our transplant colleagues nationally, our team has various methodologies and metrics for assessing our ability to optimize access to transplant. Leveraging our medical record system (Epic), our teams have been able to capture a multitude of data points starting at the time of referral for any patient who is referred to any of our transplant programs. Collecting this level of data is integral to understanding how we are performing, not only as an individual transplant center but also as a transplant system. Our team here at BCH is in alignment that there certainly is value in collecting this information in a standardized fashion, starting at the time of referral, across all transplant centers.

With this said, our Center has some concerns and outstanding questions about this additional data collection request that we feel prudent to bring forward to HRSA for consideration.

- **Clear Operational Definitions:** The term "referral" for transplant can vary from program to program and center to center. HRSA will need to provide a very clear operational definition as to what qualifies as a referral for transplant. The current entry point for a patient into UNet comes at the time that they are added to the waitlist. This is a very clear, objective, and standard point in time. Time of referral for transplant seems to be much more subjective and could lend itself to inconsistencies. How does the HRSA plan to account for this?
- **Generation of Downstream Metrics:** As with other data elements that are collected on UNOS forms, we anticipate that these new referral and evaluation data points will at some point result in new program metrics. It is unclear to our team how these newly proposed data elements will ultimately be used to evaluate program performance and secondarily how those metrics will be leveraged by the OPTN or otherwise. Currently, many data elements that are entered into UNOS forms are reported publicly on the bi-annual SRTR reports. More transparency as to how this data will be leveraged and reported would be helpful in understanding the overarching intent of this proposal. Additionally, it is important to further understand how this information will be stratified and evaluated for specific populations such as pediatrics. To advance the care of children it is critically important that pediatric-appropriate measures are collected and evaluated against appropriate comparative groups.
- **Evaluating Access to Transplant Care:** To fully capture equitable access to transplant care one needs to first evaluate the overall incidence of organ failure using chronic kidney disease, heart failure, cirrhosis, etc. registries. Transplant programs are one piece of this puzzle and can only manage the referrals when they are

made. Consistent education of the referring provider community for timely and appropriate transplant referral would be an additional step in optimizing equitable access to transplant care. In some cases, referring providers might have the medical misunderstanding when to refer for transplant and for what indications. If metrics will be developed, based on this data directive, to assess access to transplant care and patient flow through the transplant process, there should be clear guidance on where accountability should be placed.

- **Documentation Efficiency:** Transplant centers across the country are already collecting many (if not all) data elements that HRSA is requesting centrally using their electronic medical record. The request to additionally report this level of data through UNet will result in an additional administrative burden to every transplant program, which our team feels has been underestimated in this proposal. We encourage HRSA to consider how this data can be captured in the most efficient manner possible and to leverage existing systems to minimize the necessity for double documentation.

Nationally, transplant programs face financial and resource limitations. If not initiated in a manner which fully accounts for the current workload of the care teams, this proposal may inadvertently impact the ability for teams to promote access to transplant care at the center of what they do.

Again, we appreciate the opportunity to provide comment on this proposal. We feel that there is value in standardizing this type of data capture but believe further information and consideration is required to truly be able to move forward with this proposal.

Thank you,

A handwritten signature in black ink, appearing to read 'HBK' with a stylized flourish at the end.

Heung Bae Kim, MD
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Boston Children's Hospital

CC. Josh Greenberg, JD
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