



September 19, 2023

**OPTN Summer Comment Period: Concepts for a Collaborative Approach to Living Donor Data Collection**

The National Kidney Foundation (NKF) applauds the Living Donation Committee for its concept paper, *Concepts for a Collaborative Approach to Living Donor Data Collection*, and appreciates the opportunity to provide commentary.

NKF supports the collaboration and alignment of the Organ Procurement and Transplantation Network (OPTN) and the Scientific Registry of Transplant Recipients (SRTR) to streamline efforts to study the long-term impact of living donation beyond kidney failure and death to encompass economic, physical, and psychosocial well-being. These data are lacking, especially sociodemographic data, and are integral to the informed decision-making process for individuals considering becoming a living donor. We further support lifetime follow-up to examine the long-term risks and benefits of living donation and the collection of donation decision data to assess why patients choose or decline to become living donors. However, the decision to donate (or not) should be maintained confidential, and additional safeguards should be added to share this information only as needed.

Adding all living donor candidates to the OPTN collection requirements would allow the evaluation of the donation process for efficiency as well as areas for improvement with respect to equity. The current state of living donation data collection and reporting occurs at 6-, 12-, and 24 months post-donation, and OPTN, in partnership with SRTR, should continue to strive for short-term follow-up at a regular cadence while also endeavoring to stay engaged with living donors long-term. Creating advisory groups with living donors is a step in the right direction to ensure their voices are prioritized in this initiative as OPTN and SRTR discern how it will foster long-term living donor engagement. In addition, as OPTN and SRTR strategize how to operationalize this endeavor, we urge both entities to leverage innovation and technology for data collection and reporting to mitigate additional administrative burdens for transplant centers.

NKF appreciates the Living Donor Committee for its attention to the importance of studying the long-term outcomes of living donors. Please contact Morgan Reid, Director of Transplant Policy and Strategy, at [Morgan.Reid@kidney.org](mailto:Morgan.Reid@kidney.org) if we can support this endeavor further.

Sincerely,

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CEO and Transplant Patient

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