

May 22, 2019

Seema Verma
Administrator,
Centers for Medicare and Medicaid Services
Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Dear Administrator Verma:

On behalf of the American Society of Nephrology (ASN), thank you and your fellow leaders within the U.S. Department of Health and Human Services (HHS), and the Centers for Medicare and Medicaid Services (CMS), for the department-wide focus on a kidney strategy to “deliver much better care, and longer lives, for Americans with kidney disease.”ⁱ ASN represents more than 20,000 physicians, scientists, nurses, and other health professionals dedicated to treating and studying kidney diseases to improve the lives of people with kidney diseases. The society commends these efforts and stands ready to support your work on behalf of the more than 40 million Americans with kidney diseases.

As you know, the current situation for those waiting for a kidney transplant is bleak: there are currently 95,000 people on the waiting list for a kidney transplant in the United States, and, in 2018 alone, more than 8,200 people on the waiting list died or were removed from the waiting list because they became too sick to receive a transplant.ⁱⁱ Recently, the ASN leadership and I lauded Secretary Azar’s pledge to “deliver more organs for transplants.”ⁱⁱⁱ ASN believes that delivering on this pledge will require objective data and clear accountability for organ procurement organizations (OPOs), which hold a critical position on the front line of organ donation.

OPOs are currently evaluated using metrics that are not considered objective or verifiable, because the denominator is based on self-reported data. The OPOs themselves have acknowledged that this approach is problematic and stated such to the Office of Management and Budget when the metrics were originally opposed.^{iv}

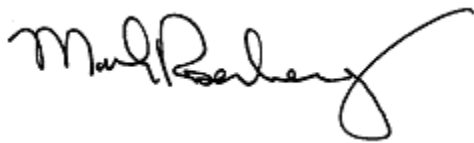
ASN respectfully recommends that you change the metrics by which OPOs are evaluated to *actual deceased donors as a percentage of in-hospital deaths among patients 75 years of age or younger with a cause of death consistent with organ donation*. The data for this metric are already available from the Detailed Mortality File of the Centers for Disease Control (CDC). This measure was one of several that was thoroughly examined in “Changing Metrics of Organ Procurement Organization

Performance in Order to Increase Organ Donation Rates in the United States” in the *American Journal of Transplantation*, July 2017,^v and was found to be a significant improvement over the current eligible death metric and can be easily implemented without requirements for the collection of new data.

Reforming OPO metrics in this way will serve multiple purposes. First, it reduces regulatory burden by using existing data. Second, it drives meaningful increases in our deceased donation system by improving our understanding of OPO performance through the use of objective data and a consistent standard for the denominator. That objective is accomplished by using existing data to enable us to identify best practices and opportunities for improvement in organ procurement efforts—critical to enabling more patients to receive a kidney transplant. This proposed change could improve outcomes for patients and their families while also reducing burden on health care providers, aligning OPO metrics with the Meaningful Measures Initiative on a fundamental level.

ASN stands ready to assist HHS in this important effort in any way possible. If you have any questions, please do not hesitate to contact Rachel Meyer, ASN Director of Policy and Government Affairs, at rmeyer@asn-online.org or (202) 640-4659.

Thank you,

A handwritten signature in black ink, appearing to read "Mark Rosenberg". The signature is fluid and cursive, with a long, sweeping tail on the final letter.

Mark E. Rosenberg, MD, FASN
President

ⁱ <https://www.hhs.gov/about/leadership/secretary/speeches/2019-speeches/remarks-to-the-national-kidney-foundation.html>

ⁱⁱ <https://optn.transplant.hrsa.gov/data/view-data-reports/national-data/>

ⁱⁱⁱ <https://www.hhs.gov/about/leadership/secretary/speeches/2019-speeches/remarks-to-the-national-kidney-foundation.html>

^{iv} https://obamawhitehouse.archives.gov/sites/default/files/omb/assets/oira_0938/0938_10292013b-1.pdf

^v Goldberg D, Kallan MJ, Fu L, et al. Changing Metrics of Organ Procurement Organization Performance in Order to Increase Organ Donation Rates in the United States. *Am. J. Transplant.* 2017;17(12):3183-3192