



The Honorable Mehmet C. Oz, M.D.
Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Re: Request to Reinstate Race and Ethnicity Data Collection through the ESRD Quality Reporting System (EQRS)

Dear Administrator Oz:

On behalf of The National Kidney Foundation (NKF), the American Society of Nephrology (ASN), and the American Nephrology Nurses Association (ANNA), we are writing to express deep concern regarding CMS's recent decision to remove race and ethnicity questions from Form CMS-2728, the End-Stage Renal Disease (ESRD) Medical Evidence Report. We respectfully urge the Centers for Medicare and Medicaid Services (CMS) to reverse this change and restore these essential demographic fields. Accurate, deidentified demographic data support research, quality improvement, and policy interventions that benefit all people with kidney disease.

Home dialysis and kidney transplant offer Americans a better quality of life and are less costly for the American taxpayer than in center hemodialysis. Increasing access to these treatments for Americans with kidney failure is essential to achieve the promise of the President's Advancing American Kidney Health Initiative Executive Order.

Understanding and Addressing Differences in Health Outcomes

Race and ethnicity data are critical for identifying and targeting differences in kidney disease incidence, access to care, and outcomes. For example, Black Americans are nearly four times more likely to develop ESRD than White Americans, and Hispanic and Native American populations also have disproportionately high rates of incidence,¹ facts we would not know without collection of race and ethnicity data from Form 2728. Without race and ethnicity data we would not know that in 2022, Black and Hispanic people with kidney failure who were under age 65 were less likely to start dialysis at home or to be waitlisted for or to get a transplant regardless of their insurance.¹ Without routine collection of race and ethnicity data, efforts to monitor these and other trends, evaluate interventions, and allocate resources fairly will be severely compromised.

Impact on the U.S. Renal Data System and NIH Research

¹ United States Renal Data System. 2024 *USRDS Annual Data Report: Epidemiology of kidney disease in the United States*. Health Disparities. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2024.



Form CMS-2728 provides data for the U.S. Renal Data System (USRDS), a key national surveillance resource National Institutes of Health (NIH) and CMS. The removal of race and ethnicity fields will undermine the ability of the USRDS to conduct demographic analyses about kidney disease. This loss would hinder public health research, health services planning, and the design of targeted interventions to improve kidney health outcomes for all Americans.

Recommended Next Steps

We respectfully request that CMS:

- 1) Reinstate self-reported race and ethnicity questions on Form CMS-2728;
- 2) Launch a stakeholder engagement process—bringing together patient advocates, clinicians, data scientists, and health equity experts—to guide appropriate data collection, use and safeguards.
- 3) Incorporate any future modifications to the Form CMS-2728 through a transparent public comment process and impact assessment.

Restoring these data fields will strengthen CMS's ability to fulfill its mission of prioritizing evidence-based care. We are prepared to assist CMS in this effort, including participation in stakeholder discussions to craft best practices for demographic data collection and use.

Thank you for your leadership and consideration. We look forward to collaborating to ensure that CMS data collection supports measurable progress toward improved outcomes in kidney care for all Americans, as President Trump's Executive Order sought to achieve.

Respectfully submitted,

A handwritten signature in black ink, appearing to read "K Campbell".

Kirk Campbell, MD,
President, National Kidney Foundation

A handwritten signature in black ink, appearing to read "Prabir Roy-Chaudhury".

Prabir Roy-Chaudhury, MD, PhD, FASN,
President, American Society of Nephrology

A handwritten signature in black ink, appearing to read "Kevin Longino".

Kevin Longino, CEO, National Kidney
Foundation

A handwritten signature in black ink, appearing to read "Tod Ibrahim".

Tod Ibrahim, Executive Vice President,
American Society of Nephrology



A handwritten signature in black ink that reads "Faith Lynch".

Faith Lynch, DNP, RN, CNN, NEA-BC, AMB-BC,
FANNA, American Nephrology Nurses
Association (ANNA)
National President

A handwritten signature in black ink that reads "Michele Kimball".

Michele Kimball, Executive Director, ANNA

