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Shalanda Young
Acting Director
The Office of Management and Budget
725 17th Street NW
Washington, DC 20503

RE: Office of Management and Budget Request for Information: Methods and Leading Practices for Advancing Equity and Support for Underserved Communities Through Government

Dear Acting Director Young:

The American Kidney Fund appreciates the opportunity to provide comments on the Office of Management and Budget's (OMB) Request for Information (RFI) on "Methods and Leading Practices for Advancing Equity and Support for Underserved Communities Through Government."

The American Kidney Fund (AKF) fights kidney disease on all fronts as the nation's leading kidney nonprofit. AKF works on behalf of the 37 million Americans living with kidney disease, and the millions more at risk, with an unmatched scope of programs that support people wherever they are in their fight against kidney disease—from prevention through transplant. Through programs of prevention, early detection, financial support, disease management, clinical research, innovation and advocacy, no kidney organization impacts more lives than AKF. AKF is one of the nation's top-rated nonprofits, investing 97 cents of every donated dollar in programs, and holds the highest 4-Star rating from Charity Navigator and the Platinum Seal of Transparency from GuideStar.

AKF commends the Administration for its focus on the entrenched disparities in our laws and public policies and, as Executive Order 13985 states, "[pursuing] a comprehensive approach to advancing equity for all, including people of color and others who have been historically underserved, marginalized, and adversely affected by persistent poverty and inequality." In our response to certain topic areas in the RFI, we will focus specifically on issues related to health equity.

Topic Area 1: Equity Assessments and Strategies

The importance of data in achieving equity

In this topic area, AKF focuses our comments on OMB's question:

How might agencies collect data and build evidence in appropriate and protected ways to reflect underserved individuals and communities and support greater attention to equity in future policymaking?

The COVID-19 pandemic put into sharp focus the importance of timely and accurate data collection and reporting in health care, especially during a public health emergency. The available data has shown the disproportionate impact of COVID-19 on minority populations and underserved communities. Having this data allows officials to direct additional resources to populations that need it the most to address disparities in health outcomes. However, during the pandemic we have seen significant gaps in the data, particularly with the timeliness, consistency, and comprehensiveness of demographic data.

We applaud the commitment of federal agencies to improve and modernize the public health data infrastructure, such as the Centers for Disease Control and Prevention's (CDC) Data Modernization Initiative. We also commend Congress for passing legislation that invests needed funding to modernize public health data and analytics infrastructure to address the fragmented and outdated public health data systems at the state, local, tribal, and territorial level. As federal agencies continue this critical work towards an improved data infrastructure, we want to stress the importance of setting federal standards for the collection and use of data. Setting common standards and practices will help ensure data is consistent and comprehensive, particularly data such as demographic information that is essential to understanding disparities that impact underserved individuals and communities.

Topic Area 2: Barrier and Burden Reduction

Addressing beneficiary barriers in federal programs

People with kidney failure, also known as end-stage renal disease (ESRD), may be eligible for multiple federal programs and benefits, including Medicare, Social Security Disability Insurance, and Supplemental Security Income. Many people with kidney failure have comorbidities and are more likely to experience poor health outcomes. For disability beneficiaries with ESRD, they are likely to be sicker and poorer than disability beneficiaries without ESRD, with higher rates of multiple chronic conditions, hospital readmission, and poverty.¹ Additionally, kidney failure

¹ Data shows that 54.2 percent of those with disabilities and ESRD had six or more chronic conditions compared to 20.5 percent for those with disabilities and without ESRD. Among hospitalized beneficiaries, those with disabilities and ESRD had a hospital readmission rate of 33.8 percent, compared to 17.3 percent for those with disabilities and

disproportionally affects people of color. Black people make up just 13% of the U.S. population, but they account for 35% of Americans with kidney failure and are 3.4 times more likely to develop kidney failure than white Americans. Hispanic Americans are 1.6 times more likely than non-Hispanics to develop kidney failure, and Native Americans are 1.2 times more likely than white Americans to develop kidney failure.

These factors contribute to barriers people with ESRD may face in navigating the process to learn about and apply for government programs and benefits. As mentioned in the RFI, these barriers may include limited proficiency in English, disability, low literacy, income or other resource constraints, limited access to technology, non-traditional or inflexible work hours, and housing insecurity.

To help address these barriers faced by underserved communities, federal agencies should ensure information about programs and the application process are presented in a culturally competent way. To achieve this, it may be helpful for agencies to work with trusted community organizations that work with and represent underserved populations. Collaborating with these community partners can ensure communication regarding federal programs and benefits are effective and clear to specific audiences. Collaboration could also provide an opportunity for federal agencies to learn about administrative burdens and barriers faced by underserved populations, which could help inform agency policies that try to balance program uptake and program integrity.

Addressing barriers to home dialysis and transplantation

Another barrier that individuals with ESRD, especially people from communities of color, is access to home dialysis and transplantation. Home dialysis has traditionally seen low rates of utilization in the United States, with 12.5% of all dialysis patients using home dialysis in 2018.² With studies showing that home dialysis for certain patients can lead to better health outcomes,³ there is clearly an opportunity and a need to increase its utilization, and AKF has been supportive of federal efforts to do so. Increasing access to home dialysis is particularly important for minority populations, who see disproportionately lower rates of its use. For example, 58% of all dialysis patients (both in-center and home dialysis) in 2018 were White, 33% were Black, and 19% were Hispanic.⁴ However, 66% of peritoneal dialysis (PD) patients were White, 24% were Black, and

without ESRD. A higher percentage of beneficiaries with disabilities and ESRD live in high poverty (37.5 percent), compared to 28.8 percent for beneficiaries with disabilities and without ESRD.

<https://www.cms.gov/About-CMS/Agency-Information/OMH/Downloads/Data-Highlight-Volume9-ESRD.pdf>

² United States Renal Data System, Annual Data Report, 2020. Volume 2, Chapter 1, Incidence, Prevalence, Patient Characteristics, and Treatment Modalities: <https://adr.usrds.org/2020/end-stage-renal-disease/1-incidence-prevalence-patient-characteristics-and-treatment-modalities>

³ Rivara, M. B., & Mehrotra, R. (2014). The changing landscape of home dialysis in the United States. *Current opinion in nephrology and hypertension*, 23(6), 586–591. doi:10.1097/MNH.0000000000000066

⁴ United States Renal Data System (USRDS): <https://usrds.org/data-query-tools/esrd-prevalent-count/>

16% were Hispanic.⁵ For home hemodialysis (HHD), 63% of HHD patients were White, 33% were Black, and 10% were Hispanic.⁶ A study has also found that Blacks and Hispanics were 30% and 19% less likely, respectively, than Whites to start on PD.⁷ Additionally, the study found minority groups (particularly Hispanic and Asian patients) were 7% to 35% less likely to initiate HHD compared with White patients, though the difference for Black patients was not statistically significant.⁸ For these disparities in home dialysis initiation, the study found socioeconomic factors played a significant role.⁹ Another study examining the reasons why patients start but then exit from a HHD program found that the primary reasons included lack of caregiver support and housing insecurity due to losing a home or being evicted.¹⁰

For transplantation, data has also shown that individuals from communities of color have lower rates of kidney transplantation. Kidney transplant is considered the best treatment option for most people with kidney failure because it increases a patient's chances of living a longer, healthier life. There are nearly 108,000 Americans on the organ transplant waiting list, with 93,000 of them—86%—waiting for a kidney. In 2020 45% of all kidney transplant recipients in the U.S. were White, 27% were Black, and 18% were Hispanic.¹¹

While there are various policy tools that could be used to address the low rate of home dialysis and transplantation in communities of color, one we want to highlight in this letter is expanding the use of the Medicare Kidney Disease Education (KDE) benefit. The KDE benefit provides for six 1-hour sessions of kidney disease education that address the choice of treatment (such as in-center dialysis, home dialysis, or kidney transplant), the management of comorbidities, and other topics. However, the percentage of eligible beneficiaries who have been provided the KDE benefit is less than two percent. We urge the Centers for Medicare and Medicaid Services (CMS) and Congress to work together to expand the use of this benefit so that it is available to more beneficiaries, such as those with stage 5 chronic kidney disease (CKD), and to expand the types of providers who can provide it. While we support CMS granting these KDE flexibilities within the ESRD Treatment Choices (ETC) Model, we believe it should be implemented throughout the Medicare program. In talking to ESRD patients, AKF has heard numerous accounts where patients were not adequately educated on their treatment options, and were not aware that home dialysis or a preemptive transplant might be a good option for them until they researched it themselves or went to a different clinician. Given the importance of patient education in

⁵ Ibid.

⁶ United States Renal Data System, Annual Data Report, 2020. Volume 2, Chapter 1, Incidence, Prevalence, Patient Characteristics, and Treatment Modalities: <https://adr.usrds.org/2020/end-stage-renal-disease/1-incidence-prevalence-patient-characteristics-and-treatment-modalities>

⁷ Shen, Jenni I. et al. Socioeconomic Factors and Racial and Ethnic Differences in the Initiation of Home Dialysis, *Kidney Med.* 2(2):105-115. Published online February 11, 2020. DOI: <https://doi.org/10.1016/j.xkme.2019.11.006>

⁸ Ibid.

⁹ Ibid.

¹⁰ Paterson B, Fox DE, Lee CH, et al. Understanding Home Hemodialysis Patient Attrition: A Cohort Study. *Canadian Journal of Kidney Health and Disease.* January 2021. doi:10.1177/20543581211022195

¹¹ Data from Organ Procurement and Transplantation Network: <https://optn.transplant.hrsa.gov/data/view-data-reports/national-data/#>

empowering patients to make the right modality choice for them, eliminating barriers to the KDE benefit is an important step in increasing the rate of home dialysis and transplantation, especially in minority populations.

Another policy tool that we urge Congress and CMS to support is including kidney disease screening in the “Welcome to Medicare” preventive visit. For many patients with kidney failure, they were not aware of their CKD until they “crashed” into dialysis. Because a person with CKD usually does not have any symptoms until their kidneys are badly damaged, having access to a kidney disease screening is critical for early detection. By detecting their CKD earlier on in the process, patients and their providers can work together on ways to slow the progression and discuss treatment modalities, including preemptive transplantation.

Topic Area 4: Financial Assistance

Ensuring patient access to charitable premium assistance

OMB seeks input on approaches and methods for assessing equity in the administration of grant programs and other forms of financial assistance run by federal agencies. However, AKF would like to take this opportunity to provide comments on ensuring equity for AKF’s federally recognized financial assistance program for people with ESRD, the Health Insurance Premium Program (HIPP). AKF’s HIPP is governed by Advisory Opinion (AO) 97-1, which was issued by the HHS Inspector General in 1997. HIPP is a charitable premium assistance program that assists 75,000 low-income or financially struggling people on dialysis or with a recent kidney transplant pay for their health insurance premiums.

HIPP pays for all types of insurance, including Medicare Part B, Medigap, Medicare Advantage, employer group health plans, COBRA and Affordable Care Act (ACA) Marketplace plans. As most dialysis patients are eligible for Medicare due to their ESRD status, over 69% of the premiums we pay are for Medigap plans, Medicare Part B and Medicare Advantage. About 21% are employer-sponsored plans and COBRA, less than 3% are for ACA Marketplace plans and the remaining 7% are primarily for off-exchange plans. It is important to note that Medicare alone—without supplemental coverage—can be unaffordable for most patients. Medicare does not have an out-of-pocket cap, and dialysis patients can face out-of-pocket costs upwards of \$10,000 per year. At the same time, over 80% of ESRD patients on dialysis are unable to work because of the burdens of the disease and because they must receive required dialysis treatments at least three times per week.

As described in our comments on Topic Area 2, above, kidney disease disproportionately affects people of color. Because Black Americans and Hispanics are more likely to have their kidney disease progress to kidney failure, over 60% of AKF HIPP grant recipients are individuals from communities of color: 34% are Black, 22% are Hispanic, and almost 6% are Asian, Pacific Islander, Alaskan Native or Native American.

Health insurers have taken steps to make it difficult for dialysis patients to accept assistance from AKF by rejecting direct payments, or by requiring patients to sign attestations that they will not accept help from a charity. Driving this policy is the misguided belief that because most ESRD patients are eligible for Medicare, those receiving premium assistance should not have the option of private insurance, especially ACA Marketplace plans. However, the choice of insurance plan is an individual decision based on individual needs. The ACA and Medicare statutes affirm that patients have choice of insurance coverage.

Additionally, Medicare coverage alone is not sufficient for a patient's eligibility on the transplant waiting list, and Medigap insurance is not available in 20 states to kidney failure patients who are under age 65 and who are eligible for Medicare because of their ESRD status. AKF pays for supplemental insurance, usually a Medigap plan, which allows low-income people access to the transplant waiting list. AKF helped 1,615 people—or 7 percent of all the 23,644 Americans who received a kidney transplant in 2020—pay for their insurance and get a life-saving transplant. And of those 1,615 people, 34% were Black and 20% were Hispanic.

Insurance company policies that make it difficult for patients to receive charitable premium assistance disproportionately impact people of color. By implementing these policies, insurers are targeting populations that have historically been marginalized by the health care system and the health insurance industry. It is important to note that if you can afford to pay your own premiums, insurance companies must take your premium payments; it is only if you cannot afford the premiums and rely on a private charity for assistance that an insurance company can discriminate against you.

To advance health equity and protect patients with high-cost chronic conditions, AKF urges HHS to require health insurers to accept financial assistance from nonprofit charities like AKF who operate their programs with certain guardrails that ensure program integrity. AO 97-1 requires strict firewalls and safeguards to protect and ensure patient choice of provider and insurance coverage, providing a safe harbor from federal beneficiary inducement laws. This protocol has set the standard for dozens of similar national charity care programs for more than two decades. Protecting access to financial assistance programs like AKF's HIPP helps advance health equity for low-income people with high-cost chronic conditions who are disproportionately from underserved communities.

Topic Area 5: Stakeholder and Community Engagement

The importance of continued engagement with trusted community partners

Stakeholder and community engagement with underserved communities is essential for federal agencies to better understand the unique challenges of these populations and to advance equity. Beyond the notice and comment process for stakeholders to respond to proposed policies, federal agencies should engage with stakeholders and underserved communities earlier in the policy development process.

To do that, we reiterate our recommendation for federal agencies to work with a wide array of trusted community partners who work closely with and represent underserved communities. Developing relationships with trusted community partners who represent racially, ethnically, linguistically, and geographically diverse populations can help establish a feedback system that federal agencies can utilize in their policy development.

Thank you for the opportunity to provide comments on this RFI. If you have questions on our response or would like to further discuss these issues, please contact Holly Bode, Vice President of Government Affairs, at hbode@kidneyfund.org.

Sincerely,



LaVarne A. Burton
President and CEO