## February 13, 2023

Department of Health and Human Services Centers for Medicare and Medicaid Services Hubert H. Humphrey Building 200 Independence Avenue, SW Washington, DC 20201

Re: Request for Public Comment on CMS-2728 End Stage Renal Disease Medical Evidence Report Medicare Entitlement and/or Patient Registration

## To Whom It May Concern:

We appreciate the opportunity to comment on the revision of the 2728 form. We enthusiastically support the intended changes, and offer some additional suggestions based on our clinical expertise and aspirations to enhance equity and person-centeredness in the care of people with end-stage renal disease.

We believe this is an opportunity to make the 2728 form, which is used both for entitlement and for end-stage renal disease patient registration, more person-centered and inclusive. These are priorities endorsed by the American Society of Nephrology (ASN), National Kidney Foundation (NKF), and the Advancing American Kidney Health (AAKH) Initiative. The data reported on this form is used by clinicians, payers, and researchers to assess the quality and type of care provided to end-stage renal disease beneficiaries. It also collects data for research and policy in this population.

We advocate for two additional questions be added to the 2728 form:

1. Ask whether the patient has engaged in advance care planning (ACP). Kidney failure is a serious illness, and all patients should have the opportunity to discuss their wishes with their healthcare provider. Furthermore, kidney failure is most prevalent among older people, whose goals and priorities are not always evident to healthcare professionals without an individualized conversation. Evidence shows that nephrology clinicians correctly identify the top health outcome priorities of their older people only 35% of the time. ACP is a way to ensure that care aligns with patients' priorities. Within oncology, ACP has been shown to increase high value care. For this reason, the American Society of Nephrology Quality Committee has proposed to include ACP as a quality measure (Quality ID 047) as part of CMS's Optimal Care for Kidney Health MVP. For the 2728 form, we suggest the following addition:

**A.20.h.** Does the patient indicate they have engaged in advance care planning including the documentation of advance directives or the discussion of their goals, values, and preferences for current and future medical treatments with their health care provider? Yes/No

**2.** Assess whether patients have been informed of <u>all</u> treatment options. The 2728 form currently contains questions about patients' understanding of their treatment options, including home dialysis modalities and kidney transplantation. We feel strongly that all patients, and particularly those with advanced age or other serious illnesses besides kidney failure, should be informed of the option of active medical management without dialysis, which is sometimes

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misunderstood as "doing nothing" but is quite the opposite. Medical management involves CKD care to preserve residual kidney function, medications to reduce uremic symptoms, and psychosocial support. Longevity with these measures is usually on the orders of months to years, similar to the prognosis of older and seriously ill patients who initiate dialysis. Assessing whether patients have been informed of all treatment options is essential for informed consent. Capturing this data on the 2728 form could help shape other kidney care policy. We propose the following question:

**A.20.i.** Does the patient indicate they received and understood the option of not starting dialysis at all, also called active medical management without dialysis? Yes/No

We appreciate your consideration of our comments. Should you have any questions, please contact Dr. Samantha Gelfand, Instructor of Medicine, Harvard Medical School via email at <a href="mailto:sgelfand@bwh.harvard.edu">sgelfand@bwh.harvard.edu</a>.

Sincerely,

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