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Renal Standing Committee National Quality Forum 1099 14th Street NW, Suite 500 Washington DC 20005

RE: National Quality Forum Renal Measures

Dear Renal Standing Committee Members,

The National Forum of ESRD Networks ("the Forum") is appreciative for the opportunity to comment on the National Quality Forum ("NQF") on the specific measures evaluated by its Renal Standing Committee. With the input of our Medical Advisory Council (MAC) and Kidney Patient Advisory Council (KPAC), we would respectfully submit our following comments and recommendations:

NQF #2594 Optimal End-Stage Renal Disease (ESRD) Starts:

Members of our KPAC were in favor of supporting this measure but did wish to offer the following comments: "We feel that ALL patients should be considered to be home patients until they are ruled out for some reason. For most patients, it would be most optimal to get a transplant before ever starting dialysis. Unfortunately, few of us currently get that opportunity. The largest percentage of patients should start at home with only the remainder starting in-center as the last choice. We also feel supportive care or conservative management should be taken into consideration. That option of not starting dialysis at all might be optimal for some patients. So, an optimal start is a good thing for patients, but in-center should be used only after other options are exhausted. We also need a shared decision measure to accompany this measure to make sure the patient is included in deciding what is truly optimal for them."

Members of our MAC also felt that a shared decision-making tool would be ideal and should include the family. Oftentimes, patients' decisions are based upon how certain choices will impact, or burden, the family without ever making sure that those who could be impacted are fully informed about the choices (e.g., home dialysis versus in-center dialysis). This view of burden is more likely to be expressed by individuals who are already struggling with limited resources and never given the opportunity to make the most informed decisions with the patient.

Recommendation: In summary, while the Forum sees room for growth and opportunity when it comes to monitoring quality through the Optimal End-Stage Renal Disease Starts measure, we fully support the NQF's decision to endorse this measure.

NQF #3695 Percentage of Prevalent Patients Waitlisted (PPPW):

The Forum did receive a positive comment from its KPAC regarding this measure ("No one should receive credit for anything related to transplant for patients until they have been placed "active" on the waitlist"), members of our MAC were concerned that nephrology practices may not have a lot of control over this measure, given the recent implementation of the "waitlist mortality measure" for transplant centers. This latter measure attributes any mortality for a waitlisted patient towards the transplant center's waitlist mortality for up to 2 years after they have been taken off the list. One unintended consequence of the PPPW could be that small transplant centers will be more cautious about waitlisting patients due to the new transplant mortality measure. Because of this, and other concerns we mentioned back in spring, I do not think NQF should endorse this measure.

<u>Recommendation</u>: Out of concern for how the PPPW could have a negative impact on smaller transplant centers, the Forum would recommend against endorsing the PPPW measure.

NQF #3659 Standardized Fistula Ratio for Incident Patients:

The Forum has long held the belief that the Fistula First focus has led to many patients being poorly served by the nephrology community. We recognize that the AV fistula is an ideal conduit for hemodialysis in most patients, however quality metrics focused on AV fistula creation as a rule have led to many patients suffering through unnecessary (and often, futile) procedures when they would have been better served with an AV graft (and even rarely by a long-term tunneled dialysis catheter). We continue to recommend a hemodialysis access metric that focuses on informed decision making with the patient and ultimate efforts to encourage "catheter last" rather than "fistula first."

<u>Recommendation</u>: The Forum agrees with the NQF in not supporting Standardized Fistula Ratio for Incident Patients measure.

NQF #3689 First Year Standardized Waitlist Ratio (FYSWR):

The Forum applauds all efforts focusing on the development of measures that targeted waitlisting in order to improve access to kidney transplantation, however we also share many of the NQF's concerns to include measuring at the provider level rather than the transplant facility level, excluding patients from the measure who are waitlisted prior to starting dialysis, or preemptively waitlisted, as well as including patients in the measure who choose not to undergo a transplant.

Recommendation: The Forum agrees with the NQF in not supporting the FYSWR measure.

NQF #3694 Percentage of Prevalent Patients Waitlisted in Active Status (aPPPW):

The Forum noted in NQF comments for this proposal multiple concerns that led to the NQF declining to recommend this measure. Some of these comments raised concerns regarding "the attribution of successful or unsuccessful waitlisting to dialysis facilities, individual practitioners, or group practices" as well as "a focus on incident maintenance dialysis populations with "stand alone" measures independent of measures targeting patients in other stages of kidney diseases, such as non-dialysis advanced CKD and prevalent dialysis; reliance on CMS-2728 data for any risk adjustment, including transplant measures; lack of adjustment for variables that are critical for patient equity, such as SDOH; and a focus on dialysis unit-specific measures without consideration of advanced CKD care and nephrologist-led care." The Forum agrees with many of these concerns.

Recommendation: The Forum agrees with the NQF in not supporting the aPPPW measure.

NQF #3696 Standardized Modality Switch Ratio for Incident Dialysis Patients (SMoSR):

The Forum strongly supports efforts to encourage home dialysis through education and informed decision-making. The Forum, however, is concerned that the SMoSR measure could lead to practitioners being encouraged to initiate patients in-center in order to gain "credit" for changing the patient to home-based therapy later on. Sometimes this may need to be done if the home training is delayed due to training dates or staff shortages, but otherwise the in-center start would be more likely to let the undecided patient become complacent and decline to switch to home.

One of our KPAC members also commented as follows: "While the measure is important, I believe the credit for the switch should be longer than 30 days (e.g., 90 days or longer). To incentivize switching for a short period could actually harm patients. We want patients to benefit from home for the longest time possible. The failure rate of home is somewhere around 40 percent after one year and 70 percent after two years. The focus of the measure should be to improve those statistics in my thinking. Another issue of concern is that once patients are in an in-center setting it is difficult to get us to change. Even the best programs may only get 9-12 percent of patients to switch. We need to have a physician level measure to start patients at home before they ever go in-center. The problems of physicians and dialysis centers not being well trained and comfortable with home dialysis, and also the social determinants of health affecting not only the patients, but also the location of the dialysis units, are challenging, and must be attributed very well if the measures are to be truly applicable."

<u>Recommendation</u>: The Forum agrees with the NQF in not supporting the SMoSR measure.

We thank you once again for your time and consideration.

Sincerely,

David E. Henner, DO

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