

April 11, 2011

National Quality Forum
Lauren Richie
601 13th Street NW
Suite 500 North
Washington, D.C. 20005

Via Email: esrd@qualityforum.org

Re: Pre-voting review for *National Voluntary Consensus Standards for End Stage Renal Disease (ESRD) 2010: A Consensus Report*

Dear Lauren Richie,

Dialysis Patient Citizens (DPC) is pleased to provide comments to the National Quality Forum (NQF) on the pre-voting review for *National Voluntary Consensus Standards for End Stage Renal Disease (ESRD) 2010: A Consensus Report*. As America's largest dialysis patient organization, DPC seeks to ensure that the patient's point of view is heard and considered by policy makers on a wide variety of issues so continued progress may be made in the quality of care and life for dialysis patients. We are pleased that Congress and the Centers for Medicare and Medicaid Services (CMS) have taken steps to develop a Quality Incentive Program (QIP) that seeks to align incentives with patient outcomes. We believe that the quality measures included in this program should, above all, be patient-centered, reflective of health outcomes for all dialysis patients regardless of the treatment modality they choose (i.e. in-center hemodialysis, home hemodialysis and peritoneal dialysis) and target levels that will ensure patients do not just meet adequate standards, but can live good quality lives. We know that a diagnosis of End Stage Renal Disease (ESRD) does not mean the end of life; it simply means the end of kidney function. With proper health care and self-management, dialysis patients can lead long, productive lives. An NQF endorsement is important to the decision making at CMS in regards to the selection of future measures for the QIP. It is with this frame of mind that we respectfully issue the following comments on this NQF report.

DPC supports the goal to develop and endorse more measures reflective of patient outcomes. We would like to issue our general support for the measures recommended for endorsement by the NQF steering committee and particularly would like to highlight those that are most closely aligned with patient outcomes and those where we have additional suggestions for slight modification of the measure.

1454 Upper Limit for Total Uncorrected Serum Calcium

Bone and mineral measures are extremely critical to dialysis patients. Patients are currently measured on these areas and in many cases receive not only the lab results, but also a separate progress report educating them on how well they are doing in keeping their calcium and phosphorus at appropriate levels. We recognize this is a measure that not only requires

proper care delivery, but also education for patients, as they have a role in managing bone and mineral metabolism through maintaining proper diet and medication adherence. DPC supports the upper limit for serum calcium because we recognize high levels of calcium can cause calcification of arteries and other cardiovascular complications for dialysis patients. Additionally, we believe with the payment changes under the Medicare program for ESRD and medications being moved into a bundled payment system, this measure is of particular importance and should be included in the QIP to ensure patients receive optimal quality care.

1460 National Healthcare Safety Network (NHSN) Bloodstream Infection Measure

Infections are the second leading cause of death in dialysis patients falling just slightly behind cardiovascular disease. We strongly support the Steering Committee's recommendation for endorsement and believe this is a crucial measure to be included in the future years of the QIP.

1463 Standardized Hospitalization Ratio (SHR) for Admissions

While we are supportive of this measure we feel it is important to note that dialysis facilities currently do not provide the totality of patients' care, and there are factors not currently treated at the dialysis facility that could lead to hospitalization of the patient. We feel this measure should be modified to measure hospitalizations related to the outcomes of dialysis treatment.

While in general we are supportive of the measures the steering committee is recommending, we are particularly concerned the Committee did not include **measure 1427 Adult Dialysis Patients - Serum Phosphorus Greater Than 6 mg/dl**. As mentioned under our comments for the upper serum calcium measure, bone and mineral measures are important to evaluating patients' health. Regulating patients' bone and mineral metabolism is vital to preventing comorbidities such as increased bone fractures, cardiovascular complications, calcification of arteries and parathyroidectomies. Dialysis does not adequately remove phosphorus from the blood, and phosphorus levels cannot be completely controlled by diet alone because, in order to maintain proper albumin, patients must eat plenty of protein. Phosphorus is commonly found in most sources of protein, and for this reason, patients are routinely prescribed phosphorus binders to remove excessive levels of phosphorus.

We are respectful of the challenges in applying and finding data and research to support the impact that outcome measures have on mortality and co-morbidities, but believe where data and research are lacking that deference to widely used clinical practices, shown to cause no harm to patients, should be considered until more definitive scientific data becomes available. Since Medicare has moved to a bundled reimbursement for dialysis care, it is important that quality measures are in place to ensure patients receive optimal care. We believe a safer route to ensure patients continue to receive proper treatment is to endorse the serum phosphorus levels below 6mg/dl measure, which is clearly an established standard of care and shows no evidence of causing harm to patients. Since the steering committee could not come to a consensus on this measure, we suggested as an alternative to a full three-year endorsement, it may be appropriate to endorse it as time-limited allowing more research to be conducted.

Not endorsing the measure could send the signal that this measure is not of clinical importance and may have negative consequences for patient care.

We thank the steering committee for its work on the ESRD measures submitted and are particularly pleased the committee makeup included dialysis patients who can attest to their experience with the delivery of quality care. This consumer perspective is of great importance, as all patients should be actively engaged with health care decisions both when it comes to their own health decisions and when it comes to policy matters that influence care delivery.

Respectfully,



Nancy L. Scott
Board President