THE NATIONAL QUALITY FORUM

CALL FOR MEASURES RENAL ENDORSEMENT MAINTENANCE PROJECT

Renal-related diseases are a leading cause of morbidity and mortality in the United States.

An estimated 31 million adults (16 percent of the population) in the United States have chronic kidney disease (CKD). It is associated with premature mortality, decreased quality of life, and increased healthcare costs totaling 24.5 percent of overall Medicare expenditures in 2008.¹ Risk factors for CKD include cardiovascular disease, diabetes, hypertension, and obesity.

Untreated CKD can result in end stage renal disease (ESRD). Currently, over half a million people in the United States have received a diagnosis of ESRD. In 2008, costs for ESRD rose 13.2 percent to \$26.8 billion. It is the only disease-specific condition that is explicitly guaranteed Medicare coverage. Additionally, racial and ethnic differences continue to persist. In 2007, rates in the African American and Native American populations were 3.7 and 1.8 times greater, respectively, than the rate among Caucasians. Additionally, the rate of ESRD in the Hispanic population was 1.5 times higher than that of non-Hispanics.² Adjusted rates of all-cause mortality rates are roughly six to eight times higher for dialysis patients than for the general population.

Other renal-related conditions include, but are not limited to, polycystic kidney disease (PKD), nephrolithiasis and lupus nephritis. PKD is a genetic disorder characterized by the growth of numerous cysts in the kidneys. About one-half of people with the most common type of PKD progress to kidney failure or ESRD. In the United States, about 600,000 people have PKD, and cystic disease is the fourth leading cause of kidney failure.³

Nephrolithiasis, or kidney stones, is the most common chronic kidney condition, after hypertension, and affects over 5 percent of adults in the United States, and the prevalence and incidence continues to rise. Kidney stones are a preventable cause of morbidity, accounting for over 5 billion dollars in economic costs each year.⁴ Lupus nephritis, inflammation of the kidneys caused by systemic lupus erythematosus (SLE), accounts for 10 percent to 30 percent of patients diagnosed with ESRD. Medical evidence has shown that up to 60 percent of adults and 80 percent of children with SLE develop nephritis.⁵ Incidence rates of ESRD due to hereditary diseases and other rare conditions such as Fabry's disease and Alport syndrome remains very low and has changed little in the past decade.¹

Other types of measures that will be considered include patient-reported outcomes and education for self-management, care coordination and transitions of care, appropriate use of more intensive therapy, fluid management, palliative care, disparities and optional management of other comorbid disease states.

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This Consensus Standards Endorsement Maintenance project consists of two activities:

1. Identification and endorsement of measures for public reporting and quality improvement addressing quality of care for renal-related diseases. Measures for consideration may include individual or composite measures of process, outcomes, structure and patient/family experience of care from a variety of care settings. Topic areas of interest include, but are not limited to CKD, ESRD, polycystic kidney disease (PKD), nephrolithiasis, and lupus nephritis.

2. Maintenance of 32 previously NQF-endorsed voluntary consensus standards relevant to renalrelated diseases. These measures were reviewed prior to 2008 as part of the *National Voluntary Consensus Standards for End Stage Renal Disease* and will be submitted for endorsement maintenance as a part of the current project.

To the extent possible, NQF encourages the inclusion of electronic specifications for the measures submitted to this project.

Any organization or individual may submit measures for consideration. To be included as part of the initial evaluation, candidate consensus standards must be within the scope of the project and meet the following general conditions as specified in the <u>measure evaluation criteria</u>:

- A. A <u>Measure Steward Agreement Form</u> with NQF must be signed unless the measure steward is a governmental organization.
- B. The measure owner/steward verifies there is an identified responsible entity and process to maintain and update the measure on a schedule that is commensurate with the rate of clinical innovation, but at least every three years.
- C. The intended use of the measure includes both public reporting and quality improvement.
- D. The measure must be fully specified and tested for reliability and validity.
- E. The measure developer/steward attests that harmonization with related measures and issues with competing measures have been considered and addressed, as appropriate.
- F. The requested measure submission information is complete and responsive to the questions so that all the information needed to evaluate all criteria is provided.

Measures without testing on reliability and validity will not be eligible for submission; although, few exceptions may apply.

To submit a measure, please complete the following:

- Online Measure Submission Form (see NQF website)
- Measure Steward Agreement Form

Please note that no materials will be accepted unless accompanied by a fully executed Measure Steward Agreement. All materials not meeting this requirement will be returned to the sender.

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Materials must be submitted using the online submission process by 6:00 pm ET on Wednesday, June 8, 2011. If you have questions, please contact Lauren Richie, MA at 202-783-1300 or e-mail renal@qualityforum.org.

^{1.} U.S. Renal Data System, USRDS 2010 Annual Data Report: Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States, National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2009. Available at <u>http://www.usrds.org/atlas.htm</u> Last accessed March 2011.

^{2.} Vassalotti, JA, Stevens, LA, Levey, AS, Testing for Chronic Kidney Disease: A Position Statement From the National Kidney Foundation, *American Journal of Kidney Disease*, 2007; 50(2):169-344, p.A1-A48.

Polycystic Kidney Disease: National Kidney and Urologic Diseases Information Clearinghouse, National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2009. Available at <u>http://kidney.niddk.nih.gov/kudiseases/pubs/polycystic/</u> Last accessed April 2011.

^{4.} Worcester EM, Coe FL, Nephrolithiasis, Journal of Primary Care, 2008 June;35(2):369-91, vii.

Costenbader, KH, et al, Trends in the Incidence, Demographics and Outcomes of End-Stage Renal Disease Due to Lupus Nephritis in the U.S., 1995-2006, *Journal of Arthritis & Rheumatism*, Published Online: March 28, 2011 (DOI: 10.1002/art.30350). <u>http://doi.wiley.com/10.1002/art.30293</u>.