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Office of Clinical Standards and Quality
Centers for Medicare and Medicaid Services
Department of Health and Human Services
7500 Security Boulevard
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May 14, 2013

Re: National Quality Forum non-endorsement of measures for dementia

Dear Dr. Goodrich,

On behalf of the Alzheimer's Association, I am writing to bring to your attention to the National Quality Forum's (NQF) Neurology Phase II project, which recently rejected dementia quality measures that are currently used in the Centers for Medicare and Medicaid Services' (CMS) Physician Quality Reporting System (PQRS). Specifically, our comments will focus on the NQF's retroactive application of new criteria for endorsement to existing quality measures within the PQRS, and the effect that the resulting rejection of dementia-related quality measures would have on the quality of care for the more than 5 million individuals with Alzheimer's disease and other dementias.

The Alzheimer's Association is the world's leading voluntary health organization for Alzheimer's disease care, support and research. Today, there are more than 5 million Americans living with Alzheimer's disease, which is the sixth-leading cause of death in the United States. Alzheimer's disease is also the only cause of death among the top 10 without a way to prevent, cure or even slow its progression. Last year, caring for individuals with Alzheimer's and other dementias cost the United States an estimated \$200 billion, 70 percent of which was borne by Medicare and Medicaid. By 2050, this number will grow to over \$1 trillion.¹

The NQF's Neurology Phase II project reviewed dementia quality measures currently included in the PQRS and rejected them as not adhering to newly-established criteria for endorsement. While we appreciate the NQF's new criteria that endorsed quality measures must have strong, evidence-based clinical outcomes, we believe it is inappropriate to retroactively apply the new criteria to existing dementia quality measures that were developed when no such criteria existed. **Until criteria can be developed to include quality-of-life outcomes, we urge CMS to retain the current PQRS dementia quality measures to provide guidance to health care providers on the appropriate care for individuals with Alzheimer's disease and other dementias.**

Studies have shown provider adherence to recommended practices for the diagnosis and treatment of Alzheimer's disease varies greatly, underscoring the importance of providing dementia quality measures.^{2,3,4} The U.S.

¹ Alzheimer's Association. (2013). *2013 Alzheimer's Disease Facts and Figures*

² Wenger N., et al. (2003). The quality of medical care provided to vulnerable community-dwelling older patients. *Annals of Internal Medicine*, 139:740-747

³ Chodosh, J., Mittman, B.S., Connor, K.I. (2008) Caring for patients with dementia: How good is the quality of care? Results from three health systems. *Journal of the American Geriatric Society*, 55(8):1260-1268

Department of Health and Human Services (HHS) has also identified the need for high-quality dementia care guidelines and measures across care settings, and recommended strategies and actions to address them in the *National Plan to Address Alzheimer's Disease*.⁵ Unlike other conditions with easily-defined clinical outcomes, neurodegenerative diseases such as Alzheimer's and other dementias rely on interventions like counseling and education, and quality measures like functional status and quality-of-life. Requiring strong evidence of clinical outcomes for NQF endorsement unfairly narrows the definition of quality care for diseases that currently have no available treatment or cure.

The nine dementia measures reviewed in October 2012 by the NQF Neurology Phase II Steering Committee were developed by the American Academy of Neurology, the American Geriatrics Society, American Medical Directors Association, the American Psychiatric Association and the American Medical Association-convened Physician Consortium for Performance Improvement® to address the challenges of providing consistent, high-quality care. Because NQF's criteria – importance to measure and report, scientific acceptability of measure properties, usability and feasibility – are better suited to diseases with clearly defined clinical outcomes, none of the dementia performance measures were recommended for continued use in the PQRS. In December 2012, the Steering Committee held a conference call to continue discussion of the dementia quality measures, and it is believed that the Committee held a follow-up vote at that time. The Alzheimer's Association is currently awaiting the final vote from NQF membership and approval by the NQF Board of Directors regarding final endorsement or non-endorsement of the dementia quality measures.

The current dementia quality measures are the only available guidelines in the PQRS addressing the treatment and care of Alzheimer's disease. Removing them may inadvertently indicate that care of dementia patients is not a high priority for CMS. In addition, without quality measures for dementia care, it will be nearly impossible to determine if physicians and specialists are performing the critical tasks associated with high-quality dementia care, and may ultimately jeopardize the care of those with this debilitating and terminal condition. The Alzheimer's Association recognizes that the Secretary of HHS has the authority to specify the use of quality measures that have not been endorsed by the NQF if the measures 1) have a high impact on health care and supports CMS and HHS priorities for improved quality and efficiency of care; 2) address gaps in the PQRS measure set; 3) impact chronic conditions; 4) are applicable across different care settings; 5) reflect the services furnished to beneficiaries by a particular specialty. The dementia measures rejected by the NQF address all these areas. Until data can be gathered to develop new practice guidelines, the Alzheimer's Association encourages CMS to continuing using these measures in the PQRS as the appropriate guide for the care of people with Alzheimer's disease and other dementias

Thank you for the opportunity to comment and for working to achieve better quality of care for individuals with Alzheimer's disease. If the Alzheimer's Association can be of any assistance, please contact Rachel Conant, Director of Federal Affairs, at RConant@alz.org or by phone at 202.638.7121.

Sincerely,



Mary Richards
Senior Director, Public Policy

⁴ Rosen, C.S., et al. (2002). How well are clinicians following dementia practice guidelines? *Alzheimer's Disease Associated Disorders*, 16 (1): 15-23

⁵ U.S. Department of Health and Human Services. (2012). *National Plan to Address Alzheimer's Disease*. Available at <http://aspe.hhs.gov/daltcp/napa/NatlPlan.pdf>