



Prioritizing Measures Gaps: Alzheimer's Disease and Related
Dementias Advisors Planning Meeting
October 31, 2013 | 10:00 am –12:00 pm ET

The National Quality Forum (NQF) convened a web meeting of the Prioritizing Measure Gaps Alzheimer's Disease and Related Dementias (ADRD) Advisors on Thursday, October 31, 2013. An [online archive](#) of the meeting is available.

Advisory Group Attendance

Cyndy Cordell, Alzheimer's Association
Penny Feldman, Visiting Nurse Service of NY
Gail Hunt, National Alliance on Caregiving
Katie Maslow, Institute of Medicine
David Reuben, University of California-Los Angeles
Mark Snowden, University of Washington
Joan Teno, Brown University
D.E.B. Potter, Government Sub-Task Leader
Cille Kennedy, Government Task Leader

Welcome and Review of Meeting Objectives

Juliet Feldman, Project Manager, NQF, welcomed the advisors and members of the public to the web meeting, reviewed the meeting objectives, and asked the advisors to introduce themselves and describe their background and interest in the project. The meeting objectives were to:

- Review project objectives and timeline
- Discuss important considerations for the conceptual framework, environmental scan of measures and measure concepts, and literature review
- Gather early input on potential approaches for prioritizing the measurement gaps
- Discuss next steps, including communication with advisors moving forward

Background and Project Overview

Wendy Prins, Senior Director, NQF, provided background information on the Priority Setting for Health Care Performance Measurement: Addressing Performance Measure Gaps in Priority Areas project, including its five sub-topic areas: Adult Immunizations, Alzheimer's Disease and Related Dementias, Care Coordination, Health Workforce, and Person-Centered Care and Outcomes. An overview of the ADRD sub-task was also provided, including the main project objectives and general project timeline.

Draft Conceptual Framework and Key Measurement Considerations

Karen Johnson, Senior Director, NQF led a discussion on the purpose of developing a conceptual framework and how it will be used to assist in the prioritization of measurement gaps. Ms. Johnson presented NQF's draft conceptual framework (see [Meeting Materials](#)) and asked for feedback from the advisors. The following themes arose during this discussion:

- Importance of initial detection and the need for it to be adequately represented in the framework.
- Prominent role that caregivers play along the entire course of disease and how their role can bridge the medical and non-medical trajectories.
- Desire for a conceptual model that is patient-centered and the need to account for the unique considerations related to capturing patient-reported data among the ADRD population.
- Recommendation to identify the outcomes of most importance for the ADRD population and reflect these outcomes in the model.

Environmental Scan of Measures and Literature Review

Ms. Johnson discussed the purpose of the environmental scan of measures and measure concepts. She described NQF's proposed approach for conducting the scan and asked for feedback on this approach. Advisors who participated in the FNIH/C-Path Alzheimer's Disease Measurement Improvement Project (AD-MI Project) (see [Meeting Materials](#) for more information) expressed that the environmental scan conducted during the AD-MI project represents publicly available U.S. measures as of last summer.

Advisors recommended first identifying those outcomes of most importance for the ADRD population and then look for additional measures related to these outcomes. Advisors also suggested identifying any measures focusing on the caregiver (e.g., caregiver support), dementia-specific measures about the patient but reported by caregivers, and existing caregiver measures that could be adopted for the ADRD population. Other recommendations included identifying what measures related to dementia are being used by health plans or States, as well as looking at what measures are used in other countries that have National Alzheimer's Plans. Ms. Johnson also described NQF's current literature review efforts and described how these efforts will inform the conceptual model and environmental scan.

Approaches for Prioritizing the Gaps

Ms. Johnson discussed the role of the project's multistakeholder committee in assessing the measurement gaps and making recommendations to HHS for their prioritization of measurement development efforts. She presented potential criteria to be used for the prioritization activities and asked for any preliminary input from the advisors. Advisors agreed that outcome measures should be a priority, especially patient-reported outcomes and patient/caregiver experience of care measures. Advisors also suggested the need to:

- Account for minority groups disproportionately affected by ADRD.
- Consider patients who do not have a caregiver.
- Consider how to approach "patient-reported" measures when dementia patients can no longer speak for themselves.

Opportunity for Public Comment

There were no comments from the public.

Summary and Next Steps

The meeting concluded with a brief discussion of next steps, including highlighting the dates for the upcoming full committee web meeting (**February 25, 2014; 3-5pm ET**) and in-person meeting (**June 2-3, 2014**). The full multi-stakeholder committee will be seated by mid-December; meanwhile, NQF will continue informal dialogue with the advisors prior to the submission of the draft conceptual framework and draft environmental scan to HHS in mid-February 2014.