



Prioritizing Measure Gaps: Alzheimer's Disease & Related Dementias (ADRD)

Committee Web Meeting

February 25, 2014 | 3:00 pm –5:00 pm ET

The National Quality Forum (NQF) convened a web-based meeting of the Prioritizing Measure Gaps Alzheimer's Disease & Related Dementias (ADRD) Committee members on Tuesday, February 25, 2014. Approximately thirty members of the public also participated in the meeting. An [online archive](#) of the meeting is available.

Committee Members in Attendance

| Name | Organization |
|--|--|
| Eleanor Perfetto, PhD (Co-Chair) | University of Maryland School of Pharmacy |
| Mary Barton, MD, MPP | National Committee for Quality Assurance |
| Barbara Baylis, RN, MSN | Providigm |
| Susan Cooley, PhD | Department of Veterans Affairs |
| Cyndy Cordell, BS, MBA | Alzheimer's Association |
| Lynn Friss-Feinberg, MSW | AARP Public Policy Institute |
| Murray Grossman, MD | American Academy of Neurology |
| Razia Hashmi, MD, MPH | WellPoint, Inc. |
| Gail Hunt | National Alliance for Caregiving |
| Matthew Janicki, PhD | University of Illinois at Chicago |
| Kristin Kahle-Wroblewski, PhD | Eli Lilly and Company |
| Katie Maslow, MSW | Institute of Medicine |
| David Reuben, MD | UCLA Division of Geriatrics, David Geffen School of Medicine |
| Martha Roherty, MPP | National Association of States United for Aging and Disabilities |
| Mark Snowden, MD, MPH | University of Washington School of Medicine |
| William Staples, PT, DHsc, DPT, GCS, CEEAA | University of Indianapolis |
| Yael Zweig, MSN, ANP-BC, GNP-BC | NYU Peal Barlow Center for Memory Evaluation and Treatment |

Welcome, Committee Introductions and Disclosures of Interest

Juliet Feldman, Project Manager, NQF, welcomed the committee members and the public audience to the web meeting, and reviewed the meeting objectives. The meeting objectives articulated were to:

- Review project goals, committee's role, and timeline
- Review draft conceptual framework and environmental scan of measures
- Discuss key questions to further refine framework and scan

Ann Hammersmith, General Counsel, NQF, led the introductions of the committee members along with their disclosures of interest.

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. She outlined the project's timeline and its five sub-topic areas: adult immunizations, Alzheimer's disease and related dementias, care coordination, health workforce, and person-centered care and outcomes. Ms. Feldman then presented an overview of the Alzheimer's disease and related dementias project, including the project's scope and objectives.

Draft Conceptual Framework for Alzheimer's Disease and Related Dementias

Karen Johnson, Senior Director, NQF, presented the draft conceptual framework and Eleanor Perfetto, co-chair of the committee, facilitated the discussion of the framework. Reactions to the framework were, in general, positive. The committee offered several recommendations for the project team to consider. First, committee members commented on the complexity of the framework. Dr. Perfetto emphasized that the purpose of the framework is to guide future measure development and noted that some amount of complexity should be expected. The committee discussed how the detailed narrative in the report should support the framework and clarify any intricacies. The committee also discussed and generally agreed that mild cognitive impairment, early onset Alzheimer's, various types of dementia (e.g., vascular, frontotemporal), and the role of community supports were adequately addressed in the current iteration of the framework. Additionally, committee members:

- Suggested distinguishing paid care provided by "professionals" (e.g., physicians, therapists) vs. that provided by direct care workers.
- Questioned the portrayal of paid medical care as a curvy line and noted that professional medical care should be present throughout the episode.
- Suggested leaving the National Quality Strategy (NQS) priorities in the framework.
- Suggested adding safety as a measurement subdomain under the care, treatment, and support domain for the person with dementia trajectory.
- Suggested that the caregiver subdomains encompass "informal" caregivers only. Caregiving provided by direct care workers can be best addressed in NQF's Prioritizing Measure Gaps for the Health Workforce project.

The NQF project team will verify these recommendations with the full committee.

Environmental Scan of Measures and Measure Concepts

Ms. Johnson discussed the process for compiling the initial environmental scan of existing measures applicable to the dementia population as well as concepts or ideas about what should be measured that could be further developed into performance measures. The initial scan identified 107 measures specifically relevant to the dementia population. The measures were mapped to the domains and subdomains in the draft framework as well as to the NQS priorities.

Committee members were asked to reflect upon the measures included in the scan and offer recommendations for additional measures or measure concepts to be included in the scan. A robust discussion ensued regarding the difference between measures of patients using instruments or scales

(e.g., PHQ-9) versus performance measures that are obtained from these types of tools and then aggregated to reflect performance by a clinician, facility, etc. NQF staff clarified that aggregated performance measures are the focus of this project. The project team will share with the committee definitions for patient-reported outcomes (PROs), patient-reported outcome measures (PROMs), and patient-reported outcome performance measures (PRO-PMs). Committee members agreed that additional research into international and caregiving is necessary. Additional discussion regarding the need for community support measures and comorbidity measures is needed. In addition, committee members discussed challenges in interpreting measures that account for persons with dementia and how measures can be structured or stratified to obtain the most accurate results.

Next Steps

Ms. Johnson described an initial set of prioritization principles for the committee to consider for use at the in-person meeting and indicated that committee members can expect additional communication from NQF regarding preparing for the prioritization exercise. Ms. Feldman then discussed immediate next steps, including circulating the meeting summary to the committee and soliciting any additional feedback on the conceptual framework and environmental scan. The committee members will gather for a two-day in-person meeting on June 2-3, 2014 during which the revised conceptual framework will be discussed to inform concrete recommendations on critical gap areas of dementia measurement for future development.