Meeting Summary

Prioritizing Measure Gaps: Alzheimer's Disease and Related Dementia Committee In-Person Meeting

The National Quality Forum (NQF) convened the Prioritizing Measure Gaps: Alzheimer's Disease and Related Dementia's (ADRD) Committee members for a two day in-person meeting on June 2 and June 3, 2014. The online archives can be found by accessing the following links: June 2, 2014 and June 3, 2014.

This is a brief meeting summary focused on describing the purpose and process of the meeting. The results and recommendations from the meeting will be synthesized in a formal report, which is the primary deliverable for this project.

Committee Members in Attendance

Name	Organization
Penny Feldman, PhD (Co-Chair)	Visiting Nurse Service of New York
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
Ryan Carnahan, PharmD, MS, BCPP	University of Iowa College of Public Health
Susan Cooley, PhD (by phone)	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.
Matthew Janicki, PhD	University of Illinois at Chicago
Kristin Kahle Wrobleski, PhD	Eli Lilly and Company
Katie Maslow, MSW	Institute of Medicine
David Reuben, MD	UCLA Division of Geriatrics, David Geffen School of Medicine
Sophie Okolo, MPH (standing in for Martha Roherty)	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
Eric Tangalos, MD, FACP, AGSF, CMD	The Mayo Clinic
Joan Teno, MD	Brown University School of Public Health
Yael Zweig, MSN, ANP-BC, GNP-BC	NYU Peal Barlow Center for Memory Evaluation and Treatment

HHS Members in Attendance

Name	Organization
Cille Kennedy	Government Task Leader, ASPE, HHS
D.E.B. Potter	Government Sub-task Leader, AHRQ, HHS

Other HHS and CMS staff who attended the meeting either in-person or via webinar included Jane Tilly, Linda Elam, Rohini Khillan, Jonalyn Lyles, Tara McMullen, Shari Ling, Fred Kobylarz, Mary Bernard, Joseph Hutter, and Angela Deokar.

Participating NQF staff:

- Karen Johnson, Senior Director, NQF
- Wendy Prins, Senior Director, NQF
- Elisa Munthali, Managing Director, NQF
- Juliet Feldman, Project Manager, NQF
- Taylor Myers, Administrative Assistant, NQF

Day 1: Monday, June 2, 2014

Introductions and Meeting Objectives

After Committee introductions, Eleanor Perfetto and Penny Feldman, ADRD Committee Co-Chairs, welcomed the Committee members and the public audience, and reviewed the meeting objectives. The objectives for the two-day meeting were to:

- Identify major quality opportunities for those with dementia and their family/caregivers
- Finalize the domains and subdomains for measurement
- Identify potential measure concepts within measurement domains and subdomains
- Prioritize opportunities for performance measurement those with dementia and their family/caregivers

Dr. Perfetto laid out the expectations for participation in the meeting, which included open sharing of and respect for views, perspectives, agreements, and differences, as well as helping to work toward consensus, meeting objectives, and staying on time.

D.E.B. Potter, the government sub-task lead from the Agency for Healthcare Research and Quality (AHRQ), provided opening remarks on behalf of the Department of Health and Human Services (HHS). Ms. Potter set the stage and framed the context for the project, including the connections to the National Alzheimer’s Project Act and their National Plan to Address Alzheimer’s Disease. She emphasized the importance of the project for HHS, as it will help inform the federal government on where to invest in measure development.

Project Overview and Related Projects

Juliet Feldman, Project Manager, NQF, provided a brief overview and background of the project and discussed the next steps. She provided an update regarding the current work of the other Prioritizing

Measure Gaps projects, specifically the Person Centered Care and Outcomes, Care Coordination, and Health Workforce sub-tasks, and noted that the ADRD Committee has been tasked to build upon the work of the other topic areas. Additionally, Ms. Feldman provided a high-level overview of additional NQF efforts focusing on person- and family-centered care, population health, and care coordination.

Discussion of Measurement Considerations

Karen Johnson, Senior Director, NQF, led the Committee in a discussion regarding measurement considerations. This conversation was designed to serve as a technical and practical "starting point" for consideration of future performance measure development.

Ms. Johnson offered clarifying definitions, distinguishing between patient- and provider/organization-level measures and describing different types of healthcare performance measures, including quality (outcome, intermediate clinical outcome, process, and structure), resource use/cost, efficiency, composite, and population health measures. Ms. Johnson also noted NQF's hierarchical preference for outcomes measures that are linked to evidence-based processes or structures, emphasized the difference between patient-reported outcomes, instruments or scales used to elicit those outcomes, and performance measures that are derived from such instruments or scales, described the different levels of analysis typically used in healthcare performance measurement, and summarized NQF’s endorsement criteria for performance measures. Elisa Munthali, Managing Director, NQF, also spoke to the group regarding NQF's past and current work on population health measurement. In addition to providing definitions for "populations" and "sub-populations", Ms. Munthali provided several examples of population health measures and discussed several measurement challenges for population health measurement.

Ms. Johnson then briefly noted several potential topic areas—including measurement for accountability and quality improvement, differing types of measurement, which entities should be held accountable for improvement, the underlying evidence base for measurement, feasibility, breadth of settings and populations, parsimony, creativity, the need for measurement for minority and/or high-risk populations, and need for both short- and long-term recommendations—that could be considered by Committee members as they prioritized areas for future measure development.

Committee members appreciated the overview of performance measurement fundamentals and related NQF projects. Members discussed several additional challenges of measuring the dementia population, including:

- The distinction between “person” and “patient”.
- How to differentiate between the dementia population and other populations.
- The desire for personalized measures that account for individual goals and issues of accountability for these measures.
- Integration of medical and social support systems.
- The presence of co-morbidity in those with dementia.
- The need to consider and adhere to the extent possible the direction set in the National Plan to Address Alzheimer’s Disease.

Setting the Stage: Quality Measurement Opportunities

Dr. Perfetto presented the latest version of the draft conceptual framework and asked the Committee for any major input. Overall, the Committee was pleased with the framework and offered suggestions for refinement, including:

- Adding experience of care and person and family/caregiver engagement as subdomains for the caregiver trajectory.
- Denoting the "course of decline" between care, treatment, and support, and end of life
- Including familial history within the population at risk domain.
- Addressing the distinction between person with dementia and proxy responders.
- Capturing care planning, family counseling and health assessment, anticipatory grief, dementia-sensitivity, and education of the formal health care and family/informal caregivers.
- Clarifying definitions for terms, such as family/caregiver and support.
- Other minor formatting and textual changes.

Dr. Perfetto then facilitated a discussion in which several committee members shared short vignettes from their personal or professional experiences related to quality opportunities for persons with dementia and their family/caregiver. These vignettes focused on the measurement domains of the ADRD framework: population at risk, symptom awareness/initial detection, care, treatment, and support, for the person with dementia and their caregivers, as well as end of live/bereavement.

The vignettes offered an opportunity for a realistic assessment of some areas of care where quality improvement is needed, and provided a moving acknowledgment of the challenges (and successes) that persons with dementia and their family/caregiver face on a daily basis. Themes from the Committee's stories reflected, among others, the need to address issues related to diagnosis (e.g., lack of assessment/referral, misdiagnosis, and communication of diagnosis), lack of knowledge in the public and among providers, coordination between clinical and other support systems (e.g., need for dementia capable systems and dementia sensitive care, role of care managers), family/caregiver support (e.g., family/caregiver health and cost of caregiver burden), the denial and "learned helplessness" that is sometimes encountered and the frequent lack of personalized care for those with dementia and their family/caregivers.

Small Group Work: Generating/Prioritizing Measure Concepts (Round 1 Prioritization)

Committee members were divided into three small groups based on the measurement domains and asked to identify two lists of their top 3-5 choices for future measure development: one list of 3-5 measurement priorities for the person with dementia and another for measurement priorities for the family/caregiver. The Committee then reconvened and shared their results:

Group #1: Population at risk/Symptom awareness and initial detection

- Population at Risk
    1. Hierarchal system – identify people with risk factors for people with cognitive impairment
    2. Educate public about risk factors

  3. Educate health care workforce
  4. Identify actions once risks are identified
- Symptom awareness and initial detection
  5. Those at high risk should be screened on regular basis
  6. Greater awareness that dementia is not just memory problems – functional, language, gate triggers
  7. Diagnosis
     - Detection should lead to diagnostic evaluation
     - Diagnostic evaluation is intentional and results in a diagnosis, occurs in a reasonable time, and is documented
  8. Family engagement is important at this time
  9. Need interventions for quality of life

Group #2: Evaluation and initial management/Care, treatment, support (mild and moderate)

- Evaluation and initial management for person with dementia
  10. Need to know who proxy decision-maker is
  11. Assessing for personal treatment goals
  12. Having care plan documented and given to person
  13. Core dementia work-up
  14. Connection to supportive services in community (should be throughout)
- Evaluation and initial management for family/caregiver
  15. Having capacity and confidence
  16. Important to assess caregiver goals for treatment
  17. Education on what to expect
  18. Caregiver burden and strain
  19. Understanding treatment options
  20. Connection to supportive services in community
- Ongoing care for mild/moderate for person with dementia (with periodic reassessment)
  21. Impact of transition of care/other illness on dementia care at follow-up
  22. Assessment of medication side-effects and efficacy/effectiveness at follow-up
  23. Have a dementia care manager
- Ongoing care for mild/moderate for family/caregiver (with periodic reassessment)
  24. Health assessment
  25. Clinician referral
  26. Caregiver participatory decision-making

Group #3: Care, treatment, support (severe)/End of life and bereavement

  27. Shared decision-making with advanced care planning – composite
      - Prognosis, treatment options, education
  28. Person-centeredness
      - Being able to shape everyday activities
  29. Hospitalization/transitions of care (including long-term care facilities) – lack of coordination between events
      - Use HCAHPS

30. Support of caregiver – composite
    - Assessment
    - Communication with family
    - Training
    - Responsive to needs
    - Listen to you – caregivers often best source of info
    - Advocacy – due to unresponsiveness of system
31. Dementia-capable health care and community care system (broader LTC)
    - Have family comment on capability of system

Round 2 Prioritization and Discussion

Committee members were then asked to conduct another round of prioritization based on the identified concepts listed above. The Committee prioritized the following concepts for future measure development (the number of votes in parenthesis):

Priorities focusing on the person with dementia
Detection should lead to diagnostic evaluation (16 votes)
Diagnostic evaluation is intentional and results in a diagnosis, occurs in a reasonable time, and is documented (11 votes)
Core dementia work-up (“initial dementia assessment”) (25 votes)
Hospitalization/transitions of care (including long-term care facilities) (7 votes)
Additional concepts considered important by the Committee
Impact of transition of care/other illness on dementia care at follow-up
Connection to support services in community (should be throughout)
Person centeredness (e.g. autonomy over everyday decisions/treated with dignity and respect)

Priorities focusing on the family/caregiver
Support of caregiver – composite (18 votes) • Assessment • Communication with family • Training • Responsive to needs; listens to you – caregivers often best source of information • Advocacy – due to unresponsiveness of system
Additional concepts considered important by the Committee
Caregiver education on what to expect
Caregiver burden and strain
Caregiver capacity and confidence

Priorities focusing on both the person with dementia and the family/caregiver
Dementia-capable health care and community care system (broader LTC) (31 votes)
Shared decision-making
• [with advanced care planning – composite (prognosis, treatment options, education)] (18 votes)
• Caregiver participatory decision-making (13 votes)
• For person with dementia: Assessing for personal treatment goals (11 votes)
Additional concepts considered important by the Committee
Need to know who is the proxy decision-maker

Committee members were also asked to identify any other "parking lot" issues that they wanted to discuss on Day 2. These included:

- Linkage between clinical and community systems, and the role of community and provider engagement and education.
- Safety issues for persons with dementia.
- Weighing importance, evidence and practicality in prioritization of potential quality measures.
- Social system/population measures.
- Personalized measures.
- Consideration of existing measures for the dementia population.
- Accommodations for people with dementia (structural measures).
- Inappropriate exclusions and the use of proxies.

Opportunity for Public Comment

George Vrandenburg from USAgainstAlzheimer's noted the importance of performance measurement and the need to connect healthcare and community systems to improve the care of the dementia population. He also noted the opportunity for a U.S. to be a global leader in these efforts.

Day 2: Tuesday, June 3, 2014

Review of Prioritization Results from Day 1

Dr. Perfetto, Committee co-chair, welcomed participants and initiated a discussion about the important role of population health measurement for this population, noting that while feasibility issues may exist, these types of measures should not be disregarded. Dr. Perfetto then reviewed the Round 2 prioritization results from the previous day and sought additional input from the Committee on their these priorities. In this portion of the meeting, Committee members gave feedback regarding the types of measures that might be used to address the prioritized concepts and the potential accountable entities for such measures.

The Committee discussed at length issues related to detection and screening. Members discussed the importance of identifying people for which detection would be most beneficial. Discussions also involved the implications of the U.S. Preventive Services Task Force's (USPSTF) recent recommendation related to screening for dementia. A subgroup of the Committee will work with NQF staff to craft language for the project's report related to screening and detection.

Another major discussion point pertained to creating a standardized core dementia work-up or “initial dementia assessment” for those who show signs and symptoms of dementia. This assessment would go beyond clinical tests and scan to address community supports, family/caregiver support and burden, and health care and community systems accountability. Committee members stressed the importance of experience of care measures and the need for systematic assessment of the person with dementia and the family/caregiver in early stages of dementia. Another subgroup of the Committee will work with NQF staff to further refine the "core work-up" concept.

The Committee also focused on the need for measures related to education and support (for the family/caregiver and for the health care system as a whole). Committee members discussed the lack of willingness and/or capacity of the health care system to provide quality care for the ADRD population, noting this as a significant performance gap. The role of health literacy and cultural competency was also discussed in relation to engaging families/caregivers. The concept of “dementia-capable health care and community system” was reiterated throughout the in-person meeting as an aspirational goal for the health care and community systems to work towards. The Committee cited various research and initiatives underway related to this topic.

Opportunity for Public Comment

Jane Tilly from the Administration for Community Living (ACL)/Administration on Aging (AOA) spoke about AOA’s recent work related to dementia-capable communities and promised to circulate a link with these materials. Shari Ling from the Centers for Medicare and Medicaid Services (CMS) commented that from CMS’ perspective, performance measures ideally would be used for both quality improvement and quality reporting. She noted that CMS hosted a listening session for persons with dementia and their caregivers about what matters most and stated that this Committee’s deliberations align with what was heard in that session.

Identification of Additional Recommendations

The Committee made several additional recommendations for future performance measure development for persons with dementia and their family/caregivers, including:

- Using the "pathway to endorsement" established by NQF to develop dementia-specific patient-reported-outcome-based performance measures from existing instruments that are reliable and valid.
- Using stratification of existing non-dementia-specific measures to assess quality of care provided to those with dementia and their family/caregivers.
- Specifying existing non-dementia-specific measures, as necessary and appropriate, so as not to explicitly exclude those with dementia and/or to allow proxy reporting for those with dementia.
- Linking community-based supports system and the health care system; the Committee indicated the need for accountability for both systems and recognized this aspirational goal as vital for improving the quality of care for the dementia population.
- Taking individual goals (of both the person with dementia as well as the family/caregiver) into account when measuring performance.

Round-Robin Reflections on Recommendations and Future Work

All Committee members were given the opportunity to offer their final thoughts related to performance measure development for persons with dementia and their family/caregiver. Committee members mentioned several topics, including the rapidly changing health care system, the consideration for disciplinary and non-disciplinary professions, viewing dementia as a lifespan issue, and reinforcing connections between medical and social systems.

Next Steps

The meeting concluded with a discussion of immediate next steps, including preparation of a draft report of the Committee’s measure gap priorities and recommendations, review of the draft report by the Committee, and public commenting on the draft report and recommendations, and a public web meeting to discuss the projects findings and solicit additional feedback on the report and recommendations. The final report for the project will be delivered to HHS on October 15, 2014.