

Priority Setting for  
Healthcare Performance  
Measurement:  
Addressing Performance  
Measure Gaps for  
Dementia, including  
Alzheimer's Disease

FINAL REPORT

OCTOBER 15, 2014



NATIONAL  
QUALITY FORUM

This report is funded by the Department of  
Health and Human Services under contract  
HHSM-500-2012-000091 Task Order 5.

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## EXECUTIVE SUMMARY

In 2011, Congress passed the National Alzheimer’s Project Act (NAPA) to address the challenges facing people with Alzheimer’s disease or related dementias. As part of the resultant National Plan to Address Alzheimer’s Disease (and its annual updates, collectively known as the “National Plan”), policymakers noted the need to identify “high-quality dementia care guidelines and (quality of care) measures across care settings.” In response, the Department of Health and Human Services (HHS) contracted with the National Quality Forum (NQF) to conduct an environmental scan for existing dementia-specific performance measures and convene a multistakeholder Committee to develop a conceptual measurement framework and recommend priorities for future performance measurement development focusing on persons with dementia and their family caregivers. Key attributes of the Committee’s recommendations include an emphasis on community-based care, person- and family-centeredness, and complex measurement approaches such as outcomes and composite measures.

Dementia—the umbrella term for decreased cognitive functioning that may interfere with daily life and activities if untreated—can be caused by many diseases and conditions. Neurodegenerative dementias such as Alzheimer’s disease usually are irreversible, progressive, and ultimately fatal. Alzheimer’s disease, the most common of the dementias, affects an estimated 5.2 million Americans, accounts for 60 to 80 percent of all dementia cases, is the sixth leading cause of death in the U.S. overall, and is a leading cause of disability and poor health. The economic burden of dementia is high and the emotional and physical burden is immense, not only for people with the condition, but also for their families and caregivers. Eighty-five percent of care and support for older adults in the U.S. is provided by family members. Currently, more than 15 million Americans are the primary caregivers for persons with Alzheimer’s disease and other dementias.

NQF convened a 21-member **multistakeholder Committee** comprised of individuals with expertise in the diagnosis, treatment, and care of people with dementia. The Committee was tasked with developing a comprehensive **conceptual measurement framework** that can be applied to Alzheimer’s disease, vascular dementia, frontotemporal dementia, dementia with Lewy bodies, and mixed dementia. The resultant framework includes five measurement domains and eleven subdomains and addresses the experiences of both the person with and family caregiver. This framework also can be applied to subpopulations disproportionately affected by dementia, such as persons with early-onset dementia, members of racial and ethnic minorities, and persons with intellectual disabilities.

With guidance from the multistakeholder Committee, NQF identified a total of **125 dementia-specific performance measures**—60

developed and/or implemented in the United States and 65 from international sources. In order to identify measurement gaps, NQF staff mapped the measures to the National Quality Strategy priority areas and the measurement domains and subdomains identified in the conceptual measurement framework. This analysis of dementia-specific measures indicated the need for performance measures focused on the health and well-being of caregivers; person- and family-centered measures, including measures of engagement with the healthcare system or other community support systems; outcome measures, especially those regarding quality of life and experience with care; and measures of affordability.

During a two-day in-person meeting, the multistakeholder Committee participated in two rounds of voting to prioritize its recommendations for future performance measure development.

## Overarching Themes

Five overarching themes emerged during the Committee's deliberations and were incorporated to some extent in its recommendations. These included:

- Importance of connection to community-based services
- Need for accountability at the community level
- Person- and family-centeredness
- Diagnostic accuracy
- Safety

## Top Priorities for Measure Development

The Committee identified the following three concepts as its highest priority areas for future measure development:

- Composite measure of comprehensive diagnostic evaluation and needs assessment

- Composite measure of caregiver support
- Measures to reflect a dementia-capable healthcare and community care system

For these concepts, the Committee offered substantial input regarding potential measure construction, sources of data, and/or levels of accountability.

## Additional Priorities for Measure Development

The Committee also identified the following three additional priority areas for future performance measure development:

- Early detection of signs and symptoms of dementia
- Shared decisionmaking
- Care transitions

The Committee also made several additional recommendations for performance measurement and for dementia research and policy more generally.

The products and recommendations included in this report align with the goals and strategies of the National Plan, particularly those regarding the care and support of those with Alzheimer's disease and their families, timely and accurate diagnosis, the need for education about dementia, and the need to increase the safety of persons with dementia. Furthermore, as evidenced by the public comments received on the draft report, the recommendations of the Committee are supported by other recognized experts and organizations dedicated to the care and support of those with dementia. Although recognizing the aspirational nature of many of the recommendations included herein, Committee members emphasized their potential for improving the quality of care, and ultimately, the quality of life, of those with dementia and their family caregivers.

## PROJECT FOUNDATION

Over the past 15 years, healthcare performance measurement in the United States has increased substantially; however, stakeholders agree that many gaps in important measurement areas still exist. Section 1890(b)(5) of the Social Security Act requires the National Quality Forum (NQF) to describe gaps in endorsed quality and efficiency measures in the Annual Report to Congress and the Secretary of the Department of Health and Human Services (HHS). NQF fulfills this role as the consensus-based entity specified in the Act

working under contract with HHS. Building on work done by NQF in 2011 and 2012 on the status of measure gaps more broadly,<sup>1,2</sup> this project was intended to advance the aims and priorities of the National Quality Strategy (Figure 1) by identifying priorities for performance measurement; scanning for potential measures and measure concepts to address these priorities; and developing multistakeholder recommendations for future measure development and endorsement.

**FIGURE 1. NATIONAL QUALITY STRATEGY (NQS) AIMS AND PRIORITIES**



In 2013, HHS contracted with NQF to systematically and comprehensively identify, analyze, prioritize, and make recommendations to fill measure gaps related to five specific measurement areas: adult immunizations, Alzheimer's disease and related dementias, care coordination, health workforce, and person-centered care and outcomes. Stakeholders acknowledge that the growth in the number of performance measures has placed greater burdens and costs on providers to collect and report data. To manage measurement resources wisely, the quality measurement enterprise must prioritize measures that matter most to consumers of healthcare and target those aspects of care that will promote the greatest improvement in desired outcomes.

## Background and Context

Dementia—the umbrella term for decreased cognitive functioning that may interfere with daily life and activities if untreated<sup>3</sup>—can be caused by many diseases and conditions. Neurodegenerative dementias (e.g., Alzheimer's disease) usually are irreversible, progressive, and ultimately fatal;<sup>a</sup> such neurological disorders can have a significant impact on cognitive and physical function. Dementia often is categorized based on its suspected underlying cause (e.g., Alzheimer's dementia, vascular dementia, frontotemporal dementia, Lewy body dementia); dementia that is caused by more than one disease or condition usually is referred to as “mixed dementia.” Alzheimer's disease, the most common of the dementias, affects an estimated 5.2 million Americans, accounts for 60 to 80 percent of all dementia cases, is the sixth leading cause of death in the U.S. overall, and is a leading cause of disability and poor health.<sup>4</sup>

The economic burden of dementia is high and the

emotional and physical burden is immense, not only for people with the condition, but also for their families and caregivers. Eighty-five percent of care and support for older adults in the U.S. is provided by family members.<sup>5</sup> Currently, more than 15 million Americans are the primary caregivers for persons with Alzheimer's disease and other dementias; in 2013, these caregivers provided an estimated 17.7 billion hours of unpaid care, valued at more than \$220 billion dollars.<sup>6</sup>

In 2011, Congress passed the National Alzheimer's Project Act (NAPA) to address the challenges facing people with Alzheimer's disease or related dementias. As part of the resultant National Plan to Address Alzheimer's Disease<sup>7</sup> and its annual updates<sup>8,9</sup> (“National Plan”), policymakers noted the need to identify “high-quality dementia care guidelines and (quality of care) measures across care settings”—the importance of which was reiterated by the Project's Advisory Council who recommended that “HHS should develop quality measures and indicators for the comprehensive care and treatment of individuals” with Alzheimer's disease and related dementias.

Around that same time, representatives from the government, advocacy groups, industry leaders, measure developers, and other interested stakeholders began a dialogue on aligning research and clinical care measurement efforts with policy-relevant measurement efforts, using dementia as a case study. To open this dialogue, the Foundation for the National Institutes of Health (FNIH) and the Critical Path Institute (C-Path) convened an invitational conference in May 2011 entitled, “Aligning Outcome Measures for Assessing Disease Status and Treatment Impact with Those for Assessing Quality Performance: Dementia as a Case Study.” As a follow-up to this conference, participants initiated the Alzheimer's Disease Measurement Improvement (AD-MI) project and established working groups to address ideas that emerged from the FNIH/C-Path meeting. One working group developed a conceptual framework to promote identification of

a There are other causes of dementia (e.g., hypothyroidism; vitamin B-12 deficiency; normal pressure hydrocephalus) that can be treated, and if they are treated in a timely manner, the dementia may be reversible.

quality measurement opportunities for Alzheimer's disease, and another conducted an environmental scan to understand the measurement landscape for Alzheimer's disease. NQF used these materials from the AD-MI project as foundational resources for the current project.

## Setting Priorities for Performance Measurement

The goal of this project was to provide HHS with recommendations on priorities for performance measurement development efforts focusing on persons with dementia and their families and caregivers. The scope of the project included consideration of Alzheimer's disease, vascular dementia, frontotemporal dementia, dementia with Lewy bodies, and mixed dementia, as well as those populations disproportionately affected by Alzheimer's disease, such as persons with early-onset dementia, members of racial and ethnic minorities, and persons with intellectual disabilities.

NQF convened a multistakeholder Committee, identified existing dementia-specific performance measures and measure concepts, and, with input from the multistakeholder Committee, developed a conceptual measurement framework for performance measure development for dementia. The project's approach and methods are included in [Appendix A](#). The multistakeholder Committee members, HHS representatives, NQF staff, and key informants involved in the project are listed in [Appendix B](#).

## Terminology and Definitions

### Dementia

For the purposes of this report, the umbrella term "dementia" will be used to refer to Alzheimer's disease and related dementias including vascular

dementia, frontotemporal dementia, dementia with Lewy bodies, and mixed dementia.<sup>b</sup>

### Family Caregiver

The caregivers who are the focus of this project are *family caregivers*, defined by Feinberg and colleagues<sup>10</sup> as follows:

The term family caregiver is broadly defined and refers to any relative, partner, friend, or neighbor who has a significant relationship with, and who provides a broad range of assistance for, an older adult or an adult with chronic or disabling conditions.<sup>c</sup>

The nature of the assistance could include helping with physical aspects of care (e.g., assisting with Activities of Daily Living (ADLs) or Instrumental Activities of Daily Living (IADLs), administering medications, caring for wounds, etc.), providing legal or financial assistance, coordinating medical and supportive care, arranging transportation, providing social and emotional support, acting as the person's legal representative, and other activities.

This broad definition of family caregiver recognizes the potential contributions of many family members (i.e., not just one primary caregiver) and includes those who live both near and far from the person with dementia. It also recognizes the dynamic nature of caregiving, in that different family members may take on multiple caregiving roles at various times throughout the course of the condition. This definition also reflects the need to consider additional family members in measure development efforts (again, not only the "primary caregiver").

<sup>b</sup> These are the conditions referred to in the *National Plan to Address Alzheimer's Disease*.

<sup>c</sup> This definition of caregiver is similar to that used by CMS; see Centers for Medicare & Medicaid Services (2007). CMS Support for Caregivers. Available at: <http://www.cms.gov/Outreach-and-Education/Outreach/Partnerships/downloads/CMSCaregivers91907.pdf>

Family caregivers typically are not paid for their caregiving activities, although they may be paid if affiliated with certain state, federal, or other programs, under certain circumstances (e.g., self-directed programs home- and community-based services (HCBS) programs through Medicaid).

Although those who provide care through the formal healthcare system (e.g., doctors, nurses, allied health professionals, direct care workers, etc.) are essential to the provision of care and support for persons with dementia, they are not included in the definition of “family caregiver” and are therefore not included in the recommendations for future performance measure development efforts in the context of this project.

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## Performance Measure

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A performance measure is a numeric quantification of healthcare quality,<sup>d</sup> resource use, cost, efficiency, or population-based attributes. Performance measures are used to quantify the performance of different aspects of the healthcare system; specifically, they aggregate data (usually, but not always, person-level data) for the entity that is being measured.

Performance measures are used for internal quality improvement efforts, accountability purposes (e.g., accreditation, certification, public reporting, and payment), or both. The ultimate goal of performance measurement is to improve the quality of care received by individuals.

Although the term “measure” sometimes is used to refer to multi-item instruments or scales used to obtain data from individuals about a particular domain of health status, quality of life, or experience with care (e.g., Consumer Assessment of Healthcare Providers and Systems [CAHPS]; Patient Health Questionnaire-9 [PHQ-9]), such

instruments or scales alone do not constitute a performance measure. However, if considered a reflection of performance, aggregated data from such instruments or scales can be used as the basis of a performance measure.<sup>e</sup>

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## Level of Analysis

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The level of analysis is the level(s) at which performance is assessed. Typically, person-level data are aggregated to assess performance at a particular level of analysis. In accountability applications, the level of analysis indicates the entity that is held accountable for performance.

*Provider-level* measures are performance measures for which the level of analysis is a provider of healthcare services (e.g., individual clinician, clinician group, hospital, clinic, nursing facility, home health agency, hospice agency, health plan, pharmacy, etc.).

*Population-level* measures are performance measures for which the level of analysis is a population (a specified geopolitical area) or some other subpopulation of individuals defined by geographical proximity, age, race, ethnicity, occupation, schools, health conditions, common interests, or any number of other characteristics.<sup>11</sup> These measures are appropriate for government, community, healthcare system, and multistakeholder accountability and can be utilized at multiple levels of analysis (e.g., state, county, city, community, etc.).

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<sup>d</sup> Healthcare quality itself is an abstract concept; it is defined by the Institute of Medicine as “the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge.” Performance measurement quantifies this abstract concept.

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<sup>e</sup> For example, NQF’s 2012 report [Patient-Reported Outcomes \(PROs\) in Performance Measurement](#) distinguishes a patient-report outcome (PRO) such as depression, a PRO measure (PROM) such as the PHQ-9<sup>®</sup> standardized tool to assess depression, and a PRO-based performance measure (PRO-PM) such as the aggregated percentage of patients with a with diagnosis of major depression or dysthymia and initial PHQ-9 score >9 with a follow-up PHQ-9 score <5 at 6 months (NQF #0711). This report uses the U.S. Food and Drug Administration definition of patient-reported outcome: “any report of the status of a patient’s (or person’s) health condition, health behavior, or experience with healthcare that comes directly from the patient, without interpretation of the patient’s response by a clinician or anyone else.” The term “patient reported outcome” has become an international term of art; the word “patient” is intended to be inclusive of all persons, including patients, families, caregivers, and consumers more broadly.



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## Community

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For this report, the term “community” is used in two different ways. First, it is used to reflect a particular subpopulation of interest (typically, but not always, defined by geography) for which performance may be assessed (see definition of level of analysis above). Second, the term also is used more broadly to describe non-medical settings in which supportive services are provided. For example, services that are provided in

locations such as the home, schools, churches, etc., would be considered “community” services (these are often referred to as “community-based” services). In contrast, services provided in settings such as hospitals, clinics, nursing facilities, etc., would not be considered “community” services. “Community-based” services may be financed via the medical system (e.g., Medicaid- HCBS) or through other mechanisms (e.g., programs funded through the Administration on Aging).

## CONSIDERATIONS FOR MEASURE DEVELOPMENT

The Committee acknowledged the many challenges of developing performance measures focused on persons with dementia and their family caregivers. Some of these challenges include:

- For the neurodegenerative conditions that are the focus of this project, there currently are no disease-modifying treatments available or any known actions for primary prevention.
- Dementia usually is a progressively debilitating and ultimately terminal condition; consequently, “typical” health outcomes may not apply, particularly in the later stages. For example, traditional outcomes such as length of survival, disease progression, and functional status may not be valid indicators of success in managing dementia, as they may be unresponsive to high quality care. Valid measures of successful treatment still need further development.
- Only about half of those who would meet the diagnostic criteria for dementia have received a diagnosis of dementia from a physician.<sup>12</sup> Because of this low diagnosis rate, it is difficult to quantify the denominator or sample population for measurement.
- Care is provided in multiple settings, within and outside of the “healthcare system,” making it potentially challenging to identify who should be held accountable for the specific care provided.
- Persons with dementia often have comorbid conditions, which can make it difficult to attribute specific symptoms or behaviors to dementia.
- Persons with dementia often rely primarily on family, friends, neighbors, or other caregivers for care and support, particularly as the condition progresses; this can place tremendous mental, emotional, financial, and physical burden on the caregiver.
- Not all persons with dementia have the support of family members or other caregivers.
- Proxy response from the family or caregiver may be needed when the person with dementia can no longer respond.
- Often measurement focused on caregivers is limited only to the “primary” caregiver; however, often many family members take on various and/or multiple caregiving roles (e.g., emergency contact, healthcare proxy, medical power of attorney, etc.) that may change over time.
- The evidence base linking many distal processes of care to desired outcomes is weak, and there may be multiple processes and structures that could be used to achieve the desired outcome.
- Various types of measures (e.g., structure, process, outcome, PRO-based, composite, etc.) could be developed from a specific measurement concept, and each has its own pros and cons; however, some measures of structures and processes may not be as meaningful to persons with dementia and their family caregivers as measures of the experience of person- and family-centered care.
- Not all processes of care and support that are important to perform need or are appropriate for performance measurement.
- Some performance measures focused on the person with dementia may allow for data collection via self-report, family caregiver proxy response, and/or staff report. Each of these approaches has pros and cons with respect to the reliability and validity of potential performance measures.
- Many care processes should be conducted repeatedly over the course of the condition, but there may not be strong evidence to support when or how often.

# CONCEPTUAL MEASUREMENT FRAMEWORK

The development of the conceptual measurement framework was an iterative process completed over the course of the project. This process was informed by the framework developed through the AD-MI project,<sup>f</sup> Committee input, and the environmental scan of measures and measure concepts (see [Figure 2](#)). The framework was used by the Committee at the in-person meeting to systematically identify and analyze gaps in performance measurement and to recommend priorities for future measure development efforts. Key points regarding the framework are as follows:

- The framework is intended to apply to various types of dementia (e.g., Alzheimer's, early-onset Alzheimer's, vascular, frontotemporal, Lewy body, mixed) and to special populations (e.g., persons with intellectual disability, including Down syndrome).
- Five overarching measurement domains (population at risk; symptom awareness and initial detection; evaluation and initial management; care, treatment, and support; and end of life and bereavement), based on the NQF [Episode of Care model](#), reflect the overall trajectory of dementia and main "categories" for potential measure development.
- The measurement domains are not "drawn to scale," other than to signal to some extent the opportunity for performance measure development. The "tails" of the domains purposefully overlap to signify the lack of "hard stops" between the domains for any particular person.
- Performance measure development for dementia should address two experiences: one for the person with dementia and another for the family caregiver.
- Measurement subdomains reflect important areas for measurement that apply, for the most part, throughout the disease trajectory. While four of the subdomains apply primarily to the person with dementia, the remainder apply to both the person with dementia and to the family caregiver.
- The need for proxy response is explicitly called out in the framework.
- The "diagnosis dots" signify the current state where a formal diagnosis of dementia may be made at any time during the course of the condition (or not at all).
- The six NQS priorities are included to denote the "North Star" for performance measure development and to help answer the overarching question of which measures are necessary to drive improvement in health and healthcare across settings of care.

## Measurement Domains

### Population at Risk

This Population at Risk domain focuses on the time period prior to the onset of dementia symptoms. Measurement for this domain is geared towards health promotion, primary prevention, and secondary prevention. However, there is opportunity for measurement to address lack of knowledge, fears, specific concerns, and stigma associated with dementia.

### Symptom Awareness and Initial Detection

The Symptom Awareness and Initial Detection domain focuses on the time period in which the symptoms of dementia initially are manifested. Specifically, dementia begins with the onset of cognitive, functional, or other noncognitive impairments that disrupts the individual's daily

<sup>f</sup> The AD-MI project is described more fully in [Appendix A](#).

life and creates challenges in planning or solving problems.<sup>13</sup> Because detection of “signs and symptoms” of dementia is a necessary step for the subsequent diagnosis and management of dementia, it is included as a distinct measurement domain.

### Evaluation and Initial Management

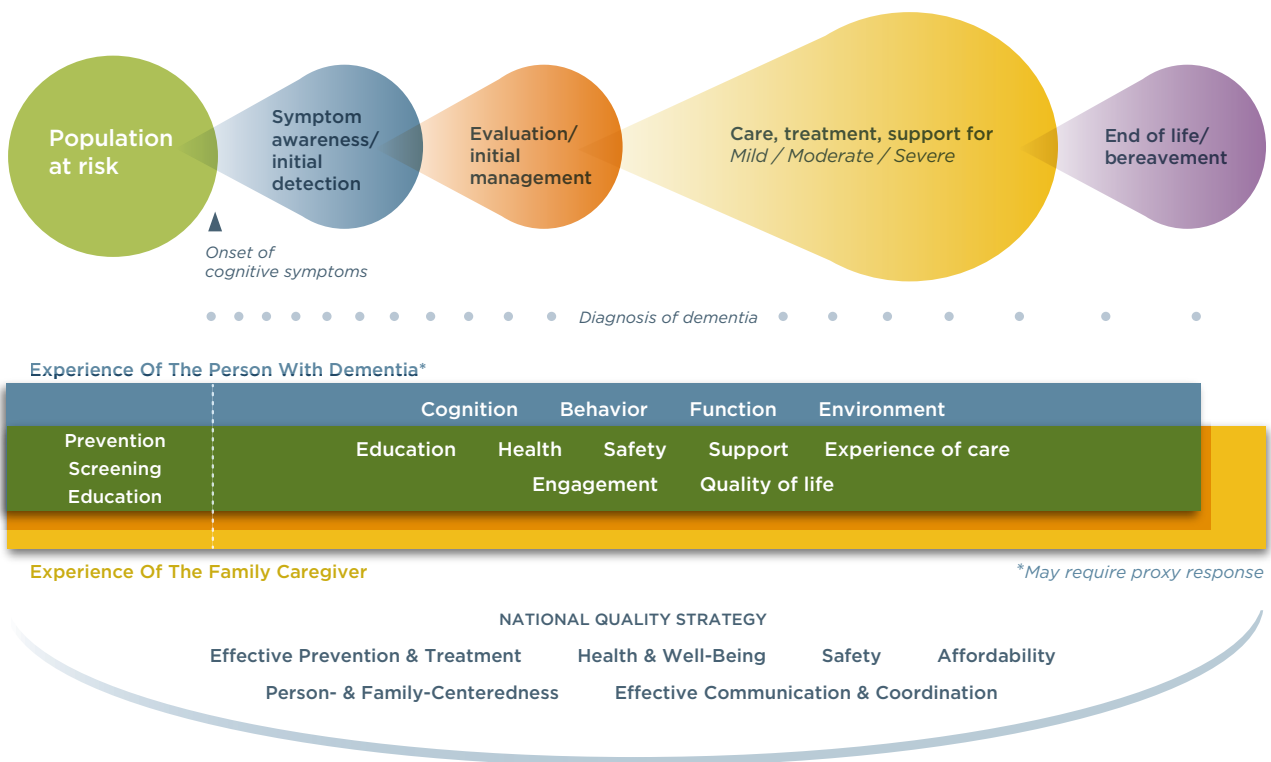
The Evaluation and Initial Management domain focuses on the period in which a healthcare professional conducts a formal evaluation in order to determine whether the person’s cognitive impairments meet the criteria for dementia. Ideally, it is during this period that a clinical diagnosis made and initial steps put in place to manage the person’s cognitive and functional impairments—although often this does not occur.<sup>14</sup> As indicated in the framework by the horizontal line of dots spanning the domains, a diagnosis of dementia may be made at any point after

onset of cognitive symptoms, although for some people, the diagnosis will not be made at all. Yet establishing a diagnosis is important to the person with dementia so that appropriate treatment and management are initiated. A formal diagnosis also is important for the family caregiver because care planning, services, and supports often become available only after a diagnosis is made. Various quality improvement opportunities related to the diagnosis of dementia were raised by the Committee, including:

- Failure to appropriately diagnose the level of cognitive impairment and/or underlying disease pathology (misdiagnosis)
- Failure to communicate the diagnosis to the person with dementia and the family caregiver
- Lack of provider knowledge or training on how to best communicate the diagnosis so that

FIGURE 2. CONCEPTUAL MEASUREMENT FRAMEWORK

CONCEPTUAL MODEL FOR PERFORMANCE MEASURE DEVELOPMENT FOR DEMENTIA:  
Maximizing quality of life, minimizing distress



the person with dementia and/or their family caregiver understands the ramifications of the diagnosis

- Issues related to documenting the diagnosis so that it is available across providers and settings of care

A structured, advanced care planning process based on the goals of the person with dementia as well as the family caregiver also should commence during this period. This process should include an upfront discussion about person-centered goals and advanced care planning for the person with dementia, appropriate documentation of these goals and desires, and periodic review and revision of the care plan, as needed, by all participants in the care plan, including the person with dementia and the family caregiver.

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### Care, Treatment, and Support

The Care, Treatment, and Support domain focuses on the stages of dementia (mild, moderate, severe) and encompasses the wide range of interventions that are used to manage dementia symptoms and support the person with dementia and the family caregiver. This period, and the three stages of dementia that it encompasses, arguably may offer the most opportunities for performance measurement for persons with dementia and their family caregivers because the types and levels of necessary care, treatment, and support typically will change as the condition progresses. Moreover, often persons with dementia receive care and support in both medical and community settings; this can result in a lack of comprehensive and coordinated care.

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### End of Life/Bereavement

The End of Life and Bereavement domain focuses on the period of advanced dementia and also captures the bereavement period experienced by the family and other caregivers. Perhaps even more than with the other domains, a “hard

stop” between this and the preceding domains should not be assumed. For example, many of the care processes relevant to the “severe” stage of dementia are applicable near the end of life. Furthermore, although diagramed at the end of the dementia trajectory and focused primarily on the family caregivers, bereavement actually begins much earlier, as both the person with dementia and the family caregiver learn to cope with the progressive losses associated with the condition.

## Measurement Subdomains

With the exception of the Prevention and Screening subdomains, all other measurement subdomains span the trajectory after onset of cognitive symptoms. However, the specific focus of the subdomains may change over the course of the dementia. For example, when cognitive symptoms first arise, support needs for the person with dementia may be relatively minor, but these likely will increase as dementia progresses. Similarly, the health, safety, and support needs of the family caregiver may become more pressing as the burden of caregiving increases. Most of the subdomains are applicable to both the person with dementia and the family caregiver (although the focus of performance measurement would be different for the two groups).

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### Prevention and Screening

These subdomains pertain to those at risk of dementia, many of whom are (or will become) family caregivers of someone with dementia, will go on to develop dementia themselves, or both. Current performance measurement opportunities for these subdomains are limited due to the lack of preventive therapies and effective methods to identify dementia prior to symptom onset. They are included in the framework as placeholders, with the assumption that, as research in these areas evolves, performance measurement opportunities will arise.

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## Education

The Education subdomain applies to both the person with dementia and the family caregiver and is relevant to all of the measurement domains to a greater or lesser extent. For those at risk of dementia, education is needed to address lack of knowledge and awareness among the general public and among care providers (both medical and community-based) about dementia and its warning signs. After the onset of dementia symptoms, education is needed on a continual basis to inform persons with dementia and their family caregivers about treatment and support options and to ensure that family caregivers are prepared and able to provide the necessary care for their loved ones and be confident in doing so. Topics for potential measure development addressing this subdomain could include adequacy and effectiveness of education about the condition itself as well as potential cognitive, functional, and behavioral changes; available services and supports, including support groups and other means of emotional and social support; and the importance of having purpose and meaningful activities in daily life to support well-being.

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## Cognition, Behavior, and Function

The Cognition, Behavior, and Function subdomains apply to the person with dementia. They represent the three major components of health and well-being affected by dementia. Assessments of cognitive, functional, and behavioral status for the person with dementia should be conducted as part of a diagnostic evaluation when signs and symptoms of dementia are recognized. Such assessments should be repeated at regular intervals throughout the course of the person's dementia because both cognitive and functional impairments typically become more significant as the condition progresses and the type and intensity of behavioral symptoms also change over time. Likewise, various types of care, treatment, and support for these issues, as necessary and

appropriate, also should be provided throughout the course of the person's dementia.

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## Environment

The Environment subdomain applies to the person with dementia, reflecting the need for measure development pertaining to the "built environment" (e.g., safety in the home, access to necessary transportation, etc.). Although overlapping with both the Safety and Care, Treatment, and Support subdomains, it is separated out to emphasize its importance.

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## Health

The Health subdomain applies to both the person with dementia and the family caregiver. Those with dementia typically have other comorbidities that must be considered in tandem with the dementia; moreover, the dementia may complicate the care and treatment for other conditions, particularly as the dementia progresses. The mental, emotional, physical, and financial stresses of caring for persons with dementia can instigate or exacerbate a variety of mental and physical health problems in family caregivers.<sup>15</sup> Furthermore, if caregivers do not have the appropriate support or if they are neglecting their own health, their ability to care for the person with dementia may be negatively impacted.

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## Safety

The Safety subdomain applies to both the person with dementia and the family caregiver and is included to reflect the need for measurement to address safety considerations. For example, people living with dementia are at greater risk for unintentional harm resulting from impaired decisionmaking (e.g., medication and financial mismanagement, driving habits, etc.). Safety precautions may be particularly important for persons with dementia who live alone. The safety of the family caregiver also is vital, as injury can impact caregiving capacity.

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## Support

The Support subdomain applies both to persons with dementia and their family caregivers. For the person with dementia, this subdomain is meant to capture a wide range of “support” activities including ADL/IADL assistance, care management, financial planning, etc. For the family caregiver, this subdomain reflects the “infrastructure” needed first to understand the capacity of the family caregivers for the various caregiving roles and then to increase that capacity to the extent possible (e.g., through one-on-one counseling, support groups, help with financial planning, respite care, coordination of supportive care, etc.).

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## Experience of Care

The Experience of Care subdomain is relevant to both the person with dementia and the family caregiver. Performance measures assessing experience of care information can inform providers about their provision (or not) of person- and family-centered care, including care that incorporates the preferences and goals of the person with dementia and his or her family caregiver. These outcomes may be as simple as persons with dementia reporting that they have received information about their condition and are confident that their doctor knows how to provide care for them. Likewise, experience of care outcomes for caregivers could include reporting that they know where to turn for help in managing dementia-related problems, that they know how to

access relevant community resources, or that they are confident in their abilities to manage dementia care. Such person-centered outcome measures may be even more meaningful to persons with dementia and their family caregivers than structural or process measures such as whether or not a clinician has a referral program in place or whether or not a clinician offered an educational session on behavioral symptom management.

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## Engagement

The Engagement subdomain applies to both the person with dementia and the family caregiver. Performance measures of engagement reflect the involvement of persons with dementia and their family caregivers in managing and evaluating their health and healthcare, and in making decisions about their care. For example, engagement measures may address involvement in care planning or access to and use of information, tools, and support systems for navigating the healthcare system and making informed decisions.

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## Quality of Life

The Quality of Life subdomain reflects general well-being and applies to both the person with dementia and the family caregiver. Although disease-modifying therapies for dementia itself are lacking, there are ways to support the quality of life that are vital to the health and well-being of the person with dementia and their family caregivers during all stages of the condition.<sup>16</sup>



# IDENTIFYING MEASUREMENT GAPS

Building on the work of the AD-MI project, an environmental scan for performance measures and concepts applicable to dementia was conducted as part of this project. Results were mapped to the NQS priorities and the measurement domains and subdomains identified in the conceptual measurement framework in order to identify measurement gaps.<sup>g</sup> It is important to note that this environmental scan purposively does not encompass the universe of measures that are indirectly related to dementia. Also, the environmental scan does not include surveys or other instruments/scales that are related to dementia, although many are reliable and valid and thus could be used as the basis for performance measure development. Additional information about the sources of information and results of the scan are included in [Appendix E](#). As an addition to the environmental scan of performance measures, participants in the AD-MI project updated their initial compilation of clinical practice guidelines related to dementia<sup>h</sup> for inclusion in this report (see [Appendix F](#)).

## Measurement Gap Analysis

A total of 125 dementia-specific performance measures and concepts were identified in the final [environmental scan](#). A total of 60 U.S. measures were identified and a total of 65 international<sup>i</sup> measures were identified. Of the 125 measures, 96 focused on the person with dementia, 14 focused

on the family or caregiver,<sup>j</sup> 9 focused on both, and the remaining 6 were structural measures that focused on availability of services or training. Not surprisingly, the scan did not identify measures directed to the population at risk; however, each of the other measurement domains is reflected in the identified measures. Also, except for Affordability, all of the NQS priorities are represented in the dementia-specific measures that were identified. More measures than expected were mapped to the Symptom Awareness and Detection domain, although this may reflect the somewhat overlapping nature of this domain with that of the Evaluation and Initial Management domain.

This analysis indicated that there are more U.S. measures under the cognition, behavior, support, and safety subdomains than under the other subdomains. Few measures were identified that assess functional status/symptoms, suggesting that others likely are needed. Of note is the absence of experience of care and quality-of-life measures. The findings for the international measures were similar, although there were substantially more measures of support than were found among U.S. measures. Based on this analysis of dementia-specific measures, the following represent current gaps in performance measurement for dementia:

- Measures for family caregivers
- Outcome measures, especially those regarding quality of life and experience with care
- Measures of affordability
- Measures of health and well-being for family caregivers

g Many of the measures could have been mapped to multiple domains, subdomains, or priorities; to the extent possible, however, NQF staff tried to be consistent in the mapping exercise.

h Foundation for the National Institutes of Health (FNIH). Alzheimer's Disease Measurement Improvement (AD-MI) December 3rd, 2012 AD-MI Conference Meeting Materials. Alzheimer's Disease Measurement Improvement Conference, Baltimore, MD.

i NQF scanned for measures from France, Australia, Canada, and the United Kingdom (UK), including Scotland; however, these results are not meant to be an exhaustive list of all dementia-specific international measures.

j Although a multitude of surveys, scales, or assessment tools used to assess caregivers were identified during the scanning process, few dementia-specific performance measures or measure concepts were found.



- Person- and family-centered measures, including measures of engagement with the healthcare system or other community support systems

## Other Measures Applicable to Those with Dementia and Their Family Caregivers

As noted earlier, the measures described above are those that apply specifically to the dementia population or to their family caregivers. However, it is important to understand that many other performance measures that are not dementia-specific can be used for these groups, assuming that it is possible to identify persons with dementia for the purposes of data analysis. Although it is beyond the scope of this project to report on all such measures, examples of these types of measures include:

**Condition-specific measures** – These are measures that apply to populations with specific medical conditions other than dementia (e.g., persons with diabetes or who have had a stroke). Performance results for such measures can theoretically be stratified by dementia status (assuming these data are available). Such measures may be particularly salient given that a substantial proportion of persons with dementia also have other conditions.<sup>17</sup> However, it is important to note that not all condition-specific measures may be appropriate for all persons with dementia; for example, a general target level for blood glucose control may not be suitable for someone with severe dementia. Thus, the information garnered from stratification of such measures should be interpreted and acted upon with caution.

**Cross-cutting measures** – Cross-cutting measures are those that cut across specific disease categorizations. Examples of cross-cutting measures include general patient-safety measures, measures of care coordination, palliative care and end-of-life measures, quality-of-life measures, measures of engagement, and measures focused on caregivers.

**Setting- or program-specific measures** – Some measures are specific to certain subpopulations, often defined by care setting or program enrollment (e.g., nursing home measures; measures targeted to those receiving Medicare home health benefits). Experience of care measures often fall into this category. Measures of long-term services and supports (LTSS) also fall into this category, and are discussed more fully below.

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### LTSS Measures

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Because persons with dementia often need LTSS<sup>k</sup>, especially as the condition progresses in severity, NQF conducted a brief search for dementia-specific measures related to LTSS as part of the environmental scan for this project. As discussed in RAND's *Improving Dementia Long-Term Care – A Policy Blueprint*,<sup>18</sup> a majority of LTSS (for all conditions, not solely dementia) are provided by unpaid, family caregivers. Medicaid finances much of the paid LTSS, with an increasing proportion of these services provided in home and community-based settings rather than in institutional settings. While most States include LTSS-specific measures in their quality management programs, there is no uniform set of measures used in each State.<sup>19</sup> Several scans for Medicaid HCBS measures have been conducted, including a compilation of potential measures conducted by NQF's Measure Applications Partnership's Dual Eligible Beneficiaries Workgroup in 2012.<sup>20</sup> However, these scans revealed no dementia-specific performance measures for HCBS in use at that time.<sup>l</sup>

Many measures in the above categories can be applied “as is” to those with dementia and their

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k Long-term supports and services includes those provided in institutional settings (e.g., nursing facilities) as well as those provided in community settings (i.e., HCBS).

l “Dementia” is not a statutory target group under Medicaid, although some states have chosen to provide HCBS to people with certain mental disorders. It was beyond the scope of this project to conduct an in-depth investigation of individual state Medicaid programs as part of the scan. However, it is likely that some states have or soon will implement dementia-specific measures for their programs. Possible examples of state programs with dementia-specific measures include Ohio, which recently began a pilot project aimed at reducing the use of atypical antipsychotic medications among long-term nursing facility residents with dementia, and Florida, which has a 1915 (c) waiver program specific to the Alzheimer's population.

family caregivers, although others may need some re-specification in order to be applicable (for example, some measures specifically exclude those with cognitive impairments). In some cases, it may not be advantageous to advocate development of very narrowly defined measures—such as heart-failure mortality among those diagnosed with dementia. Instead, when appropriate, users could be encouraged to stratify the results of the nondementia-specific measures to gauge performance for those with dementia. Again, as noted earlier, use of information from stratified analyses should be considered carefully. For example, differences in performance rates on a heart failure measure for individuals with dementia versus those without dementia may be as expected; on the other hand, such differences may signal a need to examine and/or modify existing care processes for persons with dementia.

## RECOMMENDATIONS FOR PERFORMANCE MEASURE DEVELOPMENT

Committee members developed a symptom and needs grid (see [Appendix C](#)) and a measurement concepts grid (see [Appendix D](#)) over the course of the project. The symptoms and needs grid—which can be used to help conceptualize potential measures—is organized by the five measurement domains from the conceptual measurement framework; the measurement concepts grid is organized by the measurement subdomains from the conceptual measurement framework. Although not exhaustive, the grids were informative for refining the conceptual measurement framework, illustrating additional measurement gap areas, and serving as a starting point for the prioritization process during the Committee's in-person meeting.<sup>m</sup>

During the meeting, the Committee participated in two rounds of voting to prioritize its recommendations for future performance measure development. In the first round, subgroups of members identified, for specific measurement domains, their top choices for measure development for both the person with dementia and for the family caregiver. After discussion of those recommendations by the full Committee, members then identified their top priorities through a second round of voting.

Neither NQF nor the Committee developed a set of criteria to use in the prioritization process. Instead, Committee members used their own judgment to balance the need for measures that are:

- Appropriate for internal quality improvement efforts, accountability applications, and/or both

- Varied in type, including not only simple process measures but also composite measures and outcome measures
- Useful for accountability at various levels within the healthcare system (e.g., for individual providers, teams, health plans, accountable care organizations [ACOs], etc.) as well as outside of the healthcare system (e.g., population-level measures for use at the community, county, or state level)
- Supported by empirical evidence, and thus likely suitable for NQF endorsement
- Applicable to the broadest population and settings possible, yet still appropriate for use with minority or other high-risk populations affected by dementia
- Feasible to implement in the short-term
- Aspirational in nature, either because of shortcomings in data sources or in the underlying science to date
- Responsive to various kinds of measurement gaps (e.g., no measures exist at all; measures exist but could be improved by expanding the target population or adding different levels of accountability; moving from simple process measures to composite or outcome measures, etc.)

### Overarching Themes

Several overarching themes emerged during the Committee's discussion over the two-day in-person meeting; all are included to some extent in members' recommendations for prioritization of measure development efforts.

<sup>m</sup> These grids were developed as an interim tool to help Committee members organize their thinking about potential measurement opportunities and were not meant to be stand-alone products of the Committee; they are included in this report for informational purposes only.

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### Importance of Connection to Community-Based Services

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The theme most often reiterated throughout the Committee's discussion is the vital role that communities play in the care of those with dementia and their family caregivers. Inherent in this theme is the idea that high-quality care for people with dementia and their family caregivers must involve both traditional medical providers as well as community-based providers of services and supports. Committee members emphasized the importance of community connections prior to onset of symptoms (to maximize awareness and recognition of signs and symptoms of dementia, which should lead to detection and diagnosis) as well as afterwards, when many varied supportive services are required. For this to happen, information flow between medical and community care providers must improve, and barriers that impede the communication of full and timely information must be dismantled.

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### Need for Accountability at the Community Level

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The Committee stressed the need for population-based measurement and accountability at the community level. This type of measurement and accountability allows for the examination of performance of the community as a whole. Such measurement would encompass both "community-based" care as well as care provided in formal healthcare settings located in the community (e.g., hospitals, nursing facilities, etc.). Thus, population-based measurement and accountability at the community level does not mean just measuring community-based care, but measuring all aspects of care in the community.

The Committee also emphasized the need to hold individuals organizations—including community-based providers and medical providers—accountable for providing high-quality care and support (including referral, as needed, to other appropriate providers) to those with dementia and their family caregivers. Members noted that

although many community agencies receive federal or state funding to provide dementia-related services and supports (e.g., through state block grants, the Medicaid program, etc.), they may not currently be subject to performance measurement or accountability that is required of providers in the formal healthcare system (e.g., home health agencies, nursing facilities, etc.). At the same time, the Committee recognized that community agencies' capacity to provide high-quality care often depends on timely and complete information from medical care providers.

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### Person- and Family-Centeredness

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The importance of person- and family-centered care, which incorporates attention to the emotional, social, and spiritual components of well-being as well to its physical components, also was central to the Committee's deliberations and recommendations. Members supported the definition<sup>n</sup> and core concepts<sup>o</sup> of person- and family-centered care developed by a separate **NQF-convened Committee** tasked with envisioning ideal person- and family-centered care and using the resulting construct as a framework to make recommendations for performance measurement to advance such care.

In their deliberations for this project, Committee members specifically voiced the importance of:

- Family caregiver engagement in the care process, starting at the time when signs and symptoms of dementia are first noticed (often by the family caregiver) and continuing throughout the course of the person's dementia
- Allowing the person with dementia and the

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n An approach to the planning and delivery of care across settings and time that is centered on collaborative partnerships among individuals, their defined family, and providers of care. It supports health and well-being by being consistent with, respectful of, and responsive to an individual's priorities, goals, needs, and values.

o Individualized care; family; respect, dignity, and compassion; information sharing/communication; shared decisionmaking; self-management; and access to care/convenience.

family caregiver to define their own goals to enhance well-being and quality of life, including both short-term and longer-term goals

- Individual and family access to information, particularly about the actual diagnosis, whether dementia or some other condition
- Adherence to the person's and family's preferences, with acknowledgment that those preferences may not always align and also may change over time
- Autonomy over everyday decisions to the extent possible for the person with dementia as well as for the family caregiver (recognizing that desires sometimes may differ)
- Considering family caregivers to be valuable sources of information about the quality of the care provided to the person with dementia
- Understanding that not everyone will desire the same outcomes for care, resulting in the need for personalized (or individualized) measurement
- Understanding that there may be trade-offs when providing person- and family-centered care; this may be especially true with safety issues
- Understanding that the needs of the person with dementia may be different than those of the family caregiver and that providers must engage with both; such efforts may need to occur separately, especially in the earlier stages of the condition when the person with dementia has the capacity to participate actively in his/her care

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### Diagnostic Accuracy

Several times throughout their discussions, Committee members emphasized the need for accuracy in determining a dementia diagnosis, including the etiology of the impairment as well as its severity. They noted that changes in cognition may be due to causes other than dementia (e.g., medication side effects). In addition, they noted

that the condition may be caused by a variety of pathologies (e.g., vascular; Lewy body, etc.), so that the scope of the work-up may vary depending on suspected etiology. They also highlighted the fact that cultural influences, language difficulties (e.g., communication with non-English speakers), and even levels of health literacy can confound the diagnostic process. Members also stressed the complexity of diagnosis in those with intellectual disabilities (e.g., Down syndrome), noting the sequential nature of the diagnostic process that is needed to determine whether cognitive or other declines are due to an underlying dementing disease or are instead a function of pre-existing intellectual disability.

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### Safety

A final overarching theme addressed by the Committee is that of the safety of persons with dementia, and the need to be mindful of and alert for issues of safety throughout the course of the condition. Members noted several obvious safety concerns for the person with dementia (e.g., falls, driving, other environmental safety issues, medication administration and/or management, wandering behaviors, impaired decisional capacity, financial safety, etc.). They also listed other—perhaps less recognized—concerns, including caregiver capacity to ensure safety while providing care in the home environment, the safety of others when interacting with someone with dementia who exhibits behavioral issues, management of co-existing medical conditions, and potential for abuse and neglect (even self-neglect) of the person with dementia.

Committee members acknowledged the trade-offs that may be necessary when trying to ensure both safety and autonomy (particularly in the home environment) or safety and person-centeredness (particularly near the end of life). They also noted the difficulties in holding providers accountable for safety when the person with dementia is living in a community setting, including situations in which the person with dementia lives alone.

## Top Priorities for Measure Development

Through the voting process described above, the Committee identified the following three concepts as its top priorities for future measure development:

- Composite measure of comprehensive diagnostic evaluation and needs assessment
- Composite measure of caregiver support
- Measures to reflect a dementia-capable healthcare and community care system

Members further refined these concepts during subsequent discussion, including offering input regarding measure construction, sources of data, and/or levels of accountability, as discussed below.

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### Composite Measure of Comprehensive Diagnostic Evaluation and Needs Assessment

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The first priority for future measure development identified by the Committee was to measure the delivery of a comprehensive assessment to establish the diagnosis of dementia, identify (and treat, if possible) contributing factors, identify support needs, and formulate a care plan—all within a reasonable timeframe and with proper documentation. Members supported the development of a measure that would include, at minimum, the following elements:

- Establish an accurate diagnosis of dementia, including the etiology and severity
  - Obtain a dementia-relevant history (includes approximate date of onset, presenting symptoms, progression of symptoms)
  - Conduct an objective cognitive examination
  - Conduct a medical evaluation to rule out other disorders and identify contributing factors (includes performing laboratory tests, conducting a focused physical exam, and identifying/eliminating high-risk medications)

- Determine functional status, living arrangements, and impact on family
- Assess needs of person with dementia
  - Complications of dementia (e.g., mood disturbance, behavioral symptoms, falls)
  - Need for social- and community-based services (e.g., adult day health)
  - Legal and financial needs
- Assess resources of the person with dementia
  - Caregivers (e.g., number, identity, availability, whether paid or unpaid)
  - Financial resources
- Evaluate driving status and other safety concerns (e.g., firearms, home safety)
- Identify a proxy/spokesperson for decisions that the person with dementia cannot or will not be able to make in the future
- Facilitate use of advance directives (e.g., documenting the discussion in the health record or creating the directive and documenting it in the health record)
- Identify caregiver needs (at baseline)
  - Strain and depression
  - Willingness to take on caregiving tasks
  - Confidence in ability to manage the condition and its complications
  - Knowledge of available resources
  - Referral for services (e.g., support groups, respite care) and training (e.g., skills for managing problem behaviors; empowering partnership with providers, etc.)

Committee members noted that performance measures for many of the above elements already exist (see [environmental scan results](#)). With this recommendation, however, members signaled their view that high-quality care at the evaluation/initial management stage should include all of the above elements. Clearly, the measurement structure of



the measure as a whole, as well as the content and structure underlying each of the elements, would need further development and specification. For example, the overall measure might be formulated as a clinimetric composite (i.e., where the component measures are considered to cause, or define, quality), with weighting of the components determined by expert consensus. Similarly, the “subelements” of a dementia-related history could include various components, such as estimated date of onset and course of symptoms, history of head trauma, family history of dementia, etc., that could be structured as a composite measure (with various options for aggregation and weighting) or as an individual measure including both required and optional components. Regardless, development of this measure can take advantage of research, testing, and lessons learned from previous development efforts.

The Committee suggested that the various elements in this measure should be completed within three to six months of initial presentation of signs and symptoms suggestive of cognitive impairment to a healthcare provider and/or the “detection” (i.e., recognition) of cognition-related decline by a healthcare provider. Diagnostic evaluation by the healthcare provider should be initiated immediately upon suspicion of cognitive impairment, which typically would include the application of a validated cognitive assessment tool.<sup>p,q</sup> More complicated or atypical presentations may require referral to a dementia specialist. Initial

suspicion or recognition of potential cognitive impairment could be based on observations of the person himself/herself, the family, or the healthcare provider.<sup>r</sup> Although some elements of this comprehensive assessment most likely would be completed only after a definitive diagnosis of dementia, limiting the measurement timeframe to no more than six months postdetection would ensure timely diagnosis and appropriate initial management of the condition.

Committee members also made some suggestions about ways to identify the denominator for the proposed measure. For example, ideally the denominator could be constructed to capture all persons with suspected cognitive impairment (some who are subsequently diagnosed with dementia and some whose cognitive or other problems are found to be reversible or not severe enough to be classified as dementia). However, current International Classification of Disease (ICD) codes do not consistently and accurately reflect assessment for suspected cognitive impairment or presentation with signs or symptoms of dementia; neither is it likely—at this time—that problem lists from electronic health records (EHRs) can be used, either alone or in addition to ICD codes, to reliably identify such a denominator. Another option might be to limit the proposed measure to certain specialist providers (e.g., neurologists, geriatricians, geriatric psychiatrists) who could more accurately determine the appropriate denominator; however, this approach would capture only a small percentage of those with dementia.

A more feasible approach—at least for the present—would be to include in the denominator only those with a new diagnosis of dementia with a certain timeframe. This would exclude those determined to have delirium or mild cognitive impairment, or those whose cognitive

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p Care should be taken to select an appropriate assessment tool, as some commonly used tools are not suitable for some specific subpopulations, where language or function may compromise the usefulness of the tool. For example, the functional skills of adults with intellectual disability may vary sufficiently so as to render most general tools ineffective. Specific tools have been developed for use with people with lifelong limited cognitive function.

q Various publications and resources about cognitive assessment tools exist, including the *NIH Toolbox for Assessment of Neurological and Behavioral Function* (Gershon et al, 2013), *Alzheimer’s Association Recommendations for Operationalizing the Detection of Cognitive Impairment during the Medicare Annual Wellness Visit in a Primary Care Setting* (Cordell et al, 2013), and *Tools for Screening, Identification, Referral, and Care Planning for People with Alzheimer’s Disease and Their Caregivers* (Lines et al, 2013).

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r Although completion of a comprehensive diagnostic evaluation and needs assessment is the ideal, the Committee acknowledged that in some cases the individual may be able to demonstrate decisionmaking capacity and refuse further evaluation against medical advice.

impairment has resolved. The measure would need to incorporate a look-back period from the date of diagnosis (e.g., three months) to ascertain whether the diagnosis was made in a timely manner, as well as a prospective approach to verify that steps subsequent to diagnosis also are conducted in a timely manner (e.g., three months postdiagnosis). This approach would not allow for the identification of those who should have had a diagnostic evaluation but did not, those who had the diagnostic evaluation but were diagnosed with something other than dementia, and those with a long-standing diagnosis of dementia. Also, it is possible that a measure specified in this manner could have the unintended consequence of disregarding a person's cognitive impairment (so as to avoid being assessed on the measure); however, it is unclear whether and to what extent that might occur.

Committee members acknowledged the challenges of data collection for this proposed measure. Currently, a few of the elements could be retrieved from claims data or other types of electronic sources such as lab or pharmacy systems, but most would require labor-intensive chart review of paper or EHR-based medical records. An aspirational goal would be for retrieval of the various elements from defined EHR fields using eMeasure specifications.

Finally, Committee members agreed that the proposed measure could be used for multiple levels of accountability, including the individual clinician or clinician group level, the facility level (e.g., home health agencies or nursing facilities), as well as at a system level (e.g., health plan, ACO, or other integrated health system). The assumption underlying clinician-level accountability is that the provider who makes the diagnosis of dementia—whether a specialist or generalist—should be able to conduct the necessary assessments and/or make appropriate referrals and connections to resources outside the traditional medical care system.

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### Composite Measure of Caregiver Support

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The Committee's second priority area for future performance measurement development addresses the family caregiver trajectory reflected in the conceptual measurement framework. Specifically, Committee members recommended development of a composite measure of caregiver support that includes, at minimum, the following elements:

- Assessment of needs and expectations
- Timeliness of communication
- Training and education (including information on what to expect regarding prognosis, complications, and treatment options, as well as specific skills training for providing care at home)
- Responsiveness to caregiver input
- Need for family caregiver advocacy when the system is nonresponsive to needs/expectations

Members noted the need to obtain data for the elements of this composite directly from the family caregiver. Ideally, therefore, the various elements would be outcome measures reflecting the experience of the family caregiver rather than measures of providers' care processes (e.g., perceptions of understanding of treatment options rather than whether treatment options were discussed; self-perceptions of competency in caregiving).

Much of the Committee's discussion about this priority area related to who should be held accountable for provision of caregiver support. Ultimately, members agreed that both the healthcare system and the broader community are responsible for improving support for caregivers of those with dementia and that the elements listed above fall within the domains of both systems. In terms of healthcare system accountability, members agreed that individual physicians should not be excused from providing and improving support in these areas (i.e., they



should at a minimum know what services exist and how to refer to them). However, they also noted the value of a multidisciplinary, team-based approach in dementia care, denoting the need for accountability at other levels than just the physician level (e.g., team, ACO, etc.).

Committee members also noted the need to measure other facets of family caregiver support, although these were not included explicitly as part of the composite measure proposed above. These other facets of support include the following:

- Capacity for providing care
- Confidence in providing care
- Burden and strain associated with caregiving roles and activities
- Participation in decisionmaking
- Access to and efficacy of support services (e.g., counseling, support groups)
- Quality and usefulness of the communication to and from the caregiver

Depending on how a caregiver support composite is conceptualized, these topic areas also could be included as components.

Finally, it is worth noting the overlap between this recommendation and the previous one, particularly as both include assessment of family caregiver needs. A major difference between the two recommendations is in the timing of the proposed measures. As mentioned earlier, the comprehensive assessment should be done soon after recognition of cognitive impairment, and the proposed measure reflects that timing. Conversely, the supportive actions catalogued in the second recommendation are most relevant after the initial management phase and should be repeated throughout the trajectory of the condition.

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### Dementia-Capable Healthcare and Community Care System

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Unlike the first two priorities recommended by the Committee, the third priority is both conceptual

and aspirational in nature. Specifically, members recommended addressing the need for measures of “dementia capability” for both the healthcare system and for community systems.

A dementia-capable healthcare system is one that is sensitive to dementia.<sup>s,t</sup> Such a system would view the care for other medical conditions “through the lens of dementia.” Examples of this sensitivity would include recognizing and taking into account that persons with dementia:

- may not have the ability to manage their other health conditions optimally (e.g., they may not be able to take medications appropriately)
- may be more vulnerable to adverse events in institutional settings (e.g., more likely to wander or fall while hospitalized)
- may need special considerations for care delivery (e.g., a quiet, soothing environment to minimize anxiety during a routine clinician office visit)

Few, if any, existing performance measures assess the adaptability of the healthcare system to these realities, and thus development of such measures at all levels of accountability is needed.

A dementia-capable (or dementia “friendly”) community is mindful of people with dementia, with the capacity to support both them and their family caregivers as needed throughout the duration of the condition.<sup>21</sup> Efforts are underway in several U.S. states, as well as internationally (e.g., in the United Kingdom), to increase dementia capability at the community level. Facets of dementia capability can include, but are not limited to:

- Increasing the awareness of signs and symptoms of dementia

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s See September 2014 issue brief and toolkit on dementia-capable states and communities from HHS’ Administration for Community Living: [http://www.aoa.acl.gov/AoA\\_Programs/HPW/Alz\\_Grants/](http://www.aoa.acl.gov/AoA_Programs/HPW/Alz_Grants/)

t See Clinics in Geriatric Medicine article, Developing Dementia-Capable Health Care Systems: A 12-Step Program (Borson and Chodosh, 2014)

- Identifying people with signs or symptoms of dementia
- Treating those with dementia and their family caregivers with respect
- Reducing the stigma associated with dementia
- Providing information, referral, support, and counseling
- Considering cognitive impairment, in addition to other functional impairments, when making eligibility determinations
- Ensuring that the health workforce is trained to care for people with dementia and assist their family caregivers
- Ensuring access to financially, geographically, and culturally accessible services that provide care and support to optimize the physical, cognitive, emotional, and spiritual health and well-being of those with dementia as well as their family caregivers (e.g., adult day care, transportation, home-delivered meals, respite care, etc.)

Community-level performance measures of dementia capability can be specified at the programmatic level (e.g., Area Agencies on Aging) or at various geographic levels (e.g., community, state, region). Although development of performance metrics to assess dementia capability at the community level is in its infancy, there has been some progress, especially in states participating in the Alzheimer's Disease Supportive Services Program under the HHS' Administration for Community Living. For example, a self-assessment tool for gauging the dementia capability of states' LTSS system<sup>u</sup> includes items on the availability of protocols for identifying those with dementia and making appropriate referrals. These items—and others

like them—could be the foundation of relatively straightforward structural measures to assess dementia capability. As an example of recent work in this area, the Minnesota ACT on Alzheimer's initiative<sup>v</sup> has developed a framework for quality measurement to evaluate progress in communities that are trying to become dementia capable. The initiative developed a *Dementia Capable Communities Toolkit*<sup>w</sup> to guide the community engagement process and provide materials to help with implementation. Potential process measures could evaluate a community's use of ACT on Alzheimer's tools to assess community needs and the community's progress in encouraging local organizations and care settings to change existing practices and add services that will increase dementia capability. Outcome measures could include increased community awareness, detection of dementia, identification of family caregivers, and ability of clinical and professional staff in various care settings to support persons with dementia and their family caregivers throughout the course of the dementia.<sup>x</sup>

## Additional Priorities for Measure Development

Although the Committee identified the concepts described above as its highest priority areas for measurement, members were clear that additional topic areas also should be addressed in future performance measure development. These additional priority areas are discussed below.

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### Early Detection of Signs and Symptoms of Dementia

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Throughout the course of the project, the Committee noted the need for earlier and increased detection of dementia, as signaled by

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<sup>u</sup> HHS, Administration on Aging. Learning Collaborative Quality Assurance Tool. Alzheimer's Disease Supportive Services Program website. [http://www.aoa.acl.gov/AoA\\_Programs/HPW/Alz\\_Grants/docs/Learning\\_Collaborative\\_Quality\\_Assurance\\_Tool-FINAL.pdf](http://www.aoa.acl.gov/AoA_Programs/HPW/Alz_Grants/docs/Learning_Collaborative_Quality_Assurance_Tool-FINAL.pdf). Last accessed September 2014.

<sup>v</sup> ACT on Alzheimer's website. <http://www.actonalz.org/>

<sup>w</sup> ACT on Alzheimer's, (2012) "Communities ACT - Dementia Capable Communities Toolkit," accessible at <http://www.actonalz.org/node/111>.

<sup>x</sup> Paone, D. (2013) "Paone Logic Model for ACTION Communities," accessible at [http://actonalz.org/download/Paone\\_LogicModel\\_Communities.pptx](http://actonalz.org/download/Paone_LogicModel_Communities.pptx)

the inclusion of the Symptom Awareness/Initial Detection domain in the conceptual measurement framework. The benefit of improved diagnostic processes and accompanying quality measures cannot be realized if the first step along that pathway (i.e., detection) is not addressed in a timely manner. Committee members noted that the Medicare Annual Wellness Exam includes “detection of cognitive impairment” as one of its core components, which further highlights its importance.<sup>y</sup>

Members acknowledged the ambiguity in the term “detection,” but in general agreed that detection may be defined, for the purposes of this project, as the recognition of people who have signs and/or symptoms of cognitive impairment that indicate the need for a diagnostic evaluation in order to determine the specific cause of the impairment (i.e., some type of dementia or some other, possibly reversible, cause).

In their discussion about the importance of awareness of the signs and symptoms of dementia, Committee members agreed that signs and symptoms of dementia may include more than just memory loss or other cognitive changes, stating that functional or other noncognitive changes (e.g., difficulties with medication and money management, behavioral symptoms, impairments in gait and balance) also may indicate dementia. Members noted that falls, in particular, may be an important sign of dementia often not recognized by physicians (i.e., falls may signal dementia-related gait or ambulation changes).

As part of their discussion about detection, some Committee members advocated routine use of a brief mental status test to screen those at high risk for dementia. In their discussion of this topic area, members acknowledged the current lack of evidence regarding the balance of benefits and harms of universal cognitive screening of asymptomatic older adults<sup>22</sup> and noted the

confusion about the terms “screening” and “high-risk.” Regarding the latter, some members initially used the term “high-risk” to describe people with signs and symptoms of dementia. As mentioned earlier, certain subpopulations often are classified as high-risk (e.g., those 80 and older, those with certain genetic traits such as the APOE-ε4 gene or other specific mutations, those with mild cognitive impairment, those with Down syndrome,<sup>z</sup> etc.). More recently, Barnes and colleagues<sup>23</sup> have identified other person-level characteristics that are associated with increased risk of dementia (e.g., age, education level, stroke, diabetes, low body mass index, need for assistance with medications or money management, and depressive symptoms) through empirical analysis of observational data and have used this information to construct a scoring system to identify “high-risk” older adults who could be targeted for cognitive assessment. Committee members discussed how the expansion of EHRs and/or other technological advances may allow for automated prompts and cues that could facilitate detection of cognitive impairment in high-risk groups and/or detect patterns of healthcare resource use that would signal possible cognitive impairment.

The Committee also emphasized the need for educational efforts to promote awareness of signs and symptoms as well as risk and preventive factors for dementia, both among the general public and among the healthcare workforce.<sup>aa</sup> Educational efforts geared towards the public also could serve to counteract fear and stigma related to dementia and reinforce the message that there are many things that can be done to manage the symptoms of dementia and maintain quality of life for those with dementia and their family caregivers. Although members did not

y Note, however, that the Annual Wellness Exam does not mandate a cognitive test for everyone.

z Particularly for adults with Down syndrome who are in their 40s, early determination of decline generally is prescribed to differentiate change due to dementia or some other cause (e.g., medication adverse reactions, depression, etc.).

aa In general, discussion of performance measurement for the healthcare workforce is outside the scope of this project; however, it is focus of another NQF prioritization project.

explicitly recommend prioritizing development of educational measures, they did suggest its consideration as an aspirational goal, potentially as part of development of dementia capable systems.

Ultimately, the Committee supported the development of performance measures of detection that include awareness of cognitive, functional, and other noncognitive signs and symptoms of dementia. However, the Committee as a group did not make specific recommendations about how such measures should be conceptualized or specified other than suggesting creation of a structural measure to assess whether there is a process or protocol in place for detection. Members acknowledged the practical difficulties in developing more sophisticated measures. For example, although they emphasized the importance of “early” detection in various discussions, they did not offer suggestions on how to operationalize the concept. Members also cautioned that there are many “sets” of signs/symptoms identified in the literature, but little evidence to support the use of any particular set. The Committee also noted the difficulties inherent in identifying a denominator for such a measure and determining which entities should be held accountable for detection. Finally, the Committee as a whole did not recommend development of a “high-risk screening measure” at this time, although some members indicated support of the process and others encouraged additional research to refine the identification of high-risk groups.

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### Shared Decisionmaking

The Committee also recommended development of measures of shared decisionmaking for both the person with dementia (when capable of participating) as well as for the family caregivers, noting its importance in the context of person- and family-centered care.

The Committee specifically recommended the development of a composite measure to assess the extent of shared decisionmaking in advanced

care planning activities. Such a measure should assess the provision of information on prognosis and treatment options as well as education that would be needed in anticipation of future decisions, particularly regarding care near the end of life (e.g., education about the pros and cons of feeding tubes).

The Committee also noted the importance of performance measures that align with individual goals. This would necessitate not only asking individuals about preferences, treatment goals, and quality-of-life goals over the course of the condition, but also asking them whether or not their preferences and goals are being met. Such measures may be particularly salient for improving the quality of end of life care.

Finally, the Committee also noted the need for a measure to assess provider knowledge of the family caregiver who is the legal representative or proxy decisionmaker.

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### Care Transitions

While the Committee acknowledged ongoing measurement efforts designed to improve care coordination regardless of medical condition,<sup>ab</sup> members emphasized the impact of dementia on other medical conditions (and vice-versa) during transitions of care (i.e., when the condition of the person with dementia may worsen as a result of delirium, medication changes, poor care coordination, etc.). They encouraged continued diligence in the development of care coordination measures that can be used across a variety of care settings.

### Additional Recommendations

Along with recommendations for prioritizing future performance measure development efforts for those with dementia and their family caregivers, the Committee made several additional recommendations for performance measurement

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ab National Quality Forum (NQF). Prioritizing Measure Gaps: Care Coordination website. [http://www.qualityforum.org/Prioritizing\\_Measure\\_Gaps\\_-\\_Care\\_Coordination.aspx](http://www.qualityforum.org/Prioritizing_Measure_Gaps_-_Care_Coordination.aspx). Last accessed September 2014.

and for dementia research and policy more generally. These included the following.

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### Recommendations for Performance Measurement

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- Where appropriate, stratify results from existing nondementia-specific measures to assess quality of care provided to those with dementia and their family caregivers and carefully consider the information gained through the analysis
- Use the “[pathway to endorsement](#)” established by NQF to develop dementia-specific PRO-based performance measures for experience of care and quality of life using existing surveys and instruments that are reliable and valid and suitable for further research
- Modify the specifications of existing nondementia-specific measures—as necessary and appropriate—so as not to exclude explicitly those with dementia and/or to allow proxy reporting for those with dementia
- Modify the various CAHPS surveys to allow proxy response for those with dementia so that the experience of care performance measures will be applicable to those with dementia
- Continue development of outcome measures, particularly experience of care, goal attainment, and quality-of-life measures
- Develop measures that can be implemented to assess performance of a wide variety of entities, such as programs for dually eligible Medicare/Medicaid beneficiaries, insurers, Medicare Advantage programs, medical homes, Programs of All-Inclusive Care for the Elderly, Social Health Maintenance Organizations, designated dementia clinics, etc.
- Develop measures that encourage use of a structured care planning process
- When developing performance measures, consider the events that might trigger

the application of the measure (e.g., a hospitalization, a referral to home health, etc.)

- For future measure development efforts, consider how additional person-level data could be collected through existing mechanisms (e.g., adding items to the Behavioral Risk Factor Surveillance System survey or CAHPS) and utilize, as appropriate, currently-existing data sources (e.g., Minimal Data Set)
- Link community-based supports systems with the healthcare system and create measures to encourage collaboration, sharing records, etc.

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### Recommendations for Dementia Research

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- Utilize existing sources of data in further research to aid in identifying those who should be assessed for cognitive impairment (e.g., use claims data to identify those with falls, emergency room visits, frequent clinician visits, hospitalization for delirium, medication mismanagement, etc.)
- Promote additional research to define those at high risk for dementia
- Promote additional research to identify specific variations in assessment and diagnostic processes for those with intellectual disabilities

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### Recommendations for Policy

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- Encourage the creation of criteria that must be met (taking into account the care setting) before allowing use of terms such as “memory care facility” or “dementia center of excellence”
- Remove real or perceived obstacles to including family caregivers in care processes or being given the diagnosis, whether dementia or some other cause of cognitive impairment (e.g., HIPAA restrictions)
- Promote a lifespan approach to minimize the risk of future development of dementia (e.g., education about risk factors for vascular

disease such as hypertension and diabetes, which can lead to vascular dementia)

- Increase use of person- and family-centered measures to assess performance of health plans and programs
- Consider development of measurement systems that measure providers on those things that are important to individuals (i.e., allow persons with dementia and their family caregivers to choose from a “menu” of measures)
- Form an HHS workgroup around the topic of detection to facilitate appropriate system response as new quality measures for detection are implemented

## ENDNOTES

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## APPENDIX A: Project Approach and Methods

NQF followed the approach and processes shown and described below, in Figure A1, to complete this project. This dementia project was one of five ongoing measurement prioritization projects at NQF. Three of the other projects (Care Coordination, Health Workforce, and Person-Centered Care and Outcomes) were considered to be particularly relevant to this project. Accordingly, the schedule for this project was phased to allow NQF and the Committee to learn from the deliberations and findings of these projects.

**FIGURE A1. FOUR-STEP PROCESS FOR ALZHEIMER'S DISEASE AND RELATED DEMENTIAS PRIORITY-SETTING PROJECT**

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- Step **1** Convene Multistakeholder Committee
  - Step **2** Identify a Conceptual Measurement Framework
  - Step **3** Environmental Scan of Measures and Measure Concepts and Analysis of Gaps
  - Step **4** Develop Committee Recommendations and Priorities for Performance Measure Development

### Convene Multistakeholder Committee

NQF convened a multistakeholder Committee to provide guidance on the project objectives. The group was comprised of individuals with expertise in the diagnosis, treatment, and care of persons with dementia. A small advisory group was formed immediately upon contract award to provide early guidance to NQF while the full Committee was being seated. These individuals continued

as members of the full Committee, which guided NQF through the remainder of the project. NQF also involved a group of federal government partners designated by HHS in a consultative role. The HHS partners provided valuable upstream guidance on the project's approach and goals in order to ensure that products will be valuable to HHS once complete.

### Identify a Conceptual Measurement Framework

A conceptual measurement framework (presented in the [Conceptual Measurement Framework](#) section of this report) was used to systematically and comprehensively analyze measurement gap areas and aid in prioritizing recommendations for future measure development efforts.

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#### Earlier Measurement Frameworks

The work done by the AD-MI project participants served as a foundation for this project. During early discussions about the conceptual framework, NQF considered two previously developed frameworks for this project. The first came from the May 2011 FNIH/C-Path invitational conference.<sup>1</sup> For this framework, staff from NQF proposed a framework based on NQF's Episode of Care measurement framework, which can be used to track the core components or domains that should be measured and evaluated over the course of an episode of care. The framework discussed at this conference included four domains (population at risk, diagnostic process, disease management, and palliative care) and also included formal and informal care trajectories.

The second framework, developed by AD-MI workgroup 2 and presented at the December 2012 AD-MI convening, depicts the key stages during



the course of the condition.<sup>2</sup> The stages include population at risk, symptom awareness, initial detection, diagnostic process, mild dementia, moderate dementia, and severe dementia. Comorbidities, complications, accidents/falls, and deaths were highlighted in the framework under the mild, moderate, and severe dementia stages.

Using the conceptual framework from the AD-MI project as a starting point, and the NQS priorities and goals as a guide, NQF staff developed an initial draft measurement framework, which the project advisors reviewed and helped to revise. Several additional inputs contributed to the development of the conceptual framework, including the environmental scan of measures and measure concepts described in the [Identifying Measurement Gaps](#) section and a literature review of articles and reports related to Alzheimer's disease and related dementias.

## Environmental Scan of Measures and Measure Concepts and Analysis of Gaps

An environmental scan for measures and concepts applicable to the dementia population was conducted, and results were mapped to the measurement domains identified in the conceptual framework (see [Appendix E](#)). The environmental scan identified existing measures applicable to dementia. By analyzing the measures identified in the environmental scan according to the key measurement domains and subdomains articulated in the measurement framework, measurement gap areas were identified.

## Committee Recommendations and Priorities for Performance Measure Development

The full multistakeholder Committee convened for a two-day in-person meeting on June 2-3, 2014 to make recommendations for the prioritization of measure development efforts for the dementia population. As part of its deliberations, the Committee considered the availability of evidence for measurement, uses of measurement for quality improvement and accountability purposes, the need for population-based measurement, and the pros and cons of different types of measures, including measures derived from patient-reported outcomes. The draft of the report was posted for public comment from August 22 to September 15, 2014 and NQF held a public webinar on August 27, 2014 to obtain additional feedback on the draft recommendations. Committee members met a final time via conference calls on September 26, 2014 and October 2, 2014 to discuss the public comments. All public comments received as well as responses from the Committee and/or NQF are included in [Appendix G](#).

## ENDNOTES

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2 Foundation for the National Institutes of Health (FNIH). Alzheimer's Disease Measurement Improvement (AD-MI) Conference Meeting Materials; December 3rd, 2012; . Baltimore, Maryland.

## APPENDIX B:

### Committee Roster, HHS Representatives, Key Informants, and NQF Staff

COMMITTEE ROSTER	
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	U.S. Department of Veterans Affairs
Cyndy Cordell, BS, MBA	Alzheimer's Association
Lynn Friss-Feinberg, MSW	AARP Public Policy Institute
Murray Grossman, MD	University of Pennsylvania, Frontotemporal Degeneration Center
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
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
Eric Tangelos, MD, FACP, AGSF, CMD	The Mayo Clinic
Joan Teno, MD	Brown University School of Public Health
Yael Zweig, MSN, ANP-BC, GNP-BC	NYU Pearl Barlow Center for Memory Evaluation and Treatment
DEPARTMENT OF HEALTH AND HUMAN SERVICES REPRESENTATIVES	
Cille Kennedy, PhD	Office of the Assistant Secretary for Planning and Evaluation
D.E.B. Potter, MS	Agency for Healthcare Research and Quality, Office of the Assistant Secretary for Planning and Evaluation
OTHER KEY INFORMANTS	
David Hoffman, MEd, CCE	New York Department of Health
George Vrandenburg, JD	USAgainstAlzheimer's
Olivia Mastry, JD, MPH	ACT on Alzheimer's
Donna Walberg, MBA	Minnesota Board on Aging
Mark A. Schulz, JD	Minnesota Board on Aging
NATIONAL QUALITY FORUM STAFF	
Karen Johnson, MS	Senior Director
Juliet Feldman	Project Manager
Taylor Myers	Administrative Manager
Kaitlynn Robinson-Ector, MPH	Project Analyst
Wendy Prins, MPH, MPT	Vice President

## APPENDIX C:

### Symptoms/Needs Grids

TABLE C1. PERSON WITH DEMENTIA GRID

Symptoms/ needs	Population at risk	Symptom awareness/initial detection	Evaluation/initial management	Care, treatment, support			End of life/ bereavement
				Mild	Moderate	Severe	
<b>Functional changes</b>	<ul style="list-style-type: none"> <li>• Know the warning signs and how to report to medical provider</li> <li>• Know the evidence linking physical and brain health</li> </ul>	<ul style="list-style-type: none"> <li>• Gait and balance</li> <li>• Incontinence</li> <li>• Weight gain</li> <li>• Aspiration</li> <li>• Motor weakness</li> <li>• Know the warning signs and how to report to medical provider</li> </ul>	<ul style="list-style-type: none"> <li>• Gait and balance</li> <li>• Know how/where to get an evaluation</li> </ul>	<ul style="list-style-type: none"> <li>• Managing finances</li> <li>• Driving</li> <li>• Managing medications</li> <li>• Language disorders (comprehension and expression)</li> <li>• Occupational functioning</li> <li>• Other executive functions</li> <li>• Dehydration</li> <li>• Skin conditions</li> <li>• UTIs</li> <li>• Nutrition</li> <li>• Vision/hearing loss</li> <li>• Access to firearms</li> <li>• Advance care planning (advance directives; surrogate decisionmaker)</li> <li>• Functional maintenance – staying socially, mentally, physically active</li> <li>• Abuse/neglect</li> </ul>	<ul style="list-style-type: none"> <li>• IADLs</li> <li>• Difficulty with some ADLs</li> <li>• Gait and balance</li> <li>• Language disorders (comprehension and expression)</li> <li>• Other executive functions</li> <li>• Dehydration</li> <li>• Skin conditions</li> <li>• UTIs</li> <li>• Nutrition</li> <li>• Vision/hearing loss</li> <li>• Abuse/neglect</li> </ul>	<ul style="list-style-type: none"> <li>• ADLs</li> <li>• Continence</li> <li>• Mobility</li> <li>• Contractures</li> <li>• Swallowing</li> <li>• Aspiration/ pneumonia</li> <li>• Language disorders (comprehension and expression)</li> <li>• Inability to communicate regarding discomfort</li> <li>• Dehydration</li> <li>• Skin conditions</li> <li>• UTIs</li> <li>• Nutrition</li> <li>• Vision/hearing loss</li> <li>• Abuse/neglect</li> <li>• Falls</li> </ul>	
<b>Cognitive changes</b>	<ul style="list-style-type: none"> <li>• Know the warning signs and how to report to medical provider</li> <li>• Know the evidence linking physical and brain health</li> </ul>	<ul style="list-style-type: none"> <li>• Delirium</li> <li>• Know the warning signs and how to report to medical provider</li> </ul>	<ul style="list-style-type: none"> <li>• Delirium</li> <li>• Know how/where to get an evaluation</li> </ul>	<ul style="list-style-type: none"> <li>• Decreased insight</li> <li>• Short-term memory deficits</li> <li>• Poor judgment</li> <li>• Delirium</li> <li>• Other executive functions</li> <li>• Misplacing items and being unable to find them</li> </ul>	<ul style="list-style-type: none"> <li>• Disoriented to date and place</li> <li>• Worse memory</li> <li>• Getting lost in familiar areas</li> <li>• Repeating questions</li> <li>• Delirium</li> <li>• Other Executive functions</li> <li>• Difficulty with calculations</li> <li>• Potential for visuospatial difficulty</li> </ul>	<ul style="list-style-type: none"> <li>• Little or unintelligible verbal output</li> <li>• Loss of remote memory</li> <li>• Inability to recognize family and friends</li> <li>• Delirium</li> </ul>	

Symptoms/ needs	Population at risk	Symptom awareness/initial detection	Evaluation/initial management	Care, treatment, support			End of life/ bereavement
				Mild	Moderate	Severe	
<b>Behavioral/ psychological issues</b>	<ul style="list-style-type: none"> <li>• Know the warning signs and how to report to medical provider</li> </ul>	<ul style="list-style-type: none"> <li>• Apathy</li> <li>• Disinhibition</li> <li>• Rigid/ritualistic behaviors</li> <li>• Know the warning signs and how to report to medical provider</li> </ul>	<ul style="list-style-type: none"> <li>• Apathy</li> <li>• Disinhibition</li> <li>• Rigid/ritualistic behaviors</li> <li>• Know how/where to get an evaluation</li> </ul>	<ul style="list-style-type: none"> <li>• Social withdrawal</li> <li>• Mood changes (apathy/depression)</li> <li>• Anxiety</li> </ul>	<ul style="list-style-type: none"> <li>• Delusions</li> <li>• Hallucinations</li> <li>• Agitation</li> <li>• Aggression</li> <li>• Apathy/depression</li> <li>• Restlessness/anxiety</li> <li>• Wandering</li> <li>• Sleep changes</li> <li>• Inappropriate sexual behavior</li> </ul>	<ul style="list-style-type: none"> <li>• Motor or verbal agitation or aggression</li> <li>• Apathy/depression</li> <li>• Sundowning</li> <li>• Sleep/wake disturbance</li> </ul>	<ul style="list-style-type: none"> <li>• Preterminal agitation</li> </ul>

TABLE C2. FAMILY CAREGIVER GRID

Symptoms/ needs	Population at risk	Symptom awareness/ initial detection	Evaluation/initial management	Care, treatment, support			End of life/ bereavement
				Mild	Moderate	Severe	
<b>Education</b>	<ul style="list-style-type: none"> <li>• Know the warning signs and how to report to medical provider</li> </ul>	<ul style="list-style-type: none"> <li>• Know the warning signs and how to report to medical provider</li> </ul>	<ul style="list-style-type: none"> <li>• Delirium indicates need for medical attention</li> <li>• Know how/where to get an evaluation</li> <li>• Nonpharmacologic management strategies</li> </ul>	<ul style="list-style-type: none"> <li>• Basic understanding of disease complications and progression</li> <li>• Delirium indicates need for medical attention</li> <li>• Disease expectations</li> <li>• Advance directives</li> <li>• Planning for the future</li> <li>• Disease specific support websites (Alzheimer's Association, LBDA, AFTD, ADEAR)</li> <li>• Dehydration</li> <li>• Skin conditions</li> <li>• UTIs</li> <li>• Nutrition</li> <li>• Basic understanding of available community services and supports (e.g., assistive devices)</li> <li>• Skills to care for PwD (e.g., ADL assistance, management of disruptive behavior)</li> <li>• Nonpharmacologic management strategies</li> </ul>	<ul style="list-style-type: none"> <li>• Management of specific behavioral issues and training on medical/nursing tasks (special diets, wound care, and managing multiple complex medications)</li> <li>• Nonpharmacologic management strategies</li> <li>• Information on prognosis/advanced illness and EoL options</li> <li>• Delirium indicates need for medical attention</li> <li>• Concrete services</li> <li>• Day programs</li> <li>• Geriatric care management</li> <li>• Dehydration</li> <li>• Skin conditions</li> <li>• UTIs</li> <li>• Nutrition</li> <li>• Management of healthcare transitions</li> <li>• Know availability (what/where) of community support (public, private)</li> </ul>	<ul style="list-style-type: none"> <li>• Management of specific behavioral issues and training on medical/nursing tasks</li> <li>• Information on prognosis</li> <li>• Nutrition</li> <li>• Delaying functional decline</li> <li>• Dehydration</li> <li>• Skin conditions</li> <li>• UTIs</li> <li>• Nutrition</li> <li>• Know what/where community support (public, private)</li> <li>• Management of healthcare transitions</li> <li>• Nonpharmacologic management strategies</li> </ul>	<ul style="list-style-type: none"> <li>• Information on prognosis/advanced illness and EoL options</li> <li>• Nonpharmacologic management strategies</li> </ul>

Symptoms/ needs	Population at risk	Symptom awareness/ initial detection	Evaluation/initial management	Care, treatment, support			End of life/ bereavement
				Mild	Moderate	Severe	
<b>Support</b>			<ul style="list-style-type: none"> <li>Identify sources of support (personal, family, community) [This is relevant to person with dementia also.]</li> <li>Plan for care coordination [This is relevant to person with dementia also.]</li> </ul>	<ul style="list-style-type: none"> <li>Financial planning</li> <li>Housing planning</li> <li>Coping strategies (e.g., avoiding frustration from repetitive questions)</li> <li>One-on-one counseling for what? (to increase coping skills and confidence, decrease burden and depression); Care planning, coping strategies/behavior management techniques</li> <li>Home safety</li> <li>Assistance in gaining access to services and supports</li> <li>Family meetings (to help family members plan and cope, and address family conflict)</li> <li>In-person and online support groups</li> </ul>	<ul style="list-style-type: none"> <li>Housing planning</li> <li>Assistance in gaining access to services and supports (e.g., assistive technologies)</li> <li>In-person and online support groups</li> <li>One-on-one counseling –for what? (to increase coping skills and confidence, decrease burden and depression); Care planning, coping strategies/behavior management techniques</li> <li>Respite care</li> <li>Family meetings</li> <li>Grief counseling before the patient dies (anticipatory grief, ambiguous loss)</li> </ul>	<ul style="list-style-type: none"> <li>One-on-one counseling (to increase coping skills and confidence, decrease burden and depression); (end-of-life care planning/implementation, coping strategies)</li> <li>Grief counseling before the patient dies (anticipatory grief, ambiguous loss)</li> <li>Respite care</li> <li>Family meetings</li> <li>In-person and online support groups</li> </ul>	<ul style="list-style-type: none"> <li>Grief counseling after the patient dies</li> </ul>
<b>Health</b>				<ul style="list-style-type: none"> <li>Depression</li> <li>Anxiety</li> <li>Stress</li> <li>Other physical health issues</li> <li>Self-management of conditions/disabilities</li> </ul>	<ul style="list-style-type: none"> <li>Depression</li> <li>Anxiety</li> <li>Stress</li> <li>Other physical health issues</li> <li>Self-management of conditions/disabilities</li> </ul>	<ul style="list-style-type: none"> <li>Depression</li> <li>Anxiety</li> <li>Stress</li> <li>Other physical health issues</li> <li>Self-management of conditions/disabilities</li> </ul>	<ul style="list-style-type: none"> <li>Depression</li> </ul>

## APPENDIX D:

### Measurement Ideas/Concepts Grids

**TABLE D1. PERSON WITH DEMENTIA GRID**

Source for information could be the person with dementia OR the family caregiver.

Measurement subdomains	Measurement Domains						
	Population at risk	Symptom awareness/ initial detection	Evaluation/initial management	Care, treatment, support			End of life/ bereavement
				Mild	Moderate	Severe	
<b>Prevention</b>							
<b>Screening</b>	<ul style="list-style-type: none"> <li>• Three-generation family history taken</li> <li>• Genetic testing in high-risk population</li> </ul>						
<b>Education</b>		<ul style="list-style-type: none"> <li>• Awareness of signs/symptoms of dementia</li> <li>• I know what I can do to help myself and who else can help me</li> </ul>	<ul style="list-style-type: none"> <li>• Willingness to provide evaluation and care</li> <li>• I know what I can do to help myself and who else can help me</li> </ul>	<ul style="list-style-type: none"> <li>• I know what I can do to help myself and who else can help me</li> </ul>			
<b>Diagnosis (This subdomain was deleted from the conceptual measurement framework during the course of the project)</b>		<ul style="list-style-type: none"> <li>• Documentation of diagnosis in medical record*</li> <li>• Awareness of signs/symptoms of dementia</li> <li>• Assessment of signs and symptoms of dementia*</li> </ul>	<ul style="list-style-type: none"> <li>• Develop care plan*</li> <li>• Discuss advance directives or other advance care plans*</li> <li>• Execute advance directives or other advance care plans</li> <li>• Documentation of diagnosis in medical record*</li> <li>• Accurate diagnosis</li> <li>• Time to diagnosis</li> <li>• Diagnostic disclosure*</li> </ul>	<ul style="list-style-type: none"> <li>• Update care plan*</li> </ul>	<ul style="list-style-type: none"> <li>• Update care plan*</li> </ul>	<ul style="list-style-type: none"> <li>• Update care plan*</li> </ul>	<ul style="list-style-type: none"> <li>• Update care plan*</li> </ul>

Measurement subdomains	Measurement Domains						
	Population at risk	Symptom awareness/ initial detection	Evaluation/initial management	Care, treatment, support			End of life/ bereavement
				Mild	Moderate	Severe	
<b>Function</b>		<ul style="list-style-type: none"> <li>• Assessment of signs and symptoms of dementia</li> <li>• Assessment of gait and balance*</li> </ul>	<ul style="list-style-type: none"> <li>• Assessment of signs and symptoms of dementia *</li> <li>• Measures of unmet need</li> </ul>	<ul style="list-style-type: none"> <li>• Assessment of IADLs, especially money management and medication management</li> <li>• Assessment of driving</li> <li>• Assessment of language disorders (comprehension and expression)</li> <li>• Maintain function to the extent possible</li> </ul>	<ul style="list-style-type: none"> <li>• Assessment of IADLs</li> <li>• Assessment of ADLs*</li> <li>• Assessment of gait and balance*</li> <li>• ADL assistance</li> <li>• Maintain function to the extent possible</li> </ul>	<ul style="list-style-type: none"> <li>• Assessment of ADLs*</li> <li>• Assessment of continence</li> <li>• Assessment of mobility</li> <li>• Assessment of swallowing</li> <li>• ADL assistance</li> <li>• Rate of aspiration pneumonia</li> <li>• Maintain function to the extent possible</li> </ul>	
<b>Cognition</b>		<ul style="list-style-type: none"> <li>• Successful detection of impairment</li> </ul>	<ul style="list-style-type: none"> <li>• Assessment of cognition*</li> <li>• Delay in cognitive decline</li> <li>• Embarrassment about memory problems</li> </ul>	<ul style="list-style-type: none"> <li>• Assessment of cognition*</li> <li>• Referral to specialists*</li> <li>• Delay in cognitive decline</li> <li>• Management of tolerance to medication and side effects</li> </ul>	<ul style="list-style-type: none"> <li>• Assessment of cognition*</li> <li>• Referral to specialists*</li> <li>• Delay in cognitive decline</li> </ul>	<ul style="list-style-type: none"> <li>• Assessment of cognition*</li> <li>• Referral to specialists*</li> </ul>	



Measurement subdomains	Measurement Domains						
	Population at risk	Symptom awareness/ initial detection	Evaluation/initial management	Care, treatment, support			End of life/ bereavement
				Mild	Moderate	Severe	
<b>Behavior</b>		<ul style="list-style-type: none"> <li>Assessment of behavioral symptoms</li> </ul>	<ul style="list-style-type: none"> <li>Assessment of behavioral symptoms</li> </ul>	<ul style="list-style-type: none"> <li>Assessment of social withdrawal</li> <li>Assessment of mood changes*</li> <li>Assessment for depression*</li> <li>Assessment for anxiety*</li> <li>Treatment for depression</li> <li>Teaching techniques to avoid/manage behavioral problems</li> <li>Reduction of behavioral symptoms</li> <li>Individualized management plan for mood and behavior*</li> </ul>	<ul style="list-style-type: none"> <li>Assessment of behavioral symptoms</li> <li>Assessment for depression*</li> <li>Assessment for anxiety*</li> <li>Treatment for depression</li> <li>Treatment for restlessness and/or anxiety</li> <li>Reduction of behavioral symptoms</li> <li>Individualized management plan for mood and behavior*</li> </ul>	<ul style="list-style-type: none"> <li>Assessment of behavioral symptoms</li> <li>Assessment for depression*</li> <li>Assessment for anxiety*</li> <li>Treatment for depression</li> <li>Reduction of behavioral symptoms</li> <li>Individualized management plan for mood and behavior*</li> </ul>	
<b>Support</b>			<ul style="list-style-type: none"> <li>Measures of unmet need</li> <li>Self-management support</li> </ul>	<ul style="list-style-type: none"> <li>Assistance with/referral for financial planning/management</li> <li>Assistance with/referral for legal planning</li> <li>Provision of alternate transportation</li> <li>Counseling</li> <li>Care management</li> <li>Measures of unmet need</li> </ul>	<ul style="list-style-type: none"> <li>Care management</li> <li>Measures of unmet need</li> <li>Delay in NF placement</li> </ul>	<ul style="list-style-type: none"> <li>Care management</li> <li>Referral to/enrollment in hospice</li> <li>Measures of unmet need</li> <li>Delay in nursing facility placement</li> </ul>	
<b>Quality of life</b>			<ul style="list-style-type: none"> <li>Assessment of well-being and social participation</li> <li>Perceived choice/independence</li> <li>Relationship strain</li> <li>Isolation</li> <li>Management of tolerance to medication and side effects</li> </ul>	<ul style="list-style-type: none"> <li>Assessment of QoL</li> <li>Provision of enjoyable activities</li> <li>Pain or other symptoms well controlled</li> <li>Assessment of well-being and social participation</li> <li>Perceived choice/independence</li> <li>Management of tolerance to medication and side effects</li> </ul>	<ul style="list-style-type: none"> <li>Assessment of QoL</li> <li>Provision of enjoyable activities</li> <li>Pain or other symptoms well controlled</li> <li>Assessment of well-being and social participation</li> <li>Perceived choice/independence</li> <li>Management of tolerance to medication and side effects</li> </ul>	<ul style="list-style-type: none"> <li>Pain or other symptoms well controlled</li> <li>Assessment of AD-related QoL</li> <li>Management of tolerance to medication and side effects</li> </ul>	<ul style="list-style-type: none"> <li>Pain or other symptoms well controlled*</li> <li>Perceived choice in EoL options</li> <li>Opportunities for “closure”</li> </ul>

Measurement subdomains	Measurement Domains						
	Population at risk	Symptom awareness/ initial detection	Evaluation/initial management	Care, treatment, support			End of life/ bereavement
				Mild	Moderate	Severe	
<b>Experience of care</b>		<ul style="list-style-type: none"> <li>Care coordination</li> <li>Time to diagnosis</li> <li>Number of visits to make diagnosis</li> </ul>	<ul style="list-style-type: none"> <li>Care coordination/accountable care coordinator</li> <li>Understanding treatment options*</li> </ul>	<ul style="list-style-type: none"> <li>Care coordination/accountable care coordinator</li> <li>Continuity of care</li> <li>Understanding treatment options</li> <li>Understanding living options</li> </ul>	<ul style="list-style-type: none"> <li>Care coordination/accountable care coordinator</li> <li>Continuity of care</li> <li>Avoid preventable hospitalizations/ ED visits*</li> <li>Understanding living options</li> <li>Provision of dementia-sensitive care</li> </ul>	<ul style="list-style-type: none"> <li>Care coordination accountable care coordinator</li> <li>Continuity of care</li> <li>Avoid preventable hospitalizations/ ED visits*</li> <li>Avoiding unnecessary procedures</li> <li>Provision of dementia-sensitive care</li> </ul>	<ul style="list-style-type: none"> <li>Care coordination/accountable care coordinator</li> <li>Avoid preventable hospitalizations / ED visits*</li> <li>Compliance with treatment preferences*</li> <li>Quality of EoL care</li> </ul>
<b>Engagement</b>			<ul style="list-style-type: none"> <li>Participatory goal setting/ planning</li> </ul>	<ul style="list-style-type: none"> <li>Participatory goal setting/planning</li> </ul>	<ul style="list-style-type: none"> <li>Participatory goal setting/planning</li> </ul>	<ul style="list-style-type: none"> <li>Participatory goal setting/planning</li> </ul>	
<b>Safety</b>		<ul style="list-style-type: none"> <li>Fall rate</li> <li>Injuries due to movement disorder (e.g., cutlery/other implements)</li> <li>Adverse events due to medication errors</li> <li>Counseling about safety*</li> </ul>	<ul style="list-style-type: none"> <li>Fall rate</li> <li>Injuries due to movement disorder (e.g., cutlery/other implements)</li> <li>Adverse events due to medication errors</li> <li>Counseling about safety*</li> </ul>	<ul style="list-style-type: none"> <li>Adverse events due to medication errors</li> <li>Injuries due to movement disorder (e.g., cutlery/other implements)</li> <li>Driving accidents</li> <li>Counseling about safety*</li> </ul>	<ul style="list-style-type: none"> <li>Adverse events due to medication errors</li> <li>Fall rate</li> <li>Wandering/getting lost</li> <li>Safe return programs</li> <li>Counseling about safety*</li> </ul>	<ul style="list-style-type: none"> <li>Adverse events due to medication errors</li> <li>Fall rate</li> <li>Pressure sores</li> </ul>	
<b>Environment</b>		<ul style="list-style-type: none"> <li>Intervention to promote safety and prevent injury</li> </ul>	<ul style="list-style-type: none"> <li>Environmental assessment (home)</li> <li>Assessments of community support (e.g., transportation, food availability, etc.)</li> </ul>	<ul style="list-style-type: none"> <li>Assessment of community environment</li> <li>Maintain function to the extent possible</li> <li>Adaptive/accommodating environment</li> </ul>	<ul style="list-style-type: none"> <li>Assessment of safety in the home</li> <li>Maintain function to the extent possible</li> <li>Adaptive/accommodating environment</li> </ul>	<ul style="list-style-type: none"> <li>Assessment of safety in the home</li> <li>Maintain function to the extent possible</li> <li>Adaptive/accommodating environment</li> </ul>	

\* Indicates that a performance measure for the concept already exists.

**TABLE D2. FAMILY CAREGIVER GRID**

Information could relate to the person with dementia OR to the family caregiver.

Measurement Subdomains	Measurement Domains						
	Population at Risk	Symptom awareness/initial detection	Evaluation/initial management	Care, treatment, support			End of life/bereavement
				Mild	Moderate	Severe	
<b>Education</b>		<ul style="list-style-type: none"> <li>Awareness of signs/symptoms of dementia</li> </ul>	<ul style="list-style-type: none"> <li>I know what I can do to help myself and who else can help me</li> </ul>	<ul style="list-style-type: none"> <li>Basic understanding of disease complications and progression and relationship to other chronic conditions</li> <li>Coping strategies (e.g. avoiding frustration from repetitive questions*</li> <li>Basic understanding of housing/care options</li> <li>I know what I can do to help myself and who else can help me</li> </ul>	<ul style="list-style-type: none"> <li>Management of specific behavioral issues*</li> <li>Information on prognosis</li> <li>Reassessment of housing/care options</li> <li>I know what I can do to help myself and who else can help me</li> </ul>	<ul style="list-style-type: none"> <li>Management of specific behavioral issues*</li> <li>Information on prognosis</li> <li>Reassessment of housing/care options</li> <li>I know what I can do to help myself and who else can help me</li> </ul>	<ul style="list-style-type: none"> <li>Understanding of EoL options</li> <li>I know what I can do to help myself and who else can help me</li> </ul>
<b>Support</b>			<ul style="list-style-type: none"> <li>Measures of unmet need</li> </ul>	<ul style="list-style-type: none"> <li>Financial planning</li> <li>One-on-one counseling</li> <li>Availability of support groups</li> <li>Self-efficacy/confidence</li> <li>Perceived adequacy of support</li> <li>Measures of unmet need</li> <li>Caregiver assessment to identify support/health needs*</li> </ul>	<ul style="list-style-type: none"> <li>Availability of support groups</li> <li>One-on-one counseling</li> <li>Availability of respite care</li> <li>Measures of unmet need</li> <li>Caregiver assessment to identify support/health needs*</li> </ul>	<ul style="list-style-type: none"> <li>One-on-one counseling</li> <li>Grief counseling before the patient dies</li> <li>Measures of unmet need</li> <li>Caregiver assessment to identify support/health needs*</li> </ul>	<ul style="list-style-type: none"> <li>Grief counseling after the patient dies</li> </ul>
<b>Health</b>				<ul style="list-style-type: none"> <li>Assessment for depression</li> <li>Treatment for depression</li> <li>Improved self-rated health</li> </ul>	<ul style="list-style-type: none"> <li>Assessment for depression</li> <li>Treatment for depression</li> <li>Improved self-rated health</li> </ul>	<ul style="list-style-type: none"> <li>Assessment for depression</li> <li>Treatment for depression</li> <li>Improved self-rated health</li> </ul>	
<b>Experience of care</b>		<ul style="list-style-type: none"> <li>Time to diagnosis</li> </ul>	<ul style="list-style-type: none"> <li>Understanding treatment options</li> <li>Diagnostic disclosure</li> </ul>	<ul style="list-style-type: none"> <li>Understanding treatment options</li> <li>Decrease in perceived burden/stress</li> </ul>	<ul style="list-style-type: none"> <li>Understanding treatment options</li> <li>Decrease in perceived burden/stress</li> </ul>	<ul style="list-style-type: none"> <li>Understanding treatment options</li> <li>Compliance with treatment preferences/decision</li> <li>Decrease in perceived burden/stress</li> </ul>	<ul style="list-style-type: none"> <li>End-of-life decisionmaking</li> <li>Compliance with treatment preferences/decisions</li> </ul>

Measurement Subdomains	Measurement Domains						
	Population at Risk	Symptom awareness/initial detection	Evaluation/initial management	Care, treatment, support			End of life/ bereavement
				Mild	Moderate	Severe	
Engagement			<ul style="list-style-type: none"> <li>Informant identified to provide history for diagnosis</li> </ul>	<ul style="list-style-type: none"> <li>Provider knows who CG is and communicates with them*</li> </ul>	<ul style="list-style-type: none"> <li>Provider knows who CG is and communicates with them*</li> </ul>	<ul style="list-style-type: none"> <li>Provider knows who CG is and communicates with them*</li> </ul>	
Quality of life							

\* Indicates that a performance measure for the concept already exists.

## APPENDIX E:

### Environmental Scan Analysis and References

For purposes of assessing the measurement gaps, NQF tagged the dementia-specific measures to the measurement domains in the conceptual framework and to the NQS priorities. Table E1 presents this mapping, for both the U.S. measures and the international measures. NQF also categorized the 125 dementia-specific measures and concepts

by the measurement subdomains specified in the framework (see Table E2). It should be noted that many measures could have been mapped to multiple domains, subdomains, or priorities; as much as possible, however, NQF staff tried to be consistent in the mapping exercise.

### Analysis

**TABLE E1. ENVIRONMENTAL SCAN RESULTS BY MEASUREMENT DOMAINS AND NQS PRIORITIES**

National Quality Strategy priorities	Measurement Domains				
	Population at risk	Symptom awareness and initial detection	Evaluation and initial management	Care, treatment, and support	End of life and bereavement
<b>U.S. Dementia-Specific Measures</b>					
Health and well-being			2		1
Person- and family centered care				5	2
Prevention and treatment		5	10	14	1
Communication and care coordination		4	3	8	
Safety			1	4	
Affordability					
<b>International Dementia-Specific Measures</b>					
Health and well-being			3	2	
Person- and family centered care				8	
Prevention and treatment		5	14	12	1

National Quality Strategy priorities	Measurement Domains				
	Population at risk	Symptom awareness and initial detection	Evaluation and initial management	Care, treatment, and support	End of life and bereavement
Communication and Care Coordination			7	10	2
Safety				1	
Affordability					

TABLE E2. ENVIRONMENTAL SCAN RESULTS BY MEASUREMENT SUBDOMAIN

Measurement Subdomains	U.S.	International
Behavior	9	9
Cognition	24	24
Education	1	0
Engagement	6	4
Experience of care	0	1
Function	2	0
Health	1	0
Prevention	0	0
Quality of life	0	1
Safety	8	2
Screening	0	0
Support	8	21
Training	1	4

## Environmental Scan References

Agency for Healthcare Research and Quality (AHRQ). National Quality Measures Clearinghouse website. <http://www.qualitymeasures.ahrq.gov/index.aspx>. Last accessed December 2013.

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National Quality Forum (NQF). Quality Positioning System website. <http://www.qualityforum.org/QPS/>. Last accessed December 2013.

National Quality Forum (NQF). Measure Inventory Pipeline website. <http://public.qualityforum.org/Pages/Measure-Concept.aspx>. Last accessed July 2014.



## APPENDIX F:

### Clinical Guidelines Related to Dementia

Participants in the AD-MI project updated their initial compilation of clinical practice guidelines related to dementia for inclusion in this report. This compilation includes clinical guidelines from 2009 to present. The guidelines are presented in order by guideline developer and then guideline title.

Guidelines	Guideline Developer	Publication Year	Source
Clinical Practice Guidelines for management of Dementia, second edition	Academy of Medicine of Malaysia	2009	<a href="http://www.acadmed.org.my/view_file.cfm?fileid=306">http://www.acadmed.org.my/view_file.cfm?fileid=306</a>
Evidence based practice guidelines for Management of Communication Disorders and Sciences	Academy of Neurologic Communication Disorders and Sciences	2012	<a href="http://www.ancds.org/index.php/practice-guidelines-9">http://www.ancds.org/index.php/practice-guidelines-9</a>
Clinical practice guideline on the comprehensive care of people with Alzheimer's disease and other dementias	Agency for Health Quality and Assessment of Catalonia (Barcelona, Spain)	2010	<a href="http://www.guideline.gov/content.aspx?id=47860">http://www.guideline.gov/content.aspx?id=47860</a>
Alzheimer's Association recommendations for operationalizing the detection of cognitive impairment during the Medicare Annual Wellness Visit in a primary care setting	Alzheimer's Association	2013	<a href="http://www.guideline.gov/content.aspx?id=47022">http://www.guideline.gov/content.aspx?id=47022</a>
Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes. Phase 1 (fundamentals, food and fluids consumption, pain management, social engagement) and Phase 2 (resident wandering, resident falls, physical restraint-free care)(Alzheimer's Association Campaign for Quality Residential Care)	Alzheimer's Association	2009	<a href="http://www.alz.org/national/documents/brochure_dcprphases1n2.pdf">http://www.alz.org/national/documents/brochure_dcprphases1n2.pdf</a>
Dementia Care Practice Recommendations for Professionals Working in a Home Setting	Alzheimer's Association	2009	<a href="http://www.alz.org/national/documents/phase_4_home_care_recs.pdf">http://www.alz.org/national/documents/phase_4_home_care_recs.pdf</a>
Benefits of early diagnosis and intervention, World Alzheimer report 2011	Alzheimer's Disease International	2011	<a href="http://www.guideline.gov/content.aspx?id=39435">http://www.guideline.gov/content.aspx?id=39435</a>
Evaluation and Management of Driving Risk in Dementia	American Academy of Neurology	2010	<a href="http://www.guideline.gov/content.aspx?id=15853">http://www.guideline.gov/content.aspx?id=15853</a>

Guidelines	Guideline Developer	Publication Year	Source
Guidelines for the Management of Cognitive and Behavioral Problems in Dementia	American Board of Family Medicine	2012	<a href="http://www.ncbi.nlm.nih.gov/pubmed/22570399">http://www.ncbi.nlm.nih.gov/pubmed/22570399</a>
Practical Guidelines for the Recognition and Diagnosis of Dementia	American Board of Family Medicine	2012	<a href="http://www.jabfm.org/content/25/3/367.full.pdf+html">http://www.jabfm.org/content/25/3/367.full.pdf+html</a>
Genetic counseling and testing for Alzheimer disease: joint practice guidelines of the American College of Medical Genetics and the National Society of Genetic Counselors.	American College of Medical Genetics and the National Society of Genetic Counselors	2011	<a href="http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3326653/pdf/nihms365764.pdf">http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3326653/pdf/nihms365764.pdf</a>
Current pharmacologic treatment of dementia: a clinical practice guideline	American College of Physicians and the American Academy of Family Physicians (ACP/AAFP)	2012	<a href="http://www.guideline.gov/content.aspx?id=43917">http://www.guideline.gov/content.aspx?id=43917</a>
ACR Appropriateness Criteria® dementia and movement disorders. (previous version: Expert Panel on Neurologic Imaging. Dementia and movement disorders)	American College of Radiology (ACR)	2010	<a href="http://guidelines.gov/content.aspx?id=32612&amp;search=alzheimers">http://guidelines.gov/content.aspx?id=32612&amp;search=alzheimers</a>
A guide to the management of psychotic disorders and neuropsychiatric symptoms of dementia in older adults, April 2011	American Geriatrics Society	2011	<a href="http://dementia.americangeriatrics.org/AGSGeriPsychConsult.pdf">http://dementia.americangeriatrics.org/AGSGeriPsychConsult.pdf</a>
Guiding principles for the care of older adults with multimorbidity: an approach for clinicians	American Geriatrics Society Expert Panel on the Care of Older Adults with Multimorbidity	2012	<a href="http://www.guideline.gov/content.aspx?id=39322">http://www.guideline.gov/content.aspx?id=39322</a>
Altered Nutritional Status in the Long-Term Care Setting	American Medical Directors Association (AMDA)	2010	<a href="http://www.guideline.gov/content.aspx?id=32490">http://www.guideline.gov/content.aspx?id=32490</a>
Delirium and acute problematic behavior in the long-term care setting	American Medical Directors Association (AMDA)	2013	<a href="http://www.guideline.gov/content.aspx?id=12379">http://www.guideline.gov/content.aspx?id=12379</a>
Dementia in the long-term care setting	American Medical Directors Association (AMDA)	2012	<a href="http://www.guideline.gov/content.aspx?id=45525">http://www.guideline.gov/content.aspx?id=45525</a>
Stroke management in the long-term care setting	American Medical Directors Association (AMDA)	2011	<a href="http://guidelines.gov/content.aspx?id=32670">http://guidelines.gov/content.aspx?id=32670</a>
Occupational therapy practice guidelines for adults with stroke	American Occupational Therapy Association (AOTA)	2012	<a href="http://guidelines.gov/content.aspx?id=15290">http://guidelines.gov/content.aspx?id=15290</a>

Guidelines	Guideline Developer	Publication Year	Source
Occupational therapy practice guidelines for adults with Alzheimer's disease and related disorders	American Occupational Therapy Association (AOTA)	2010	<a href="http://guidelines.gov/content.aspx?id=16321&amp;search=alzheimers">http://guidelines.gov/content.aspx?id=16321&amp;search=alzheimers</a>
Guidelines for the Evaluation of Dementia and Cognitive Change	American Psychological Association (APA)	2012	<a href="http://www.apa.org/pi/aging/resources/dementia-guidelines.pdf">http://www.apa.org/pi/aging/resources/dementia-guidelines.pdf</a>
Acute pain management in the perioperative setting, Practice guidelines, updated report	American Society of Anesthesiologists Task Force on Acute Pain Management	2012	<a href="http://guidelines.gov/content.aspx?id=35259">http://guidelines.gov/content.aspx?id=35259</a>
Appropriate use criteria for amyloid PET: a report of the Amyloid Imaging Task Force, the Society of Nuclear Medicine and Molecular Imaging, and the Alzheimer's Association	Amyloid Imaging Task Force, the Society of Nuclear Medicine and Molecular Imaging and the Alzheimer's Association	2013	<a href="http://www.guideline.gov/content.aspx?id=47559">http://www.guideline.gov/content.aspx?id=47559</a>
Clinical practice with anti-dementia drugs: a revised (second) consensus statement from the British Association for Psychopharmacology	British Association for Psychopharmacology	2011	<a href="http://www.ncbi.nlm.nih.gov/pubmed/21088041">http://www.ncbi.nlm.nih.gov/pubmed/21088041</a>
Clinical practice with anti-dementia drugs: a revised (second) consensus statement	British Association for Psychopharmacology	2010	<a href="http://www.bap.org.uk/pdfs/Anti-dementia_2010_BAP.pdf">http://www.bap.org.uk/pdfs/Anti-dementia_2010_BAP.pdf</a>
4th Canadian Consensus Conference on the Diagnosis and Treatment of Dementia	Canadian Consensus Conferences on the Diagnosis and Treatment of Dementia (CCCDTD)	2012	<a href="http://cjns.metapress.com/content/t267211753311587/fulltext.html">http://cjns.metapress.com/content/t267211753311587/fulltext.html</a>
Review and update: clinical practice guidelines on the pharmacological management of dementia	Canadian Consensus Conference on the Diagnosis and Treatment of Dementia (CCCDTD)	2013	<a href="http://www.ncbi.nlm.nih.gov/pubmed/24565367">http://www.ncbi.nlm.nih.gov/pubmed/24565367</a>
Stroke rehabilitation. In: Canadian best practice recommendations for stroke care	Canadian Stroke Network/Heart & Stroke Foundation of Canada (CSN/HSFC)	2010	<a href="http://guideline.gov/content.aspx?id=34091">http://guideline.gov/content.aspx?id=34091</a>
Clinical practice guideline for dementia. Part I: diagnosis & evaluation.	Clinical Research Center for Dementia of South Korea (with support from the National Evidence-based Healthcare Collaborating Agency, Seoul, Republic of Korea)	2011	<a href="http://jkma.org/src/SM/jkma-54-861-s002.pdf">http://jkma.org/src/SM/jkma-54-861-s002.pdf</a>

Guidelines	Guideline Developer	Publication Year	Source
High-dose donepezil (23 mg/day) for the treatment of moderate and severe Alzheimer's disease: drug profile and clinical guidelines.	Donepezil 23 mg Expert Working Group (EWG)	2013	<a href="http://www.ncbi.nlm.nih.gov/pubmed/23462265">http://www.ncbi.nlm.nih.gov/pubmed/23462265</a>
EFNS-ENS guidelines on the diagnosis and management of disorders associated with dementia	European Federation of Neurological Societies (EFNS)	2012	<a href="http://www.guideline.gov/content.aspx?id=38470">http://www.guideline.gov/content.aspx?id=38470</a>
EFNS guidelines on the molecular diagnosis of channelopathies, epilepsies, migraine, stroke and dementias	European Federation of Neurological Societies (EFNS)	2010	<a href="http://www.guideline.gov/content.aspx?id=25709">http://www.guideline.gov/content.aspx?id=25709</a>
EFNS guidelines for the diagnosis and management of Alzheimer's disease	European Federation of Neurological Societies (EFNS)	2010	<a href="http://www.guideline.gov/content.aspx?id=38471">http://www.guideline.gov/content.aspx?id=38471</a>
Recommendations for the diagnosis and management of Alzheimer's disease and other disorders associated with dementia: EFNS guideline	European Federation of Neurological Societies (EFNS)	2010	<a href="http://www.guideline.gov/content.aspx?id=38471">http://www.guideline.gov/content.aspx?id=38471</a>
Sleep disorders in neurodegenerative disorders and stroke.	European Federation of the Neurological Societies (EFNS)	2011	<a href="http://www.guideline.gov/content.aspx?id=34909">http://www.guideline.gov/content.aspx?id=34909</a>
Use of neuroimaging in the diagnosis of dementia, EFNS Task Force	European Federation of Neurological Societies (EFNS)	2013	<a href="http://www.guideline.gov/content.aspx?id=43906">http://www.guideline.gov/content.aspx?id=43906</a>
Dementia and Cognitive Impairment Diagnosis and Treatment Guideline	Group Health Cooperative	2012	<a href="http://www.ghc.org/all-sites/guidelines/dementia.pdf">http://www.ghc.org/all-sites/guidelines/dementia.pdf</a>
Assessing cognitive function. In: Evidence-based geriatric nursing protocols for best practice	Hartford Institute for Geriatric Nursing	2012	<a href="http://www.guideline.gov/content.aspx?id=43917">http://www.guideline.gov/content.aspx?id=43917</a>
Comprehensive assessment and management of the critically ill. In: Evidence-based geriatric nursing protocols for best practice	Hartford Institute for Geriatric Nursing	2012	<a href="http://www.guideline.gov/content.aspx?id=43919">http://www.guideline.gov/content.aspx?id=43919</a>
Delirium. In: Evidence-based geriatric nursing protocols for best practice	Hartford Institute for Geriatric Nursing	2012	<a href="http://www.guideline.gov/content.aspx?id=43920">http://www.guideline.gov/content.aspx?id=43920</a>
Depression in older adults. In: Evidence-based geriatric nursing protocols for best practice	Hartford Institute for Geriatric Nursing	2012	<a href="http://www.guideline.gov/content.aspx?id=43922">http://www.guideline.gov/content.aspx?id=43922</a>
Family caregiving. In: Evidence-based geriatric nursing protocols for best practice	Hartford Institute for Geriatric Nursing	2012	<a href="http://www.guideline.gov/content.aspx?id=43925">http://www.guideline.gov/content.aspx?id=43925</a>

Guidelines	Guideline Developer	Publication Year	Source
Health care decision making. In: Evidence-based geriatric nursing protocols for best practice	Hartford Institute for Geriatric Nursing	2012	<a href="http://www.guideline.gov/content.aspx?id=43927">http://www.guideline.gov/content.aspx?id=43927</a>
Pressure ulcer prevention. In: Evidence-based geriatric nursing protocols for best practice	Hartford Institute for Geriatric Nursing	2012	<a href="http://www.guideline.gov/content.aspx?id=43935">http://www.guideline.gov/content.aspx?id=43935</a>
Recognition and management of dementia. In: Evidence-based geriatric nursing protocols for best practice	Hartford Institute for Geriatric Nursing	2012	<a href="http://www.guideline.gov/content.aspx?id=43921">http://www.guideline.gov/content.aspx?id=43921</a>
Reducing adverse drug events in older adults. In: Evidence-based geriatric nursing protocols for best practice	Hartford Institute for Geriatric Nursing	2012	<a href="http://www.guideline.gov/content.aspx?id=43938">http://www.guideline.gov/content.aspx?id=43938</a>
Diagnosis and treatment of ischemic stroke	Institute for Clinical Systems Improvement (ICSI)	2012	<a href="http://www.guideline.gov/content.aspx?id=38254">http://www.guideline.gov/content.aspx?id=38254</a>
Prevention of falls (acute care). Health care protocol	Institute for Clinical Systems Improvement (ICSI)	2010	<a href="http://www.guideline.gov/content.aspx?id=36906">http://www.guideline.gov/content.aspx?id=36906</a>
Genetics of dementia: update and guidelines for the clinician	International Society of Psychiatric Genetics	2012	<a href="http://www.ncbi.nlm.nih.gov/pubmed/22815225">http://www.ncbi.nlm.nih.gov/pubmed/22815225</a>
Palliative care for the patient with incurable cancer or advanced disease. Part 1: approach to care	Medical Services Commission (British Columbia)	2010	<a href="http://www.guideline.gov/content.aspx?id=38903">http://www.guideline.gov/content.aspx?id=38903</a>
Palliative care for the patient with incurable cancer or advanced disease. Part 2: pain and symptom management.	Medical Services Commission (British Columbia)	2011	<a href="http://www.guideline.gov/content.aspx?id=38885">http://www.guideline.gov/content.aspx?id=38885</a>
Palliative care for the patient with incurable cancer or advanced disease. Part 3: grief and bereavement	Medical Services Commission (British Columbia)	2011	<a href="http://www.guideline.gov/content.aspx?id=38887">http://www.guideline.gov/content.aspx?id=38887</a>
Management of dementia	Ministry of Health (Malaysia)	2009	<a href="http://www.moh.gov.my/attachments/4484.pdf">http://www.moh.gov.my/attachments/4484.pdf</a>
Ministry of Health Clinical Practice Guidelines: Dementia, Clinical practice guidelines on dementia	Ministry of Health, (Singapore)	2013	<a href="http://www.moh.gov.sg/content/moh_web/healthprofessionalsportal/doctors/guidelines/cpg_medical/2013/cpgmed_dementia_revised.html">http://www.moh.gov.sg/content/moh_web/healthprofessionalsportal/doctors/guidelines/cpg_medical/2013/cpgmed_dementia_revised.html</a>
Ministry of Health Clinical Practice Guidelines: Dementia (reproduction in part)	Ministry of Health, (Singapore)	2013	<a href="http://www.moh.gov.sg/content/dam/moh_web/HPP/Doctors/cpg_medical/current/2013/Dementia/Dementia%2010%20Jul%202013%20-%20Booklet.pdf">http://www.moh.gov.sg/content/dam/moh_web/HPP/Doctors/cpg_medical/current/2013/Dementia/Dementia%2010%20Jul%202013%20-%20Booklet.pdf</a>

Guidelines	Guideline Developer	Publication Year	Source
Delirium: diagnosis, prevention and management	National Collaborating Centre for Acute and Chronic Conditions, National Institute for Health and Clinical Excellence (NICE) (London, UK)	2010	<a href="http://www.guideline.gov/content.aspx?id=24121">http://www.guideline.gov/content.aspx?id=24121</a>
Clinical practice guidelines for quality palliative care	National Consensus Project for Quality Palliative Care	2009	<a href="http://www.guideline.gov/content.aspx?id=14423">http://www.guideline.gov/content.aspx?id=14423</a>
Introduction to the recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease	National Institute on Aging and the Alzheimer's Association	2011	<a href="http://download.journals.elsevierhealth.com/pdfs/journals/1552-5260/PIIS1552526011001002.pdf">http://download.journals.elsevierhealth.com/pdfs/journals/1552-5260/PIIS1552526011001002.pdf</a>
The diagnosis of dementia due to Alzheimer's Disease: Recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease	National Institute on Aging and the Alzheimer's Association	2011	<a href="http://ac.els-cdn.com/S1552526011001014/1-s2.0-S1552526011001014-main.pdf?_tid=b1889042-2df0-11e2-9679-00000aacb35d&amp;acdnat=1352852436_2aa77f8915b0a191f29376928a2340f6">http://ac.els-cdn.com/S1552526011001014/1-s2.0-S1552526011001014-main.pdf?_tid=b1889042-2df0-11e2-9679-00000aacb35d&amp;acdnat=1352852436_2aa77f8915b0a191f29376928a2340f6</a>
The diagnosis of mild cognitive impairment due to Alzheimer's diseases: Recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease	National Institute on Aging and the Alzheimer's Association	2011	<a href="http://www.alz.org/documents_custom/diagnostic_recommendations_mci_due_to_alz_proof.pdf">http://www.alz.org/documents_custom/diagnostic_recommendations_mci_due_to_alz_proof.pdf</a>
Toward defining the preclinical stages of Alzheimer's disease: Recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease	National Institute on Aging and the Alzheimer's Association	2011	<a href="http://ac.els-cdn.com/S1552526011000999/1-s2.0-S1552526011000999-main.pdf?_tid=37496aec-2dfd-11e2-90e4-00000aacb35d&amp;acdnat=1352857815_e6c7dd765996fba53216b27f6a7db02e">http://ac.els-cdn.com/S1552526011000999/1-s2.0-S1552526011000999-main.pdf?_tid=37496aec-2dfd-11e2-90e4-00000aacb35d&amp;acdnat=1352857815_e6c7dd765996fba53216b27f6a7db02e</a>
Guidelines for the neuropathologic assessment of Alzheimer's disease, National Institute on Aging and the Alzheimer's Association	National Institute on Aging and the Alzheimer's Association	2012	<a href="http://www.ncbi.nlm.nih.gov/pubmed/22265587">http://www.ncbi.nlm.nih.gov/pubmed/22265587</a>
Donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease, 2011, Mar.	National Institute for Health and Clinical Excellence (NICE) (London, UK).	2011	<a href="http://www.guideline.gov/content.aspx?id=34279">http://www.guideline.gov/content.aspx?id=34279</a>

Guidelines	Guideline Developer	Publication Year	Source
NIH Consensus Development Conference statement on preventing Alzheimer's disease and cognitive decline	National Institutes of Health (NIH) Consensus Development Conference	2010	<a href="http://www.guideline.gov/content.aspx?id=34016">http://www.guideline.gov/content.aspx?id=34016</a>
Clinical guidelines for stroke management 2010	National Stroke Foundation (Melbourne, Australia)	2010	<a href="http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/cp126.pdf">http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/cp126.pdf</a>
Rehabilitation. In: Clinical guidelines for stroke management 2010	National Stroke Foundation (Melbourne, Australia)	2010	<a href="http://www.guideline.gov/content.aspx?id=24173">http://www.guideline.gov/content.aspx?id=24173</a>
Evidence-based interventions to reduce family caregiver strain and burden, Putting evidence into practice:	Oncology Nursing Society (ONS)	2013	<a href="http://www.guideline.gov/content.aspx?id=15693">http://www.guideline.gov/content.aspx?id=15693</a>
Dementia. Diagnosis and treatment.	Regional Health Council, Regional Center for the Coordination of the Network for the Assistance to Patients with Dementia (Milan, Italy).	2011	<a href="http://guidelines.gov/content.aspx?id=32599">http://guidelines.gov/content.aspx?id=32599</a>
Caregiving strategies for older adults with delirium, dementia and depression 2010 supplement	Registered Nurses' Association of Ontario (RNAO)	2010	<a href="http://guidelines.gov/content.aspx?id=32418">http://guidelines.gov/content.aspx?id=32418</a>
Screening for delirium, dementia and depression in older adults 2010 supplement	Registered Nurses' Association of Ontario (RNAO)	2010	<a href="http://guidelines.gov/content.aspx?id=32417">http://guidelines.gov/content.aspx?id=32417</a>
Stroke assessment across the continuum of care; Stroke assessment across the continuum of care 2011 supplement	Registered Nurses' Association of Ontario (RNAO)	2011	<a href="http://www.guideline.gov/content.aspx?id=34755">http://www.guideline.gov/content.aspx?id=34755</a>
Management of patients with stroke: rehabilitation, prevention and management of complications, and discharge planning	Scottish Intercollegiate Guidelines Network (SIGN)	2010	<a href="http://guideline.gov/content.aspx?id=23849">http://guideline.gov/content.aspx?id=23849</a>
Management of patients with dementia. A national clinical guideline. (previous update: Interventions in the management of behavioral and psychological aspects of dementia)	Scottish Intercollegiate Guidelines Network (SIGN)	2009	<a href="http://guidelines.gov/content.aspx?id=8809&amp;search=alzheimers">http://guidelines.gov/content.aspx?id=8809&amp;search=alzheimers</a>
Dementia	Singapore Ministry of Health	2013	<a href="http://www.moh.gov.sg/content/moh_web/healthprofessionalsportal/doctors/guidelines/cpg_medical/2013/cpgmed_dementia_revised.html">http://www.moh.gov.sg/content/moh_web/healthprofessionalsportal/doctors/guidelines/cpg_medical/2013/cpgmed_dementia_revised.html</a>



Guidelines	Guideline Developer	Publication Year	Source
Functional screening for older adults in the community	Singapore Ministry of Health	2010	<a href="http://www.guideline.gov/content.aspx?id=39343">http://www.guideline.gov/content.aspx?id=39343</a>
Clinical practice guidelines for the management of pain, agitation, and delirium in adult patients in the intensive care unit	Society of Critical Care Medicine	2013	<a href="http://www.guideline.gov/content.aspx?id=43903">http://www.guideline.gov/content.aspx?id=43903</a>
Mood, memory, and cognition. In: Menopause and osteoporosis update 2009	The Society of Obstetricians and Gynaecologists of Canada (SOGC)	2009	<a href="http://www.guideline.gov/content.aspx?id=13613">http://www.guideline.gov/content.aspx?id=13613</a>
Screening for Cognitive Impairment in Older Adults: U.S. Preventive Services Task Force Recommendation Statement	U.S. Preventive Services Task Force	2014	<a href="http://www.guideline.gov/content.aspx?id=48059">http://www.guideline.gov/content.aspx?id=48059</a>
Acute confusion/delirium	University of Iowa College of Nursing, John A. Hartford Foundation Center of Geriatric Nursing Excellence	2009	<a href="http://www.guideline.gov/content.aspx?id=14340">http://www.guideline.gov/content.aspx?id=14340</a>
Bathing persons with dementia	University of Iowa College of Nursing, John A. Hartford Foundation Center of Geriatric Nursing Excellence	2013	<a href="http://www.guideline.gov/content.aspx?id=44984">http://www.guideline.gov/content.aspx?id=44984</a>
Oral hygiene care for functionally dependent and cognitively impaired older adults.	University of Iowa College of Nursing, John A. Hartford Foundation Center of Geriatric Nursing Excellence	2011	<a href="http://guideline.gov/content.aspx?id=34447">http://guideline.gov/content.aspx?id=34447</a>
Draft Guidance for Industry Alzheimer's Disease: Developing Drugs for the Treatment of Early Stage Disease	US Food and Drug Administration	2013	<a href="http://www.fda.gov/downloads/Drugs/GuidanceComplianceRegulatoryInformation/Guidances/UCM338287.pdf">http://www.fda.gov/downloads/Drugs/GuidanceComplianceRegulatoryInformation/Guidances/UCM338287.pdf</a>
Practice guideline for the psychiatric evaluation of adults	Work Group on Psychiatric Evaluation, American Psychiatric Association Steering Committee on Practice Guidelines	2011	<a href="http://www.guideline.gov/content.aspx?id=9317">http://www.guideline.gov/content.aspx?id=9317</a>
Guidelines for the biological treatment of Alzheimer's disease and other dementias	World Federation of Societies of Biological Psychiatry (WFSBP)	2011	<a href="http://www.ncbi.nlm.nih.gov/pubmed/21288069">http://www.ncbi.nlm.nih.gov/pubmed/21288069</a>

## APPENDIX G:

### Public Comments Received on Draft Report

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#### Alzheimer's Association

**Laura Thornhill**

##### *General Comments*

The Alzheimer's Association appreciates the opportunity to comment on the National Quality Forum's (NQF) Draft Report on Priority Setting for Healthcare Performance Measurement: Addressing Performance Measure Gaps for Alzheimer's Disease and Related Dementias. As the world's leading voluntary health organization in Alzheimer's care, support, and research, we applaud the work of the Committee. We are keenly aware of the challenges associated with Alzheimer's disease and related dementias, including measuring the quality of care for individuals whose conditions will not improve. It is just as important that their care be evaluated and enhanced.

The Association appreciates the Committee's acknowledgement of the cognitive assessment element of the Annual Wellness Visit (AWV). Although assessing an individual for cognitive impairment is a required element of the AWV, we are unaware of data that delineates the assessment processes being used. To address this, we suggest that the Committee recommend use of specific objective tools for cognitive assessment during the AWV unless both the beneficiary and an informant can confirm that no cognitive impairment symptoms are evident. This request is consistent with recommendations put forth by the Alzheimer's Association in 2013 in *Alzheimer's and Dementia: The Journal of the Alzheimer's Association*, as well as the National Plan to Address Alzheimer's Disease. Both the Alzheimer's Association and the National Institute on Aging have identified brief cognitive assessment tools suitable for use during the AWV.

We also support the Committee's recommendation that various Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys be modified to allow for proxy response. The Association has additional concerns regarding CAHPS surveys that

we note here for the Committee's consideration. Under the Hospice CAHPS survey, for example, caregivers can only provide feedback after the death of the patient. Similarly, if an individual with dementia is discharged from the hospital, s/he and his or her caregiver are no longer eligible for the survey. We believe that patients and caregivers should have the opportunity to provide feedback during their experiences, and that that feedback should be used to improve those experiences.

##### **>Committee Response**

Thank you for your comment. A recommendation regarding use of specific tools for cognitive assessment is outside the scope of this project. However, we have added to the report the citations for the NIA and AA publications that you referenced. We agree that timely feedback on experience of care is needed.

##### *Conceptual Framework*

The Alzheimer's Association fully supports the structure developed by the Committee. The domains follow the logical progression of the disease and a person's experience with it, while the subdomains span populations and a range of issues from education and support to health and safety. This approach acknowledges the full scope of dementia and its reach.

##### **>Committee Response**

Thank you for your comment. We appreciate your support of the framework.

##### *Priorities for Measure Development*

The Alzheimer's Association supports the proposed priorities for measure development. Prioritizing diagnosis underscores its importance in planning and the major diagnosis gap that currently exists. Inclusion of health care and community systems demonstrates the breadth of care that individuals and caregivers need. We particularly commend

the Committee for its recommended composite measure of caregiver support. Given the lack of treatments and the degenerative nature of the disease, caregivers are central to the health, safety and quality of life of those with dementia. As noted by the Committee, however, caregiving takes its own tolls. Family and friends provide billions of hours of unpaid care every year. They bear additional health care issues like depression, as well as the associated costs. We applaud the Committee's effort to bring caregivers' roles and needs to the forefront.

#### **>Committee Response**

Thank you for your comment. We appreciate your support of the recommendations.

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#### **Alzheimer's Foundation of America**

**Eric Sokol (Alzheimer's Foundation of America) on behalf of Charles Fuschillo, Jr.**

##### *Priorities for Measure Development*

The Alzheimer's Foundation of America (AFA) appreciates the hard work demonstrated by the multi-stakeholder Committee convened by the National Quality Forum (NQF) and support the vast majority of priorities and recommendations made in the draft report.

AFA commends NQF for recognizing the need for a timely and accurate diagnosis and the need for earlier and increased detection of dementia. With early detection, individuals with Alzheimer's disease can receive available therapy earlier in the disease progression when most available treatments for Alzheimer's disease are most helpful. Delaying nursing home placement by just one year will save a payee more than \$75,000, according to a 2013 survey of long-term care costs.

Patient-centered, coordinated care delivery models and expansion of caregiver training and supports will help bend the astronomic cost curve necessary to care for a person with Alzheimer's disease, while increasing healthier outcomes for diagnosed individuals and family caregivers.

Recently AFA released a report, "Cost of Care: Quantifying Care-Centered Provisions of the 'National Plan to Address Alzheimer's Disease,'" that quantifies several of the plan's care delivery provisions and offers a cost-benefit analysis of their implementation.

The report finds that implementation of the caregiver models will provide significant cost savings while promoting better health outcomes for individuals with Alzheimer's disease and improving quality of life for their caregivers.

Competent and consistent quality measures will ensure best practices and expedite adoption of these innovative person-centered care delivery models that provide more efficient care, while allowing those living with dementia to delay placement in institutional settings.

Emergency room and inpatient care can be vastly improved through the recognition of the special needs of those with Alzheimer's disease. While specialized training for emergency room staff is essential, AFA also recommends that all hospitals establish specific protocols for patients with dementia. Such standards and training will allow dementia patients to avoid complications and lower rates of re-hospitalizations.

In addition, while there has been movement in the adoption of dementia capable living communities, critical issues still need to be addressed. AFA in conjunction with the Perkins Eastman Research Collaborative recently released "Excellence in Design: Optimal Living Space for People With Alzheimer's Disease and Related Dementias," an extensive report that details best design practices and other considerations concerning residential care settings for individuals living with Alzheimer's disease. AFA urges NQF to consider the findings and recommendations found in this report when developing quality measures for dementia-based community care facilities and supports.

#### **>Committee Response**

Thank you for your comment. We appreciate your support of the recommendations. We agree that healthcare providers need to recognize and adapt to the special needs of those with dementia; this was discussed at length during our deliberations is reflected in the report under the recommendation regarding a dementia-capable healthcare and community care system. We will consider incorporating the Excellence in Design citation in that section of the report.

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## American Academy of Neurology

**Amy Bennett**

### *General Comments*

Thank you for the opportunity to comment on your efforts to prioritize measure gaps for people with Alzheimer's. The American Academy of Neurology (AAN) looks forward to the opportunity to implement some of the work group's suggestions during future measure development projects, including the pending update to the dementia measurement set planned with the American Psychiatric Association. The AAN appreciates the attention spent highlighting the measure challenges encountered for this population.

The AAN has developed several guidelines related to dementia that were not included in Appendix F: Clinical Guidelines Related to Dementia, including the 2010 Update: Evaluation and Management of Driving Risk in Dementia.

### **>Committee Response**

Thank you for your comment. We have added this updated guideline to Appendix F of the report.

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## American Health Care Association

**Urvi Shah**

### *General Comments*

1. The Aims and Priorities: Good patient and family care starts with clear, concise information and ongoing education throughout the dementia journey. Often times we see family members given information upfront; the education must continue. Even when death is imminent, well-being must not only apply to the affected individual but also to the family/caregivers. Consider ways to measure this.
2. When we talk about caregivers and person- and family-centered care, we must ensure this includes the population of young caregivers. These vulnerable caregivers, especially ones without access to supportive resources, have been shown to be at greater risk for burden than those who can call upon resources. This, in turn, will lead to a greater strain on the health care system – providing care for the caregivers themselves. Research has shown that caregivers of persons with dementia have been found to be more burdened and more vulnerable to

health problems than other caregiver groups (Schulz & Martire, 2004; Papastavrou et al., 2007; Sussman & Regehr, 2009). According to CDC, approximately 25-29% of caregivers age 50 and over provide care to someone with dementia; the average age of the caregiver to a person with Alzheimer's disease is 48 years old; and 18% of children 8 to 18 years old provide unpaid care for someone (Alzheimer's Association, 2009).

3. We talk about performance measures, quality indicators, policy, and research – all of which are critical to care of persons with dementia. Equally important is the measuring of performance gaps of availability and accessibility to resources. How are we effectively measuring the needs of the caregiver (not just the stress, burden, etc.)? Research has shown that the physical and emotional impact of caregiving on family members of people with dementia was estimated to result in \$9.1 billion in increased health care costs in 2012 in the United States (Mittelman & Bartels, 2012). This statistic truly indicates a significant gap and an opportunity to find cost-effective ways to mitigate risk and realize the maximum benefits of interventions for both the individuals diagnosed with dementia and their caregivers.

### **>Committee Response**

Thank you for your comment. We agree that education is needed throughout the illness trajectory and have modified the report to make this more clear. As indicated in the Conceptual Measurement Framework, the report narrative, and the recommendations for future measure development, we also agree with your observations concerning the need for measures of availability and accessibility to resources as well as for various types of measures focused on caregivers. We also appreciate your allusion to younger caregivers even though we purposely did not call out particular caregiver groups in our report and recommendations.

### *Conceptual Framework*

The fourth domain of the Conceptual Framework-Care, Treatment and Support- “arguably may offer the most opportunities for performance measurement for the person with dementia and their family/caregivers, because, as the condition

progresses, the person's cognitive and functional abilities decline precipitously."

Because AHCA/NCAL represents 12,000 long term care organizations, we recognize that of the five overarching measurement domains we are likely to interact with families and patients during the fourth and final domains. Within the fourth domain, AHCA/NCAL would like to point out that this presents the greatest opportunity to look at issues related to well-being. Well-being is the ultimate achievement of a nursing center in providing optimal, person-centered care. This would not only give credence to the notion that individualized care is critical to the highest level of quality care for residents but, would also point the profession toward successful strategies found throughout the country.

Many measures commonly used in the skilled nursing care setting are easy to access given that they are derived from standardized, universal data collection tools such as the Minimum Data Set (MDS). However, these do not fully capture all the critical elements of the well-being of the resident. We suggest not to easily accept the measures that are "low hanging fruit". A current AHCA/NCAL workgroup tasked with exploring ways to identify and measure quality care for persons with dementia is considering potential use of data from the MDS assessment capturing rejection of care and physical or verbal behavioral symptoms, directed toward self or others, to potentially construct new measures that capture significant aspects of well-being.

#### **>Committee Response**

Thank you for your comment. We agree that the report would benefit from a greater emphasis on well-being and it has been modified accordingly. We also have added the recommendation to utilize, as appropriate, currently-existing data sources such as the MDS for future development of dementia-specific performance measures.

#### *Priorities for Measure Development*

1. AHCA is aware that, like other populations with certain chronic conditions that frequently use Emergency Department care, persons with dementia are a unique group whose needs must be addressed through tailored, individualized approaches in

this setting. We believe it is important for the measurement framework to incorporate measures that address this and other settings of care that serve significant numbers of persons with dementia.

2. AHCA/NCAL is also focused on the importance of accuracy of dementia diagnosis: Identify specific type of dementia and ensure care/treatment is appropriate for dementia type. Often times we see a diagnosis of dementia – specified unknown. To provide effective care the dementia type must be specified to the greatest extent possible.

3. Non-pharmacological interventions:

a. The measurement strategies proposed seem light on recommendations related to supporting education of caregivers relative to stage-specific non-pharmacological interventions.

b. Similarly, policy to support research on stage-directed non-pharmacological interventions would be helpful.

c. We need to measure the efficacy of interventions in individuals with dementia. Doing so will hopefully avert complacency in care for these individuals. In other words, once they have a dementia-specific diagnosis, it does not mean that they remain on the same treatment/care for the duration.

d. Measure the level of engagement/participation of the individual with dementia. Well-being includes the measurement of activity engagement.

e. Often times discussion of dementia focuses significantly on the cognitive aspects and rightfully so. There is an equal need to measure functional levels to ensure optimal care and quality of life; it is the holistic approach of addressing the needs of mind and body.

#### **>Committee Response**

Thank you for your comment. We interpret this comment as being generally supportive of the Conceptual Measurement Framework and the recommendations. We also agree that education about non-pharmacological interventions is needed throughout the course of the condition. While not emphasized in the text of the report, this was included as a need during the moderate stage of dementia (see Appendix C) and we will expand the grid to reflect this need for each stage of dementia.

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## America's Health Insurance Plans

### Carmella Bocchino

#### *General Comments*

Greater emphasis should be placed on patient safety, (e.g. fall prevention, medication safety). In addition, while decisions about end of life care are included in the report's conceptual framework it is not emphasized in the rest of the report. As a result, we recommend that the priority areas for future measurement not only reflect the inclusion of patient safety, but also incorporate decisions about end of life care within the shared decision-making priority area.

#### **>Committee Response**

Thank you for your comment. We agree that the safety of person with dementia as well as the family/caregiver is tremendously important, as reflected in the discussion of safety in the Overarching Themes section of the report and in its inclusion in the Conceptual Measurement Framework. While patient safety measures were not included in our recommended priorities for future measure development, we strongly encourage stratifying existing patient safety measures when appropriate to assess quality of care for persons with dementia and their family/caregivers. We also agree that the shared decisionmaking section of the report would benefit from additional mention of end-of-life care and will modify it accordingly.

#### *Priorities for Measure Development*

We recommend modifying the list of priority areas for future measurement development as follows:

##### Highest Priority:

1. Comprehensive diagnostic evaluation and needs assessment
2. Shared decision-making (decisions about end of life care)
3. Patient Safety
4. Composite measure of caregiver support
5. Measures to reflect a dementia-capable health care and community care system

##### Additional priority areas:

6. Early detection of signs and symptoms of dementia

## 7. Care transitions

### **>Committee Response**

Thank you for your comment. We are not able to re-order the priorities at this time since this resulted from the prioritization process that was used to come to the rankings. While we appreciate that different groups may rank these items differently, we believe we must adhere to the process that was put in place.

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## Piramal Imaging

### **James Scott (Applied Policy, L.L.C.) on behalf of Susan De Santi**

#### *General Comments*

We thank you for the opportunity to provide comments on the recent draft report titled "Priority Setting for Healthcare Performance Measurement: Addressing Performance Measure Gaps for Alzheimer's Disease and Related Dementias." Piramal's portfolio includes Neuraceq™ (florbetaben F18), a specialized molecule used in positron emission tomography (PET) imaging to detect beta-amyloid in the brain, a widely recognized marker for Alzheimer's disease. Neuraceq™ received FDA approval in March 2014. By developing novel PET tracers for molecular imaging, Piramal Imaging is focusing on a key future field of modern medicine that enables early differentiated diagnosis, patient stratification, and tailored intervention.

We urge future quality measure development to be inclusive of all beta-amyloid imaging agents.

There are currently three different beta-amyloid imaging agents available today. While there have been no head-to-head comparative studies of the three, there are differences in chemical structures, applied dose, image acquisition time, overall radiation exposure, reading methodologies, and side effect profiles. The FDA has acknowledged the differences between the three agents by requesting that users complete tracer-specific reader training programs prior to usage. [1],[2] Therefore, it is imperative that any quality measure that includes beta-amyloid imaging be designed in such a manner that quality related to the class of imaging agents, rather than a single agent, can be determined.

Again, we thank you for the opportunity to provide feedback on the draft report. We look forward to



working with both your organization and HHS in the future as the recommendations from the report are integrated into current quality initiatives.

[1] Amyvid (Florbetapir F18 injection) Prescribing Information, Eli Lilly & Co.

[2] Vizamyl (Flutemetamol F18 injection) Prescribing Information, GE Healthcare.

### **>Committee Response**

Thank you for your comment. We agree that measures focused on identifying those with dementia prior to the onset of symptoms will be increasingly important as research and evidence in this area evolves.

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### **Actavis**

**James Scott (Applied Policy, L.L.C.) on behalf  
Gavin Corcoran**

#### *Priorities for Measure Development*

We thank you for the opportunity to provide comments on the recent draft report titled “Priority Setting for Healthcare Performance Measurement: Addressing Performance Measure Gaps for Alzheimer’s Disease and Related Dementias.”

Actavis is an innovator in key therapeutic categories, including Alzheimer’s treatments. We support the three priority areas identified in the report for the development of future quality measures.

We agree that a composite measure is a top priority.

We were pleased to see that one of the top priorities for measure development as identified by the Committee was the development of a comprehensive composite measure evaluating the timely establishment of a diagnosis of dementia, the identification of contributing factors and support needs and the formulation of a care plan that is well documented. We agree that, while quality measures addressing some of these elements exist, it is imperative that there is a mechanism with which we can evaluate the totality of care provided to a patient that has recently been diagnosed with Alzheimer’s. With the proper evaluation and diagnosis delivered in the early stages of the disease, health care providers have more options available to them to treat patients and manage their symptoms.

We agree that caregiver support is also a crucial area to measure.

We agree with the Committee’s identification of another top priority area: that of caregiver support throughout the trajectory of a patient’s experience with dementia. Today, caregivers of patients suffering from dementia can face extreme burdens that have a negative impact on not only their quality of life, but also their mental and physical health. Healthcare providers need to address the needs of not only the patients suffering from dementia, but also the caregivers that support them.

We support the development of a dementia-capable health care and community care system.

We stand ready to support the Committee and the Department of Health and Human Services (HHS) in addressing the ability of the healthcare and community care systems to meet the needs of dementia patients. As the burden of Alzheimer’s disease and related dementias continues to increase on Americans, it is essential that we address ways in which the healthcare system and our communities can adapt to the unique needs of these patients. This includes increasing the awareness of the signs and symptoms of dementia, which could lead to earlier diagnosis. Early diagnosis provides health care practitioners with more available options for treating symptoms and extending quality of life.

We look forward to working with both your organization and HHS in the future as the recommendations from the report are integrated into current quality initiatives.

### **>Committee Response**

Thank you for your comment. We appreciate your support of our recommendations.

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### **Piramal Imaging**

**James Scott (Applied Policy, L.L.C.) on behalf  
Susan De Santi**

#### *Priorities for Measure Development*

We thank you for the opportunity to provide comments on the recent draft report titled “Priority Setting for Healthcare Performance Measurement: Addressing Performance Measure Gaps for

Alzheimer's Disease and Related Dementias.”

Piramal's portfolio includes Neuraceq™ (florbetaben F18), a specialized molecule used in positron emission tomography (PET) imaging to detect beta-amyloid in the brain, a widely recognized marker for Alzheimer's disease. Neuraceq™ received FDA approval in March 2014. By developing novel PET tracers for molecular imaging, Piramal Imaging is focusing on a key future field of modern medicine that enables early differentiated diagnosis, patient stratification, and tailored intervention. We support the three priority areas identified in the report for the development of future quality measures.

We suggest that future quality measure development to encompass all dementia assessment tools, including newer and more advanced technologies, such as beta-amyloid imaging.

We were pleased to see that one of the top priorities for measure development as identified by the Committee was the development of a comprehensive composite measure that would evaluate several elements of care provided to a dementia patient, including the establishment of a diagnosis of dementia. As the report notes, changes in cognition can be caused by problems other than dementia, and may also be the result of a variety of pathologies. A beta-amyloid PET scan can help physicians estimate beta-amyloid neuritic plaque density in adult patients with cognitive impairment who are being evaluated for Alzheimer's disease and other causes of cognitive decline. A negative beta-amyloid scan may help rule out Alzheimer's Disease as a cause of a patient's cognitive decline. These scans are an adjunct to other diagnostic evaluations performed by the physician when evaluating a patient.[1] Therefore, we hope that as the Committee and National Quality Forum continues to work in the area of Alzheimer's Disease and dementia quality measure development, all dementia assessment tools are considered.

We look forward to working with both your organization and HHS in the future as the recommendations from the report are integrated into current quality initiatives.

[1] Neuraceq™ (florbetaben F18) Prescribing Information, Piramal Imaging.

### **>Committee Response**

Thank you for your comment; we appreciate your support of our recommendations. We also appreciate the news regarding the evolution of medical science for diagnosis.

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### **Eli Lilly and Company**

#### **Phyllis Ferrell**

##### *General Comments*

On behalf of our colleagues at Eli Lilly and Company, we would like to thank NQF for the opportunity to provide general comments on the draft recommendations addressing performance gaps for Alzheimer's Disease (AD) and Related Dementias.

As you have importantly called out in the Background of this report, AD is a devastating and increasingly prevalent disease for which there is no cure, prevention, or disease-modifying treatment. If significant systemic changes don't happen soon, AD and other dementias will continue to overwhelm persons afflicted with dementia-causing diseases their families and healthcare systems ill-equipped to deal with the volume and complexity of dementia cases.

We support the top priorities identified for measure development: 1) comprehensive diagnostic evaluation and needs assessment, 2) composite measure of caregiver support, and 3) measures to reflect a dementia-capable health care and community system. Our comments related to these priorities are provided in the comments section of the “Priorities for Measure Development”.

Efforts are already underway to improve the care of persons with AD, and we urge the NQF to partner with CMS, measure developers, and other stakeholders to implement quality measures that take advantage of these efforts. Importantly, the Medicare Annual Wellness Visit (AWV) already includes a cognitive assessment component. Electronic quality indicators related to the AWV could be developed; key elements might include whether a cognitive assessment was completed, what tool was used, and what follow-up occurred. The NIA and the Alzheimer's Association have already made recommendations on appropriate cognitive assessment tools that could be included in the AWV (Gershon et al., 2013 and Cordell et al., 2013). The



AWV therefore seems like a reasonable point of entry for quality indicators related to comprehensive diagnostic evaluation, further supporting the first priority.

Should you have any specific questions or wish to discuss our comments, please contact us via email at the addresses provided below. Thank you for considering our suggestions.

#### **>Committee Response**

Thank you for your comment. We appreciate your support of the top priorities identified by the Committee. We agree that the Annual Wellness Visit may provide a venue for detection of those with signs or symptoms of dementia and/or for the conduct of an objective cognitive examination. We appreciate the references regarding recommendations for cognitive assessment tools and have included these in the report.

#### *Priorities for Measure Development*

On behalf of our colleagues at Eli Lilly and Company, we would like to thank NQF for the opportunity to comment.

Lilly supports the top priorities identified for measure development.

Regarding the first priority comprehensive diagnostic evaluation, we suggest adding an element related to detection. A timely diagnosis cannot occur in the absence of a systematic method for identifying persons with cognitive impairment (CI). In the current system, people are often not diagnosed until they are in the later stages of dementia (Larson et al., 2004). This leads to delayed treatment of symptoms and care coordination. A systematic approach to identifying CI and initiating the diagnostic process is supported by experts in the field (Borson et al., 2013). A patient has a better prognosis the earlier AD is diagnosed; this will especially be the case when disease modifying treatments are available for clinical use.

We also suggest that this first priority call out more clearly the importance of diagnosing the severity of cognitive impairment and suspected etiology. Effective communication and care coordination are enhanced when persons with dementia and their families understand the cause of the symptoms and anticipated disease trajectory. New proposed

guidelines highlight advancements in the field that allow for identifying approximate staging along the continuum of AD severity (Albert et al., 2011; McKhann et al., 2011) while also identifying the causal pathology of the dementia syndrome. Blood tests to rule-out reversible causes of CI, neuroimaging techniques, and neuropsychological assessment tools may aid in establishing the severity of impairment and suspected etiology. Though new, regulatory-approved advanced diagnostics that identify the hallmark amyloid pathology of AD are not yet part of standard practice, electronic medical records and claims-based codes already include coding options for the clinical syndrome of dementia, and specific neurodegenerative diseases (e.g., AD). Such efforts by NQF to promote effective communication of diagnoses will be instrumental in helping partners such as the WHO establish meaningful codes as the science develops.

In considering the second stated priority of a composite measure of caregiver support, we urge NQF to recommend the inclusion of Patient/Proxy-reported Outcome Measures in quality metrics. Collaborations with groups such as PCORI to promote the development of relevant, caregiver-reported outcomes and, where appropriate, patient-reported outcomes, would serve to enhance the person- and family-centeredness of care.

Should you have any specific questions or wish to discuss our comments, please contact us via email at the addresses provided below. Thank your consideration.

#### **>Committee response**

Thank you for your comment. We agree that early detection of the signs and symptoms of dementia is vital. However, detection often occurs prior to the beginning of a comprehensive diagnostic evaluation and therefore we have not included it as an element in the proposed composite measure. We agree on the need for diagnostic accuracy and will include this in the text for the first priority. We also agree that the recommended composite measure of caregiver support should include caregiver-reported outcome measures and this is reflected in the report.

**Genentech, Inc.****Roshini Epasinghe (Genentech, Inc.) on behalf of Mauricio Silva de Lima***General Comments*

Additional comments relevant to the draft report for NQF's consideration are as follows:

As a complement to this effort, NQF and other stakeholders can continue to stress the importance of raising awareness and identification of dementia. A key barrier to the identification and treatment of dementia is the stigma around it, which a more robust and informed public dialogue could potentially help alleviate.<sup>1,2</sup>

One challenge often encountered in quality measurement is the lack of data sources that can be used to track patient centered outcomes and advance quality measure development, testing, and implementation<sup>3</sup>. Identification and development of clinical registries is a critical step in this process, and another area where NQF could consider demonstrating leadership.

NQF has recognized a critical need: development of a support system for older adults without active caregivers. The improvement of community care systems is a robust and compelling way to address this need. Building onto this, NQF (or partners) might encourage these community care systems and/or collect "best practices" from existing demonstrations projects as a means to expedite high quality care country-wide.<sup>4</sup> Learnings from these novel endeavors, such as the Alzheimer's Community Care SAFE (Safety, Adaptability, Family, Education) project in Florida, may be seminal in the development of new quality measures and initiatives.<sup>5</sup>

Genentech urges NQF to consider the development and or prioritization of a process/infrastructure for the rapid development and testing of quality measures to address ongoing advances in treatments and treatment pathways for Alzheimer's disease and related dementias. Treatment-related quality measures regarding detection of risk factors, management of relevant comorbidities (e.g., cardiovascular disease), and non-pharmacological treatments (important lifestyle changes and other health behaviors, community support practices) of dementia should be considered early on as means to improve overall patient level outcomes.

Due to character limits, please contact Genentech Managed Care Medical Communications at (800) 821-8590 for supporting references.

Thank you for the consideration of Genentech's comments.

**>Committee response:**

Thank you for your comment. We agree that reducing the stigma associated with dementia is an important goal and recognize that increasing dementia capability at the community level may help in this effort. We also appreciate the example of a community initiative to improve the safety of persons with dementia.

*Conceptual Framework*

Genentech is very supportive of this effort to lead an organized, thoughtful approach to the creation of performance measures related to Alzheimer's disease and dementia, and we appreciate the opportunity to submit comments.

At the highest level, we agree on the fundamental value of the five overarching themes and areas of priority: Importance of connection to community-based services; Need for community-level accountability; Person- and family-centeredness; Diagnostic accuracy; and Safety. We view these themes are aligning with the National Quality Strategy, a blueprint to improve the quality of care for all Americans.

As a complement to NQF's existing framework, we suggest the consideration of attenuating the cost of dementia on society as an additional theme. Identifying opportunities that help to minimize long-term costs and overall burden to society while maintaining or improving care for patients will be very important.<sup>1</sup>

**REFERENCES**

[1] Alzheimer's Association. Report: Alzheimer's disease to cost United States \$20 trillion over next 40 years. [http://www.alz.org/news\\_and\\_events\\_19623.asp](http://www.alz.org/news_and_events_19623.asp). Published May 19, 2010. Accessed September 11, 2014.

**>Committee response**

Thank you for your comment. We agree that measurement to mitigate the societal costs of dementia increasingly will be needed. This belief is

reflected in our inclusion of the priorities for measure development from the National Quality Strategy (particularly that of affordability) in the Committee's Conceptual Measurement Framework.

#### *Priorities for Measure Development*

Genentech views the three priorities areas for future measure development as important for improved quality of care. In addition, it may be important to consider elevating "early detection of signs and symptoms of dementia" from an "additional priority area" to a "highest priority area". This measure concept domain is crucial because it defines an essential step on the pathway towards a diagnosis of Alzheimer's disease or other neurodegenerative syndromes. High quality diagnostic practices should begin with early detection as part of the spectrum of practices around diagnosis.<sup>1</sup>

Furthermore, it may be helpful to augment the current priorities with the following additional concepts which have implication across several of the five overarching themes.

**Alzheimer's Disease and Dementia Screening:** Considering that 50% of AD patients remain undiagnosed<sup>2</sup>, the development of measures that promote dementia screening (e.g. integration of dementia screening into annual wellness visits in older adults<sup>3</sup>) are important to incent high quality care. Early identification could have important implications for the patient's overall health and well-being, safety, and management of other comorbidities, and also may lead to lower healthcare costs.<sup>3,4</sup> We view this topic as a crucial step on the pathway to an existing prioritized measure area #1 and #3.

**Differential Care Based on Type of Dementia:** Optimal treatment for patients with dementia requires development of treatment plans that differ based on the type and severity of dementia.<sup>5</sup> Measures that address differential care needs complements another NQF priority area – to develop, measures that establish the importance of differential diagnoses as a critical first step in delivering proper care.

**Monitoring of Patients with Dementia:** Measures that support standardized monitoring of patients with cognitive complaints, mild cognitive problems, and early stages of dementia could be very valuable

for diagnosis and treatment. Tracking these patients can help identify clinical concerns, safety concerns, and guide the development of long-term treatment plans for patients with the earliest signs of dementia. Monitoring can be facilitated through the identification of risk factors, biomarkers including genetic risk factors, family history, and clinical presentation to understand patients at risk for incipient neurodegenerative disease.<sup>4</sup>

**Health Information Technology:** NQF might consider encouraging the development of measures that incent the use of health information technology platforms to facilitate Alzheimer's disease and dementia screening to help minimize the burden on health care professionals and health systems more broadly.<sup>6</sup>

#### REFERENCES

- [1] Cordell CB, Borson S, Boustani M, Chodosh J, Reuben D, Verghese J, This W, Fried LB. Alzheimer's Association recommendations for operationalizing the detection of cognitive impairment during the Medicare Annual Wellness Visit in a primary care setting. *Alzheimer's Dement.* 2013;9(2):141-150.
- [2] Alzheimer's Association. 2014 Alzheimer's Disease Facts and Figures. Chicago, IL: Alzheimer's Association; 2014.
- [3] Wolfs CAG, Dirksen CD, Kessels A, Severens JL & Verhey, FRJ. Economic evaluation of an integrated diagnostic approach for psychogeriatric patients. *JAMA Psychiatry.* 2009;66(3):313-323.
- [4] Lyketsos, CG. Prevention of unnecessary hospitalization for patient with dementia. *JAMA.* 2012;307(2):197-198.
- [5] Sperling RA, Aisen PS, Beckett LA, Bennett DA, Craft S, Fagan AM, et al. Toward defining the preclinical stages of Alzheimer's disease: recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's Dement.* 2011;7(3):280-292.
- [6] Department of Health & Human Services. Doctors and hospitals' use of health IT more than doubles since 2012. <http://www.hhs.gov/news/press/2013pres/05/20130522a.html>. Published May 22, 2013. Accessed September 11, 2014.

**>Committee Response**

Thank you for your comment. We realize that the ordering of the “early detection” and “diagnostic evaluation” priorities might be confusing, given that detection is required prior to conduct of a diagnostic evaluation and needs assessment. Our recommendations reflect our charge to prioritize concepts for future performance measure development; they should not be construed as suggesting that detection is somehow less important than diagnosis. We did not prioritize measurement efforts focused on screening because of current insufficiency of evidence regarding the balance of benefits and harms of screening asymptomatic community-dwelling adults for cognitive impairment. We assume that if and when evidence of benefit of such screening becomes available, development of relevant performance measures should follow. We also agree that treatment plans will differ based on the type and severity of dementia, and this is reflected in the report by noting that periodic review and revision of the care plan will be required. Finally, we appreciate your suggestions regarding potential measure development focused on patient monitoring and use of information technology.

**Healthcentric Advisors****Rosa Baier***Priorities for Measure Development*

On behalf of the RI Safe Transitions Project's Advisory Board, we are writing to provide comments on “Prioritizing Measure Gaps.”

The Safe Transitions Project is a Medicare-funded project led by Healthcentric Advisors, the New England Quality Improvement Organization. Its multi-stakeholder Advisory Board (including clinicians and policymakers) has advised the project on the sustainability and spread of interventions to improve care transitions since 2009.

The Advisory Board applauds NQF for including transitions in its discussion of measure gaps, but advises that transitions measures be given a higher priority. Our work demonstrates that patients with dementia are at higher risk for unplanned transfers and transitions, which can negatively affect their

experiences and contribute to adverse outcomes (Daiello et al., 2014).

The Advisory Board articulates its vision as:

“A healthcare system where discharged patients and their caregivers understand their conditions and medications, know who to contact with questions (and when), and are supported by healthcare professionals who have access to the right information, at the right time.”

To further this vision, we need measures that help us to identify variation and allocate resources to high-risk patients. Although there are NQF-endorsed measures for hospital admissions and readmissions, the issues are broader than hospitalization or even utilization – we need measures specifically to evaluate dementia patients' experiences and outcomes throughout the care continuum.

Rosa Baier, Healthcentric Advisors

Rebekah Gardner, Healthcentric Advisors

Safe Transitions Advisory Board:

Virginia Burke, RI Health Care Association

Lynne Chase, Healthcentric Advisors

Kathy Calandra, Healthcentric Advisors

Kathleen Connell, AARP

Gary Epstein-Lubow, Butler Hospital

Stefan Gravenstein, Healthcentric Advisors  
(Facilitator)

Steven Kempner, Coastal Medical

Stephen Kogut, University of RI, College of Pharmacy

Gus Manocchia, BCBSRI & the BCBSRI Patient-Centered Medical Home Project (Chair)

Edward Martin, Home & Hospice Care of RI

Ellen Mauro, RI Department of Human Services

Brian Montague, Lifespan Hospital System

Paula Parker, RI Division of Elderly Affairs

Nancy Roberts, VNA of Care New England

Gina Rocha, Hospital Association of RI

Beth Russell, Leading Age Rhode Island

Francisco Trilla, Neighborhood Health Plan of RI

Ana Tuya-Fulton, Butler Hospital

**>Committee Response**

Thank you for your comment. We agree that outcome measures and measures of experience of care are needed for the dementia population, and this is reflected in the Committee's Conceptual Measurement Framework, report, and recommendations. Also, per our recommendations, we agree that development of measures related to care transitions should be a priority in future development efforts, even though this topic area was not included in our top three priorities. We are not able to re-order the priorities at this time since this resulted from the prioritization process that was used to come to the rankings. While we appreciate that different groups may rank these items differently, we believe we must adhere to the process that was put in place.

**Homewatch International**

**Jette Hogenmiller (Homewatch CareGivers International, Inc.) on behalf of Leann Reynolds - President**

*Priorities for Measure Development*

We applaud the NQF measurements proposed for "Alzheimer's Disease and Related Dementia". There may be value in adding the Lawton activities of daily living/instrumental activities of daily living (ADL/IADL) to the list of "Clinical Guidelines Related to Dementia". This tool has been used for over 30 years with published studies in related to use of the tool in populations of seniors and clients with dementia. This tool is one that Homewatch CareGivers, a homecare company, has embraced given the tools reliability and validity, and alignment with our core business of supporting ADL'S/IADL's in our clients. We have adapted the tool as per use in geriatric and university settings, as well as refined to decrease cultural biases.

An additional tool that might be added to the guidelines resource is the GPCOG, a cognitive screening tool. We have certainly found in our care of clients with dementia in the home setting that late diagnoses are more common than early. We use the GPCOG, as recommended by a number of agencies to include the Alzheimer's Association, as a screening tool to promote early referral for client displaying cognitive impediments.

The measure related to support for all caregivers, family and medically knowledgeable trained (paid caregivers) would be a significant contribution. As the report indicates, the challenges are significant for providing care for individuals with dementia and not well described for caregivers.

There may be value in discussing the Eden Alternative™ philosophy of care, which emphasizes client directed care (shared decision-making).

Are there any plans to examine various client dementia supportive programs delivered by homecare and other organizations looking at measures of effectiveness to better help families identify helpful approaches to care?

Thank you for the opportunity to comment about one of our passions - exceptional care for clients with dementia and support of their circle of caregivers.

**>Committee Response**

Thank you for your comment. We appreciate your support of our recommendations regarding caregiver support. While we have included Appendix F in order to provide information on recent clinical practice guidelines related to dementia, the identification of specific tools such as the Lawton ADL/IADL scale or the GPCOG was not a goal of this project. We will consider your suggestion to include a decision of the Eden Alternative philosophy in the shared decisionmaking section.

**>NQF Response:**

NQF has no plans to review supportive programs for dementia; other entities may be thinking of funding or doing this work, but if so, we are unaware of those efforts.

**MIPT, Inc.**

**Lise Mccarthy**

*Priorities for Measure Development*

I have a gerogeriatric (patient population 80 years+) house-calls physical therapy practice. The concerns and problems primarily affecting my patients with dementia and their caregivers at home mainly relate to increasing impairments, functional limitations and disability as the dementia progresses. A physical therapy doctor (DPT) or a physical therapist who is



board-certified clinical specialist in geriatric physical therapy (GCS) is ideally suited to take on greater responsibility in the evaluation and management of this population if the person with dementia is medically stable. Such a highly trained physical therapist can assess and monitor for changes, as well as screen for the need for medical referral. Separating “impairments” from “functional limitations” would better incorporate the physical therapy model of care and help engage these physical therapists to more clearly understand their primary and secondary care roles.

RE: Appendix C: Symptoms/Needs Grids

Table 1. Person with Dementia Grid

Recommend under “impairments” symptoms: delays in processing for vision, hearing, swallowing, comprehending and speaking; inadequate muscle force generation capacity and incoordination of strength; abnormal muscle tone; collapsing posture; delayed or weak balance reactions; inadequate balance control; mood dysregulation; pain especially with movement or weight-bearing force.

Recommend under “functional limitations”: insufficient gross motor capability for lifting, lowering, reaching, carrying; insufficient fine motor capability for manipulating, holding and releasing; incomplete transfer sequencing for getting in/out any seated environment, and pathologically slow movement through space (e.g. stepping, walking).

Underlying comorbidities can exaggerate the dementia presentation, and affect care planning and treatment. The above impairments and functional limitations cause a person with dementia to become increasingly disabled and in need of increased external supports from people or equipment. People with dementia have a high risk of posture collapse, a high fall risk and a high pain risk. The number one modifiable dementia risk factor is physical activity. The brain takes ~20% of oxygen in the blood stream. People with brain conditions (including those with dementia) should be engaged in safe aerobic exercise (e.g. walking, seated pedal exercise) as a prescribed treatment to help ensure their brain is getting sufficiently good blood perfusion. Physical therapists have the knowledge and skills to assess and monitor aerobic capacity, and train caregivers to assist the patient with dementia in a prescribed

“exercise dose” regimen to address inadequate oxygenation.

Assistive technology assessment by a physical therapist for a walker that best supports the trunk and upper body is paramount to keeping people with advanced dementia optimally moving in the home so the caregiver burden is optimally minimized, and the risk of functional decline and subsequently impairments and comorbidities are slowed or lessened. The Alpha Basic Dolomite walker and the U-Step walker with and without platform attachment provide needed stabilizing support from collapsing postures, reduce fall risk, reduce pain-related stiffness and caregiver burden, and post-pones the need for more expensive equipment (e.g. mechanical lift, reclining wheelchairs).

Fall assessment and risk reduction interventions should be included in all stages of dementia not just in the advanced stage; falls exponentially increase with age and with dementia. Fall injury risk, (especially as it relates to osteoporosis, gender, age, medication use in people with dementia) should be considered throughout. ADLs and IADLs support should be included in all stages.

Contracture assessment and management should be considered in moderate and advanced stages of dementia since muscle tone often changes in these stages as the brain-body disconnection progresses. Contractures are best managed before they impair function and personal care, and become painful.

Pain contributes to falls and aberrant/distressing behaviors. Pain limits movement and physical activity, and can make the severity of dementia and depression symptoms worse. Pain assessment should be ongoing with every visit. Caregivers can be educated and trained to track pain behaviors using a pain assessment tool such as the PAINAD to help clinicians determine if non-medicinal and/or medicinal interventions are effective.

Under the columns for mild, moderated and advanced care, treatment, support:

Recommend vision/hearing “loss” (resulting from an injury/condition) be separated from vision/hearing “processing delays” (resulting of the advancing dementia process).

Recommend that people with moderate and severe

dementia have their dementia staged by a geriatric specialist (e.g. trained PT, OT, ST), in order to improve the success of the treatment plan. Staging dementia beyond mild, moderate and advanced may be useful to the global Care Plan and treatment. For example, a person in Stage 4 Alzheimer's dementia (moderate dementia) is still fairly self-aware and so tends to deny their deficits and refuse care that they see as not needed vs. a person in Stage 5 AD (also considered moderate dementia) is no longer self-aware enough to deny the need for interventions and so refusal is usually related to communication breakdown (e.g. hearing processing delay combined with hearing loss and lack of access to a Pocket Talker). Successful intervention approaches incorporate these differences between the various stages of dementia.

Thank you for the opportunity to contribute. This document should prove quite helpful as starting point to guide all healthcare professionals' decisions about the care needs and treatment approaches for people with dementia.

#### **>Committee Response**

Thank you for your comment. The symptom needs and measurement concept grids (in Appendix C and D) were developed over the life of the project as a tool to help refine the conceptual measurement framework and serve as a starting point for the our prioritization process. As such, they were not meant to be exhaustive, stand-alone products of the Committee. Because they were interim tools used by the Committee and were included for informational purposes only, we are unable to make the changes you suggest. However, we do appreciate your suggestions for additions to the grids and thank you for distinguishing "impairments" and "functional limitation."

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#### **Normandale Center for Healing & Wholeness**

**Deborah Paone**

##### *General Comments*

With 20 years of experience in health systems/continuum of care and 10 years in community-based services--both focusing on older adults and their caregivers, I applaud the Committee for bringing a more inclusive focus on creating "dementia-capable health care and community care systems." However,

there is a deficit in language and focus on the community care system side in this current report. One cannot hold a provider network or service network accountable if they are not part of the team in an integrated way. For example, the Committee identified as a first priority, the measurement of a comprehensive assessment -- with care plan and support needs identified within a defined timetable. Many of the elements described in the list of items to be assessed are generally outside of the knowledge and customary capacity/experience of the medical provider team, and are, if done at all, usually done by the home and community based providers (e.g., care consultants in the community as part of the Long Term Services and Supports or LTSS. For example: determining functional status (best done in the home environment), need for social and community-based services, caregiver needs, financial/legal concerns, driving status and safety in the home concerns, etc. Physicians and nurses may not be familiar with the assessment tools that address these issues, nor with the nuances of how local resources work/are set up---nor are they likely to have the structure/time to conduct home visits and/or monitor the services after they've been set up. The Committee might consider widening/revising the language to be more "clinic+community providers/supports" inclusive versus "clinic-centric." The Committee's attention to developing a composite measure of caregiver support is also laudable. One suggestion is to focus not only on the timeliness of communication but to the recognition of the types of information needed to be exchanged across stakeholders and that the information flows in multiple directions to/from the caregiver --and needs to be integrated and coordinated so that it is accurate and usable by the caregiver. Thank you for the opportunity to comment on this report.

#### **>Committee Response**

Thank you for your comment. As reflected in the report, we agree that increased linkage between "traditional" health care and community-provided supports is needed. The clinician-focus of the first priority area (comprehensive diagnostic evaluation and needs assessment) is not meant to minimize the role of the community in providing many of the services identified. Rather, it reinforces the idea

that even if such services and supports are not provided directly by a clinician within the medical system, the clinician (or facility, health plan, etc.) still bears a responsibility to ensure that such services are provided (e.g., through referrals or connections to appropriate community providers). We also agree with your observation regarding the need for integrated and coordinated communication and have modified the report accordingly.

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**Submitted separately by the Leadership Team organizations of the Dementia Action Alliance:**

**CCAL Advancing Person-Centered Living, The Eden Alternative, Planetree, AMDA: The Society of Post-Acute and Long-Term Care Medicine, LeadingAge Georgia, CareGivers United**

**Karen Love, Chris Perna, Susan Frampton, Christopher Laxton, Walter Coffey, Betsy Arnold**  
*General Comments*

Thank you for the opportunity to provide comments to your report, "Priority Setting for Healthcare Performance Measurement: Addressing Performance Measure Gaps for Alzheimer's Disease and Related Dementias". As the Leadership Team organizations of the Dementia Action Alliance – AMDA: The Society for Post-Acute and Long-Term Care Medicine, CareGivers United, CCAL: Advancing Person-Centered Living, LeadingAge Georgia, Planetree, and The Eden Alternative - we are submitting one set of joint, united comments on the report.

We applaud the Committee members for their extensive process and efforts to identify priorities for the development of healthcare performance measurements for dementia. Given the escalating human, societal, and economic impact of dementia, it is a timely and important undertaking. Overall, the report is very good. In the interest of brevity, we limited our comments to items that are especially noteworthy or of concern.

It is laudable that the Committee members recognized the importance and value of including the person's and family's experience of care and their individual goals in performance measurement. These are foundational aspects of person- and family-centered care. The following are several examples of language in the report we highly support:

"...however, some structures and processes may not be as meaningful to persons with dementia and their family/caregiver as information on the experience of person- and family-centered care." [Page 9, 10th Bullet]

"The Committee also noted the importance of performance measures that align with individual goals. This would necessitate not only asking individuals about preferences and treatment goals over the course of the condition, but also asking them whether or not their preferences and goals are being met." [Page 28, 3rd Paragraph]

"Continue development of outcome measures, particularly experience of care, goal attainment, and quality of life measures." [Page 29, 3rd Bullet]

The report uses the term "person" throughout to refer to people who have dementia. We applaud the decision to use this term as it is what persons who are living with dementia prefer to be called rather than "patient". "Patient" stigmatizes them and continues the medical/disease ethos.

We feel it is a serious oversight not to have included one person living with dementia in the early stage as a minimum as a member of the Committee. Their absence from participation limits a key stakeholder perspective from informing the contents and comprehensiveness of the report. The patient rights movement has made it a standard convention in our nation's healthcare culture to include people affected by the health condition in decision-making for that condition. We highly recommend that this oversight be remedied going forward.

Page 3 of the report identifies three items as its highest priority areas for measure development and an additional three areas for future development after the first three have been developed. We feel there is a misalignment in the order of priorities. The first priority area includes "comprehensive diagnostic evaluation and needs assessment," yet it is not until the second set of priorities that "early detection of signs and symptoms of dementia" is addressed. Early detection is needed BEFORE the diagnostic evaluation and needs assessment happens. We recommend that the first priority area in the highest priority section be changed to – "Early detection of signs and symptoms of dementia and comprehensive diagnostic evaluation and needs assessment".



We are pleased overall, the report has a person-centered ethos, however, there remain undertones of a medical/disease orientation. Person-centeredness is based on a holistic orientation to healthcare that includes focus on the emotional, social, and spiritual components of well-being as well as the physical compared to the medical/disease orientation that focuses primarily on the physical component. The World Health Organization and the Institute on Medicine hold person-centered practices as the gold standard.

Therefore, the following are suggested wording changes for your consideration, to strengthen the person-centered ethos of the report:

Page 14/Cognition, Behavior, and Function. Replace “They represent the three major areas of illness and impairment associated with dementia” with – They represent three major components of health and well-being affected by dementia.

Page 14/Safety. Replace “...and is included to reflect the need to reduce and mitigate the potential for unsafe acts. For example, people living with dementia are at greater risk for general disability and may experience frequent injury from falls, thus reinforcing the need for safety precaution” with – and is included to reflect the need to address safety considerations. For example, people living with dementia are at greater risk for unintentional harm resulting from impaired decision-making such as medication and financial mismanagement and driving safety.

Page 15/Education. Replace “Performance measures addressing this subdomain could include training on complications and progression, management of specific behavioral issues, and prognosis information” with – Performance measures addressing this subdomain could include education about the condition as well as cognitive and behavioral changes, support groups and other means of emotional and social support, and the importance of having purpose and meaningful things to do in daily life to support well-being.

Page 16/Quality of Life. Replace “While disease modifying therapies for dementia itself are lacking there are interventions to manage many of the symptoms of dementia; such interventions can help to maintain the quality of life of the person with dementia...” with –While no cures currently exist,

there are ways to support the quality of life that are vital to the health and well-being for a person living with dementia and their care partners during all stages of the condition.

Lastly, we suggest changing the title of the report to “Priority Setting for Healthcare

Performance Measurement: Addressing Performance Measure Gaps for Dementia including Alzheimer’s Disease”. Pages 6 and 7 of the report note that the term “dementia” is used throughout to refer to Alzheimer’s disease and related dementias, yet the inclusive term is not included in the title. The term “dementia” is the appropriate and widely accepted term, and therefore, should be reflected in the title of the report.

#### **>Committee Response**

Thank you for your comment. We appreciate your overall support of both the report and our emphasis on person- and family-centered care. We realize that the ordering of the “early detection” and “diagnostic evaluation” priorities might be confusing, given that detection is required prior to conduct of a diagnostic evaluation and needs assessment. However, our prioritization for future measure development was not meant to reflect temporal order of clinical processes, nor was it intended to suggest that diagnosis is more important than detection (or vice versa). Due to the importance of early detection, we will keep it as a separate recommendation for future measure development. We agree that with your suggestions to more explicitly call out need for emotional, social, and spiritual components of well-being and the report has been modified accordingly. We also agree with your suggestion to change the title of the report.

#### **>NQF Response**

We agree that the “patient voice” provides a key stakeholder perspective. We often are able to include at least one person with the relevant condition on our various Committees. When this isn’t feasible, we seek to obtain this perspective by including other informed individuals such as those with pertinent consumer and/or advocacy background and expertise.

## **The Hartford Change AGENTS Initiative Dementia Caregiving Network**

**Kathryn Zahm (The Gerontological Society of America) on behalf of The Hartford Change AGENTS Initiative Dementia Caregiving Network**

### *General Comments*

These comments were generated from an iterative process among Dementia Caregiver Network members.

The Dementia Caregiving Network (DCN) is a newly established interprofessional Hartford Change AGENTS Initiative working to achieve improvements in services, supports, and care for persons with dementia and their family caregivers. The DCN is part of the Hartford Change AGENTS Initiative (<http://www.changeagents365.org/>), which is headquartered at The Gerontological Society of America and is supported by The John A. Hartford Foundation. Since January 2014, DCN has identified core concepts that define or influence practice change activities in dementia caregiving. The mission and activities of the DCN align with the NQF's Performance Measures for Dementia project.

The DCN wishes to thank and congratulate the NQF and its committee for a thorough and thoughtful presentation of results in the draft report. The DCN appreciates the enormous effort completed by NQF and the AD-MI project to catalogue and report performance measures applicable to dementia. The DCN commends the NQF Performance Measures for Dementia's goal to "provide recommendations on priorities for performance measurement development efforts focusing on persons with dementia and their families and caregivers." Specifically, the DCN applauds NQF on separately identifying "families" and "caregivers" as separate populations potentially in need of distinct measurement of care experiences. The DCN agrees that valid and reliable measures of quality are necessary in order to assure adequate care and improve dementia treatment.

As the DCN considered its general comments, one question was raised, regarding the environmental scan. In the report's description of measures, and in the environmental scan spreadsheet, it is not clear what the committee hopes to communicate by listing and categorizing available guidelines. Might the NQF report summarize commonalities or

strengths/weaknesses of measures? Similarly, it is not transparent as to how the committee cross-walked the environment scan with endorsed sets of quality measures for dementia in the United States, including CMS 2013 Physician Quality Report System Measures #280 – 288, and the medically oriented measures from Odenheimer and the interdisciplinary Dementia Measures Work Group. The DCN suggests that the NQF indicate, in text and/or tabular form, where endorsed US measures and items do or do not fit in the environmental scan and gap analysis.

### **>Committee Response**

Thank you for your comment. After further discussion, we have replaced the term "family/caregivers" in the report with "family caregivers". However, we also have modified the report to emphasize the scope of this definition, recognizing the potential contributions of many family members who provide a broad range of assistance, as well as the dynamic nature of the caregiving role and the need to consider additional family members in measure development efforts.

### **>NQF Response**

The purpose of identifying the available measures was to illuminate gaps in measurement and thereby inform the Committee for their prioritization efforts. We agree that a discussion of the strengths and weaknesses of the available measures would be useful and informative, but this was beyond the scope of the project. The PQRS dementia measure set and the measures described by Odenheimer and colleagues are essentially the same. Those measures are included in the environmental scan list of measures; you can find them by filtering the Measure Steward column of the Excel file for "American Medical Association - Physician Consortium for Performance Improvement (AMA-PCPI)". Additional columns in that spreadsheet indicate the NQF number assigned to the measures (if applicable) and the current endorsement status. Nine of the 10 measures were evaluated for NQF endorsement in 2012 but were not endorsed.

### *Conceptual Framework*

The DCN views family caregiving within a social ecological model in which coordinated practice

change can impact the caregiver through interface with the health system at the level of the person, organizations, community and/or policy; this social ecological model is consistent with the NQF's conceptual model. The DCN suggests that NQF consider the following additions

a. Identification of a family member or caregiver. The DCN suggests that "identification of a family member or caregiver" should parallel the important indicator of establishing and documenting a dementia diagnosis. The specific person(s) may occupy one or more caregiving roles, and the individual(s) and role(s) may change over time. In the NQF report, within the description of the measurement domain of Evaluation and Initial Management, the conceptual model suggests that a diagnosis of dementia may (or may not) be made, and documented, "at any point during the episode and, for some individuals, will not be made at all." The DCN wishes to emphasize the important correlate to diagnosis, of identifying one or more individual(s) as "a" or "the" caregiver. The presence or absence of a family member or other individual, an emergency contact, a proxy respondent, and a legal surrogate decision-maker are distinct measureable elements, and the definition of these could be clearer in the model.

b. Family caregiver Safety. The DCN's opinion is that family caregiver Safety is of relatively greater importance than currently indicated. In the NQF model as written, within the description of measurement subdomains, the NQF committee defines the Safety subdomain as "applicable to the person with dementia" and the "Health subdomain is applicable to the family/caregiver and is included to draw attention to their health and safety." The DCN suggests that family caregiver Safety should exist as a separate subdomain, or be included under a new subdomain of family/caregiver Functioning rather than Health.

c. Family caregiver Functioning. The DCN has concern that the NQF model's subdomain of Support does not address the variable nature of how an individual caregiver may or may not have the capacity to engage with support services or act in distinct caregiving roles. Given that the NQF committee's "Top Priority" for measure development is a "comprehensive diagnostic evaluation and needs assessment" which includes "identify caregiver needs

(at baseline)," the DCN suggests that family caregiver capacity or family caregiver Functioning be included as a measurement subdomain.

### **>Committee Response**

Thank you for your comment. We agree that identification of family members and caregiver(s) is both important and measureable, and this is reflected by its inclusion in the recommendation for a composite measure of the comprehensive diagnostic evaluation and needs assessment. We have added some text to the report to reflect the various roles (e.g., emergency contact, etc.) of these family members and caregivers. We agree that Safety should be a measurement subdomain for the family/caregiver and have updated the Conceptual Measurement Framework accordingly. We also agree that measures of caregiver capacity can be conceptualized using the Support, Experience of Care, and/or Engagement subdomains already defined in the Conceptual Measurement Framework and have modified the report to make this more explicit.

### *Priorities for Measure Development*

The DCN strongly agrees with the NQF priorities: 1) a comprehensive diagnostic evaluation and needs assessment, 2) a composite measure of caregiver support; and, 3) measures to reflect a dementia-capable health care and community care system for patient treatment and family support. The DCN suggests that NQF consider the following:

a. Community-based services and community-level accountability. The DCN believes that the NQF committee's division of quality measurement into services that are "medical" versus "community" is unnecessary and has the potential to derail production of universally valid and reliable measures. Instead, the DCN suggests that the NQF committee consider that the NQF Performance Measures for Dementia report takes no stance as to where specific services are delivered; this can be done while acknowledging that high quality dementia care can likely be delivered heterogeneously, as best fits a specific population or community. Effective dementia care does not, by definition, "transcend the traditional medical system," as stated in the NQF report. If the final report does include a dichotomy

of “medical” and “community” services, the DCN suggests that the report include more discussion of what the committee means by “community” and “community agency,” including categorization of services such as long term care and home health agencies.

b. Comprehensive diagnostic evaluation and needs assessment. The DCN applauds the NQF committee's success in defining the content of a comprehensive assessment. The DCN appreciates the detailed reporting of ideas to define the denominator for a composite measure and agrees that the proposed measure could be used to assess accountability at the level of the clinician/provider, facility or regional system levels. The DCN understands that early discussions within the NQF committee acknowledged the difficulties, complexities and potential costs associated with measurement at the individual patient / family level; the DCN suggests that the NQF report reiterates that the committee chose not to address quality measurement at the level of the individual patient.

c. Composite measure of caregiver support. The DCN again praises the NQF committee in endorsing and recommending caregiver assessment at the highest level of priority for measurement development. One suggestion, as described above, is to increase the emphasis on including “capacity for providing care” in measure development as a recommended rather than optional element. This suggestion aligns with the DCN's suggestion to add family caregiver Functioning as a subdomain in NQF's conceptual measurement framework.

### **>Committee Response**

Thank you for your comment. We agree that more discussion is needed to better describe “community” and the report has been modified accordingly. We agree that many services for those with dementia and their family/caregivers can be provided through a “medical environment” or a “community environment” and did not mean to imply a particular stance about where they should be provided. In fact, we maintain that performance of such services should be measured in both environments and that both environments should be held accountable for their performance of these services. We do not understand your suggestion regarding quality

measurement at the level of the individual patient, as performance measurement by definition requires aggregation of patient-level information. We appreciate your emphasis on measuring caregivers' capacity of providing care, which we listed as an “additional element” that should be considered when actually developing the caregiver support composite. These additional elements were not intended to be considered as “optional” components per se, but instead were included so as to ensure serious consideration of these elements in a potential composite measure of caregiver support.

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### **Roger Renfrew**

#### *Priorities for Measure Development*

Thanks very much for the webinar on measures for dementia. This was helpful in terms of work that I am doing in our system.

I know that this topic is somewhat out of your charge but I believe requires editorial comment.

We should be screening ‘some population’ of older adults. I am fully aware that this is a Class I recommendation from USPSTF. At the same time the concept of simply increasing symptom awareness is insufficient. We might decrease the undiagnosed dementia cases from 50% to 45 %, but this will not meet the goal of early detection.

My experience as a geriatrician embedded in a small Adult Primary care practice was that once we started screening (all adults >74 y/o) we found cases, many of which were MCI. These cases provided opportunity for future planning and confirmation of capacity at a time when one can confirm that legal affairs are in order or encourage that work be done. Also a significant number of the dementia cases we found, could have been found by awareness but were not. Sometimes this is simply the busyness of Primary Care and sometimes a ‘conspiracy of silence’ between the patient/caregiver dyad and the provider.

The present approach will convince us we are doing something, but will leave tremendous variability in care. The simple introduction of a Minicog and posing 2 questions about memory and organization by an MA, can bring a consistent approach to this issue at minimum cost. Positive findings do create an issue that must be addressed. We need to be aware of false positive diagnosis if the downstream work is not

done well. If we truly want early detection we must bite the bullet and screen.

Keep up the good work.

**>Committee Response**

Thank you for your comment. The Committee agrees that those with signs or symptoms of cognitive impairment should receive a diagnostic evaluation to determine the specific cause of the impairment. Although some members of the Committee expressed support for screening of asymptomatic individuals, they acknowledged the lack of empirical evidence to enable the assessment of the benefit versus harms of screening. Nonetheless, members recommended further research to identify those who should be screened.



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