Discussion Memo

October 24, 2013

TO: **Advisors to NQF's Alzheimer's and Related Dementias project**
FR: **Juliet Feldman and Karen Johnson**
RE: **Preparation for 10/31/2013 Advisory Group Webinar**

The Alzheimer's and Related Dementias Advisory Group will meet by WEB MEETING on October 31, 2013 from 10 AM – 12 PM EST.

Please follow the instructions below 15 minutes prior to the scheduled start time:

1. Direct your web browser to the following URL: nqf.commpartners.com
2. Under "Enter a meeting," type in the meeting number **948235** and click on "Enter."
3. In the "Display Name" field, type in your first and last name and click on "Enter Meeting." Audio will be transmitted through the phone, so turn off your computer speakers.
4. Dial **1-866-599-6630** and use confirmation code **88298484**. Note: All advisory participants will have an open line.
5. If you need technical assistance during the meeting, you may press *0 to alert an operator or send an email to: nqf@commpartners.com.

The purpose of the web meeting is to:

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

This memo is intended to provide background information on the Alzheimer's Disease and Related Dementias (ADRD) project and serve as discussion guide for the web meeting. Prior to the web meeting, ***please review this briefing memo and be prepared to discuss the key questions***. Please note that because several advisory group members will be able to attend the call only from 10-11am, the discussion of the Project Overview and Activities section during the call will be brief.

Contents

Background

In 2011, Congress authorized the establishment of the National Alzheimer's Project Act (NAPA) to address the many challenges facing people with Alzheimer's disease and their families. As part of the resultant *National Plan to Address Alzheimer's Disease* *("National Plan")*,[1] policymakers specifically 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 members of 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.[2]

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. Specifically, 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"*, to begin dialogue on aligning.

As a follow-up to this conference, participants initiated the Alzheimer's Disease Measurement Improvement (AD-MI) Project. Working groups were established to address ideas that came out of the meeting. One group (Workgroup #1) was created to develop a conceptual framework to promote identification of quality measurement opportunities for Alzheimer's disease (further discussed in the

---

[1] U.S. Department of Health and Human Services, Assistant Secretary for Evaluation and Planning. National Plan to Address Alzheimer's Disease.

[2] U.S. Department of Health and Human Services, Assistant Secretary for Evaluation and Planning. 2013 Recommendations of the Public Members of the Advisory Council on Alzheimer's Research, Care, and Services.

Draft Conceptual Framework section). HHS has instructed NQF to revise draft conceptual framework developed by Workgroup #1, based on input from key stakeholders convened by NQF.

A second workgroup group (Workgroup #2) conducted an environmental scan to understand the measurement landscape in Alzheimer's disease (further discussed in the Environmental Scan section). HHS has instructed NQF to revise the environmental scan developed by Workgroup #2, based on input from key stakeholders convened by NQF.

Project Overview

In response to the National Plan and to build on work that resulted from the AD-MI project as described above, the ADRD project will provide HHS with recommendations for prioritizing performance measurement efforts related to the Alzheimer's disease and dementia population. Because few performance measures currently address dementia, identifying a path forward for measure development can be used to increase awareness of important practices and/or outcomes that can drive improvement in health and health care in this area.

To accomplish this task, NQF will convene a 15-20 member multistakeholder committee with expertise in the diagnosis, treatment, and care of patients with dementia. NQF also will convene 6-8 key leaders in the field to provide guidance during the initial phases of the project; members of this group will also serve on the full multistakeholder committee (see Appendix A for Advisory Group Roster). Key project activities will include:

- Scanning and synthesizing evidence to inform the selection and/or modification of a conceptual framework for measure development
- Conducting an environmental scan of relevant measures and measure concepts
- Analyzing measures and concepts against the framework
- Obtaining committee recommendations for measurement priorities
- Utilizing NQF's process for multistakeholder input and of public comment to accomplish the activities listed above

The project will span a 15-month time frame.

Activities	**Dates**
Multistakeholder Committee Nominations period closes	October 15, 2013
Advisory Group web meeting: Obtain preliminary guidance on draft framework	October 31, 2013
Finalize multistakeholder committee roster	December 15, 2013
Draft framework and environmental scan to HHS	February 15, 2014
Committee web meeting: Feedback on draft framework and environmental scan	February 25, 2014
In-person Committee (2-day) meeting: Obtain multistakeholder recommendations to address priorities for measure development and endorsement	June 2-3, 2014
Public comment period (3 weeks)	September 2014
Public webinar: Feedback on report recommendations	September 2014
Deliverable: Final Committee Report	October 15, 2014

Draft Conceptual Framework and Key Measurement Considerations

The conceptual framework will be used to assess the comprehensiveness and adequacy of available dementia measures and help prioritize measurement gaps. The NQS aims, priorities, and goals will serve as a foundational framework to help identify measures necessary to drive improvement in the quality of care for those with dementia and for their caregivers.

Earlier Conceptual Models

During NQF's preliminary thinking around the conceptual framework, NQF primarily considered two frameworks from the May 2011 FNIH/C-Path invitational conference and the AD-MI project (see Appendix B). The first framework, based off NQF's Episode of Care measurement framework, was proposed by NQF staff as a starting point for Alzheimer's disease measurement at the FNIH/C-Path convening (see Figure 2 in Appendix B). The second framework was developed by AD-MI Workgroup #2, which was presented at the December 2012 AD-MI convening (see Figure 3 in Appendix B).

NQF's Draft Conceptual Framework

Building off of these two conceptual models, Figure 1 below presents NQF's draft conceptual model. This model is an extension of the generic Episode of Care framework (see Figure 4 in Appendix C), specifically tailored for the ADRD population and their caregivers. Key points from this draft model include:

- Recognition of the stages of Alzheimer's/dementia
- Inclusion of other measurement domains, such as safety and comorbidities, across the dementia trajectory
- Inclusion of different measurement trajectories (e.g., a trajectory for the patient vs. a trajectory for the caregiver)

Key Questions for Advisors related to the Conceptual Framework:

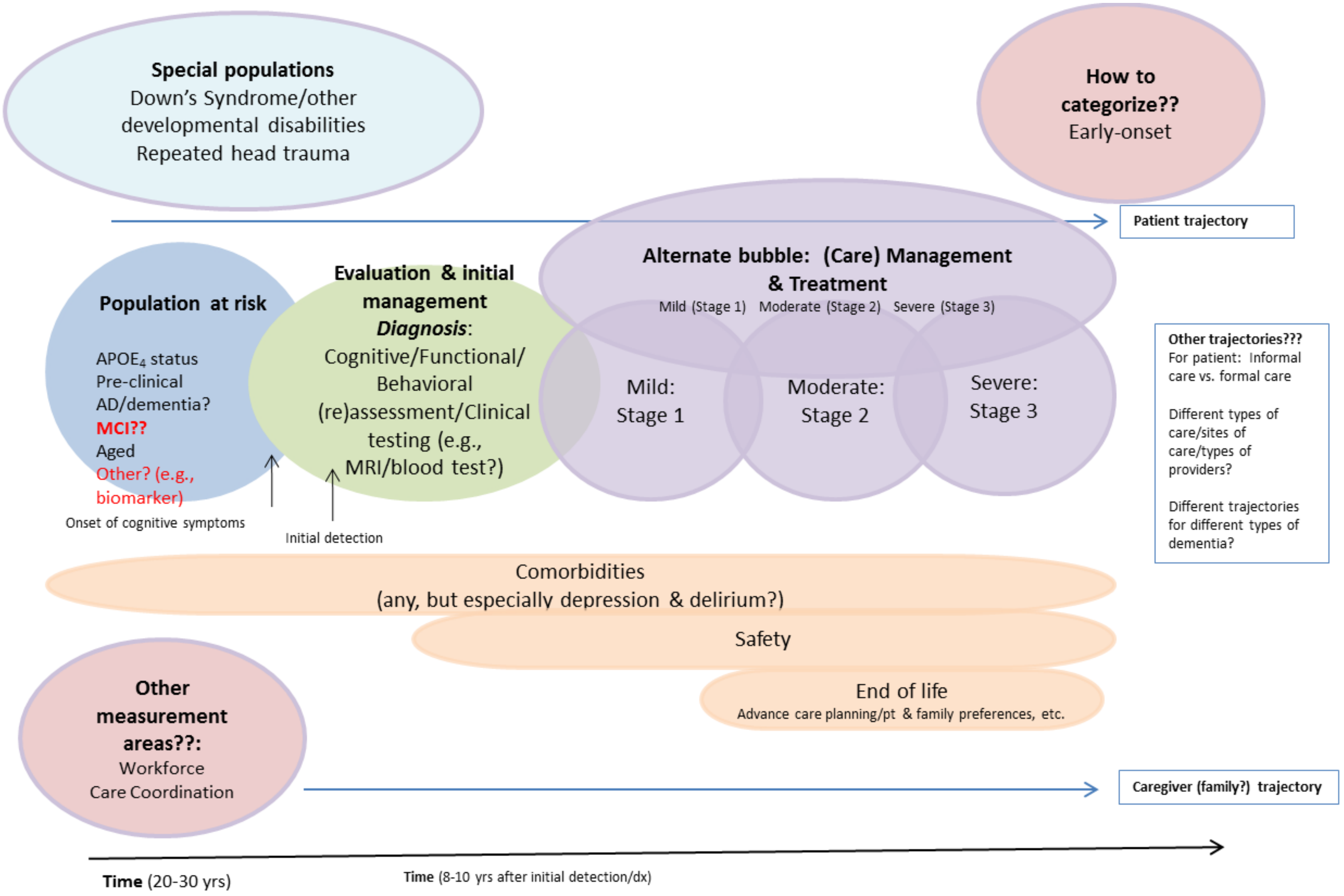
- What are your initial impressions of NQF's draft model? Are important elements missing or are there any elements that should be removed? How can this model be used to consider other types of dementias?
- What are the outcomes of interest for ADRD?
- Is this model applicable for measure development around early onset AD and other types of dementias besides AD (vascular, frontotemporal, etc.)?
- Is this model applicable for measure development that will include special populations (e.g., Downs Syndrome)? If not, what portions of the model should be different for these subgroups? Or is it okay that the conceptual model not include these populations?
- Where does MCI fit on this model (if at all)? Should those with MCI be considered another population at risk? Or should they be represented elsewhere in the model?
- Have we adequately covered the "at-risk" populations? Are there others?
- Does the mild-moderate-severe differentiation work for dementia in general? Should the stages be differentiated with distinct bubbles or included in one bubble? Or should the model reflect the proposed new NIA-AD diagnostic criteria/guidelines (i.e., new AD progression classification)?
- How should advanced dementia and end-of-life care be reflected in this model?
- Do the separate patient/caregiver trajectories adequately represent the caregiver perspective? If not, how might that perspective best be reflected?
- Are additional measurement trajectories needed (e.g., to distinguish formal vs. informal care)?

- Are there any other particular conditions that should be displayed separately or called out in the co-morbidities bubble (e.g., depression, delirium)?

Additional questions for later discussion:

- Should the entire model be expanded in some way to reflect other measurement domains (e.g., workforce, care coordination, patient-centered care)? What might that look like?
- Do we need to incorporate the NQS goals/priorities or components of the Multiple Chronic Conditions (MCC) framework (see Appendix C)?

Figure 1. NQF's Draft Conceptual Framework



Other Relevant Frameworks

Please refer to Appendix C for further information on two other relevant frameworks: NQF's Episode of Care Framework and NQF's Multiple Chronic Conditions (MCC) Framework.

Literature Review

NQF is currently reviewing the literature and evidence base to determine what measurement areas are most relevant and likely to have the largest impact on the health and well-being of patients with Alzheimer's disease and related dementias. This literature review will inform the refinement of the conceptual framework as well as prioritization of measurement gaps. Our listing of potential measurement domains and determination of the high-impact measurement areas will be revised over time with input received from the multistakeholder group.

NQF's approach thus far has been to first scan clinical guidelines and systematic reviews related to the prevention and management/treatment of dementia. Our initial research focus areas included:

- Prevention
- Screening
- Diagnosis
- Symptom/psychiatric management
- Treatment

Please see Appendix D for an overview of our preliminary findings. There are several areas that NQF has yet to deeply investigate, including patient and caregiver experience, caregiver burden, caregiver education and support, care coordination, provider and system capacity, safety, end-of-life care, and comorbid conditions.

Key Questions for Advisors related to the Literature Review:

- Which of these areas do you think are "ripe" for performance measure development? Should we further investigate some of these measurement domains?
- For those areas that we have investigated (prevention, screening, diagnosis, etc.), are any potential measurement domains missing in Appendix D?
- Does our assessment of evidence resonate with you? Do any of our findings appear incorrect?
- How should we best summarize evidence from the literature? Or has it already been summarized?
- How can we best utilize committee members in this effort?

Additional questions for later discussion:

- What other broad categories should we consider (e.g., patient and caregiver experience, caregiver burden, caregiver education and support, care coordination, provider and system capacity, safety, end-of-life care, and comorbid conditions)?
- For those areas we have yet to further investigate, are there any summaries of evidence that you suggest we look at?
- What kinds of research should we do to support the caregiver perspective?
- Are there additional tools or resources used to assess quality and drive improvement for this population (e.g., clinical guidelines, assessment tools, biomarkers, etc.) that you recommend we look at?
- Where do you suggest that we identify more information about those disproportionately affected by Alzheimer's disease (e.g., people with younger-onset dementia, racial and ethnic minorities, and people with intellectual disabilities)?

Environmental Scan of Measures and Measure Concepts

As noted earlier, one deliverable of this project is an environmental scan to identify both existing performance measures related to ADRD as well as measure concepts that could form the basis of performance measures.

As part of the AD-MI initiative, Workgroup #2 was charged with conducting an environmental scan of measures and guidelines directly or indirectly related to Alzheimer's, identifying gaps in existing measures, and consolidating this information into a comprehensive reference document. Representatives from the AD-MI Workgroup #2 have developed a manuscript that presents the findings of and conclusions from the AD-MI environmental scan, including an assessment of where gaps in available measures. The AD-MI representatives will make this manuscript available to you prior to our web meeting. **Please note that this article is not yet publicly available; the AD-MI representatives have asked us to only distribute this article to the NQF Advisory Group and only with the stipulation that it not be further circulated at this time.**

Some key findings from the AD-MI environment scan include:

- Major sources of U.S. measures were ACOVE, AMA-PCPI, PQRS (60 measures total) – intent of Workgroup #2 was to create a complete list of available quality measures for AD, dementia, or cognitive impairment

- 54 measures developed outside of the US were identified (not a complete list; measures identified are illustrative examples)
- Research measures, clinical measures, and guidelines were also identified

NQF's plan is to augment the results found in the AD-MI scan with additional measures or concepts identified through AHRQ's National Quality Measures Clearinghouse, CMS' Measure Pipeline Inventory, as well as reports from earlier relevant measure endorsement, framework, and rule-making projects.

Key Questions for Advisors related to the Environmental Scan:

- How can we best build on what has already been done by the AD-MI project?
- Do you know of additional measures or concepts not already included in the AD-MI scan?
- How can we best utilize committee members in this effort?
- Should we spend more time looking into non-U.S. measures?
- Would an analysis of currently-endorsed measures that are not specifically related to ADRD but applicable to that population be of benefit (e.g., we already have several diabetes measures that can be applied to the dementia population)?
- Should we further investigate other types of measures (research measures, guidelines, etc.)? If so, where should we focus our search (e.g., particular measurement domains, etc.)?
- Are there any specific sources you recommend we investigate for additional measures related to ADRD?

Prioritizing the Measurement Gaps

Because a considerable amount of work has been done to identify existing dementia measures and measurement gap areas, we believe the primary value in this project will lie in making recommendations to HHS for their prioritization of measurement development efforts. NQF intends to structure this project and engage the multistakeholder committee in such a way that results in a tangible roadmap with actionable recommendations. As we begin to think about this prioritization exercise, there are a number of criteria or principles that the committee may want to use during the prioritization exercises, including:

- Focusing on measures that can be used for both accountability and quality improvement
- Ensuring that the measurement area is supported by a solid evidence-base
- Focusing on measuring outcomes versus care processes (particularly patient-reported outcomes)
- Ensuring that the measurement area takes into account the broadest population and settings as possible
- Ensuring that any measurement approach considers how care is provided through the lens of dementia

Key Questions for Advisors related to Prioritization:

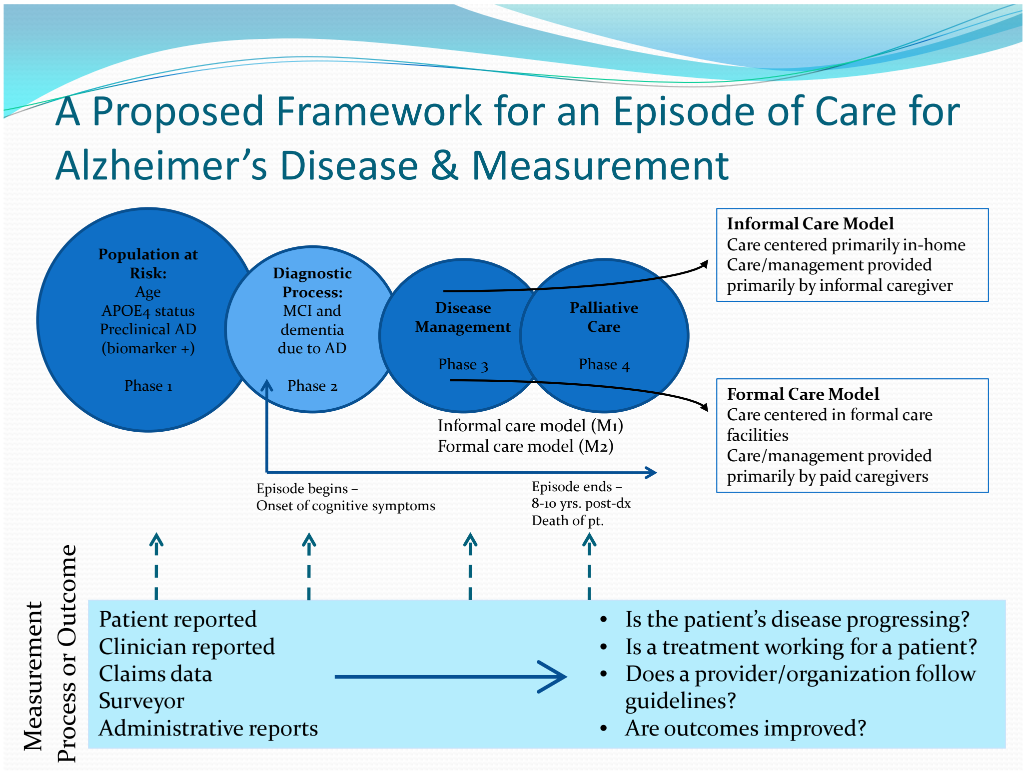
- Do you agree with these principles?
- Can you suggest any refinements to these principles?
- Can you suggest additional principles that we should consider?
- Do you have any suggestions or considerations for how we should approach the prioritization?

Appendix A – Advisory Group Roster

Advisor	***Title and Organization***
Cyndy Cordell	Director, Healthcare Professionals, Alzheimer's Association
Penny Feldman	Senior VP, Research and Evaluation, Visiting Nurse Service of NY
Gail Hunt	President and CEO, National Alliance for Caregiving
Katie Maslow	Scholar in Residence, Institute of Medicine
David Reuben	Director, Multicampus Program in Geriatric Medicine, University of California-Los Angeles
Mark Snowden	Associate Professor, Psychiatry and Behavioral Sciences, University of Washington School of Medicine
Joan Teno	Professor of Health Services, Policy, and Practice, Brown University
DEB Potter	Senior Survey Statistician, AHRQ; Government Subtask Lead

Appendix B – AD-MI Conceptual Models

Figure 2. Framework from May 2011 FNIH/C-Path Convening



A Proposed Framework for an Episode of Care for Alzheimer's Disease & Measurement

Population at Risk:
Age
APOE4 status
Preclinical AD
(biomarker +)

Phase 1

Diagnostic Process:
MCI and
dementia
due to AD

Phase 2

Disease Management

Phase 3

Palliative Care

Phase 4

Informal Care Model
Care centered primarily in-home
Care/management provided primarily by informal caregiver

Formal Care Model
Care centered in formal care facilities
Care/management provided primarily by paid caregivers

Informal care model (M1)
Formal care model (M2)

Episode begins –
Onset of cognitive symptoms

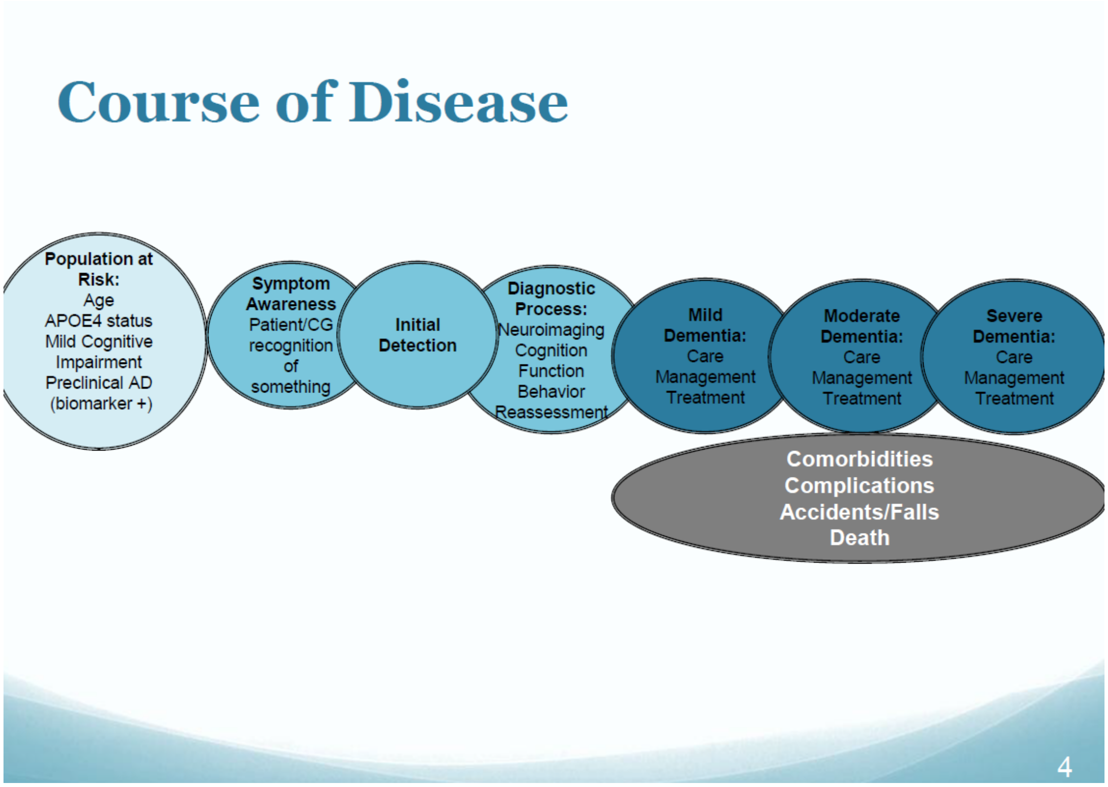
Episode ends –
8-10 yrs. post-dx
Death of pt.

Measurement
Process or Outcome

Patient reported
Clinician reported
Claims data
Surveyor
Administrative reports

- Is the patient's disease progressing?
- Is a treatment working for a patient?
- Does a provider/organization follow guidelines?
- Are outcomes improved?

Figure 3. Framework from Dec. 2012 FNIH/C-Path Convening



Course of Disease

Population at Risk:
Age
APOE4 status
Mild Cognitive Impairment
Preclinical AD (biomarker +)

Symptom Awareness
Patient/CG recognition of something

Initial Detection

Diagnostic Process:
Neuroimaging
Cognition
Function
Behavior
Reassessment

Mild Dementia:
Care Management
Treatment

Moderate Dementia:
Care Management
Treatment

Severe Dementia:
Care Management
Treatment

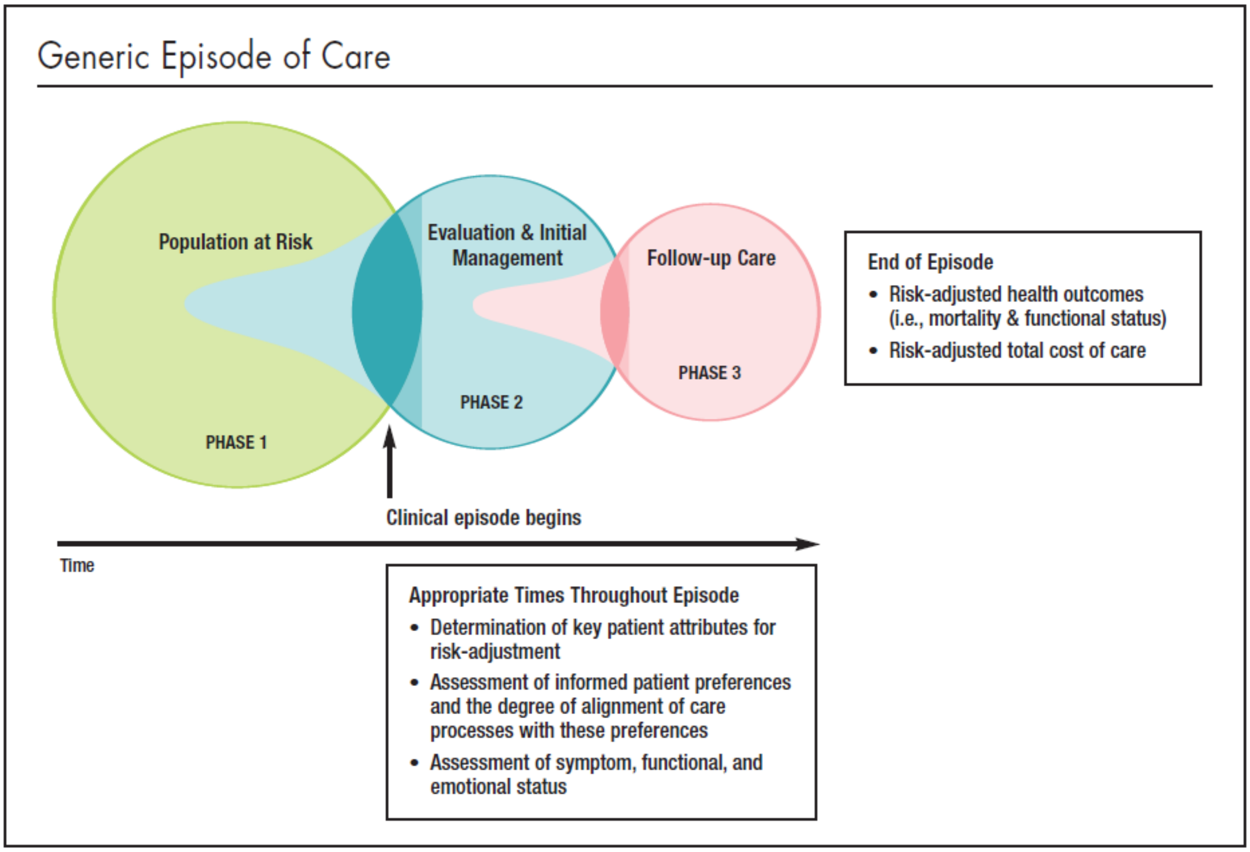
Comorbidities
Complications
Accidents/Falls
Death

Appendix C – Other Relevant Frameworks

Episode of Care Measurement Framework

NQF's Episode of Care Framework defined an episode as, "a series of temporally contiguous healthcare services related to the treatment of a given spell of illness or provided in response to a specific request by the patient or other relevant entity." This episode of care model can be used to track the core components—population at risk, evaluation and initial management, and follow-up care—that must be measured and evaluated over the course of an episode of care. This report has been applied to a number of conditions, including acute myocardial infarction, low back pain, breast and colorectal cancers, diabetes, and substance use illness.

Figure 4. Episode of Care Framework



Multiple Chronic Conditions Measurement Framework

NQF's Multiple Chronic Conditions (MCC) Framework,[3] can also be considered, as applicable, to ensure a patient-centered approach that considers measurement needs across different types, sites, and providers of care.

This model is designed to illustrate the complexity of providing care for an individual with MCCs by showing the various ways that conditions, patient and family preferences, sites and providers of care, and types of care interact (see Figure below). Also represented in the model are the social and environmental context in which the individual lives and receives care and the public and private health policy priorities that guide the delivery of care

Within the center ring of the model is an individual with multiple different conditions that may have a greater or lesser effect on that individual. Also included in the inner ring are the family and friends who care for the individual, along with the individual's goals and preferences for care.

---

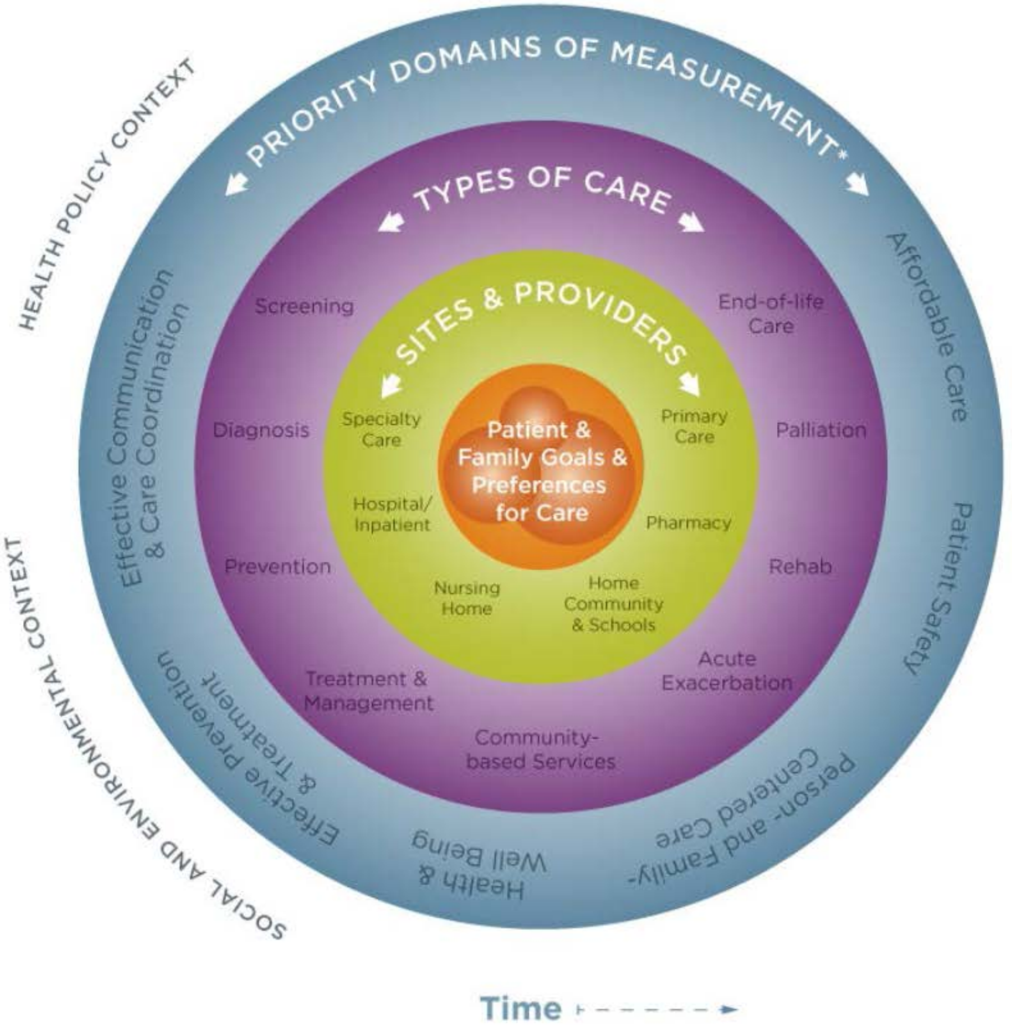
[3] Report from the National Quality Forum: Multiple Chronic Conditions Measurement Framework. May 2012.

Depending on their conditions and preferences, individuals can receive care in various sites from various providers. Examples of sites most relevant for individuals with MCCs included in the second ring of the model are: primary care, specialty care, hospital/post-acute, nursing home, community (including school and workplace), home (including both formal and informal care), and pharmacy. The types of providers offering care to the individual (e.g., internists, hospitalists, nurse practitioners, social workers) also shift depending on the needs of the individual.

The types of care individuals receive, included in the third ring of the model (i.e., screening, primary and secondary prevention, diagnosis, treatment and management, community services, management of an acute exacerbation, rehabilitation, palliation, and end-of-life care), are not necessarily linear or mutually exclusive. For example, an individual with congestive heart failure may be seen in the hospital for an acute exacerbation but also may need continuing treatment and management of diabetes and lung cancer at the same time. Additionally, palliative care can occur at many points during the course of a disease or condition and is not exclusive to end-of-life care. End-of-life care can include hospice care, which can occur at multiple sites of care. These real-life examples reinforce the need for a flexible model that can capture the complexity of often-changing healthcare needs over time.

The outer ring of the model highlights the priority domains of measurement appropriate for use with individuals with MCCs. The domains intentionally align with the NQS to promote harmonization across public and private sector programs supporting this population. These domains support the key measure concepts for individuals with MCCs identified by the Steering Committee. Each priority domain of measurement may be addressed using several types of measures, including structure, process, outcome, efficiency, cost/resource use, and composite measures. The use of outcomes measures, when available, and process measures that are most closely linked to outcomes are preferable.

Figure 5. Multiple Chronic Conditions (MCC) Framework



* Each priority domain of measurement may be addressed using several types of measures, including structure, process, outcome, efficiency, cost/resource use, and composite measures. The use of outcomes measures, when available, and process measures that are most closely linked to outcomes is preferable.

Appendix D – Preliminary Findings from Literature Review

During an initial scan of literature, NQF identified interventions/practices that may impact the health and well-being of ADRD patients and their caregivers. NQF categorized these interventions/practices based on the extent to which the literature indicated that they led to improved quality of health, reduced costs, or disparities. Please see the color-key below.

🟩 Evidence suggests intervention/practice **leads to** improved quality or health, reduced costs, or disparities
🟨 Some research has been done but **evidence insufficient** to make a conclusive recommendation
🟥 Evidence suggests intervention/practice **does not lead to** improved quality or health, reduced costs, or disparities

The following are the interventions/practices identified during NQF's initial literature review. **Please note that this does not represent a comprehensive scan of available literature** and does not account for key topic areas, including patient and caregiver experience, caregiver burden, caregiver education and support, care coordination, provider and system capacity, safety, end-of-life care, and comorbid conditions.

Prevention
Medical conditions and prescription and non-prescription medications
Medical conditions
🟨 Diabetes
🟨 Vascular risk factors (for vascular dementia)
🟨 Depression
🟨 Traumatic brain injury/head trauma
Medications
🟨 Statins
🟨 Estrogen
🟨 Anti-hypertensives
🟨 Anti-inflammatory medications
🟨 Growth hormone-releasing hormone (GHRH)
Social/economic/behavioral factors
🟨 Education (cognitive reserve/engagement)
🟨 Smoking
🟨 Alcohol use
🟨 Social support
🟨 Physical Activity
🟨 Sleep Patterns
Nutritional factors
Antioxidants
🟥 Vitamin C

Vitamin E
Mineral
Zinc
Fruit
Vegatables
Fish (omega-3 fatty acids); DHA
Toxic environmental factors
Other (e.g., compounds targeting A-beta metabolism)
Screening
Cognitive testing
Screening tests (Mini-Mental State Examination, the Clock Draw Test, category fluency, Neuropsychiatric Inventory nursing Home Version (NPI-NH), Cohen-Mansfield Agitation Inventory (CMAI), Neuropsychiatric Inventory Questionnaire, Geriatric Depression Scale, etc.)
Laboratory data/tests (cerebrospinal fluid measures of Ab, genetic markers)
Physical/neurological examination
Neuroimaging
PET, SPECT, CT or MRI scans
MRI diffusion tensor imaging and medial temporal lobe measurements
Biomarkers: showing level of beta-amyloid accumulation in brain & showing neurons in the brain are injured/degenerating
Genetic testing
APP gene for Early-onset AD
APOE e4 gene
Plasma amyloid-B
Diagnosis
Diagnostic criteria
DSM-V Diagnostic criteria
National Institute of Neurological and Communicative Disorders and Strokes-Alzheimer's Disease and Related Disorder Association (NINCDS-ADRDA) criteria
National Institute on Aging and the Alzheimer's Association proposed new criteria and guidelines for diagnosing Alzheimer's disease
Symptom/psychiatric management
Ongoing monitoring/assessment
Education of patients and families about illness, treatment, and sources for additional care and support
Treatment
Psychosocial treatments
Behavior-oriented treatments
Stimulation-oriented treatments
Recreational activity

Art, music, humor, pet, light, aroma-, massgae therapy; accupuncture; Snooezelen Multisensory Stimulation Therapy, Transcutaneuous Electrical Nerve Stimulation
Emotion-oriented treatments
Psychotherapy, reminiscence and validation therapy
Cognition-oriented treatments
Pharmacologic treatments
Treatment of cognitive and functional losses
Acetylcholinesterase inhibitors (AChEIs)
Tacrine (Cognex)
Donepezil (Aricept)
Rivastigmine (Exelon)
Galantamine (Razadyne)
NMDA receptor antagonist - Memantine (Namenda)
Vitamin E
Other agents (NSAIDs, statins, estrogen supplementation)
Treatment for psychosis and agitation
Antipsychotics
Benzodiazepines
Anticonvulsants, lithium, beta-blockers
Treatment for depression and related symptoms
Antidepressants
Electroconvulsive therapy
Treatment for sleep disturbance
Disease-Modifying Therapies
Agents targeting amyloid-B
Vascular risk factor modification