NATIONAL QUALITY FORUM

Meeting Materials

Priority Setting for Health Care Performance Measurement: Addressing Performance Measure Gaps for Alzheimer's Disease and Related Dementias

Contents

Alzheimer’s Disease and Related Demenita’s Committee Meeting Agenda

June 2, 2014 – June 3, 2014

NQF Conference Center at 1030 15th Street NW, 9th Floor, Washington, DC

Remote Participation Instructions:

Streaming Slides and Audio Online

- Direct your web browser to: http://nqf.commpartners.com
- Under “Enter a Meeting” type the meeting number for Day 1: **800234** or for Day 2: **606178**
- In the “Display Name” field, type your first and last name and click “Enter Meeting”

Teleconference

- Committee Members/Other Designated Speakers: Dial **(888) 802-7237** and use conference ID code for Day 1: **36222004** and for Day 2: **36222067**
- Non-Committee Members: Dial **(877) 303-9138** and use conference ID code for Day 1: **36222004** and for Day 2: **36222067**

Meeting Objectives:

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

Day 1: Monday, June 2, 2014

8:30 am **Breakfast**

9:30 am **Welcome and Introductions**
Penny Feldman, Co-Chair
Eleanor Perfetto, Co-Chair
Christine Cassell, President and CEO
Karen Johnson, Senior Director, Performance Measurement

9:45 am **Project Overview and Related Projects**
Penny Feldman
Eleanor Perfetto

- Goals for the meeting, review agenda
- Expectations for Committee discussions

*DEB Potter***,** *Agency for Healthcare Research and Quality, HHS*

- Opening Remarks - Context for Project

Juliet Feldman, Project Manager

- Reminder of project scope, objectives, and timeline
- Related projects

10:00 am **Discussion of Measurement Considerations**
Karen Jonhson
Elisa Munthali, Managing Director, Performance Measurement

- ABCs of measurement
- Overview of NQF endorsement criteria
- Measurement challenges
- Considerations for measurement prioritization

11:00 am **Break**

11:15 am **Setting the Stage: Quality Measurement Opportunities**
Eleanor Perfetto

- Review current framework
- Discussion of quality opportunities (from committee’s vignettes)
    - 8-10 committee members to share brief vigenttes (2-3 min.) and brief committee discussion to follow each

12:45 pm **Opportunity for Public Comment**

1:00 pm **Lunch**

1:30 pm **Small Group Work: Generating/Prioritizing Measure Concepts (Round 1 Prioritization)**
Karen Johnson

- Review of pre-meeting committee exercise results
- Committee will be divided into three groups based on measurement domains
- Small groups will identify additional measure concepts for persons with dementia and family/caregivers and prioritize them

3:00 pm **Break**

3:15 pm **Report Out from Small Groups**
Penny Feldman
All Committee Members

- Share and discuss prioritized measure concepts
- Q&A with other committee members

4:30 pm **Round 2 Prioritization and Break**
Eleanor Perfetto

- Committee voting

4:45 pm **Discussion of Round 2 Results**
Eleanor Perfetto

- Depending on results, possible 3rd round of voting

5:15 pm **Opportunity for Public Comment**

5:30 pm **Adjourn**

Day 2: Tuesday, June 3, 2014

7:30 am **Breakfast**

8:00 am **Welcome, Goals, Review Agenda, Recap of Day 1, Clarifications**
Karen Johnson

8:15 am **Review of Prioritization Results from Day 1**
Eleanor Perfetto

- Review results from Day 1
- Clarifications, suggestions for additions or deletions
- Ensure scope of framework is covered
  Discuss priorities in further detail: level of analysis, data source, type of measure, how it fits other measurement goals, etc.

9:45 am **Opportunity for Public Comment**

10:00 am **Break**

10:45 am **Identify Additional Recommendations**
Penny Feldman

- Based on discussions from Day 1, the committee will further explore key issues and develop recommendations for the short-and long-term
- Potential issues for committee discussion include:
  - Measure methodology considerations
  - Use of non-dementia-specific measures
  - Assessing quality through the "lens of dementia"
  - Role of the community and the need for social/behavioral interventions/support
  - Longer-term measurement opportunites
  - Delivery system change
  - Other "parking lot" issues

12:15 pm **Lunch and Round-Robin Reflections on Recommendations and Future Work**
Penny Feldman

1:40 pm **Opportunity for Public Comment**

1:55 pm **Wrap Up/Next Steps**
Juliet Feldman

2:00 pm **Adjourn**

Committee Roster

Penny Feldman, PhD *(Co-Chair)*
Visiting Nurse Service of New York, New York, NY

Eleanor Perfetto, PhD *(Co-Chair)*
University of Maryland School of Pharmacy, Baltimore, MD

Mary Barton, MD, MPP
National Committee for Quality Assurance, Washington, D.C.

Barbara Baylis, RN, MSN
Providigm, Prospect, KY

Ryan Carnahan, PharmD, MS, BCPP
University of Iowa College of Public Health, Iowa City, IA

Susan Cooley, PhD
Department of Veterans Affairs, Palm Beach Gardens, FL

Cyndy Cordell, BS, MBA
Alzheimer's Association, Chicago, IL

Lynn Friss-Feinberg, MSW
AARP Public Policy Institute, Washington, D.C.

Murray Grossman, MD
American Academy of Neurology, Philadelphia, PA

Razia Hashmi, MD, MPH
WellPoint, Inc., Simsbury, CT

Gail Hunt
National Alliance for Caregiving, Bethesda, MD

Matthew Janicki, PhD
University of Illinois at Chicago, Chicago, IL.

Kristin Kahle-Wrobleski, PhD
Eli Lilly and Company, Indianapolis, IN

Katie Maslow, MSW
Institute of Medicine, Washington, D.C.

David Reuben, MD
UCLA Division of Geriatrics, David Geffen School of Medicine, Los Angeles, CA

Martha Roherty, MPP
National Association of States United for Aging and Disabilities, Washington, D.C.

Mark Snowden, MD, MPH
University of Washington School of Medicine, Seattle, WA

William Staples, PT, DHsc, DPT, GCS, CEEAA
University of Indianapolis, Indianapolis, IN

Eric Tangalos, MD, FACP, AGSF, CMD
The Mayo Clinic, Rochester, MN

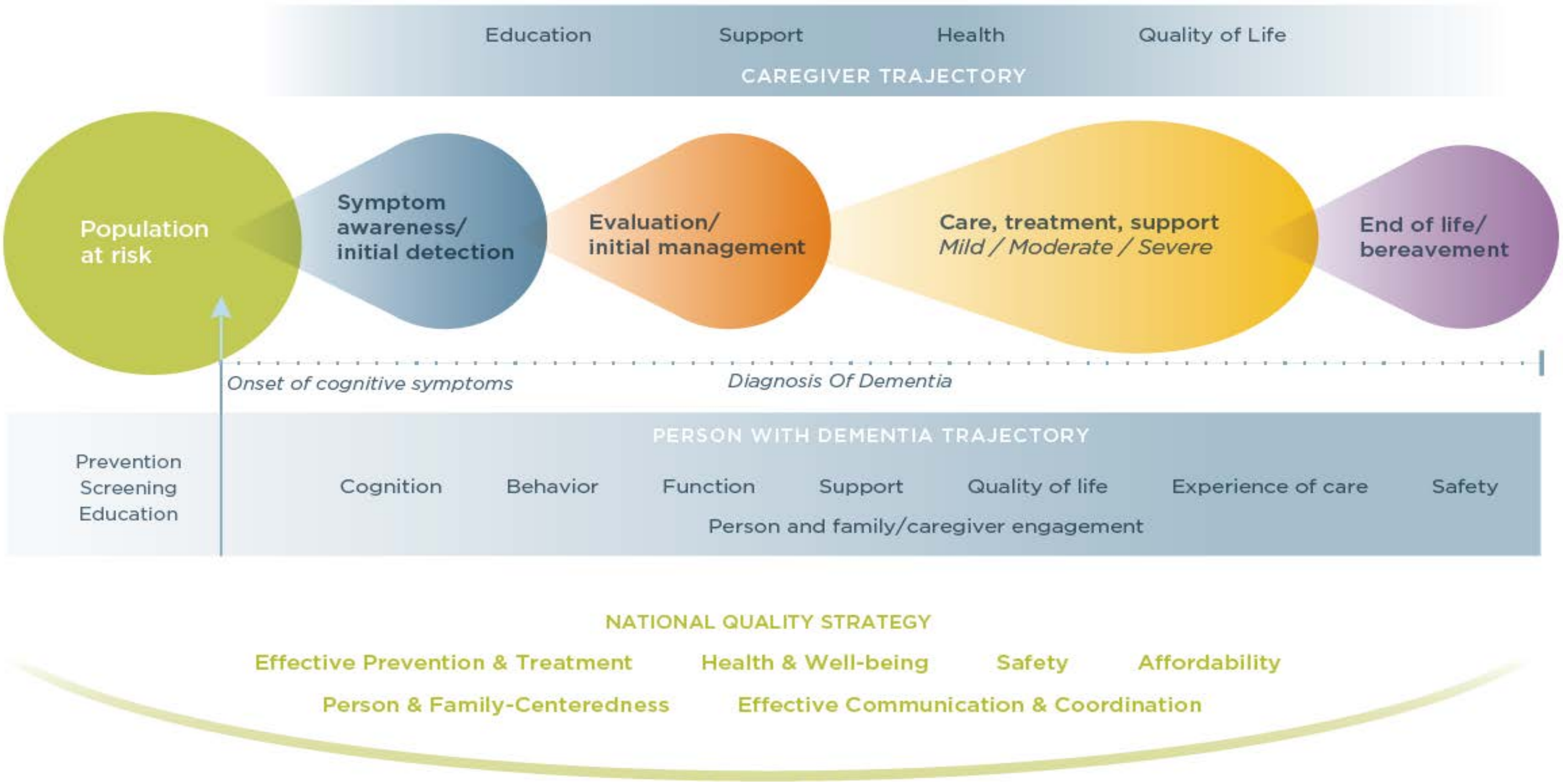
Joan Teno, MD
Brown University School of Public Health, Providence, RI

Yael Zweig, MSN, ANP-BC, GNP-BC
NYU Pearl Barlow Center for Memory Evaluation and Treatment, New York, NY

Conceptual Framework - Latest Version

CONCEPTUAL MODEL FOR PERFORMANCE MEASURE DEVELOPMENT FOR DEMENTIA:

Maximizing quality of life, minimizing distress



Education Support Health Quality of Life

CAREGIVER TRAJECTORY

Population at risk

Symptom awareness/ initial detection

Evaluation/ initial management

Care, treatment, support
Mild / Moderate / Severe

End of life/ bereavement

Onset of cognitive symptoms

Diagnosis Of Dementia

PERSON WITH DEMENTIA TRAJECTORY

Prevention
Screening
Education

Cognition Behavior Function Support Quality of life Experience of care Safety

Person and family/caregiver engagement

NATIONAL QUALITY STRATEGY

Effective Prevention & Treatment Health & Well-being Safety Affordability

Person & Family-Centeredness Effective Communication & Coordination

Brief Summaries from Other Prioritizing Measure Gaps Projects

In addition to the topic of Alzheimer's disease and related dementias (ADRD), HHS also contracted with NQF to prioritize measurement gaps related to Person- and Family-Centered Care and Outcomes, Care Coordination, Health Workforce, and Adult Immunizations.

The deliverable dates for the ADRD project are purposely phased three months behind these other four projects **so that the ADRD project could be informed by the work of the Person- and Family-Centered Care and Outcomes, Care Coordination, and Health Workforce committees.** The following briefly summarizes some of the deliberations and recommendations from the in-person meetings that were held in April of this year (complete summaries of these meetings can be found on the NQF website: click on the individual project links, under "Materials", click View All, then select the Meeting Summary link).

All content described below is draft and will be vetted by the respective committees after a public comment period that is scheduled for June 23-July 14, 2014.

Person- and Family-Centered Care and Outcomes

Purpose: This project will develop specific recommendations for performance measurement to address person- and family-centered care, including measures based on patient-reported outcomes. The committee defined:

- **Person- and family-centered care** means that the person and their family feel that their individual needs, priorities, and goals for health are met.
- **Care Team** includes all health care and supportive services workers who interact with individuals and families.
- **Family** is defined by each individual.

Core concepts:

1. **Individualized care** – My care team knows me and takes into account my needs, priorities, and goals for my physical, mental, spiritual, and social health.
2. **Family** – My family is supported and involved in my care as I choose.
3. **Respect, dignity, and compassion** are always present.
4. **Information sharing/communication** – there is a free flow of information between and among me and my care team(s).
5. **Shared decisionmaking** – I am helped to understand my choices and I make decisions with my care team, to the extent I want or am able.
6. **Self-management** – I am prepared and supported to care for myself, to the extent I am able.
7. **Access/ convenience** – I can obtain care and information, and reach my care team when I need and how I prefer.

Framework for Performance Measurement of Person- and Family-Centered Care

The following table is organized by the core concepts for person- and family-centered care and the classical quality assessment categories of structure, process, and outcome. In addition to being the organizing concepts, the core concepts can be considered outcomes because they represent the desired experience with care.

Although some structures and processes were identified, the Committee agreed that the priority is measuring the person and family experience with care. Key recommendations regarding performance measurement included focusing on outcomes (person- and family- reported experience) and on the person across settings and time.

Core Concept	Structure	Process	Outcome*
	Organizational structure or systems that support person- and family-centered care	***Interaction between person/family and the care team that are intended to facilitate achieving the experience reflected in the core concepts***	***Desired outcomes of person- and family-centered care (particularly the experience with care)***
Overarching	• Person/family advisory group [label]	• At the end of each encounter ask how did this go? What could we do better?	• I received all the care I needed and wanted exactly when and how I needed and wanted it.
1. <u>Individualized care</u> – My care team* knows me and takes into account my needs, priorities, and goals for my physical, mental, spiritual, and social health.	• System supports use of person-reported tools: o standard person reported outcome measures (PROMs) that match the person's view of what matters or what bothers or interferes with their life o person centered outcome measures (PCOMs) that may be highly individualized (e.g., my treatment will be successful if I can walk up the bleachers at Fenway Park on the 4th of July with my grandkids, I will be able to tend my garden without being in constant pain, etc.) o Tools to assess preferences for care and decision-making style/approach	• Find out the individual's health care priorities and goals are --what matters most and/or what is most bothersome to the person using standard PROMs and PCOMs • Systematic assessment of PROs and well-being • Home team visit by a care team member (chronic illness) • Use the PROM and/or PCOM with persons to co-develop the plan, mange care, and monitor progress • Create a comprehensive individualized plan that incorporates the individual's needs, priorities, and goals for physical, mental, spiritual, and social health	• My care team members know me • My preferences for care/treatment are supported • I received all the care I needed and wanted. • The care I got matches my goals and preferences • My care team asks me about my top health goals and most important health problems • What's important to me is at the center of my care **CAHPS Measures** •
2. <u>Family</u> – My family** is supported and involved in my care as I choose.	• Practice infrastructure, e.g. Relationship with appropriate services to support – practice and non-practice based. • Environment design: welcomes and supports family involvement	• Ask about family support and involvement in care • Assess family caregivers' strengths and limitations	• Assessment of PF/ CF experience WRT Support of family care partners by other care partners • **CAHPS Measures** •

Core Concept	Structure	Process	Outcome*
	• Family support/discussion groups [label] • Recertification requirements for providers ties to family engagement as part of the evaluation process.		
3. Respect, dignity, and compassion are always present.	• Culture of respect: system treats clinicians with respect and dignity • Respectful environmental design: Support for privacy for persons and families • Systems are respectful of persons and clinicians time	• Person-centered communication o Positive support: empathy, legitimizing o Active listening	• I and my family are treated with respect, dignity, and compassion • My time was respected **CAHPS Measures** • CAHPS Clinician (NQF#005) Providers are Polite and Considerate
4. Information sharing/communication – there is a free flow of information between and among me and my care team(s).	• Providers are not rushed, have time to answer all questions • Information sharing architecture (Information Commons) • Systems support access to personal information o Individual portal to health record, clinical notes, careplan, test results [label] o Connect to personal health record o Procedure to for corrections • Able to obtain standard information on: o Health problems o Treatments o Providers (profile, quality) [label] o Costs	• Person-centered communication o High levels of elicitation, checking for understanding, open-ended questions • Bidirectional information sharing • Use systematic approach to collecting information • Help persons/care team prepare for visit/encounter o Identify what person wants to accomplish before the visit through email, phone o Prepare list of questions o Bring someone along	• Were you heard? • Did you tell them everything you wanted? • Were your questions answered? • Did you leave your appointment with questions unanswered? • Did you understand? • Do you know what to do before your next visit? • Were you given someone to follow up with? • I can obtain any information I need when I need it, in a format I prefer • My care team has the right information at the right time (also could ask care tem) • Care team keeps me, my family, and other care teams informed of my status and careplan • Does your care team share information? • Does your care team agree, have the same

Core Concept	Structure	Process	Outcome*
	• Ability of system to receive information in a flexible manner by: o Time o Mode-paper, electronic, in person o Literacy level o Language o Readiness to learn o Sensory impairment • Integrated, interoperable EHR		opinion? Aare they on the same page? • Is information verified and corrected if an error is identified **CAHPS Measures** • CAHPS Clinician (NQF#005) How Well Providers (or Doctors) Communicate with Patients • CAHPS Clinician (NQF#005) Individual Item: Follow up on Test Results
5. Shared decisionmaking – I am helped to understand my choices and I make decisions with my care team, to the extent I want or am able.	• Organization has clear requirements for engagement • Staff training in engagement • System tools to support engagement and shared decisionmaking	• Elicitation of preferences for shared decision-making • Care partners work with individuals to make decisions and to co-produce and implement a care plan that has the best chance of attaining the person's goals • Discuss and obtain advance directives • Ask about surrogate decisionmakers	• Care received matches preferences • Utilization measures at end of life (e.g., emergency visits) • Were you told about treatment options and their pros and cons? • Person/family understanding of treatment options **CAHPS Measures** • CAHPS PCMH Providers Discuss Medication Decisions (Adult)
6. Self-management – I am prepared and supported to care for myself, to the extent I am able.	• Options for support – individual and family support/discussion groups online, group meetings, etc. [label] • Systems support person/family instruction/education – written, video, languages	• Instructions and training provided in format preferred by person/family • Assess activation (PAM) • Check understanding/ comprehension of key points	• Did you get the information you needed: o to take care of yourself? o To anticipate what might happen to you? o What problems to watch for and what to do? • Confidence in ability to manage care • Adherence to treatment **CAHPS Measures** • CAHPS PCMH - Providers Support You in Taking Care of Your Own Health

Core Concept	Structure	Process	Outcome*
7. Access/ convenience – I can obtain care and information, and reach my care team when I need and how I prefer.	• At a system level, time is considered important [i.e., respectful not to waste] • Availability of a help line for questions • Options for communications with follow-ups (multiple channels for communication telephone/e-mail/text [label] • Individual portal to health record, clinical notes, careplan, test results [label] • One stop shopping for care with integrated EHR • Weekend and after-hours appointments; virtual appointments • Same-day appointments • Systems for managing flow and waiting times • Systems for coordinating visits with multiple providers on the same day • Navigator/coach/coordinator services [label] • Interdisciplinary care team, including navigator, social worker/case manager/coach; all have clearly defined roles • Average length of time in days between the day a person makes a request for an appointment with a		• Able to access providers • **I** get everything I need exactly when I want and need it • I received all the care I needed and wanted exactly when and how I needed and wanted it. • I know who to contact for what • My schedule or availability determines when my care is provided • Was my time used efficiently? • My care team cared about my time • When I have to wait, I am given an explanation and choices **CAHPS Measures** • CAHPS Clinician (NQF#005) Getting Timely Appointments, Care, and Information • CAHPS Clinician (NQF#005) Getting Timely Answers to Medical Questions by E-mail

Core Concept	Structure	Process	Outcome*
	physician and the third available appointment for a new patient physical, routine exam, or return visit exam. (IHI) [label] - Average waiting time (for scheduled appointment, ED visit, hospital admission, etc.) [label]		

Standard Label for Person- and Family-Centered Care

Information about some structures that support the delivery of person- and family-centered care could be useful to consumers to identify providers who will best meet their needs and preferences. This might include things such as whether they have evening and weekend hours, access to health records, communication via email, etc. Information provided in a standardized format would allow individuals to weight various aspects in terms of what is most important to them.

Person- and Family-Centered Care

Organizational Statement of Person- and Family-Centered Care: 2-3 sentences

Individual/Family Advisory Group: Yes/No, URL link

Individual Portal to Electronic Health Record: Yes/No
Entire Record: Yes/No
Partial Access – Test Results: Yes/No; **Clinical Notes:** Yes/No
Link to Personal Health Record: Yes/No

Non-emergency Communication Options – Phone**:** yes/no, **email:** yes/no, **text:** yes/no
Hours of Operation: (including extended hours evenings, weekends)
Ease of Scheduling Appointments
Same-day appointments: yes/no
Avg. # days to available appointment: xx days
Average wait time (from appointment/arrival to clinician): xx minutes

Individual/Family Support
Navigator/coordinator/coach: yes/no
Individual support groups: yes/no, URL link
Family support groups: yes/no, URL link

Profiles of the Care Team: URL link (education, training, certification, specialties, languages)

Participate in External Quality Performance Measurement: yes/no
Person-centered care measures: yes/no, URL link
Other quality measures: yes/no, URL link

Affordability
Insurance Plans Accepted: URL link

Care Coordination

Purpose: This project specifically explored coordination between safety-net providers of primary care and providers of community and social services that impact health. For purposes of this project and its conceptual framework, the team has developed a hybrid definition of previous AHRQ and NQF definitions that additionally incorporates the important linkage to community services, as follows:

"Care coordination is the deliberate synchronization of activities and information to improve health outcomes by ensuring that care recipients' and families' needs and preferences for healthcare and community services are met over time."

Recommended Measurement Domains and Subdomains

The following table presents three columns, each containing potential domains for measurement and various sub-domains. The domains are displayed as italicized terms and the sub-domains are displayed as bullet points. The domains and sub-domains are generally organized to move through time from left to right. For example, the "Goal-setting" domain occurs prior to the "Goal attainment" domain.

Joint Creation of Person-Centered Plan of Care	**Utilization of the Health Neighborhood to Execute the Plan of Care**	**Achievement of Outcomes**
Comprehensive Assessment	*Quality of Services*	*Experience*
• Document care recipient's current supports and assets • Assess function • Assess social needs • Assess behavioral health needs • Assess medication management needs • Assess health literacy • Measure care recipient/family level of activation/engagement • Capture preferences and goals • Estimate health risk level and customize CC approach appropriately • Continuous holistic monitoring	• Adequacy of community services to support self-management/wellness • Timeliness/reliability of services • Accessibility of services	• Care team's experience of care coordination o Care recipient o Family o Primary care providers o Community service providers

Goal-setting	*Linkages / Synchronization*	*Progression Toward Goals*
• Person-centered communication • Shared-decision making • Set goals to address needs identified in assessment • Prioritize appropriate, guideline-driven interventions to improve health outcomes • Update plan of care regularly	• Shared documentation and understanding of care coordination goals by clinical providers, community providers and care recipient/family • Appropriate community services identified and contacted based on needs assessment • Care recipient/family successfully engages with and utilizes community services • Bi-directional communication to facilitate coordination • Frequent and accurate communication to solve problems	• Resolution of unmet needs, as documented in ongoing assessment • Services congruent with person-centered goals and preferences • Maximized health outcomes and functional status • Reduce patient risk through interventions • Increased care recipient/family level of activation • Improvement of care recipient experience
Shared Accountability		*Efficiency*
• Plan of care documents who is a part of the care team, including community providers • Plan of care assigns responsibilities for meeting care recipients' goals and care team members accept them		• Reduction of duplication in care coordination services • Avoidance of redundant intake/assessment processes • Avoidance of repeat testing/inappropriate use • Reduce total cost of care

Potential Measure Concepts

At the in-person meeting, committee members divided into three sub-groups to brainstorm potential measure concepts for each of the measurement sub-domains. The Committee shared their progress, highlighting these and other draft concepts:

- Creation of Person-Centered Plan of Care
    - # of care recipients for whom a comprehensive assessment containing all of the sub-domains is documented / total # of care recipients enrolled
    - # of care recipients at risk of falling who received in-person communication about the risks of falling and set targeted goals with their provider/ total # of care recipients at risk of falling
    - # of care recipients with an accurate checklist of their care team and a description of the roles within that team / total # of care recipients
- Utilization of the Health Neighborhood to Execute the Plan of Care

  - # care recipients reporting self-efficacy in managing chronic conditions / total # of individuals receiving care for chronic conditions
  - # of care recipients receiving recommended community services within three months / total # of individuals whose plan of care indicates a need for a community service
  - # of community providers reporting ability to engage in direct messaging technology with primary care providers / total # of community providers
- Achievement of Outcomes
  - # of care recipients who feel their care team communicates with one another and works together to achieve patient’s goals/ total # of care recipients
  - # of family members who experienced hassle throughout the treatment of care process/ # of care recipients with multiple chronic illnesses

Health Workforce

Purpose: This project considers and prioritizes opportunities to measure workforce deployment in the context of prevention efforts and care coordination. The work is intended to broaden the current scope of measurement related to workforce considering elements across the spectrum of healthcare delivery, and examines opportunities for measurement beyond healthcare delivery.

Recommended Measure Domains and Potential Concepts

The following table outlines the measurement domains and potential concepts identified by the committee.

Domain	**Measure Concept**
Assessment Of Community Workforce Needs	Evaluate the composition of the composition of teams that are performing well on national measure sets
Recruitment And Retention	Level of standard deviation from ideal forecasting at the state level
	Amount of standard deviation from ideal workforce retention and recruitment by discipline (data/evidence based development needed)
Workforce Diversity And Retention	Retention as measured in: discipline area, geographic location, organization, industry, employment vs. unemployment
	Mean score on existing standardized tools for patient experience as it pertains to cultural competecy
	Community level minority representation of workforce as represented in census data
Capacity and Productivity	General Health Proxy: Infant mortality rate in country or state as compared to workforce credentials (team mix)
	Performance on national measure set (i.e. ACO set) as compared to team mix (provider mix, workforce credentials)
	Ratio of healthcare workforce discipline specific workers to specific populations (baseline)
Experience	Using existing CAHPS data for members and patient experience to address issues identified from survey.
Training and Development	Training to improve access via HIT; use of accreditation entities: schools, certifying bodies, employer of workforce accreditation bodies.
	Evaluation of current faculty to teach care in new models and competencies (hours and reteachability)
	Hours of training (clinical/schools) in new delivery systems.
	Core competencies in care of older adults
	Use of training and core competencies (QI only)
Clinical Community and Cross Disciplinary Relationships	Access to services for social issues
	Patient perception of team based care: perception of adequacies of team based care
	Facility use of team based care
	Practice to community resources
Infrastructure	adequacy of workforce).
	Telehealth (behavioral health, geographic shortage area, use for decision making). Distance based measurement (workforce extender).
	Integrated personnel H.I.E. personnel (management of systems); # of health systems on H.I.E.
	E-Approval for prior authorization.
	Patient ability to use after visit data
	True meaningful use of H.I.E.

Relevant Excerpts from Other NQF Reports

Patient Reported Outcomes in Performance Measurement

The following is an excerpt from NQF's 2012 report Patient-Reported Outcomes in Performance Measurement (see pages 5, 10-11).

Patient-Reported Outcomes Tools & Performance Measures

Patient-reported outcomes (PROs) are defined as "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."[15] "PRO" 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. It is intended as well to cover all persons receiving support services, such as those with disabilities. Key PRO domains include:

- Health-related quality of life (including functional status);
- Symptoms and symptom burden (e.g. pain, fatigue);
- Experience with care; and
- Health behaviors (e.g., smoking, diet, exercise).

Various tools (e.g., instruments, scales, single-item measures) that enable researchers, administrators, or others to assess patient-reported health status for physical, mental, and social well-being are referred to as PRO measures (PROMs). In order to include PROs more systematically as an essential component of assessing the quality of care or services provided, and as part of accountability programs such a value-based purchasing or public reporting, it is necessary to distinguish between PROMs (i.e., tools) and aggregate-level performance measures.

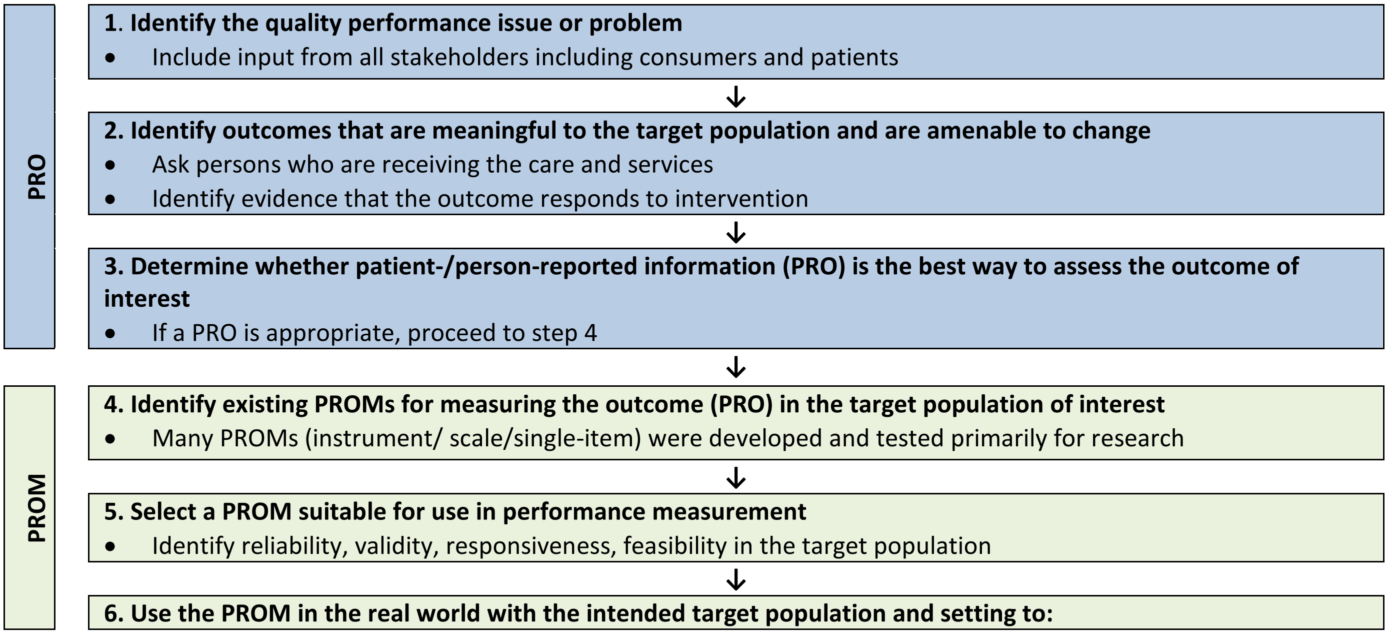
A PRO-based performance measure (PRO-PM) is based on PRO data aggregated for an entity deemed as accountable for the quality of care or services delivered. Such entities can include (but would not be limited to) long-term support services providers, hospitals, physician practices, or accountable care organizations (ACOs). NQF endorses PRO-PMs for purposes of performance improvement and accountability; NQF does not endorse the PROMs alone. However, the specific PROM(s) used in a PRO-PM will be identified in the detailed measure specifications to ensure standardization and comparability of performance results. Table 1 illustrates the distinctions among PRO, PROM, and PRO-PM.

Table 1. Distinctions among PRO, PROM, and PRO-PM: Two Examples

Concept	Patients With Clinical Depression	Persons with Intellectual or Developmental Disabilities
PRO (patient-reported outcome)	Symptom: depression	Functional Status-Role: employment
PROM (instrument, tool, single-item measure)	PHQ-9©, a standardized *tool* to assess depression	Single-item measure on National Core Indicators Consumer Survey: *Do you have a job in the community?*
PRO-PM (PRO-based performance measure)	Percentage of patients 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)	The proportion of people with intellectual or developmental disabilities who have a job in the community

The pathway displayed in Figure 2 lays out the critical steps in developing a PRO-based performance measure suitable for endorsement by NQF and generating the evidence that it meets NQF criteria for endorsement. It begins with the conceptual basis for identifying a PRO for performance measurement; the pathway then proceeds through selecting a PROM and developing and testing a performance measure to achieving NQF endorsement of a PRO-PM and using the performance measure for accountability and performance improvement. This pathway describes how a PROM may form the basis of a PRO-PM that NQF could eventually endorse based on the NQF criteria.

Figure 2. Pathway from PRO to NQF-endorsed PRO-PM



1. Identify the quality performance issue or problem
- Include input from all stakeholders including consumers and patients

2. Identify outcomes that are meaningful to the target population and are amenable to change
- Ask persons who are receiving the care and services
- Identify evidence that the outcome responds to intervention

3. Determine whether patient-/person-reported information (PRO) is the best way to assess the outcome of interest
- If a PRO is appropriate, proceed to step 4

4. Identify existing PROMs for measuring the outcome (PRO) in the target population of interest
- Many PROMs (instrument/ scale/single-item) were developed and tested primarily for research

5. Select a PROM suitable for use in performance measurement
- Identify reliability, validity, responsiveness, feasibility in the target population

6. Use the PROM in the real world with the intended target population and setting to:

- Assess status or response to intervention, provide feedback for self-management, plan and manage care or services, share decision-making
- Test feasibility of use and collect PROM data to develop and test an outcome performance measure

↓

PRO-PM

7. Specify the outcome performance measure (PRO-PM)

- Aggregate PROM data such as average change; percentage improved or meeting a benchmark

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8. Test the PRO-PM for reliability, validity, and threats to validity

- Analysis of threats to validity, e.g., measure exclusions; missing data or poor response rate; case mix differences and risk adjustment; discrimination of performance; equivalence of results if multiple PROMs specified

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NQF Endorsement Process

9. Submit the PRO-PM to NQF for consideration of NQF endorsement

- Detailed specifications and required information and data to demonstrate meeting NQF endorsement criteria

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10. Evaluate the PRO-PM against the NQF endorsement criteria

- Importance to Measure and Report (including evidence of value to patient/person and amenable to change)
- Scientific Acceptability of Measure Properties (reliability and validity of PROM and PRO-PM; threats to validity)
- Feasibility
- Usability and Use
- Comparison to Related and Competing Measures to harmonize across existing measures or select the best measure

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11. Use the endorsed PRO-PM for accountability and improvement

- Refine measure as needed

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12. Evaluate whether the PRO-PM continues to meet NQF criteria to maintain endorsement

- Submit updated information to demonstrate meeting all criteria including updated evidence, performance, and testing; feedback on use, improvement, and unintended adverse consequences

Population Health Endorsement Maintenance: Phase II

The following is an excerpt from NQF's 2012 report Population Health Endorsement Maintenance: Phase II Technical Report (see pages 3, 6-7).

Introduction – Population Health Definition and Context

Population health is the collective well-being and functional ability of an identified group of people to experience their full capabilities. It has multiple environmental, behavioral, social, and biological determinants. Population health is generally understood as a systems-level concept that describes health outcomes of a group of individuals that are measured through a broad spectrum of public health, clinical care, socio-economic, and physical environmental determinants that function interdependently and cumulatively. Population health not only focuses on disease and illness across multiple sectors, but also on health and wellbeing, prevention and health promotion, and disparities in such outcomes and improvement activities within a group and/or between groups. Identifying valid and reliable measures of performance across these multiple sectors can be challenging. Data collection, health assessments at individual and aggregate levels, payment structures, quality of patient care, public health interventions, and other components present challenges in shaping widespread, standardized implementation of population health measures, but overcoming these challenges is critical to any strategy to understand and improve it.

Given the multi-dimensional focus of population health, developing strategies to strengthen the measurement and analysis of population health—longitudinally and cross-sectionally—and the explanation of health outcomes for specific populations, can be best accomplished using a collaborative approach that includes public health, healthcare delivery systems, and other key sectors whose policies, practices, and procedures influence health. Social, environmental and behavioral factors can have significant negative impact on health outcomes and economic stability, and these along with other upstream determinants contribute to 60 percent of U.S. deaths[2]. Using the right measures can determine how successful initiatives are in reducing this mortality and excess morbidity and help focus future work to improve population health in appropriate areas.

Recognizing population health as a core societal value and fundamental aim of both public health and healthcare systems, the National Quality Strategy (NQS) includes three interlinked aims—better care, affordable care, and healthy people/communities. The NQF-convened National Priorities Partnership (NPP) as part of its input to the Secretary of Health and Human Services on the NQS[3] recommended a three-tiered approach to population health to address the national priority of working with communities to promote the wide use of best practices to enable healthy living and well-being:

1. Promoting healthy living and well-being through community interventions that result in improvement of social, economic, and environmental factors.
2. Promoting healthy living and well-being through interventions that result in adoption of the most important healthy lifestyle behaviors across the lifespan.
3. Promoting healthy living and well-being through receipt of effective clinical preventive services across the lifespan in clinical and community settings.

Existing Population and Community Health Indicators

The authors developed a crosswalk of selected total population health indicator reports, community health assessments, and sample performance reports from various governmental agencies, clinical care organizations, and community and non-profit organizations. (The paper presents a comprehensive list of these indicators/measures; a few are included in Table 1 as an illustrative example.)

The findings suggest little to no synergy for determining measurement priorities between the different stakeholder groups. In many instances, funders' priorities were often elevated but did not always reflect the needs of the local constituents. The authors believe that these and other factors contribute to the significant variability in population-based survey design and questions.

Table 1: Indicators used to access population health, determinants of health, and improvement activities (excerpt from Commissioned Paper on Population Health)

Concept/Domain	Indicator/Measures
Health status/Health-related quality of life (total population)	• Life expectancy • Expected years with chronic disease
Health Outcomes-Final (total population)	• Mortality • Health status and health-related quality of life
Health Outcomes-Intermediate (total population-level)	• Levels of risk behaviors (e.g. diet, physical activity, tobacco use, alcohol/drug use) • Physiologic measures (e.g. controlled blood pressure or cholesterol levels)
Determinants of health	
Social environment	• Poverty • Affordable and adequate housing
Physical environment	• Built environment (transportation options, availability of healthy foods) • Exposure to environmental hazards (air, water, food safety)
Health improvement activities	
Capacity	• EHR and integrated surveillance systems
Process	• Materials translated, health literacy • Quality improvement projects
Outcomes	• Preventable hospitalizations and readmissions • Patient satisfaction

Definition of Key Measurement Terms

These and other definitions can be found in NQF's Glossary.

Accountability - An obligation or willingness to accept responsibility for performance.

Accountability Applications - Use of performance results about identifiable, accountable entities to make judgments and decisions as a consequence of performance, such as reward, recognition, punishment, payment, or selection (e.g., public reporting, accreditation, licensure, professional certification, health information technology incentives, performance-based payment, network inclusion/exclusion).

eMeasure - eMeasures are performance measures that have been developed for use in an EHR or other electronic system. eMeasures pull the information needed to evaluate performance directly from the electronic record. They can be far more efficient than traditional approaches of extracting data from paper charts or claims databases.

Episode of care - Treatment of many health conditions crosses time and place. An *episode of care* includes all care related to a patient's condition over time, including prevention of disease, screening and assessment, appropriate treatment in any setting, and ongoing management.

Measure - A healthcare performance measure is a way to calculate whether and how often the healthcare system does what it should. Measures are based on scientific evidence about processes, outcomes, perceptions, or systems that relate to high-quality care. NQF-endorsed measures are tools that show whether the standards for prevention, screening, and managing health conditions are being met.

- **Structural measures** -Structural measures assess healthcare infrastructure.
- **Process measures** - Process measures assess steps that should be followed to provide good care.
- **Outcome measures** -Outcome measures assess the results of healthcare that are experienced by patients. They include endpoints like well-being, ability to perform daily activities, or even death. An intermediate outcome measure assesses a factor or short-term result that contributes to an ultimate outcome, such as having an appropriate cholesterol level. Over time, low cholesterol helps protect against heart disease.
- **Patient engagement and patient experience measures** - Patient engagement and patient experience measures use direct feedback from patients and their caregivers about the experience of receiving care. The information is usually collected through surveys.
- **Composite measures** - Composite measures combine multiple measures to produce a single score. The information can be greater than the sum of its parts because it paints a more complete picture.
- **Resource use measures** - comparable measures of actual dollars or standardized units of resources applied to the care given to a specific population or event—such as a specific diagnosis, procedure, or type of medical encounter.

Patient-reported outcomes and measurement - Patients are a great source of information on health outcomes. Who better to answer questions such as, "Did you understand your doctor's instructions?" or "Can you walk several steps without pain?" NQF is working to increase the use of patient-generated information as part of performance measurement.

- **PATIENT-REPORTED OUTCOME (PRO**): information about the patient, as communicated by that person
- **PRO MEASURE (PROM**): an instrument, scale, or single-item measure that gathers the information directly from the patient
- **PRO-BASED PERFORMANCE MEASURE (PRO-PM):** a way to aggregate the information that has been shared by the patient and collected into a reliable, valid measure of health system performance.

Population Health -Improving the health of the population through the delivery of effective preventive services, the promotion of healthy lifestyle behaviors, the use of community indices of health, and the assessment of environmental factors. Examples may include, but are not limited to, measures that address whether communities foster health and wellness as well as reflect national, state, and local systems of care that are reliable and effective in the prevention of disease, injury, and disability.

Provider - Performance measures for which the level of analysis is a provider of healthcare services that is accountable for the care delivered to their patients, e.g., clinician, hospital, clinic, health plan, pharmacies, etc.

**Quality Improvement - ***Quality improvement (QI)* encompasses all of the work people are doing to improve healthcare and the health of individuals and populations. QI is both systematic and ongoing. Healthcare professionals and providers, consumers, researchers, employers, health plans, suppliers and other stakeholders all contribute to effective quality improvement.

Stratification—division of a population or resource services into distinct, independent strata, or groups of similar data, enabling analysis of the specific subgroups. This type of adjustment can be used to show where disparities exist or where there is a need to expose differences in results.

Additional Journal Articles/Reports

National Plan to Address Alzheimer's Disease: 2014 Update

April 2014; U.S. Department of Health and Human Services

The Future of Quality Measurement from Improvement and Accountability

June 2013; American Medical Association

Achieving the Potential of Health Care Performance Measures: A Timely Analysis of Immediate Health Policy Issues

May 2013; Robert Wood Johnson Foundation