NATIONAL QUALITY FORUM

HHSM-500-2012-00009I—Task Order 11

Meeting Summary

Measure Applications Partnership

Dual Eligible Beneficiaries Workgroup Web Meeting

Thursday, November 21, 2013 | 1:00-3:00 pm ET

The National Quality Forum (NQF) convened a web meeting of the Measure Applications Partnership (MAP) Dual Eligible Beneficiaries Workgroup on Thursday, November 21, 2013. An online archive of the meeting is available.

Workgroup Members in Attendance:

Alice Lind, Workgroup Chair
Richard Bringewatt, SNP Alliance
Gwendolen Buhr, American Medical Directors Association
Adam Burrows, National PACE Association
Mady Chalk, subject matter expert: substance use
Anne Cohen, subject matter expert: disability
Steven Counsell, MD; America's Essential Hospitals
Leonardo Cuello, National Health Law Program
James Dunford, subject matter expert: emergency medical services
Nancy Hanrahan, subject matter expert: care coordination
Jennie Chin Hansen, American Geriatrics Society
Jamie Kendall; Administration for Community Living
Daniel Kivlahan, Veterans Health Administration
Samantha Meklir, Health Resources and Services Administration
D.E.B. Potter, Agency for Healthcare Research and Quality
Cheryl Powell, Centers for Medicare & Medicaid Services
Juliana Preston, HealthInsight
Clarke Ross, Consortium for Citizens with Disabilities
Joan Zlotnik, National Association of Social Workers

Welcome and Review of Meeting Objectives

Alice Lind, workgroup chair, welcomed the group to the web meeting and reviewed the meeting objectives:

- Explore similarities and differences between surveys and performance measures using the NQF framework for Patient-Reported Outcomes (PROs) in performance measurement

- Review selected resources currently available for assessing quality of life
- Engage workgroup members in a discussion of the challenges and opportunities related to measuring quality of life in the dual eligible beneficiary population

Ms. Lind also shared the focus of the project over the coming year, including the content and timing of reports.

Perspective from CMS

Cheryl Powell, Centers for Medicare & Medicaid Services (CMS), provided the perspective of the Medicare-Medicaid Coordination office on quality of life measurement and what they are seeking from MAP's guidance. Knowing that it is a complex topic, she welcomed the group to think critically about the specific challenges for measuring quality of life as well as plausible methods to obtain desired information on quality of life outcomes. CMS is interested in the group's thinking about key elements of quality of life and what aspects are able to be measured.

NQF Framework on Patient-Reported Outcomes in Performance Measurement

Dr. Karen Adams, Vice President, NQF, presented on recent NQF work regarding Patient Reported Outcomes (PROs):

- Dr. Adams explained distinctions between a PRO and a Patient-Reported Outcome Performance Measure (PRO-PM) as well as how a PRO can evolve to become a PRO-PM.
- Workgroup discussion noted the importance of capturing firsthand experiences of the beneficiary population and the need to be flexible in allowing trusted individuals to serve as proxies for individuals with cognitive limitations.
- Noting the point that NQF does not endorse surveys, workgroup members questioned NQF's endorsement of CAHPS tools and sought further guidance on the distinctions between surveys and performance measures generated from surveys.

Current Approaches to Assessing Quality of Life

Presentation by Amaru Javier Sanchez, Project Analyst, NQF and Sarah Lash, Senior Director, NQF:

- Mr. Sanchez defined the term "quality of life" as a multidimensional concept consisting of physical, material, social, emotional, and developmental aspects.
- Mr. Sanchez discussed the format, strengths, and weaknesses of some widely known quality-of-life assessments including the 36-Item Health Survey (SF-36) and the World Health Organization (WHO) Quality of Life Instrument (WHOQOL).
- Ms. Lash discussed the format, strengths, and weaknesses of the Patient-Reported Outcomes Measurement Information System (PROMIS) and the Money Follows the Person (MFP) evaluation survey on quality of life.
- Many assessments, surveys, and tool are available to evaluate quality of life, but the vast majority of them are focused on health aspects including symptoms, functions, and

everyday activity limitations. Current resources fall short of being person-centered and including important concepts such as dignity and self-determination.
- One workgroup member suggested that the project monitor progress of SAMHSA's plans to field test the WHO-BREF survey.
- Another workgroup member suggested the project consult the Cash and Counseling program's prior experience with measuring quality of life.

Workgroup Perspectives: Challenges and Opportunities in Measuring Quality of Life

Presentations by Jamie Kendall, Administration for Community Living; Anne Cohen, MAP Disability Subject Matter Expert; Adam Burrows, National PACE Association; and Richard Bringewatt, SNP Alliance:

- Ms. Kendall discussed the need for clinicians to be less paternalistic and more person-centered in taking a holistic approach to addressing the critical needs of each individual through specialized goals.
- Ms. Cohen discussed the concept of "dignity of risk" and how it pertains to the quality of life for a person with disabilities. In sharing an anecdote, she illustrated how preconceived notions of the quality of life experienced by a person with disabilities can negatively affect the type of care they receive. She called for changes to be made in both social and clinical settings to improve cultural competency and expand community health resources.
- Dr. Burrows emphasized that beneficiaries want their health providers to be "allies" in maintaining good health. He suggested three main concepts as essential to the concept of quality of life:
    - Palliation: symptom control including distress related to having a serious health condition
    - Security: confidence that one's basic needs will be met
    - Control: autonomy and sense of self-determination
- Mr. Bringewatt discussed the extent to which poverty complicates consideration of quality of life issues in the dual eligible population. Mr. Bringewatt also noted that health plans are limited in their capabilities to pay for any services and supports beyond medical care, even when doing so has been proven to improve health outcomes and quality of life. Some measures of quality of life components relate to healthcare delivery, such as health literacy, ensuring dignity, nutrition, and addressing disparities; other concepts are more global and relate to basic needs.

Workgroup Discussion

- One workgroup member observed the complexity of respecting dignity of risk and individuals' personal choice for how they choose to engage with the health system in light of the quality improvement activities being discussed.

- One workgroup member observed that some quality of life indicators are best measured at the population level because they are systemic issues.
- Members questioned potential unintended consequences of surveying the dual eligible population, including burdening them or being condescending by implying that one's circumstances need "fixing."
- Several workgroup members observed that the outcomes sought in quality of life will broaden expectations for the role of the provider. Changes in the health system are necessary to support more positive, empathetic, and relationship-based care. A participant suggested that physicians need training in how to ask questions pertaining to patients' quality of life in an appropriate way.
- One workgroup member requested additional information on the results of using the quality of life measurement tools.

Next Steps

The meeting concluded with a reminder of important dates and meetings:

- December 2-10: Early commenting on measures under consideration
- January: Public comment on draft report on MAP's pre-rulemaking input
- January/February: Workgroup review and public comment on draft report on dual eligible beneficiaries, including past and present work related to:
    - High-need population subgroups
    - Family of measures
    - Measurement of quality of life
- February 1: MAP 2013/2014 pre-rulemaking recommendations due to HHS
- February 28: MAP report on dual eligible beneficiaries due to HHS

The next web meeting of the MAP Dual Eligible Beneficiaries Workgroup is scheduled for December 20, 2013, 1-3pm ET. The focus will be reviewing the progress of MAP's other workgroups on pre-rulemaking recommendations and formulating additional input to the MAP Coordinating Committee, if needed.