

**HIT Policy Committee
Quality Measures Workgroup**

PATIENT AND FAMILY ENGAGEMENT TIGER TEAM

October 28, 2010

The Quality Measure Workgroup is one of seven workgroups within the HIT Policy Committee that will provide initial recommendations on quality measure prioritization and the quality measure convergence process pertaining to measure gaps and opportunities for Meaningful Use Stage 2.

The workgroup was divided into six tiger teams, each focused on a different measure domain. These tiger teams were charged with identifying a set of sub-domains, prioritizing these sub-domains, and identifying key measure concepts within each sub-domain.

The Patient and Family Engagement tiger team members include Michael Barry, Christine Bechtel, Susan Edgman-Levitan, Judy Hibbard, Lew Kazis, David Lanksy, Eugene Nelson, Dana Safran, Joshua Seidman, Paul Tang, Kalahn Taylor-Clark, Paul Wallace, and James Weinstein.

The group first focused its attention on identifying a set of sub-domains and then identified a broad range of measure concepts, including—

<ul style="list-style-type: none"> • Patient Activation—patient’s ability to set goals and self-manage and engage in care effectively. • Outcome of Activation—once the patient is activated, what do they do? Include measuring health outcomes. • Provision of effective self-management resources and tools, in accordance with patients’ preferences. • Self-management of health risk behaviors and preventive care in general (not just chronic conditions). • The feedback loop of the patient’s data to the clinician. • Patients’ engagement with their own data (e.g., displays) tools that help translate data into actions, etc. • Did shared decision making occur and was the clinician aware of the patient’s preferences? • Efficacy of shared decision making—did the patient understand what he/she was making a decision about? • Did shared decision making actually make a difference (is the patient comfortable with the decision) including concordance with patient’s preferences/values and service delivery? • Connection to community resources for health promotion, complex chronic DM and care, and social/other non-medical needs/ support, including online patient/caregiver communities. 	<ul style="list-style-type: none"> • Functional Health Status—level of functional ability in physical, mental, and social domains. • Disease Status—patient self reports or diagnostic tests for specific health conditions, focus on patient-reported outcomes and how health information technology can enable this for the high-variation, high-volume, high-cost conditions with appropriate outcome tools. • Risk Status—two sources: report of health behaviors (eating, exercise, etc.) and biometric variables. Measures of avoidable risk of death that are based on both biometric variables and lifestyle variables. • Caregiver as a proxy for patient, in each of the sub-domains. • In situations where caregiver present, measurement of caregiver’s engagement, health status, communication preferences, etc. in each of the sub-domains. • Potential for technology to increase a family member/caregiver’s participation and decrease some of the family/caregiver burdens. • Facilitation of peer networks, enabled by health information technology that would provide a social support for caregivers/family members, as well as medical guidance. • Methods by which patients prefer to communicate (e.g., phone, email, portal, paper)
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The group examined these concepts using the following criteria: the state of measure development, endorsement status, potential impact to improve patient-centered care and quality of care delivered to patients, the importance of collecting patient-reported data, and measures with the ability to impact at the individual patient level as well as the population level.

The group narrowed its focus to the following nine measure concepts recommendations based on what aspects of care, which are enabled by health information technology, have the most impact to improve health outcomes.

1. Self-Management/Activation

Definition: Measures that show that the patient understands what his/her role is in his/her own care process and has the knowledge, skills, and confidence to move forward in this role, including resources and support for self-management.

Recommended Measure Concept 1.1: Self-Management

Discussions leading to this measure concept recommendation focused on provisions of effective, personalized self-management resources and tools, in accordance with patients' preferences, and also the need to measure self-management of health risk behaviors and preventive care of both acute and chronic conditions.

The group recognized that several Consumer Assessment of Healthcare Providers and Systems (CAHPS) questions are relevant to self-management/activation. Other example measures include other patient experience surveys and the Promoting Healthy Development survey.

Recommended Measure Concept 1.2: Patient Activation

Patient activation includes a patient's ability to self-manage his/her care and engage in his/her care effectively. The group discussed the importance of gearing the measure concepts toward measuring whether a patient is continuing to manage his/her care, measuring health outcomes, and measuring whether the patient has been led in the "right direction" by his/her healthcare provider regarding that patient's plan of care.

Example measures that the group discussed included Patient Activation Measure (PAM): 13- and 6-item surveys. Meaningful Use Stage 2 could, for example include percentage of patients with activation scores recorded, and Meaningful Use Stage 3 could, for example include percentage of patients with a (positive) change in activation.

2. Honoring Patient Preferences and Shared Decision Making

Definition: Measures that demonstrate that the patient has the knowledge to make informed decisions or an informed choice about his/her care. Also includes the quality of decision making, connecting patients to resources, assessing patients' preferences and whether the care that was delivered is in accordance with the patient's preferences and values.

Recommended Measure Concept 2.1: Shared Decision Making focused on measuring a patient's knowledge and confidence about his/her care process and measuring a patient's preferences and values.

Discussions leading to this measure concept recommendation highlighted that shared decision making should be about honoring a patient's preferences/values in treatment choices. The group focused on two key decision quality constructs—measuring the patients' knowledge and confidence about his/her own care process and measuring the patients' preferences and values.

The measure concept recommendation focuses on three areas:

- Did shared decision making occur and was the clinician aware of the patient's preferences?
- Did the patient understand what they were making a decision about (was shared decision making done well)?
- By the patient engaging in shared decision making, did it make a difference (is the patient comfortable with his/her decision, and was the care that was delivered in accordance with the patient's preferences/values)?

Example measures that the group discussed included the CAHPS family of instruments and decision quality measures that focus on the following:

- Measuring the patient's knowledge—how informed was the patient about the things a person should know.
- Measuring patient preferences—the extent to which the decision was personalized to reflect the patient's goals and concerns.
- Measuring the process—the extent to which the interaction between provider and patient indicated serious attention to informing and involving the patient in the decision process.

Recommended Measure Concept 2.2: Patient Preferences

The group discussed and inferred that when a patient is knowledgeable and confident to make a decision, that patient is not only in a position to make informed decisions that match his/her values and preferences, but also improves his/her likelihood of receiving the most appropriate medical care. The group also discussed including measures and measurement tools that focus on whether the care delivered was in line with the patient's preferences. In addition, the group acknowledge the need for measures that capture how people prefer to communicate (paper, portal, universal serial bus [USB], emails, PHR, etc.).

Example measures that the group discussed included the CAHPS family of instruments and collection of data on patient preferences through a PHR, portal, mobile application, handheld computers, or kiosks at the point of care.

Recommended Measure Concept 2.3: Patient Experience of Care

The group highlighted some specific topics within the scope of patient experience of care when recommending measure concepts. The topics included a patient's assessment of their clinician's skills and ability to work with a patient's health team to coordinate care, and patient's evaluating if they are receiving the care they should be from their clinicians and if it has benefitted their overall health and made impacts on their life.

For Meaningful Use Stage 2 the group explored CAHPS and other patient experience surveys, and for Meaningful Use Stage 3, the group considered CAHPS or other surveys that would have evolved further.

3. Patient Health Outcomes

Definition: Measures that focus on optimizing three states (Disease/Disability, Health Risk, and Functioning Health) at the level of the individual patient or the population level.

Recommended Measure Concept 3.1: Disease/Disability Status

Measurement of disease/disability status includes patient self reports or clinician-provided diagnostic tests for specific health conditions. Disease status can be measured at the individual patient level.

The group acknowledged that many disease/disability status measures in existence are reports from diagnostic tests (e.g., HbA1C under control, Blood Pressure control, etc.). The group recommended measure concepts that focus on patient-reported outcomes and how health information technology can enable these with appropriate outcome tools for the high-variation, high-volume, and high-cost conditions.

Recommended Measure Concept 3.2: Health Risk Status

The group concluded that health risk status should measure avoidable risk of death that is based on both biometric variables and lifestyle variables. Health risk status can be measured at both the individual patient level and population level.

Examples of measures that the group discussed include Meaningful Use Stage 2—percentage of patients with functional status and health risk status recorded; Meaningful Use Stage 3—percentage of patients with functional status improved or decline in functioning reduced; Meaningful Use Stage 2—percentage of patients with health risk status recorded; and Meaningful Use Stage 3—percentage of patients with health risk status reduced.

Recommended Measure Concept 3.3: Functional Health Status

Measuring functional health status is important because of the need to understand the level of patient ability in physical, mental, and social domains. Such measures are a key mechanism for establishing patient goals with respect to outcomes of care (e.g., are patients functioning at a higher level), as well as for assessing the mental and social factors that impact patients' ability to achieve their desired outcomes. Functional status can be measured at both the individual patient level and population level.

Examples of measures that the group discussed include Healthy Seniors Survey, (including VR-12 and/or VR-36) and the How's Your Health survey. Meaningful Use Stage 2 could, for example include percentage of patients with functional status and health risk status recorded, and Meaningful Use Stage 3 could, for example include percentage of patients with functional status improved or decline in functioning reduced. Meaningful Use Stage 2 could, for example also include percentage of patients with health risk status recorded, and

Meaningful Use Stage 3 could, for example also include percentage of patients with health risk status reduced.

4. Community Resources Coordination/Connection

Definition: Measures that show if a patient was connected to community resources.

Recommended Measure Concept 4.1: Community Resources Coordination/Connection

The group discussed the importance of connecting patients to community resources for health promotion, complex chronic disease management and care, and social/other non-medical needs/support, including online patient/caregiver communities. Improving health outcomes, including functional status, often requires other non-health institution resources (e.g., support groups, transportation, etc.).

Based on the discussion, the group noted it was unaware of any measures in existence that aim to capture whether patients were referred to community resources and how patients can benefit from being connected to resources in their communities. As a result, any measures developed under this concept will likely be new.

Methodologic Issues

In addition to the deliberations on sub-domains and measure concepts, the group also focused on methodologic issues for using patient-reported data in meaningful use clinical quality measures. Many of the sub-domains that the group identified can best be measured and assessed only by capturing data from patients (and caregivers or family members). The most commonly accepted data collection methods pertaining to the group's identified sub-domains involve standardized surveys to samples of patients. These types of surveys can be expensive and are rarely administered at the individual "eligible professional" level because of methodology (e.g., sample size), attribution, and cost concerns. The group discussed two alternative pathways for collecting patient-reported outcomes and experience data.

The first approach is an "add on" to the current system and does not require embedded health information technology. This approach focuses on using a standard survey that is administered to a defined population and followed over time (similar to the approach being used for the Health of Seniors Survey.) The second approach embeds collection of patient-reported data into the flow of care and into a health system's processes for assessing, treating, and following up with patients over time. This is a "design in" approach and requires embedding patient-reported data into health information technology used by health systems.

The group further discussed high-level methodologic issues for using the first approach of collecting patient and family/caregiver data. The issues include determining the timing of survey administration, assessing the strengths and limitations of the different modes of administering the survey (examples, phone, paper, email, etc.), determining who should administer the survey, determining the sample size and who should be included in the sample of patients receiving surveys, executing measure computations, and determining how the data collected can be used most effectively to support progress toward quality health care.

While both approaches were considered worthwhile, more is known about survey methods. The group recommended further exploration and development of the second approach (embedding data collection and use into the flow of care) and suggested more work be done to explore ways this is already occurring in several health systems.

RFI Sample Questions

The group proposed and outlined some additional key questions that the Office of the National Coordinator for Health Information Technology should capture in the release of the Request for Information (RFI).

Self-Management/Activation and Honoring Patient Preferences and Shared Decision Making.

Questions that the group discussed include—

- Can patient experience, functional status, or other survey results be fed back into decision support programs to ensure treatment recommendations and other care plans reflect the patient's feedback?
- How else can patient-generated data be embedded into care flow?
- Is there a way to ensure that data is embedded into a feedback loop between patients and providers? What tools and methods can be implemented to support this feedback loop?
- What are the best tools for creating the feedback loop between the data and the patient (e.g., graph displays and other strategies for using data to support action by patients)?
- Are there other patient experience surveys that should be considered?
- How can experience surveys best be health information technology enabled?
- Do the measures identified in the RFI for patient and family engagement need to be adapted in cases where the caregiver is a decision maker/proxy for the patient?

Patient Health Outcomes

Questions that the group discussed include—

- Is there a dimension to these measures, or do the measures need to be adapted in cases where the caregiver is a decision maker/proxy for the patient?
- What tools are available to measure the health/functional status and/or risk status of the caregiver?

Community Resources Coordination/Connection

Questions that the group discussed include—

- How can we measure the extent to which patients are connected to community resources?
- Is there a dimension to these measures, or do the measures need to be adapted in cases where the caregiver is a decision maker/proxy for the patient?