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IAP Quality Measurement Learning Series

CONSIDERATIONS FOR MEASURING PERSON AND FAMILY ENGAGEMENT AND ACTIVATION IN MEDICAID

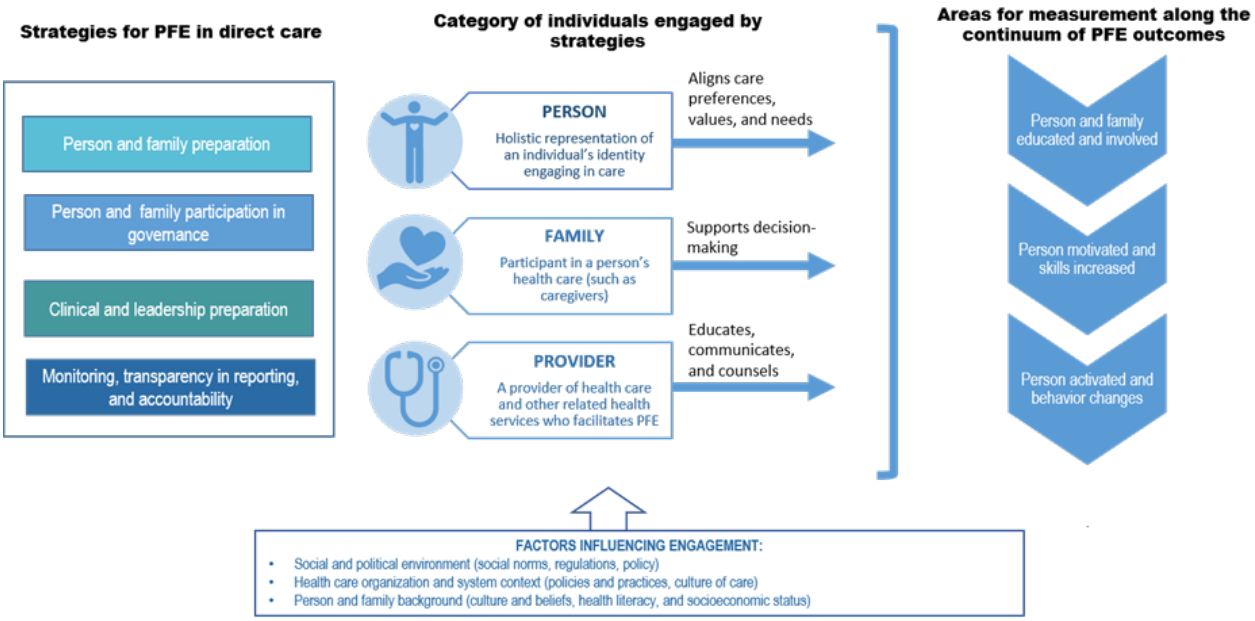
This brief provides state Medicaid agencies with an overview of the current approaches and challenges to measuring person and family engagement (PFE) and activation, for purposes of improving quality of care. PFE can enhance safety through person and family education, increase person and provider satisfaction through their investment with care, and ultimately improve health outcomes and lower costs (Carman et al. 2014). As such, PFE in care can be considered to be a key strategy for advancing quality, necessitating measures to help state Medicaid agencies gauge the implementation of PFE and its outcomes in health care delivery settings.

CMS definition of person and family engagement

"Patients and families are partners in defining, designing, participating in, and assessing the care practices and systems that serve them, to assure they are respectful of and responsive to individual patient preferences, needs, and values. This collaborative engagement allows patient values to guide all clinical decisions, and drives genuine transformation in attitudes, behaviors, and practice." (CMS 2016)

Within the PFE framework shown in the figure below, the PFE continuum begins with person and family education and involvement, and then leads to person and family motivation and activation to make more informed choices, satisfaction with care, and provider retention. Ultimately, this can lead to changes in health outcomes and costs.

Figure 1. Understanding measurements areas for person and family engagement in direct care



Source: Based on content in Barello et al. (2014) and Carman et al. (2013, 2014).

Using this continuum as a guide, existing PFE measures were identified by searching through peer-reviewed literature, gray literature, and CMS publications. Key concepts used for the search included person, patient, or family engagement, experience, satisfaction, behavior, and education. Information on the measures included in this analysis is derived from eight separate sources: Altarum Institute, Child and Adolescent Health Measure Initiative, CMS Quality Measure Inventory in August 2017, Medicare and Medicaid Research Review, Frontiers in Psychology, Health Research and Education Trust, BioMed Research International, and Psychology Services Limited. Of the 35 measures identified, 18 are process measures and 17 are patient-reported outcome measures. Many of them also refer to specific conditions or settings, such as cardiovascular health, home health, and smoking cessation, whereas a few others are applicable for more general uses across health care settings. Note that some of these measures are composites of multiple items within a single survey instrument. These composite measures are often referred to as *scales,* but, for consistency, this brief will refer to them as *measures*.

Current measures of engagement and activation in direct care

Given PFE's continued and increasing importance in improving quality of care, evidence-based measures are necessary to capture the degree to which various initiatives increase PFE. However, the lack of shared guidelines to achieve PFE contributes to variation in the types of instruments used to carry out reliable assessments of PFE. Within the PFE assessment "tool box" are several existing measures that can be grouped into the three areas: education and involvement, motivation and self-efficacy, and behavior change and activation. The box below describes these PFE measure categories. Attachment A includes more details on the individual PFE measures reviewed for this brief.

Description of categories of PFE measures reviewed in this brief

- **Education and involvement** – Measures in this category capture the extent to which providers build the capacity of people and their families to be proactive in their own care. Educational activities by providers include health education and counseling. Involvement of a person and his or her family in the person's direct care includes shared decision making and establishing treatment goals that reflect a person's preferences, values, and needs.
- **Motivation and self-efficacy** – A person's motivation is the anticipated result of provider efforts to communicate and collaborate with beneficiaries in treatment. Measures of motivation and efficacy are designed to capture attitudes, perceptions, and confidence of the individual. Indicators under this category examine health literacy, patient trust in providers, and a willingness to seek relevant health information.
- **Behavior change and activation** – Behavior change and activation can be considered the penultimate goal of PFE strategies (the ultimate goal being better health outcomes). Activation measures track changes in behavior, particularly with respect to a person's capacity for self-care and demonstrated ability to maintain a healthy lifestyle, even in times of stress.

Education and involvement measures. The 20 PFE measures reviewed in this measurement area capture the bidirectional flow of information between a person receiving care and his or her provider that results in treatment decisions based on the patient's preferences, medical evidence, and clinical judgement (Carman et al. 2013). As shown in Attachment A, the 15 measures that use administrative data sources focus on physician counseling, patient education, communication, and shared decision making; the administrative data sources for these measures include the Outcome and Assessment Information Set (OASIS), electronic medical records, and registry data. The three measures from the Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys examine provider efforts to assist patients and families navigate their health care and the extent to which this is conducted with cultural and linguistic competence.

Motivation and self-efficacy measures. Nine survey measures, all which rely on self-reported data, track the level of patient motivation, confidence, and skills. Many of these measures are based on the transtheoretical model that includes the Stages of Change detailing the levels of an individual's readiness to act on a new healthier behavior (Prochaska and DiClemente 2005).[1] One well-known example is the Patient Activation Measure, which assesses an individual's knowledge, goal-orientation, and capacity for proactively managing one's health and treatment. Some recently developed measures also take a closer look at the complex emotional and motivational experience of patients as they engage in the management of their own care. The Patient Health Engagement Scale offers a psychological elaboration of the "process-like and multi-dimensional experience, resulting from the conjoint cognitive (think), emotional (feel), and conactive (act) enactment of individuals toward their health management" (Graffigna et al. 2015). The Patient Activation Supplement for the Medicare Current Beneficiary Survey is designed to capture patients' confidence in their capacity for self-care and their ability to seek information about their diagnosis or treatment.

Behavior change and activation measures. During the review process, six measures were identified that focused on the behaviors of an activated person who is ready to engage in his/her care, or perceptions that correlate highly with healthy behaviors such as exercise, weight management, and commitment to a treatment regimen. The Morisky Medication Adherence Scale is a four-question survey that assesses patients' likelihood of continuing their prescribed drug therapy and indicates patients' reasoning for non-adherence. The Altarum Consumer Engagement measure uses items in a survey to assess three domains of engagement: commitment, informed choice, and navigation. These three domains describe how consumers think and act on information about their health care. Two administrative measures are related to medication adherence.

Considerations for measuring person and family engagement

Although selecting specific measures to assess PFE will depend on the purposes and capacity for measurement, the review uncovered several considerations to assist states with understanding limitations crosscutting measures reviewed. These limitations largely are due to PFE's complex and multicomponent nature and the relative recent emergence of the field. Key considerations for discussion include data sources and burden, cultural and linguistic appropriateness of existing instruments, and inclusion of family in measurement.

Data sources and burden. Of the three measurement categories listed above, education and involvement measures can most easily leverage administrative data as a source. Due to the emotional and perceptual dimensions of motivation and activation, capturing information about the other two categories must rely on person-level reporting. Consequently, measures in the categories of motivation and self-efficacy and behavior change and activation are often subject to the same advantages and challenges as quality measures for which surveys are the data source (for example, burden of data collection, nonresponse bias, and recall bias).

[1] The six stages of change include: (1) precontemplation—not ready to take action and unaware that behavior is problematic; (2) contemplation—beginning to recognize that behavior is problematic; (3) preparation—intending to take action in the immediate future or taking small steps toward behavior change; (4) action—making specific overt behavior modifications; (5) maintenance—sustaining action for at least six months and working to prevent relapse; and (6) termination—not returning to old unhealthy habit (Prochaska and Velicer 1997).

Cultural and linguistic competency. Developing and validating measures is a resource-intensive undertaking. Given the relatively recent development of PFE measures, it is not surprising that these measures are often validated for a limited number of languages and do not always address a broad array of cultural and linguistic appropriateness and health literacy (McQuillen et al. 2013). For example, the majority of survey sources for identified measures are available only in English or Spanish. More of these instruments may be translated over time, but for now, states should use and interpret these measures with caution for underrepresented populations. A tool to help states in thinking about cultural competency in fielding PFE measures are the National Standards for Culturally Appropriate Services (CLAS) in health care (Think Cultural Health n.d.). Documentation for the National CLAS Standards describes how to integrate these standards into measurement and continuous quality improvement activities.

Inclusion of family in measurement. The majority of engagement measures assess person- or patient-level outcomes. The few that examine family or community involvement are primarily aimed at caregivers of family members, such as parents of children in treatment (though less so for adult caregivers of elderly parents). Surveys containing at least one question on caregiver engagement or involvement in decision making for their family member's care or treatment include the CAHPS Medicaid 5.0 (Adult and Child) Survey, the CAHPS item set for children with chronic conditions, and the Child and Adolescent Health Measurement Initiative (CAHMI): Promoting Healthy Development Survey. Until more validated measures are developed for family engagement, there is a fairly limited selection and states may want to consider identifying proxy measures using CAHPS and CAHMI as example measures.

Conclusion

There are a variety of measures currently available that states can use to assess PFE, depending on the aspect for assessment. And, an even larger selection of measures should become available as the field and interest in PFE continues to grow. In particular, key areas for further development are cultural and linguistic competency in PFE quality measurement and family engagement. Given the diversity of the Medicaid population, state efforts to address these gaps will be critical to engaging *all* beneficiaries and their families. The examples of PFE measures highlighted in this brief should be seen as a starting point for states to consider and not an exhaustive list of measures available.

Attachment A. Person and Family Engagement Measures Reviewed, August 2017

CMS Measure ID	NQF ID	Measure Title	Steward
Education and Involvement			
0007, 0024, 0031	9999	Adult Smoking Cessation Advice/Counseling	Centers for Medicare & Medicaid Services (CMS)
0209	0520	Drug Education on All Medications Provided to Patient/Caregiver During Short-Term Episodes of Care	Centers for Medicare & Medicaid Services (CMS)
0976	9999	Drug Education on High-Risk Medications Provided to Patient/Caregiver at Start of Episode	Centers for Medicare & Medicaid Services (CMS)
0978	9999	Drug Education on All Medications Provided to Patient/Caregiver During Long-Term Episodes of Care	Centers for Medicare & Medicaid Services (CMS)
1444	0375	Venous Thromboembolism Discharge Instructions	The Joint Commission
1668	1647	Beliefs/Values Addressed (if desired by the patient)	Deyta, LLC
1673	2631	Percent of Long-Term Care Hospital Patients with an Admission and Discharge Functional Assessment and a Care Plan That Addresses Function	Centers for Medicare & Medicaid Services (CMS)
1985	9999	Patient-Centered Surgical Risk Assessment and Communication	American College of Surgeons
2386	9999	Discussion and Shared Decision Making Surrounding Treatment Options	American Gastroenterological Association
2517	0005	Consumer Assessment of Healthcare Providers and Systems (CAHPS) for PQRS Clinician/Group Survey	Agency for Healthcare Research & Quality (AHRQ)
2595	2631	An Application of Percent of Long-Term Care Hospital Patients with an Admission and Discharge Functional Assessment and a Care Plan that Addresses Function	Centers for Medicare & Medicaid Services (CMS)
2704, 2705	9999	Drug Education on All Medications Provided to Patient/Caregiver during All Episodes of Care	Centers for Medicare & Medicaid Services (CMS)
2826	9999	Aspirin Use and Discussion	National Committee for Quality Assurance
2829	9999	Behavioral Health Risk Assessment - Maternal Care	American Medical Association - Physician Consortium for Performance Improvement (AMA-PCPI)
2840	9999	Consumer Assessment of Healthcare Providers and Systems (CAHPS) Children with Chronic Conditions Supplemental Item set	Agency for Healthcare Research & Quality (AHRQ)
2857, 2905	9999	Consumer Assessment of Healthcare Providers and Systems (CAHPS) for Accountable Care Organizations	Agency for Healthcare Research & Quality (AHRQ)
2924	2631	Application of Percent of Long-Term Care Hospital Patients with an Admission and Discharge Functional Assessment and a Care Plan That Addresses Function	Centers for Medicare & Medicaid Services (CMS)
3146	9999	Documentation of discussion with patients about potential use of field-directed therapies prior to destruction of actinic keratoses	American Academy of Dermatology
3471	9999	Patient engagement prior to uterine artery embolization for symptomatic leiomyomata and/or adenomyosis	Society of Interventional Radiology
N/A	N/A	Child and Adolescent Health Measurement Initiative (CAHMI): Promoting Healthy Development Survey	Johns Hopkins Bloomberg School of Public Health

CMS Measure ID	NQF ID	Measure Title	Steward
Motivation and Self-Efficacy			
1700	0228	3-Item Care Transitions Measure (CTM-3)	University of Colorado Denver Anschutz Medical Campus
2842	9999	Consumer Assessment of Healthcare Providers and Systems (CAHPS) Cultural Competence Item Set	Agency for Healthcare Research & Quality (AHRQ)
5525	9999	Application of IRF Functional Outcome Measure: Discharge Self-Care Score for Medical Rehabilitation Patients	Centers for Medicare & Medicaid Services (CMS)
5526	9999	Application of IRF Functional Outcome Measure: Discharge Mobility Score for Medical Rehabilitation Patients	Centers for Medicare & Medicaid Services (CMS)
N/A	N/A	Consumer Assessment of Healthcare Providers and Systems (CAHPS) Health Literacy Item Set	Agency for Healthcare Research & Quality (AHRQ)
N/A	N/A	Patient Activation Measure (PAM)	University of Oregon
N/A	N/A	Patient Attitude, Motivation and Perception Assessment (PAMPA): Patient Attitude Questionnaire (PAQ)	Psychology Services, Ltd.
N/A	N/A	Patient Attitude, Motivation and Perception Assessment (PAMPA): Patient Motivation Inventory (PMI)	Psychology Services, Ltd.
N/A	N/A	Patient Attitude, Motivation and Perception Assessment (PAMPA): Patient Perception Questionnaire (PPQ)	Psychology Services, Ltd.
N/A	N/A	Patient Health Engagement Scale (PHE-s)	Università Cattolica del Sacro Cuore, Milan, Italy
Behavior Change and Activation			
4074	0541	Medication Adherence for Cholesterol (Statins)	Pharmacy Quality Alliance (PQA, Inc.)
5583	9999	Continuation of Medications Within 30 Days of Inpatient Psychiatric Discharge	Centers for Medicare & Medicaid Services (CMS)
N/A	N/A	Altarum Consumer Engagement (ACE) measure	Altarum Institute
N/A	N/A	Medicare Current Beneficiary Survey (MCBS) Community Questionnaire, Patient Activation Supplement	NORC at the University of Chicago
N/A	N/A	Morisky Medication Adherence Scale (MMAS-4)	University of California, Los Angeles Fielding School of Public Health

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