National Committee for Quality Assurance

Serious Illness Care: Person-Driven Measures for Accountability

Contents

Executive Summary

NCQA has undertaken a project to develop a suite of performance measures suitable for use in serious illness care accountability programs. Measures will evaluate the quality of care through the lens of patient goals. The project is funded by the Gordon and Betty Moore Foundation.

In this report, we describe the rationale for and approach to goal-based, person-driven measures focusing on:

- The need for serious illness care performance measures.
- The serious illness care landscape.
- Stakeholder involvement.
- Measure concepts under development.

Growing demand for community-based serious illness care has resulted in the launch of new programs by health systems, hospices, medical groups, home health agencies and free-standing corporations formed to deliver only serious illness care—but payers and regulators do not require programs providing community-based serious illness care to report relevant performance measures (Section IV).

Value-based purchasing models, including accountable care organizations (ACO) and alternative payment models (APM), have the potential to encourage providers to use the lowest-cost care approach that achieves high-quality outcomes. Yet without performance measures that address meaningful components of quality, the pressure to decrease costs could overwhelm the payment equation and adversely impact care quality.

Because community-based serious illness care is an emerging care model in an emerging specialty practice, measure development is challenging. Serious illness care delivered outside hospitals or hospice remains heterogeneous; limited evidence is available for building measures based on a specific care model or for supporting clinical process measures of serious illness care.

The Institute of Medicine (IOM) has called for the person's goals, preferences and values to drive serious illness care (Pizzo, Walker and Bomba, 2014) and measurement (Section III), but no current measures used in major reporting programs are designed to improve alignment between a person's goals and care plans, care delivered and care outcomes (Sanders et al., 2018). To guide measure development, NCQA engaged stakeholders through a multidisciplinary panel and a learning collaborative of 11 organizations delivering serious illness care. NCQA also retained 2 paid patient partners who live with serious illness, to inform and guide measure development.

In the first phase of its work, NCQA will develop process measures designed to build person-driven measures for evaluating goal-concordant care. We are training learning collaborative sites on structured approaches to serious illness conversations and goal setting, to allow us to evaluate tools we need. These sites will also test three process measures addressing assessment, care planning and goal documentation. In the next phase, we will conduct a pilot in selected programs using standardized serious illness conversations and goal-setting, and will develop and test person-driven measures suitable for inclusion in accountability programs.

I. Case Study

Mary

Mary is a 72-year-old widow with two grown daughters and three grandchildren. She lives in an accessible condominium. She and her husband moved to the condo 15 years ago assuming they would live there for the rest of their lives. Mary was diagnosed with COPD 10 years ago, and also has congestive heart failure, type 2 diabetes, angina and high blood pressure.

Two years ago, Mary's husband died unexpectedly from a heart attack; she was hospitalized for pneumonia a month later. Until those events, Mary watched her grandchildren, shopped, volunteered at the local hospital, went to church, hosted Sunday dinner every week and shared housekeeping with her husband. Her ability to maintain her activities and overall health declined after the pneumonia. Now, she only leaves her home to go to church and frequent doctor appointments. She worries that her daughters, neighbors and friends from church are overburdened by helping her.

Mary says socializing with friends and family, going to church and living in her condo are most important to her. She fears she will have to move into a nursing home. She wants less hassle from care, which includes breathing tests, more than 10 pills a day, daily glucose monitoring and appointments every other week for doctor visits and tests. She wants fewer visits and a number to call so she can talk to a nurse or doctor if she has trouble breathing or her weight increases suddenly.

In the health care system where Mary receives care, care quality is measured by whether she receives a colonoscopy, a mammogram, an annual skin check and flu and pneumonia vaccines, whether her HbA1C is <9, whether she takes a prescribed statin and beta-blocker and whether her physician has billed for an advance care planning visit. Her doctors ask her to rate her pain at every visit, which she finds irritating because she is more concerned about her ability to breathe.

II. Purpose

Community-based serious illness care has emerged as a new model designed to address the needs of people like Mary.

This report presents a rationale for and an approach to developing person-driven measures to address critical gaps in serious illness care, as reflected by the misalignment between what is important to Mary, the care she receives and provider incentives. It describes the serious illness care landscape and the rising demand for the need for serious illness care performance measures ("measures"), and lays out NCQA's approach to person-driven measure development.

In serious illness care, where almost every care decision brings trade-offs among outcomes and care burden, it is not possible to presume the person's desired outcome.

III. Background

A. Definition

Serious illness is "[a] health condition that carries a high risk of mortality and either negatively impacts a person's daily function or quality of life or excessively strains the caregiver." (Kelley and Bollens-Lund, 2018). Community-based serious illness care does not have a standard definition, but usually includes medical care focused on managing and improving symptoms associated with disease or treatments and 24/7 telephone support. Less frequently, it includes services such as in-home physician visits for primary or palliative care, aide visits, in-home nursing care, behavioral health care and spiritual support.

B. Demand and Accountability

Growing demand for community-based serious illness care has resulted in the launch of new programs by health systems, hospices, medical groups and home health agencies (Henry, Scholle and French., 2018), as well as free-standing corporations formed to deliver serious illness care exclusively (Frist, 2017; Teno et al., 2018). Currently, payers and regulators do not require organizations providing community-based serious illness care to report relevant performance measures (see Section IV). Informants interviewed by NCQA described community-based serious illness care as the "Wild West" because it lacks accountability, even while its reach expands. Calls for accountability programs and robust, person-centered measures are coming from across the health care system (Cohn et al., 2017; Pizzo, Walker and Bomba, 2014; Teno et al., 2018).

A desire for dedicated serious illness care funding is, among other factors, driving demand for targeted performance measures. Current health care financing is not designed to meet the needs and preferences of people with serious illness. Palliative care leaders have called for new serious illness payment models (Ryan and Rogers, 2018). Value-based purchasing models, including accountable care organizations (ACO) and alternative payment models (APM), have the potential to encourage providers to use the lowest-cost care approach that achieves high-quality outcomes (Blumenthal and Jena, 2013), but without relevant performance measures, the pressure to decrease costs could overwhelm the payment equation and adversely impact care quality (Ryan and Rogers, 2018; Sanders et al., 2018).

Although demand is growing for performance measures, measure developers face barriers and challenges. One barrier to creating evidence-based performance measures is the emerging (but not mature) evidence base linking specific serious illness care models to desired patient outcomes (Henry, Scholle and French, 2018). Studies of community-based serious illness care have addressed heterogeneous care models and patient populations (Davis et al., 2015), which limit their value in developing evidence-based guidelines or performance measures. Although studies show promising benefits of serious illness care (Colligan et al., 2017; Lustbader et al., 2017), the evidence to support measures based on specific processes or models of care is inadequate (Henry, Scholle and French., 2018). When performance measures prematurely rely on emerging models, they have the potential to anchor the field in a less-than-ideal model and hinder innovation.

Another barrier is the dearth of high-quality studies that establish evidence-based guidelines for treating people with serious illness, most of whom have multiple chronic conditions (Boyd et al., 2005; Reuben and Tinetti, 2012; Tanenbaum, 2012). Clinical trials designed to identify the most-effective treatments for discrete conditions typically exclude these people (Crome et al., 2011; Fortin et al., 2006). Consequently, measures based on evidence for treating a single disease, when applied to people with serious illness and multiple chronic conditions, may cause harm (Boyd et al., 2005; Reuben and Tinetti, 2012; Tinetti, Fried and Boyd, 2012).

Many evidence-based single-condition measures are poorly suited to measuring the quality of care for people with serious illness (Tanenbaum, 2016), and even those that are relevant might be inadequate for measuring person-centered serious illness care. Evidence-based measures promote care standardization based on presumed outcome preference. Diabetes measures of care presume that people with diabetes want to avoid blindness, neuropathy and kidney failure. Measures of care for people with myocardial infarction (MI) presume that an otherwise healthy person hospitalized following MI is willing to take medication that decreases the risk of another MI. In serious illness care, however, where almost every care decision brings trade-offs between treatment burden and outcomes, a performance measurement system cannot presume the desired outcome. Consequently, person-centered care demands measures that link care to the person's goals.

C. Person-Driven Measurement

People's goals, preferences and values should drive their serious illness care (AHRQ, 2015; IOM, 2001; IOM, 2015; Sanders et al., 2018). Since the Institute of Medicine (IOM) published the report *Crossing the Quality Chasm: A new health system for the 21st century*, experts have echoed its call for a move to person-centered care "that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions" (Hurtado, Swift and Corrigan, 2001). The same report called for measures to compare the quality of care across providers and health care organizations.

Increasingly, experts agree that "performance measurement should center on [patient and family] goals and preferences" (Giovannetti et al., 2013; Pizzo, Walker and Bomba, 2014; Reuben and Tinetti, 2012; Sanders et al., 2018). But no measures used in major reporting programs are designed to improve goal concordant care – alignment between goals and care plans, care delivered and care outcomes (Sanders et al., 2018). We discuss person-driven measure development in Section VI D.

In the case study, Mary wants care and support to stay in her home, but the measures evaluating the quality of her care focus on cancer screening, HbA1C level and compliance with taking prescribed blood pressure medications and statins. These interventions add to Mary's care burden and increase health care costs, even though the links between each measured process and her goals, as well as her health and quality of life, are unclear.

Mary's experience illustrates how people's priorities for serious illness care are anything but standard. One person may want an intervention with a significant risk of mortality to avoid a slow and severe functional decline, while another would choose care that supports comfort as a condition advances. One person wants aggressive pain management, another prioritizes being alert.

High-quality conversations and goal-setting processes are necessary precursor to person-centered care and person-driven measures. People need information about prognosis and treatment options and treatment outcomes to contextualize the goal-setting process. Person-centered, goal-concordant care is impossible without an informed patient or surrogate decision maker. We discuss the need for standardized approaches to conversations and goal setting in Section VI D.

Although person-driven measures are needed, their development will not be easy. The infinite variety of individual goals, preferences and values poses a challenge to development of person-driven measures to evaluate goal-concordant care. Equally challenging is the shifting nature of goals and preferences, which can change over time as illness progresses. Despite these challenges, we have concluded that we must work toward patient-driven measures.

Person-centered, goal-concordant care is impossible without an informed patient or proxy decision maker.

IV. Serious Illness Care Measurement Landscape

At the outset of the project, we conducted an environmental scan that included key informant interviews, a targeted literature review (measure recommendations, serious illness care measures, reviews of evidence for community-based palliative care) and site visits with 14 organizations providing serious illness care (Henry et al. 2018).

Through the environmental scan, we explored serious illness care definitions, organization, structures, recommended measures and measures in use. We also considered necessary components of goal-based care.

A. Population

Serious illness care programs and researchers use different criteria to define who should receive serious illness care. Kelley and Bollens-Lund (2018) developed a conceptual definition for serious illness: “A health condition that carries a high risk of mortality and either negatively impacts a patient’s daily function or quality of life or excessively strains the caregiver.” But a conceptual definition must be translated into an operational definition, ideally through a value set that defines claims a population using claims, diagnosis codes, or treatment codes. Kelley and Bollens-Lund approaches to using Medicare claims data and conclude that standard administrative data are inadequate to identify a patient population that aligns with the conceptual definition.

While policy discussions tend to focus on people in the several years of life, in practice, most sites we visited focus primarily on people in the last year of life (Henry, Scholle and French, 2018). We observed programs using the following eligibility criteria for program entry: life expectancy; the “surprise question” (“would you be surprised if this person were to die within one year?”); diagnosis with specific conditions or multiple chronic conditions; home-bound status; and utilization of emergency departments and in-patient hospital stays. Program staff explained that they use these criteria to limit the population because demand outpaces resources and they want to prioritize serious illness care for those with the greatest need.

B. Clinical Practice Guidelines

The National Consensus Project on Quality Palliative Care (“NCP”), an initiative of the National Coalition for Hospice and Palliative Care (NCHPC), developed consensus guidelines for palliative care across eight domains, with a focus on hospice and in-patient palliative care programs (NCP, 2013). While the majority of guidelines are relevant to community-based serious illness care (e.g. medical, psycho-social and spiritual care), they do not address considerations to community-based serious illness care, such as safety for patients receiving care in the home from unregulated organizations (e.g. physician practices) and social service needs (e.g. transportation, food and housing). The NCHPC is leading an effort to update the guidelines to apply to community-based serious illness care. One goal of the drafting committee is evidence-based guidelines for inclusion in the Agency for Healthcare Research and Quality (AHRQ) National Guideline Clearinghouse™ (NCHPC, 2017).

C. Current Measures

The National Quality Forum (NQF) maintains a portfolio of 36 hospice and palliative care measures; more than one third address physical symptoms or treatment (NQF, 2016). Measures cluster in pain and dyspnea assessment and management, advance care planning and end-of-life resource utilization (Table 1). The American Academy of Hospice and Palliative Medicine (AAHPM) recommended 10 fully developed, valid, clinically-relevant, cross-cutting indicators to be used for internal benchmarking, comparison across programs and quality improvement (Dy et al., 2015) (Table 2). Most AAHPM measures focus on hospice or on in-patient specialty palliative care and do not address social needs, the quality of serious illness conversations and goal setting or alignment between goals, care provided and care outcomes.

Table 1. NQF Palliative and Hospice Portfolio

NQF Care Domains	Subjects
Physical (14/36)	Pain (10/14), dyspnea, managing side effects of pain medication, external beam radiotherapy
Psychological and psychiatric (1/36)	Health-related quality of life in chronic obstructive pulmonary disease (COPD) patients
Cultural (1/36)	Cross-cultural communication
Spiritual, religious, existential (1/36)	Discussion of spiritual/religious concerns
Ethical and legal (3/36)	Advance care plan
Care at the end of life	Family evaluation of hospice, receipt of chemotherapy or ICU use at the end of life, deactivated implanted cardiac defibrillator, patients not admitted to hospice or admitted for fewer than three days
Social	*No measures*

Table 2. AAHPM Measuring What Matters

Indicator
Comprehensive assessment
Screening for physical symptoms
Pain treatment
Dyspnea screening and management
Discussion of emotional and psychological needs
Discussion of spiritual/religious concerns
Documentation of surrogate
Treatment preferences
Care consistency with documented care preferences
Patient/family care quality global assessment

Payers dictate reporting requirements for serious illness care. With the exception of the hospice benefit, the Medicare Care Choices Model (MCCM) and capitated payments made by health plans or ACOs for wraparound serious illness care, we found no payment mechanism specifically designed for serious illness care. For Medicare beneficiaries, serious illness care programs may use one or more of the following payment mechanisms to cover the cost of nonhospice, community-based serious illness care:

- Medicare clinician and group (MD, NP, PA) payments for conducting medical evaluation and management (an approach used by some hospices and home health agencies providing serious illness care outside those Medicare benefits).
- Medicare CPT[1] codes for advance care planning, chronic care management services and annual wellness visits.
- Medicare home health benefit (limited to people with a need for skilled care, not for ongoing unskilled care such as assistance with bathing or food preparation).
- Health plan, health system or ACO funding (funding from capitated payments or overhead).

For clinician and group payments, Medicare incentives encourage providers to report self-selected quality measures through the Physician Quality Reporting System, but CMS does not require that these measures be tailored to the population served. Medicare Home Health Compare measures, such as those that evaluate improvement in functional status, are relevant to people with serious illness (CMS, 2018), but they apply to only a small subset because the benefit requires a need for skilled care and eligibility for the home health benefit is time limited. Hospice measures are also relevant to people with serious illness, but they apply only to the small subset who elect the hospice benefit, usually in the last weeks of life.

Home health, hospice and ACOs *must,* and clinicians and groups *may,* report patient experience using CAHPS® surveys. Survey items address communication, timely appointments, how providers respond to patient questions and shared decision making. Hospice CAHPS is the only experience-of-care survey that addresses care at the end of life. A family member receives the survey after the person's death.

In summary, most community-based serious illness care delivered outside hospice or home health benefits is not subject to performance measurement designed to address the quality of care.

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[1] Current Procedural Terminology © 2018 American Medical Association. All rights reserved.

V. Stakeholder Engagement

Measure development will require extensive engagement from patients and caregivers, and from experts in palliative care and health care delivery and payment. Patients and caregivers who support measure development will help to create person-driven, goal-concordant measures.

A. Patients and Caregivers

As discussed in Section III B, a person's values and preferences should drive care (Reuben and Tinetti, 2012) and measurement. Increasingly, organizations such as the Centers for Medicaid & Medicare Services (CMS, 2017), the NQF (NQF, 2017) and PCORI (Acaster et al., 2012; Nass et al., 2012) emphasize the need to involve patients, caregivers and families in measure development. For example, in the *Blueprint for the CMS Measures Management System*, CMS suggests that patients and families be involved in measure development through broad stakeholder panels, patient-and-family-only panels and focus groups to develop meaningful outcome measures (CMS, 2017). Community-based participatory research (CBPR) goes a step further: It "equitably involves … community members, organizational representatives, and researchers in all aspects of the research process" (Israel et al., 1998).

We are using CBPR techniques in this project by engaging more than 71 people with serious illness and their caregivers at multiple levels. Two people living with serious illness have been contracted as members of the project team. Two more people with serious illness and one caregiver to a family member with serious illness serve on the project stakeholder panel. Each of the 11 learning collaborative sites will convene a person-and-family advisory board of 6 or more people with serious illness and caregivers to provide feedback on program's quality improvement projects and related efforts.

B. Stakeholders

To guide this project, we convened a multidisciplinary stakeholder panel composed of experts representing diverse disciplines, health care settings and medical specialties, as well as payers, health plans, health systems, patients and families. The panel provides feedback on project design, direction and priorities, and on measure concepts, specifications and testing approaches and results. To obtain focused feedback from palliative care experts, we also met with other Gordon and Betty Moore Foundation serious illness accountability grantees who are addressing patient experience and clinical measures, serious illness care system implementation, updates and revisions to NCP guidelines, dissemination of community-based serious illness care and the use of registries to improve serious illness care quality. This additional expert feedback helps us coordinate efforts and build synergies among related endeavors.

Learning collaboratives are an effective mechanism for engaging organizations to address complex problems that need multiple information sources (Rockville 2012). NCQA has used learning collaboratives in measure development efforts when an evidence base is lacking and when a practice area is developing. The serious illness learning collaborative comprises 11 sites in 9 states: Alabama, California, Illinois, New Jersey, New York, North Carolina, Pennsylvania (2), Utah (2) and Virginia. Organizational homes for the programs include hospice (1), the Veterans Administration Medical Center (1), an academic medical center (1), a stand-alone hospice agency (1), medical groups (2) and health systems (5). Ten are housed within larger nonprofit organizations; 1 is a for-profit organization that contracts with health plans and ACOs. Two provide specialty care (oncology and pulmonology); 3 provide primary care.

To support process measure development and testing, learning collaborative sites provided feedback on priority areas for quality and gaps in processes, and will provide chart-review data relevant to assessment, care planning and goal documentation measures. Section VI D describes site roles in developing person-driven measures.

Patients and caregivers who support measure development will help to create person-driven, goal-concordant measures.

VI. Serious Illness Care Measure Development

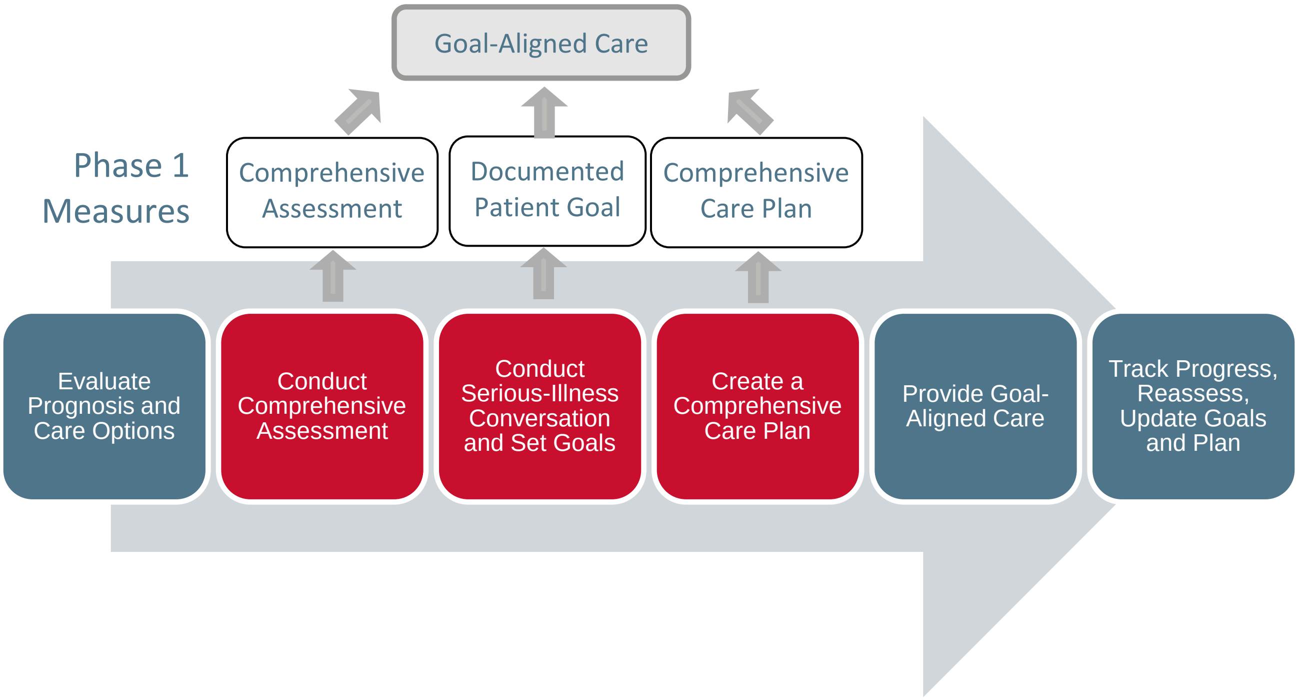
NCQA is developing a suite of serious illness care measures suitable for inclusion in accountability programs. NCQA has focused on selecting measures that address a quality gap and support processes for moving to person-driven measures for evaluating goal-concordant care.

A. Logic Model

In the absence of evidence that link specified processes to desired outcomes, a logic model shows how a measure will promote desired outcomes. To develop a serious illness care measurement logic model, we identified the processes needed to deliver care that aligns with a person's goals, then linked those processes to measures to be tested. We identified the care processes needed for goal-based care from informant interviews, the literature, clinical practice guidelines, site visits and expert input. The logic model linking care process and measures to goal-aligned care is shown in Figure 1.

We considered each care process as a potential measure target. The first phase of this project determined whether a measure concept linked to the process would build toward goal-based measures, whether the process was sufficiently important to measure and the feasibility of developing and testing measures. We concluded that three measure concepts were feasible for immediate development: Comprehensive Assessment, Documentation of Patient Goals and Comprehensive Care Plan (Figure 1, in red). The remaining processes, as well as serious illness conversations and goal-setting, are relevant to measures that will be developed in the second phase of the project.

Figure 1: Logic Model for Phase 1 Serious Illness Care Measures



B. Process Measures

Comprehensive Assessment

We will develop and test a comprehensive assessment measure that evaluates the percentage of patients who receive specific elements of a comprehensive assessment.

To understand how illness affects a patient and before setting patient goals, the provider conducts a comprehensive assessment addressing medical, physical, psychosocial, functional, spiritual and support needs (NCP, 2013). The need for a comprehensive assessment was emphasized by serious illness program staff during site visits, informants and the NCP guidelines. Reflecting the importance of assessment in serious illness care, all but one current CMS hospice measure addresses screening or assessment.

We will consider these elements for inclusion in a comprehensive assessment measure:

- Symptoms.
- Physical health.
- Behavioral health.
- Cognitive function.
- Physical function.
- Spiritual needs.
- Activities/independent activities of daily living.
- Caregiver strain and capabilities.

Elements are based on existing NCQA measures and NCP guidelines (NCP, 2013)

Challenges to comprehensive assessments include observed heterogeneity in assessment approaches by serious illness care programs. Some elements, such as caregiver assessment, may be conducted so infrequently or informally that it would not be feasible to include them in a measure.

Goal Documentation

NCQA will also develop and test a measure assessing whether patient goals are documented in the health record. We found widespread support for this in the literature, among informants and among serious illness care programs (Pizzo, Walsh and Bomba, 2014; Sanders et al., 2018). The logical connection between documenting goals and providing person-driven care supports face validity to the process measure, but informants raised concerns about a goal-documentation measure.

Informants cautioned that documenting goals without a mechanism for updating them can lead to care that aligns with outdated goals. People with serious illness fluctuate between periods of stability and instability as a disease progresses. Changes in health and prognosis bring changes in goals, values and preferences. For example, a person who does not want a feeding tube for swallowing problems as a life sustaining intervention when death is near may choose to have one when swallowing is the major problem getting in the way of living life.

Informants suggested that provider interest in “good scores” on goal-based measures may create conflict or lead providers to encourage patients to accept easy-to meet goals that do not align with what matters most to them. This could undermine the foundation of a goal-based measurement system.

In a future phase, we will consider whether measures of the quality of the serious illness conversation are feasible and desirable, such as patient engagement in shared decision-making measures described below.

Comprehensive Care Plan

We will develop and test a comprehensive care plan measure.

A comprehensive care plan reflects patient goals and addresses a broad range of care domains, not only medical treatment. A care plan that is shared with providers facilitates coordinated care for co-managed patients. As with comprehensive assessment and documented goals, a comprehensive care plan has support in NCP guidelines and among stakeholders and serious illness care programs. But during site visits, we saw heterogeneity in care plan development (who was involved, what was included), documentation (layperson-friendly format vs. physician notes) and sharing (how and with whom).

A comprehensive care plan is both necessary and beneficial for delivering and measuring goal-based care. It serves as an action plan for achieving goals and a yardstick for tracking progress. A shared care plan is also necessary for care coordination among providers who co-manage people with serious illness.

We will test two care plan components: the plan for treatment, services and supports, and the plan for life-sustaining treatment. To identify specific elements of each measure for testing, we started with those in current measures addressing similar patient populations, such as older adults living in the community who need assistance with one or more activities of daily living, and people with cancer. We also considered elements from NCP guidelines.

C. Population

After defining the concept being addressed in the measure, the next step is to define the denominator (who is included in the measure). Measures for health plans or ACOs, where the population includes patients without serious illness, specify criteria to determine which patients to include in measurement. Measures for programs that serve only patients with serious illness need not define serious illness.

For this project, we adopted the Kelley and Bollens-Lund (2018) definition of serious illness as a working definition for measure development: “A health condition that carries a high risk of mortality and either negatively impacts a patient’s daily function or quality of life or excessively strains the caregiver.” As they observed, translating this definition into easily accessible administrative data (e.g. claims, demographics, payer) is a complex and challenging process.

The first phase of this project is addressing program-level measures. For these measures, the denominator is patients enrolled in the program for a specific time (to be determined during measure testing). We will evaluate the denominator for plans and ACOs during the next project phase.

D. Serious Illness Conversation and Goal Setting

To capture data needed to develop goal-based measures, we must start with clinicians conducting and documenting standardized serious illness conversations. We will train clinicians from learning collaborative sites in a structured approach to serious illness care conversations and goal setting. Serious illness care conversation training will be provided by the United States Department of Veterans Affairs (VA) National Center for Ethics in Health Care as part of its Life-Sustaining Treatment Decisions Initiative (VA, 2018), which contains elements of the Vital Talk (2018) communication training and the Ariadne Labs Serious Illness Conversation model (Aridane, 2018).

Goal-setting training will be based on a goal attainment scaling model that was tailored by Jennings and Reuben (Jennings et al. 2017) for use on people with dementia and their caregivers, and piloted recently in seven sites that provide care to older adults with functional limitations (Giovannetti, 2017). In goal attainment scaling, the provider and the person receiving care identify what is most important to the person, then together translate that into a specific, actionable goal. They scale the goal, defining what constitutes meeting, doing better than or doing worse than the goal. The specificity of this approach makes it a promising target for measurement.

After training, clinicians at each site will use the techniques they learned to set goals with at least 20 patients. Sites will report qualitative data about the experience of goal setting. They will also report patient-level data from assessment, conversation and goal-setting, care plan and monitoring progress toward goals. At the end of the pilot, NCQA will conduct site visits, including focus groups and individual interviews with patients, caregivers and providers about the goal-setting processes and experiences.

We will use data captured during the pilot to characterize the dynamics of the intervention to evaluate the efficacy of serious illness conversations and goal setting. This information will inform the design of a demonstration project that will test goal-based outcome measures.

E. Person-Driven Measures

Person-Driven Measures of Goal-Concordant Care

In the next phase of this project, we will develop and test person-driven measures for serious illness care. The remaining care processes in the Logic Model (Figure 1) will be relevant to this effort.

Measure concepts addressing goal-concordant care could take several forms:

- Goal concordance with the ***care plan.***
- Goal concordance with ***care delivered.***
- Goal concordance with ***care outcomes.***
- Goal attainment (a goal has measurable targets; the target is met or there is progress toward the meeting it).
- Processes associated with improved alignment between goals and outcomes or attainment.

Across informant interviews and in the literature (Cohen 2017; IOM, 2015; Teno et al., 2018), there were calls for measures of concordance between goals and care plans, care received and care outcomes. There was feedback that measures must anticipate the well-documented reality that goals change over time as illness progresses, and so must address current goals, not ones that are stale or defunct. We will consider concordance measures, including whether it is feasible to assess concordance between goals and care plans or care received, given the range of goals and possible modalities to achieve them. We will also consider the feasibility of ensuring that goals that are the basis of measurement are current and informed and evaluating whether progress toward goals is tracked.

Serious Illness Conversation and Goal-Setting

NCQA will also consider how to address the quality of serious illness conversations and goal-setting in the next project phase. One measure concept under consideration would evaluate patients' engagement in serious illness and goal-setting conversations. A modified CAHPS survey for serious illness care has the potential to address communication, such as the CAHPS Clinician and Group Communication Composite shown in Table 3, and new items addressing shared decision making in serious illness care could be used to assess patient engagement.

Table 3. CAHPS Clinician and Group Survey

Communication Composite
In the last 6 months, how often did this provider explain things in a way that was easy to understand?
In the last 6 months, how often did this provider listen carefully to you?
In the last 6 months, how often did this provider seem to know the important information about your medical history?
In the last 6 months, how often did this provider show respect for what you had to say?

(AHRQ, 2018).

A patient engagement or experience measure has the potential to mitigate concerns about poor-quality conversations and goal setting becoming the basis for person-driven outcome measures of goal-concordant care.

Person-centered, goal-directed care is impossible without an informed patient or surrogate decision maker.

VII. Conclusion

NCQA will explore options for goal-based measures by piloting and measuring processes of goal-based care in 11 learning collaborative sites. This pilot is building toward expanding to test the scientific soundness of goal-based measures for serious illness care (the next pilot training). Person-driven measurement is the logical target for serious illness-care measures, but with accountability comes challenges and risks.

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About NCQA

The National Committee for Quality Assurance (NCQA) is a private, nonprofit organization dedicated to improving health care quality. With support from the Gordon and Betty Moore Foundation, NCQA is exploring ways to measure and evaluate the quality of care for people living with serious illness. NCQA convened a national stakeholder advisory group and learning collaborative to guide development of standards and measures. NCQA also hired two patient partners to ensure that the patient's perspective guides the project.

NCQA is committed to ensuring that health care evaluation programs address the needs of people with serious illness, and works to develop quality measures that reflect the preferences and goals of the people served.