

# Quality Measurement and Accountability for Community- Based Serious Illness Care

## Synthesis Report of Convening Findings and Conclusions

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## Executive Summary

The movement of U.S. health care to value-based payment presents a critical opportunity to improve accountability for the quality of serious illness care, while constraining the growth of spending. The changing incentives in the health care system are driving innovation in the delivery of serious illness care in traditional Medicare, Medicare Advantage and commercial plans. Implementation of an accountability system for serious illness care is vital for ensuring that cost containment efforts do not result in undertreatment or worse quality of care for the seriously ill.

In May 2017, the Gordon and Betty Moore Foundation convened 45 serious illness care experts and stakeholders in Banff, Alberta, Canada, to identify a path forward for building an accountability system for high-quality, community-based serious illness care programs. Participants included practicing palliative care physicians, patient advocates, academic researchers, quality and policy experts, government leaders and health plan representatives. The group reached consensus on a definition of the serious illness population, the necessary components of an accountability system and guiding principles for quality measurement. In addition, convening participants identified a starter set of quality measures, future pathways for implementation of an accountability system and needed future research.

### Foundations of an Accountability System

Convening participants developed a consensus definition of serious illness as “a condition that carries a high risk of mortality and either negatively impacts a person’s daily function or excessively strains their caregivers.” In addition, there was consensus that an accountability system must include three fundamental components, including value-based payment, publicly-reported performance information, and an accreditation and certification program. Each of these three components should utilize appropriate quality measures and development of the components should be synergistic and coordinated.

### Guiding Principles and Measure Starter Set

The group also developed guiding principles for measurement. The principles focus on promoting patient-centered care that reflects patient preference and experience of care; increasing care coordination across the care continuum; minimizing burden of patients, families and providers; and avoiding unintended consequences. Based on the guiding principles and current gaps in measures, the convening attendees agreed on a starter set of measures for an accountability system. The measure set addresses well-being of patients and caregivers, patient and family experience of care, process measures of clinical care and advance care planning, patient safety, utilization and costs, and access to care.

### Appropriate Measure Denominators

A breakout group of participants considered how to best operationalize the consensus definition of serious illness. They recommended that a measure denominator for the seriously ill be based on a combination of diagnosis and utilization, including use of home health, skilled nursing and/or durable medical equipment. At the same time, the group recognized that some measures will only be applicable to a specific disease or subgroup and recommended that narrower denominators be developed for such measures.

## Future Scenarios

Community-based programs for persons with serious illness in Medicare Advantage have experienced striking growth and some large accountable care organizations (ACOs) are also using these programs to improve care of the seriously ill. Convening participants focused on two potential future scenarios for wider adoption of an accountability system for community-based serious illness care: (1) an alternative payment model for persons with serious illness and (2) a co-creation patient registry.

**(1) Adoption of an alternative payment model.** In February 2017, the Coalition to Transform Advanced Care (C-TAC) submitted a model called the Advanced Care Model for consideration by the Physician-Focused Payment Model Technical Advisory Committee at the Department of Health and Human Services. The Advanced Care Model is a team-based model that includes concurrent palliative care and curative treatment. In August 2017, the American Academy of Hospice and Palliative Medicine also submitted an alternative payment model proposal to the advisory committee. The major differences between the models are that the American Academy of Hospice and Palliative Medicine model includes a broader patient population with a potentially longer life expectancy and allows participation by providers unable to take significant downside risk.

**(2) Development of a co-creation patient registry.** A co-creation registry forms a partnership between the patient and family and the care team for eliciting patient preferences for care to inform an individual care pathway for the patient. Patients enter information about their symptoms and quality of life through a web portal or on registration during an office visit. This data is then “fed forward,” or made available, to clinicians in real time along with other clinical data to support decision-making at the point of care. The co-creation registry idea has emerged as part of an American Academy of Hospice and Palliative Medicine-lead effort to develop a single National Palliative Care Registry in place of the three existing clinical registries. An integrated registry would serve as the backbone for a co-creation learning system.

## Next Steps and Research Needed

Convening participants developed a series of critical next steps (which are outlined below) and identified research needed to move toward implementation of an accountability system for community-based serious illness care. These represent first steps and should be undertaken with urgency to build momentum toward wide adoption of an accountability system.

There are technical measurement issues, such as reliability and validity of proxy responses and measure responsiveness to intervention, that should be addressed with further research. Approaches to measuring “goal concordant” care and value need to be developed, and a Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey should be developed that can be administered to patients and families after enrolling in community-based programs to assess experience of care. Moreover, public reporting needs to be improved so that measures are easily understood and actionable.

Further study is needed to fully assess the sensitivity, specificity and positive predictive value of different measure denominators, and how they can be enhanced by using functional and cognitive status information from post-acute care patient assessments. More work is also needed on the calculation of denominators using data from electronic health records (EHRs).

Finally, additional outreach and stakeholder engagement will be needed to align efforts on payment models, the co-creation registry, and other initiatives, to successfully implement an accountability system that is centered on the patient and family and meets the needs of all stakeholders.

## Background and Overview

Industrialized nations are faced with the challenge of a growing population of frail, older persons. In the U.S., about two-thirds of Medicare beneficiaries have multiple chronic conditions and one-third have functional limitations.<sup>1,2</sup> At the same time, there are concerns about the growing proportion of U.S. gross domestic product devoted to health care, which is projected to hit 20 percent by 2025.<sup>3</sup> In part, the volume-based incentives in the health care system that have resulted in this level of spending have also resulted in concerns over the quality of care that is provided to patients. Providing value-based care—rather than volume-based—to people with serious illness, while constraining the growth of health care costs, is a critical policy challenge that presents significant opportunities for innovation in care delivery.

In May 2017, the Gordon and Betty Moore Foundation convened 45 serious illness care experts and stakeholders in Banff, Alberta, Canada, to identify a path forward for building an accountability system for high-quality, community-based serious illness care programs. The goal of the convening was to create guiding principles, begin identifying appropriate quality measures, specify an approach to defining measure denominators that best capture the serious illness population, and identify research needs and next steps.

This paper presents a synthesis of the main points of consensus on these stated goals, including:

- 1) A **definition of serious illness**;
- 2) The **components of an accountability system** for serious illness care, including **value-based payment, public reporting, and accreditation and certification**;
- 3) A set of **guiding principles** for an accountability system for community-based programs for persons with serious illness;
- 4) A **starter set of measures** as a foundation for the accountability system components;
- 5) Initial recommendations for **identifying the measure denominator** of individuals with serious illness who would benefit from enhanced services;
- 6) Recommended **next steps and research needed** to implement an accountability system; and
- 7) Two potential future scenarios—a **co-creation learning system and an alternative payment model**—that will further catalyze implementation of a wide-scale accountability system and measures for community-based serious illness care.

## Movement to Value-Based Care

In the U.S. health care system, payment has traditionally been based on a fee-for-service structure that rewards volume rather than value of care. Fee-for-service incentivizes providers to deliver more clinical services, which increases cost burden for patients and overall system spending, and potentially harms patients. For serious illness care, these incentives encourage the use of expensive acute care services and persistent, intensive disease treatment without full discussion of patients' likelihood of benefit or

personal goals. Despite the overutilization of services, half of the caregivers of patients hospitalized due to serious illness have reported less than optimal care.<sup>4</sup> Implementation of the Affordable Care Act has accelerated the movement away from fee-for-service to value-based care. In a value-based system, payment is based on the quality of care provided. In some cases, payment is also based on cost containment. Holding providers accountable for quality and cost provides opportunities to transform serious illness care to be more patient-centered and focused on care planning, coordination and team-based care.

The National Academy of Medicine has noted that by helping to clarify and honor patient preferences, quality could potentially be enhanced by avoiding costly care that is undesired by a patient and family and unlikely to benefit or may even harm the patient.<sup>5</sup> Patients generally prefer to receive home- and community-based palliative care when feasible, which studies show decreases costs.<sup>6</sup> Additionally, people with serious illness have multiple chronic conditions and are receiving their care from multiple physicians in various settings of care, resulting in care fragmentation and an increased risk of medical errors. Enhanced care coordination can help to reduce this fragmentation while improving the experience of care and reducing avoidable complications.<sup>7</sup> University of Pennsylvania Professor Ezekiel J. Emanuel estimates that enhanced care coordination of chronic illness could reduce health care spending by \$40 billion per year.<sup>8</sup>

*“An accountability system is needed to ensure that cost containment pressures do not lead to undertreatment or worse quality of care for vulnerable, seriously ill patients.”*

Innovation in health care delivery, payment and benefits is critical to improving the value of care for seriously ill patients. The changing incentives in the health care system have led to innovation in the delivery of serious illness care, in both the private and public sectors. For example, Aspire Health is a privately held company that contracts with Medicare Advantage and other managed care plans to provide home-based palliative care to high-need, high-cost patients in 23

states. At the same time, the Medicare Medical Care Choice Model demonstration program allows over 140 participating hospices to provide services to hospice-eligible Medicare beneficiaries without forgoing disease-directed treatment.<sup>9</sup>

As the U.S. health care system moves from volume-based incentives to value-based incentives, an accountability system is needed to ensure that cost containment pressures do not lead to undertreatment or worse quality of care for vulnerable, seriously ill patients. Patients and families living with serious illness prioritize different care processes and outcomes than healthier populations, and thus require a unique approach for defining quality care. Use of existing and new quality measures should guide innovation while also monitoring for unintended consequences.

### [The Need to Focus on Quality: Learning from the Medicare Hospice Benefit Experience](#)

The implementation experience of the Medicare Hospice Benefit provides an important lesson on the need for quality measurement and transparency in serious illness care. Unlike nursing homes and home care agencies, hospices were not subject to Medicare quality reporting requirements until recently. Since implementation of the hospice benefit, there have been unintended consequences in hospice care that went undetected for many years due to this lack of monitoring and oversight of care quality.

The Medicare Hospice Benefit was designed based on the presumption that savings from reduced hospitalizations at the end of life would offset new spending on hospice services. Payment rules were formulated based on the typical disease trajectory of cancer at that time. However, the typical hospice patient today is a person with multiple chronic conditions, such as dementia, congestive heart failure and chronic obstructive pulmonary disorder. Hospices were initially not allowed to discharge stabilized patients and were required to continue providing care without further compensation once the patient had utilized the 210 days covered by Medicare. This resulted in the unintended consequence of hospices focusing on enrolling patients highly likely to die within the 210-day period.

These concerns were a major reason for the change to the current per-diem payment for hospice. However, changes to the per-diem payment structure have also had unintended consequences. For-profit hospice has proliferated, and the focus has shifted to enrolling patients with a predictable—and more profitable—long length of stay, especially nursing home residents.<sup>10,11</sup> These changes have led to significant quality concerns. In addition, studies show that one in seven hospice patients who die during routine hospice care do not receive a professional visit by hospice staff in the last two days of life. Moreover, nearly one in ten hospices appear to not provide any visits by professional staff in the last two days of life.<sup>12</sup>

In this time of rapid growth of community-based programs for persons with serious illness,<sup>13</sup> program implementers need to take steps to ensure the monitoring and accountability of these evolving programs. Public trust is key. The impact of “death panels” mythology on the political discourse about advance directives signifies the importance of an accountability system with actionable quality measures to assure the public that quality of care and patient preferences are not sacrificed for cost savings.

## Defining Serious Illness

### A Proposed Definition

There are multiple related but slightly differing definitions of serious illness. C-TAC defines serious illness as “occurring when one or more conditions become serious enough that general health and function decline, and treatments begin to lose their impact.” The National Academy of Medicine has defined “persons with serious illness as those with complex and pressing care needs due to a particular disease,” including “people who have some years of self-care disability, often at the ends of their lives.”<sup>14</sup>

At the measures convening, Amy Kelley of the Icahn School of Medicine at Mount Sinai, proposed a definition of serious illness that is similar to the C-TAC and National Academy of Medicine definitions, but adds additional nuance. Kelley presented the work of a subgroup of convening participants, who reached consensus on defining serious illness as “a condition that carries a high risk of mortality and either negatively impacts a person’s daily function or excessively strains their caregivers.”

**Proposed 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 their caregivers.

## Epidemiology of Serious Illness

As the definitions show, the serious illness population is diverse, and understanding shared characteristics among the population is difficult. Examples of serious illnesses include cancer, heart failure, chronic obstructive pulmonary disease, kidney failure, liver failure, Alzheimer’s disease, Parkinson’s disease and amyotrophic lateral sclerosis. Individuals with these conditions are among the highest-cost and highest-need patients in the health system, and many individuals are living with more than one of these conditions. It is projected that by 2030, more than nine million Americans age 85 or older will have multiple chronic conditions.<sup>15</sup> As long-term, chronic conditions have become the most common causes of death, people are more likely to have prolonged periods of functional dependency.<sup>16</sup> While the majority of people with serious illness are older adults, a small but significant number of children require care for serious illness. The highest cost pediatric patients have similar rates of chronic conditions and cognitive and functional limitations.<sup>17</sup>

*“Focusing on patients with persistent needs, rather than those at the end of life, has far greater potential to positively impact care quality and costs over the long term.”*

Importantly, most people with serious illness, and the high costs that are associated with serious illness, are not in their last year of life. Among the costliest five percent of patients who account for 50 percent of all U.S. health care spending in a given year, about half recover and have lower costs in subsequent years. Only about 10 percent of these patients are in their last year of life. The remaining 40 percent are patients with multiple chronic conditions, often accompanied with functional and cognitive impairment, that have persistently high costs.<sup>18</sup>

As the number of frail older people with multiple chronic conditions continues to grow, the need for team-based, well-coordinated serious illness care is increasing rapidly. Focusing on patients with persistent needs, rather than those at the end of life, has far greater potential to positively impact care quality and costs over the long term. In addition, some patients with a period of high costs followed by lower costs may still be appropriate patients for serious illness care programs, depending on their overall health status and prognosis.<sup>19</sup> For example, persons with dementia may not need the full Medicare Hospice Benefit given a disease trajectory of relative stability until there is a sudden and unpredictable event, such as pneumonia.

## The Three Components of an Accountability System

As described above, there is a great need for accountability in serious illness care, given the high cost of treatment, low quality of care, and the incongruence between patient preferences and the care that is delivered. Ideally, external accountability and internal performance improvement should be synergistic and built around the same data and measures. Ensuring accountability for serious illness care carries unique challenges, including the broad diversity of diseases, conditions and settings to be assessed, as well as variation in individual patient and family priorities for care.

In establishing an accountability system, the first step is determining what constitutes high-quality care. What constitutes quality of care should be driven by clinical guidelines and American Board of Family Medicine evidence-based core competencies for high-quality serious illness care (see Table 1). Quality measures should be built around these core competencies, with the involvement of patients, their caregivers and clinicians, and serve as the basis for accountability.

<b>Table 1. Core Competencies for High-Quality, Community-Based Serious Illness Care Programs</b>
<ul style="list-style-type: none"> <li>• Identification of the target population</li> <li>• Team-based care</li> <li>• Caregiver training</li> <li>• Attention to social determinants of health</li> <li>• Communication training and supports</li> <li>• Goal-based care plans</li> <li>• Symptom management</li> <li>• Medication management</li> <li>• Accessibility (including 24/7 coverage)</li> <li>• Transitional care</li> <li>• Measurement of value for accountability and improvement</li> </ul>

At the convening, there was consensus that there are three fundamental components to an accountability system. These components are shown in Figure 1. The first component is value-based payment, which establishes financial accountability for the delivery of patient-centered care. The second component, publicly-reported performance information, establishes reputational accountability for providers and permits clinicians, patients and their caregivers to make more informed decisions about care. The third component, an accreditation and certification program, helps ensure that a certain standard of quality is being met across programs. Each of these three components should utilize measures to assess the core competencies, and their development should be synergistic and coordinated.

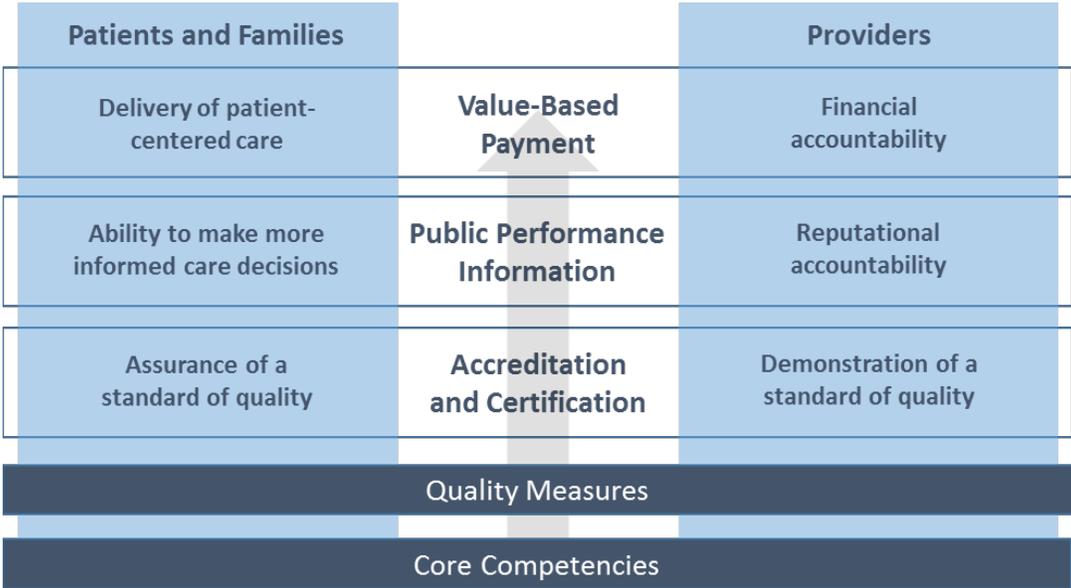


Figure 1. The Three Components of an Accountability System and Their Impact on Patients, Caregivers and Providers

## Value-Based Payment Programs

Adjustments to provider payment are essential to establishing accountability. Without different incentives, providers are less likely to change their behavior, develop new approaches to care, deliver higher quality services and decrease costs of care. In a broad accountability system, there may be multiple payment structures with a variety of risk models.

To provide the right incentives, any value-based payment structure must bridge from fee-for-service to a value-based structure, be as simple and streamlined as possible with frequent incentives, provide population-level payments that support patient-centered care, align with optimal delivery structures and processes (as defined in an accreditation model) and utilize appropriate quality measures for performance assessment. New payment models ideally will include sufficient down-side risk so that providers may qualify for the advanced alternative payment models track in the Centers for Medicare & Medicaid Services' (CMS) Quality Payment Program, which provides a five percent payment bonus. For any new value-based payment structure, monitoring and evaluation are essential for identifying and mitigating unintended consequences.

## Current Status and Next Steps

A previous analysis by Discern Health found more than 30 existing payment models that have established accountability for providers treating people with serious illness.<sup>20</sup> While more than half of these models are sponsored by CMS, private entities such as health systems and private insurers are also implementing models.<sup>21</sup> Some of these models include a much broader population (e.g., ACOs), but have nonetheless altered incentives for providing care to the seriously ill.

Importantly, there are ongoing efforts by the American Academy of Hospice and Palliative Medicine and C-TAC to develop new alternative payment models for serious illness care. There are also opportunities to build a new payment model around a registry. These efforts are described in more detail in the Future Scenarios section.

## Publicly Reported Performance Information

Beyond their use in payment and accreditation, quality measures should be publicly reported. This type of information can be used not only by consumers and their families to make more informed decisions about where to seek care, but also by their providers about where to refer their patients. Not all quality measures will be as appropriate and informative for public reporting as others. Publicly reported measures should focus on outcomes that are meaningful to patients, including patient and caregiver experience, patient safety and concordance with patient goals for care.

## Current Status and Next Steps

The Centers for Medicare & Medicaid Services has implemented public reporting programs for hospitals, nursing homes, home health agencies and other providers, and there are other smaller reporting programs sponsored by other entities, including private payers and state governments. However, there is very little publicly available information on the performance of serious illness care programs.

For the serious illness population, special care should be taken in conceptualizing a public reporting structure. These patients—and their caregivers, in many cases—are a vulnerable population likely to have limitations in function and cognition that may impede their ability to access and understand

quality information. Additional research is needed on how to make publicly reported information more easily understandable and actionable by people with serious illness and their caregivers.

### Accreditation and Certification Program

The third component of an accountability system is an accreditation and certification program. A national accreditation program for serious illness care would provide patients and their caregivers with assurance that their providers are accountable for meeting a baseline standard of quality. The standards used in an accreditation and certification program should align closely with the core competencies shown in Table 1.

Achieving accreditation would allow providers to demonstrate the quality of the care they provide and could be a criterion for participation in a value-based payment model. Additionally, accreditation status could be used by health plans for network development and contracting, provider credentialing and performance assessment.

### Current Status and Next Steps

In 2011, The Joint Commission implemented certification programs for hospital-based palliative care, and in 2017 implemented certification for community-based palliative care provided in the home by home health agencies and hospices. These certification programs are a major step towards increased accountability for palliative care programs.

In addition, the National Committee for Quality Assurance has begun initial efforts to define an accreditation and certification program for community-based serious illness care, including outlining principles, defining key program elements and developing standards. In contrast to The Joint Commission programs, the National Committee for Quality Assurance has determined that ACOs and/or health systems would be the ideal unit of accountability, given the need to involve multiple providers and coordinate care across systems.

The National Committee for Quality Assurance has stated that standards should be evidence- or consensus-based, flexible and supportive of high-quality care. As part of its development process, it has been conducting site visits with serious illness programs to better understand these programs. One of their key initial findings is that there is significant heterogeneity among serious illness care programs. For this reason, an accreditation and certification program must strike the right balance between highly specific standards to ensure fidelity and flexibility for programs to provide the set of services that best meets the needs of their patients. The National Committee for Quality Assurance will continue its process to define the standards, measures and value proposition for this program.

### Implementing an Accountability System

As noted above, quality measurement is the foundation of all three accountability system components. As additional steps are taken to develop and implement value-based payment, public reporting, and accreditation and certification, it is essential to identify and develop the right set of quality measures. The following sections include guiding principles for measurement, a proposed starter set of measures and future research to refine the measurement set. Among the issues the Banff group considered was the proper definition of a denominator for the serious illness population and ways to define value in serious illness.

## Data Needs

Robust data from multiple sources are needed to implement a measurement approach for these components of an accountability system. Necessary data types include clinical, pharmacy, patient preference, patient and caregiver experience, functional and cognitive status, patient safety, and cost and utilization. Key data sources include post-acute care data assessments, which are being aligned as part of the Improving Medicare Post-Acute Care Transformation Act (IMPACT Act), electronic health records, personal health records, clinical data registries, patient surveys and reports and claims databases. Each of these data sources has its own set of advantages and limitations in providing necessary data. Strategies for addressing specific data challenges are presented throughout the following sections.

## Paths to Implementation

Currently, the largest growth in community-based programs for the seriously ill is occurring in population-based payment systems such as Medicare Advantage plans and ACOs. Efforts to develop accountability for serious illness care in Medicare Advantage that measures quality of care and network adequacy is an important research priority. Further expansion of accountability systems for serious illness could potentially come as part of an alternative payment model.

At the convening, participants focused on implementation of an alternative payment model and development of a co-creation patient registry. Each of these proposed paths would require measure development, improvements in the data infrastructure and implementation of the three components of an accountability system. An alternative payment model may be implemented in the short term, while the co-creation registry is likely to be a long-term effort. These paths are not mutually exclusive, and ideally should complement one another. The final section of this paper outlines how these paths may unfold and the next steps for each.

## Guiding Principles for Measurement

During this time of innovation in the creation of new delivery models (e.g., Aspire Health, Aetna Compassionate Care Program, community-based palliative care programs) and testing of a potential new Medicare benefit (e.g., the Medicare Care Choices Model demonstration that allows hospices to provide palliative care services along with care for potentially extending life), it is important that actionable quality measures guide the further development of these programs. In addition, quality measures are needed to provide transparency and accountability to ensure the public that these programs are focused on improving the quality of life and care of this vulnerable population, not primarily focused on constraining cost.

Participants in the convening were asked to provide their input on a set of guiding principles for the further development and use of measures. In an online survey, they were asked to rank the importance of a draft set of principles. The full set of principles was refined based on the feedback received. The final set of principles is listed in Table 2, and is described in the following sections. It should be noted these are a set of ideals, and it is not expected that a measure would fulfill all these criteria.

<b>Table 2. Guiding Principles for Measurement</b>	
1.	The unit of measurement is the patient and their family or close friends, who often provide the needed care to maintain seriously ill persons in the community.
2.	Measures should be comprehensive, but not too burdensome to patient, family, and professional and lay health care providers.
3.	Measures should focus on the patient and caregiver experience and reinforce shared accountability across providers to address the current fragmentation of the health care system.
4.	Measures should identify aspects of care that are salient to patients and their caregivers throughout their disease trajectory.
5.	Measures need to be actionable and under the control of health care providers.
6.	The patient is the best source of information on their symptoms and quality of life, but many persons with a serious illness, and the majority of those close to death, are unable to report. Measurement strategies are needed to collect information on these patients from proxy sources rather than not examining their quality of care.
7.	Ample consideration should be given to the process of care and the timeframe within the disease trajectory that is measured to avoid the unintended consequence of forcing a process of care that the patient and caregiver do not need or are not ready or willing to undertake.
8.	It is impossible to measure everything. Measures should be selected based on importance to the patient and caregiver, prevalence of the concern, actionability and psychometric properties of the measures.
9.	Avoid measures that have a significant ceiling effect, which occurs when a large portion of results are concentrated at the upper or lower limit of possible responses. With a ceiling effect, it is difficult or impossible to discern differences in performance across providers.
10.	Choose structure and process measures that are clearly linked to outcomes and that matter to the patient and caregiver.
11.	The ultimate measurement set needs to accommodate different delivery models. There should not be a separate measurement set for each delivery model, but instead a set of common measures, where possible.
12.	Careful consideration should be given to using expert opinion and the impact of outliers when establishing thresholds or benchmarks for population-based measures (e.g., rate of referral to hospice or hospice length of stay). They can result in measures that have an unreasonably high (or low) bar for performance, or a threshold or benchmark that is not actually tied to high-quality care.
13.	Measures of structure and process of care should not result in fiscally unreasonable expectations for community-based programs.

### Promoting Patient-Centered Care

Putting the patient at the center of their own care, and having their preferences guide care, is essential for promoting high-quality serious illness care. Measures should focus on the patient's experience, regardless of where he or she falls in their disease trajectory. As caregivers, a patient's family members are also part of the unit of care and their experiences are important to measure as well.

## Care Coordination

Measures can also help to shape the care delivery system around the patient. For instance, establishing shared accountability for a patient's care that includes providers from across the care continuum helps to promote care coordination and team-based approaches to care. Measures that focus on aspects of care that are actionable by the provider will result in the clinician engagement necessary to influence care delivery.

## Minimizing Burden

There are important tensions and tradeoffs that should be acknowledged and considered in decision-making about measures. Measure sets will need to balance the opposing goals of being comprehensive and parsimonious, capturing what is most important to the patient and caregiver while not being overly burdensome. Patients are the best source of that information, but many seriously ill people and many persons near death are unable to report their symptoms. Caregivers can serve as proxies when patients are unable to respond.

## Avoiding Unintended Consequences

It is important to consider the potential for unintended consequences from the choice of measures and how measures are defined and implemented. An unintended consequence to avoid is forcing a process of care that the patient does not want. For example, many dying patients and their caregivers find spirituality an important part of their care. Yet, not all people who are dying want to discuss their religious beliefs with a health care professional or spiritual care provider.<sup>22</sup> A measure focused on spiritual counselling should not result in unintended consequences by forcing the patient to be seen by a spiritual care counselor.

Measures of structure or process should not result in fiscally unreasonable expectations for these programs or care that results in unintended consequences. There is significant variation in the size and focus of palliative care programs and not all programs will have the resources and capacity to operate at the same level. There should be flexibility in how programs can meet service standards, such as the use of telemedicine or working with community entities, including faith leaders. In addition, care should be taken when establishing measure thresholds and benchmarks to appropriately account for expert opinion or outliers.

## Choosing Appropriate Process Measures to Avoid Unintended Consequences

The selection of process measures needs to be based on high-quality evidence that links that process to patient- and caregiver-reported preference and outcomes. In addition, caution is needed when establishing cut points for process measures. Cut points should be based on empirical research and should incorporate the population distribution, expert opinion and—most importantly—associations with patient- or caregiver-reported outcomes. For example, the use of late referrals to hospice for accountability must carefully consider that about one in five hospice patients either previously refused hospice or suffered an acute medical event that resulted in a late hospice referral.

## Proposed Measure Starter Set

Based on the guiding principles for measurement and the current gaps in measures, the convening attendees agreed on a starter set of measures that was modified based on additional expert review.

The proposed measure starter set, presented in Table 3, includes well-being of patients and caregivers, experience of care, process measures of clinical care, advance care planning, safety, utilization and costs and access. The table indicates whether the proposed measure is an existing measure, would need to be modified from an existing measure or is a new measure. For existing measures, the National Quality Forum endorsement status is noted. Even for existing measures, further work may be needed to examine the psychometric properties of modifying the denominator to focus on the seriously ill.

<b>Table 3. Proposed Measure Starter Set</b>					
<b>Domain</b>	<b>Proposed Starting Measures and Tools</b>	<b>Data Source</b>	<b>Existing</b>	<b>Modified</b>	<b>New</b>
<b>Well-Being of Patients and Caregivers</b>	Integrated Palliative Care Outcome Scale (IPOS)-5 (Cicely Saunders Institute, United Kingdom) <sup>23</sup>	Patient, family or clinician at time of visit	•		
<b>Experience of Care</b>	Patient and Family Experience of Ongoing Care Survey (to be administered 2 to 3 months after enrollment in a community-based program)	Patient or proxy respondent			•
	Serious Illness Experience of Care Module for Medicare Advantage and ACO populations	Patient or proxy respondent			•
	CAHPS Hospice Survey (modified for serious illness population; to be administered to family member 2 to 3 months after patient death)	Bereaved family		•	
<b>Clinical Care</b>	Comprehensive Assessment at Admission – Percentage of Patient Stays During Which the Patient Received All Care Processes Captured by Quality Measures (NQF #1617, NQF #1634, NQF #1637, NQF #1638, NQF #1639, NQF #1647, NQF #1641, as applicable)	Chart or EHR Review	•		
	Caregiver Assessment	Chart or EHR Review			•
	Advance Care Plan (NQF #0326; modified to focus on the serious illness population)	Chart or EHR Review	•		
<b>Safety</b>	Medication Reconciliation Post-Discharge (NQF #0097)	Chart or EHR Review	•		
	Unwanted Care that Is Not Goal Concordant (consider framing as medical error or sentinel event)	Professional Review			•
	Patient or Family Assessment of Whether Care Is Goal Concordant	Survey			•
	Total Cost of Care (NQF #1604): Adapted for Serious Illness	Utilization Data		•	

<b>Cost and Utilization</b>	Potentially Avoidable Emergency Department Visits	Utilization Data	•		
	Rate of Risk-Standardized Acute, Unplanned Hospital Admissions Among Medicare Fee-For-Service (FFS) Patients 65 Years and Older with Multiple Chronic Conditions (NQF #2888)	Utilization Data	•		
	Discharge to Community (CMS Skilled Nursing Facility Quality Reporting Program measure)	Utilization Data	•		
<b>Access</b>	Hospice Enrollment and Enrolled More than 3 Days Before Death (NQF #0216)	Utilization Data	•		
	Community-Based Program for Seriously Ill Offered	Utilization Data			•

### Next Steps and Research Needed to Refine the Starter Measures

The starter measure set should be refined over time based on additional research and future developments in the field. Some of the most critical research questions are presented in this section. In addition, the measure set should be refined as new guidelines and standards are developed and released. The National Coalition for Hospice and Palliative Care is updating guidelines for best practices in community-based serious illness care, which will fill the gap in current evidence-based recommendations for these programs. Similarly, The Joint Commission’s existing programs and the National Committee for Quality Assurance process to develop standards and an accreditation program will define the critical components of these programs. The measure set should evolve to reflect and be synergistic with existing and evolving guidelines and standards.

### Critical Measurement Challenges

**Small numbers.** A significant issue for quality measurement of serious illness care is small numbers. Many community-based palliative care programs are small and may treat only a small number of patients in a year. For accountability models at the palliative care program- or provider-level, small numbers of patients results in small sample sizes for quality measures, which in turn results in low measure reliability. The Medicare Payment Advisory Commission highlighted this issue in its 2017 Report to the Congress and suggested as a solution that CMS move to population-based measures that assess performance for a group of providers rather than at the individual provider-level.<sup>24</sup> Depending on the proposed definition of the denominator, the small number of persons served per provider is an important constraint on the implementation of an accountability program.

At the same time, small numbers of seriously ill patients also present a challenge in larger models that encompass a broader population. For example, in an ACO model the seriously ill typically represent a small portion of the patient panel. The impact of care for the seriously ill portion of the population on overall quality and cost measures can be so small that it may not be worth investing significant resources into improving the quality of their care. This is compounded by the fact that very high-cost—often seriously ill—patients are considered outliers and are excluded from cost measures by CMS, including in ACO models.

**Measure responsiveness.** Additional research is needed to assess the responsiveness of measures to intervention. The issue of responsiveness interacts with the issue of small numbers. If sample sizes are

small, it may take a very large change in results for a given measure from one period to the next to yield a statistically significant result.

**Proxy response.** A recent study found that proxies tend to report more physical, affective, cognitive and social limitations for elderly and disabled Medicare beneficiaries than the beneficiaries report themselves.<sup>25</sup> The field needs a better understanding of the reliability and validity of proxy response for seriously ill patients throughout their disease trajectory.

#### Development of Patient and Family Experience of Care Surveys for the Seriously Ill

Three specific recommendations were made regarding the existing survey instruments to assess patient and family experiences of care. First, the development of a survey to assess patient and family experiences of ongoing serious illness care in a community-based program was identified as a next step. This survey, to be developed for inclusion in the CAHPS family of surveys, would be administered about two to three months post-enrollment in community-based programs for persons with serious illness. A second priority was a proposal to add a module to ongoing surveys of care experiences in Medicare Advantage plans and ACOs to capture the experience of seriously ill individuals in these programs. These modules would need to operationalize the proposed definition of denominator. The third priority was to adapt the existing CAHPS Hospice Survey for use across settings of care in which seriously ill individuals receive care. As with all CAHPS instruments, the perspective of the patient and family should play an essential role in development of the new survey, the new module and the adaptation of the CAHPS Hospice Survey.

#### Measuring Goal Concordance

In the development of a CAHPS enrollment survey and refinement of the existing CAHPS bereaved family member survey, “goal concordance” with care is an important domain. Additional research is needed to examine its validity, actionability and other psychometric properties. For example, an important concern is that a person may want to die at home, but transfer to a hospital with general inpatient-level hospice care may be warranted to provide desired symptom control. Goal concordant care is not just about life-sustaining care, but it is also about what is important to the person and outcomes that they want to avoid. Prospective measurement may generate more valid and reliable results, but as recently noted by University of Washington Professor Joan Teno and colleagues, there are important challenges that should be taken into consideration.<sup>26</sup> They include:

- 1) Patient and family readiness for information and discussion of goals, to avoid distress and anxiety. This has been termed “information toxicity.”<sup>27,28</sup>
- 2) Prospective measurement requires more time and resources with reflection on what is the right denominator.

Given the limitations of relying on these approaches, the focus should be on measuring key aspects of the quality of communication from the consumer perspective (e.g., Did the provider listen to you? Were you allowed to ask all your questions? Was information provided in way you can understand?) Future research on the best approach to this consumer perspective is needed.

#### Measuring Value

The National Quality Forum defines value of care as a “measure of a specified stakeholder’s preference-weighted assessment of a particular combination of quality and cost of care performance.” Given the

importance of patient preference in defining quality—especially in serious illness care—patient preference should also inform assessments of value.<sup>29</sup>

Additional research is needed on how to most appropriately assess value in serious illness care. At the measures convening, University of Michigan Associate Professor Andrew Ryan presented an approach for establishing accountability for value by “linking” quality, spending and payment. Numerous national programs now jointly reward provider performance related to quality and spending. He identified three linking models used in these programs: unconditional, conditional and hurdle, citing the pros and cons for each.

In an unconditional model, quality and spending measures are given independent weights. An example of this model is the Hospital Value-Based Purchasing program. This model provides more flexibility in determining the weights of measures, but can reward providers for poor quality care, so long as it is less expensive. Recent research has found that low-quality hospitals receive incentive payments under the Hospital Value-Based Purchasing program due to use of an unconditional model.<sup>30</sup> The U.S. Government Accountability Office also raised this issue in a report in June 2017.<sup>31</sup>

In a conditional model, quality and spending are considered jointly. This addresses the issue of poor quality providers receiving financial rewards for reduced spending, but provides less flexibility in determining domain weights for quality and can result in threshold effects. An example of this model is the Physician Value-Based Payment Modifier.

In a hurdle model, both minimum quality and spending targets must be met. This model guarantees that a minimum standard is met, but provides less flexibility in determining measure weights. An example of this model is the Medicare Shared Savings Program in which ACOs must meet both a spending hurdle and a quality hurdle to receive shared savings payments.

The Oncology Care Model, the Comprehensive End-Stage Renal Disease Model, and Home Health Value-Based Purchasing are examples of programs that currently link quality and spending for seriously-ill populations or will do so in the near future. Additional analysis is necessary to determine which model may be most appropriate for a serious illness accountability system.

Ryan also identified several challenges that must be considered and addressed for any of these linking models. There are potential unintended consequences, including “cherry-picking” healthy patients and/or avoiding sick patients in these types of models. Rigorous risk-adjustment is critical to avoiding these issues. Simulation models can be used to identify these potential unintended consequences.

In addition, there are pros and cons to different approaches to attribution or determining what provider(s) or organization is held accountable for the quality and cost of care. Prospective attribution allows for clinician and organizational knowledge of which patients are being attributed to them, permitting more focused care during the episode. Retrospective attribution is less administratively complex, but providers do not know which patients are attributed to them—and on whom to focus their attention—during the episode.

#### [Convening Stakeholders to Propose Enhancements to EHR Functionality](#)

Barriers to EHR functionality that were discussed at the convening included missing and inaccessible data elements for quality improvement and measure gaps for serious illness care. With the implementation of the IMPACT Act, data elements and quality measures from post-acute care patient

assessments are being standardized. These standardized elements and measures, including functional and cognitive status, can be mapped and made interoperable with EHRs. However, without a critical mass of EHR users requesting these changes, or policy changes requiring them, EHR vendors are unlikely to take the steps necessary to establishing interoperability. There is an opportunity to convene stakeholders to align and prioritize these and other key EHR interoperability and information opportunities. Medical specialty societies and provider trade associations would be key stakeholder groups to involve. A broad approach could also help spread the costs of changes across many different groups.

## The Denominator: Who Should Be Offered Enhanced Services?

Any care model and payment system requires a means of identifying who should be offered enhanced services. For the serious illness population, the denominator should mirror the consensus definition of serious illness as closely as possible. If the population definition—or the denominator of a quality measure—is too broad, too many individuals may be included (i.e., low specificity), reducing the value of the program. On the other hand, if the denominator too narrow, too many individuals who would benefit will be excluded (i.e., low sensitivity). This tradeoff directly impacts the cost and resources needed to effectively screen the population, as well as the feasibility of incorporating small and community-based programs. At the same time, while high-cost patients often have high needs, these groups are not completely overlapping. Some high-need patients will not be highest cost and vice versa. The most important consideration is for whom community-based palliative care will have the greatest impact on quality and/or cost.

As noted in the Defining Serious Illness section of this paper, Icahn School of Medicine at Mount Sinai Associate Professor Amy Kelley presented a working definition of serious illness for refinement at the measures convening. Kelley created and tested several different denominators that utilize different data sources and place varying degrees of emphasis on sensitivity versus specificity, high need versus high cost and other tradeoffs. At the convening, Kelley led a discussion of potential standard denominators, considering current and future data availability.

### Recommendations

A breakout group at the convening that was assigned the denominator issue recommended using a combination of diagnosis and utilization, including use of home health, skilled nursing facilities and/or durable medical equipment. Administrative data from home health and skilled nursing facility claims include functional measures, while durable medical equipment can serve as a useful proxy for function in the absence of direct information on functional status.<sup>32</sup>

Some measures may be appropriately based on this broad denominator of the seriously ill population (e.g., measures of access). However, many other measures will only be appropriate or applicable to a specific disease or condition subgroup and denominators will need to be adapted for specific uses. The convening participants recommended that specific denominators are needed, for example, for those with substance use disorders, behavioral and mental health disorders, homelessness, dementia and social deprivation. Moreover, some measures may require further specification of the denominator population. For example, measures for the denominator of individuals with a clearly and consistently stated preference to die at home. Importantly, the need for more specific denominators may decline

over time if CMS prioritizes population-based approaches over alternative payment models. See the Future Scenarios section below for more on this issue.

## Next Steps and Research Needed

### Review of Other Denominators

As noted earlier in this paper, Medicare Advantage plans are increasingly implementing community-based palliative care, either using vendors such as Aspire Health, developing their own programs, or contracting with palliative care services in their communities.<sup>33</sup> These models use (often proprietary) algorithms to identify patients at high risk of mortality or high spending to whom enhanced services are offered. There is an opportunity to learn from these algorithms and their overall approach to identifying and targeting the right patients.

### Developing a Gold Standard and Testing Alternatives

Additional research is also needed to compare the precision of different denominator definitions. Initial efforts should focus on developing a “gold standard” definition that contains all the elements from the consensus definition. A telephone survey to define the denominator would add considerable costs to the process. Thus, it is important that it is possible to calculate a proposed denominator from existing administrative and mandatory assessment data. Testing should compare the sensitivity, specificity and positive predictive value of these alternatives compared to the gold standard to help identify denominators that balance predictive value with feasibility of implementation.

### Using Post-Acute Care Assessments

By 2018, skilled nursing facilities, inpatient rehabilitation facilities and long-term care hospitals will be using standardized data elements as part of implementation of the IMPACT Act. These data elements include functional and cognitive status, which are essential in identifying the seriously ill. Home health agencies will implement the same data elements in 2019. While these data will not capture the entire population with serious illness, rather only those with an episode of care in one of these settings, the data are widely available and already being collected. Moreover, all the elements in the IMPACT Act are in the public domain so community-based serious illness programs can implement the same data elements. Analyses should be conducted to understand the degree to which the function and cognitive status data elements would enhance the working denominator and the portion of the seriously ill that would be excluded because they have not utilized post-acute care.

### Using Telephone Screening

Serious illness care programs may consider a brief second-tier telephone screen as an effective way to increase sensitivity and specificity of identifying patient need for enhanced services from among individuals being identified in a broader initial screen. Research is needed to determine how many individuals would need to be contacted to find the most patients meeting denominator criteria at the lowest cost.

### Using EHR Data

The long-term goal for defining denominators and identifying the right patients with serious illness is a fully automated approach that utilizes EHR and other data to make determinations at the point of care. In the short-term, there is a critical need to identify data now that can be analyzed to find patients

more rapidly. Additional steps can be taken to identify patients using currently available administrative data.

### Outreach

In addition to rigorous quantitative testing, it is important to ensure that any denominator definition has face validity with providers, patients and their caregivers. Interviews and focus groups can be used to gather input and feedback on the definition. Gaining this input and some level of consensus will also give the definition more legitimacy. With consensus comes the ability to influence EHR vendors to incorporate essential data elements into their products.

In addition, uptake of a denominator definition will depend greatly on whether it meets the needs of CMS and other agencies. It is vital to engage the relevant agencies early to share developments. Relevant units within CMS include the Center for Medicare, the Center for Clinical Standards and Quality, and the Center for Medicare and Medicaid Innovation. Other agencies include the Health Resources and Services Administration, the Veterans Health Administration, the Agency for Community Living and the Medicare Payment Advisory Commission.

### Future Scenarios

As noted, community-based programs for the seriously ill are growing rapidly in Medicare Advantage plans and some ACOs. At the convening, the group focused on two other potential future scenarios for the wide adoption of an accountability system for community-based programs for persons with serious illness: (1) adoption of an alternative payment model for persons with serious illness and (2) development of a co-creation patient registry. These scenarios are not mutually exclusive, and over the long term, a more population-based approach may be most feasible and impactful.

#### Scenario 1: Alternative Payment Model

The Affordable Care Act established the Center for Medicare and Medicaid Innovation at CMS to develop and test new models of care delivery and value-based payment, also known as alternative payment models. Center for Medicare and Medicaid Innovation has implemented more than 80 models since 2010. While most models include a broad set of providers and patients with various conditions and levels of acuity, the Medicare Care Choices Model focuses on allowing hospices to provide palliative and supportive care services under the Medicare Hospice Benefit to patients meeting hospice-eligibility criteria still receiving treatment with the goal of prolonging life, if possible. Eligible participants include traditional fee-for-service Medicare beneficiaries, individuals who are dually eligible for Medicare and Medicaid, and who are also eligible for the hospice benefit. Other than Medicare Care Choices Model, no Center for Medicare & Medicaid Innovation (CMMI) models focus on palliative care.

While existing CMMI models have been developed internally, a new mechanism exists for models to be proposed by outside stakeholders and tested by CMMI. The Medicaid and CHIP Reauthorization Act (MACRA) of 2015 established the Physician-Focused Payment Model Technical Advisory Committee. The advisory committee is authorized to make comments and recommendations to the Health and Human Services Secretary on model proposals submitted by stakeholders. In addition to establishing the Payment Model Technical Advisory Committee, MACRA established the Quality Payment Program for Medicare physician payment. This program will allow physicians participating in qualifying advanced

alternative payment models to receive a five percent payment bonus, in addition to any payments received through the model.

#### C-TAC Advanced Care Model

In February 2017, C-TAC submitted a model (called the Advanced Care Model) to the Physician-Focused Payment Model Technical Advisory Committee.<sup>34</sup> This is a team-based model that includes concurrent palliative care and curative treatment. Specific services include advanced care planning, comprehensive care management, home and telephonic visits and 24/7 clinician access. The payment model is a per member per month payment with phased-in two-sided risk. Eligible participants include physicians, hospitals and health systems, home health agencies and hospice. Importantly, the target population is individuals with a life expectancy of 12 months who meet certain clinical criteria which runs the risk of excluding many high-need, high-cost patients with indeterminate or variable prognoses, similar to the unintended consequences stemming from implementation of the Medicare Hospice Benefit, as described in the Background and Overview section.

#### American Academy of Hospice and Palliative Medicine Model

In August 2017, the American Academy of Hospice and Palliative Medicine submitted an alternative payment model proposal to Physician-Focused Payment Model Technical Advisory Committee.<sup>35</sup> The care delivery and payment models outlined are similar to those proposed in C-TAC's Advanced Care Model. The major differences between the models are that the American Academy of Hospice and Palliative Medicine model includes a broader patient population with a longer (or less predictable) life expectancy, and allows participation by providers unable to take significant downside risk to due to their size, geography and/or market position.

#### Changing Priorities in Value-Based Payment

There are signals that federal policymakers may slow the pace of movement toward alternative payment models or even move away from alternative payment models in the future. As noted earlier in this paper, the Medicare Payment Advisory Commission has identified the small numbers issue as a critical shortcoming on the current approach to alternative payment models and the Quality Payment Program more broadly, and has recommended a focus on population-based, as opposed to provider-based, approaches as a solution. Moreover, in August 2017, CMS canceled implementation of some new alternative payment models and shifted others from mandatory to voluntary participation. These developments indicate potential changes in value-based payment policy that should be monitored and steps should be taken to prepare for a long-term period of uncertainty in the rate of shift to value-driven population-based payments.

#### Scenario 2: Co-Creation Learning Health System

An approach to establishing a registry-based, co-creation learning health system was also discussed. A co-creation registry creates a partnership between the care team and the patient and caregiver for eliciting patient priorities, concerns and preferences for care to design an individual care pathway. Patients enter, or "feed forward," information about their symptoms and quality of life through an app, a web portal, at a kiosk or on a tablet at home or in the waiting room, prior to an office visit.<sup>36</sup> These data are made available to clinicians in real time along with other clinical data to inform decision-making at the point of care. This co-creation approach was pioneered by the Swedish Rheumatology Quality Register<sup>37</sup> and efforts are underway to develop a learning health system in the U.S. for inflammatory bowel disease.<sup>38</sup>

The co-creation registry idea has emerged in the context of an American Academy of Hospice and Palliative Medicine-led collaborative working on developing a single National Palliative Care Registry in place of the current three free-standing registries.<sup>39,40,41</sup> The stated objective of the planning process is to consider ways to integrate the registries. An integrated registry would serve as the backbone for a co-creation learning system.

### Next Steps and Research Needed

Steps should be taken to align accountability efforts for serious illness care, across patient populations, settings and payment models. Engagement with The Joint Commission, the National Committee for Quality Assurance and other accrediting bodies should continue to both drive development and uptake and to ensure field involvement in decisions on standards. Work with C-TAC and the American Academy of Hospice and Palliative Medicine on their proposed alternative payment models should continue and the measure set and other information developed at the measures convening should be shared with these groups. Additional engagement with the Physician-Focused Payment Model Technical Advisory Committee and CMMI through comment and direct outreach will help ensure that the recommendations of the convening are reflected in the final decisions regarding these models. In addition, engagement with the Learning and Diffusion Group at CMMI, which collects lessons learned from CMMI's alternative payment model development and implementation, may help inform the final design of these models. As the models move through the review process, efforts should be made to harmonize their approaches as much as possible.

If a new alternative payment model for serious illness moves forward to implementation, CMS should fund the development of actionable new measures and modification needed for current measures to complete the set. Developers of the new and modified measures should seek National Quality Forum endorsement.

To take the co-creation registry from concept to a pilot test, the first step is to form a lead team. This team would spearhead planning of the registry and would be responsible for aligning efforts with the ongoing serious illness registry planning process and developing a business model and strategy to fund the implementation and operation of the registry. The lead team should also work to coordinate efforts with other patient registries that have relevance to the serious illness population, such as the PRIME Registry operated by the American Board of Family Medicine. The lead team should have representation from patients and caregivers, care teams, clinicians, researchers and the operators of the existing serious illness and palliative care registries. The team should gather input from health information technology experts, health system leaders, payers and implementation scientists.

### Conclusion

Measurement is the foundation for ensuring quality health care and improving the experience and outcomes for patient care. Currently, a robust accountability and measurement system does not exist for holistically assessing the quality of community-based serious illness programs. The purpose of the measures convening was to move this effort forward: to create guiding principles, begin identifying appropriate quality measures, specify an approach to defining measure denominators that best capture the serious illness population, and identify research needs and next steps.

The discussions resulted in solidifying three components of an accountability system for community-based serious illness care. The three components of an accountability system—value-based payment,

public reporting, and accreditation and certification—will only be effective if the right set of rigorous, valid, actionable and meaningful quality measures are included.

In this paper, we have identified a set of guiding principles for measurement and a starter set of measures for use by an accountability system and its components. We have also proposed a standard measure denominator and a series of considerations for the use of denominators in practice. The principles, measures and denominator were identified through a consensus-based process involving multiple stakeholders. Further, we have presented two potential pathways for implementation of a large-scale accountability system: implementation of alternative payment models for Medicare physician payment and a registry-based co-creation learning system.

We have identified a series of research priorities for more fully defining the proposed starter set measures. There are technical measurement issues, as well as a series of issues regarding the deployment of denominators, that need to be addressed. Moreover, additional research is needed to facilitate implementation of a co-creation learning system and payment models. Beyond research, outreach and stakeholder engagement will be needed to align efforts, build momentum and design an accountability system that is centered on the needs of patients and their caregivers.

Finally, the “Serious Illness Quality Alignment Hub,” led by the Center to Advance Palliative Care, will continue this work. The hub will oversee a national effort to identify, prioritize and monitor the most actionable and high-impact opportunities and activities that lead to a robust accountability system for community-based serious illness care. As part of the hub, the Center to Advance Palliative Care will collaborate with the National Quality Forum to flesh out the measure starter set described in this report; also, the National Quality Forum will lead a quality measurement workgroup, host a series of annual convenings, and create implementation tools to help providers understand and integrate quality measures into community-based serious illness care. The Quality Alignment Hub will be co-led by Amy Kelley, associate professor at the Icahn School of Medicine at Mount Sinai, and Allison Silvers, vice president of payment and policy at the Center to Advance Palliative Care. They can be reached at [hub@capc.org](mailto:hub@capc.org).

## Appendix A: Convening Participants

- Robert Arnold, Professor of Medicine, University of Pittsburgh; Director, Institute for Doctor-Patient Communication; Director, Institute for Doctor-Patient Communication; and Medical Director, UPMC Palliative and Supportive Institute
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- Amy Berman, Senior Program Officer, John A. Hartford Foundation
- Beth Berselli, Program Officer, Gordon and Betty Moore Foundation
- Janet Bull, Chief Medical Officer, Four Seasons Compassion for Life
- Jen Bunker, Research Coordinator, University of Washington
- Helen Burstin, Chief Scientific Officer, National Quality Forum
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- Marcy Carty, Vice President of Network Performance and Innovation, Blue Cross Blue Shield of Massachusetts
- Janet Corrigan, Chief Program Officer, Gordon and Betty Moore Foundation
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- Marc N. Elliott, Senior Principal Researcher, RAND Corporation
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- Torrie Fields, Senior Program Manager, Blue Shield of California
- Barbara Gage, Research Associate Professor, George Washington University
- Laurie Graig, Senior Program Officer, National Academies of Sciences, Engineering and Medicine
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- Debra Ness, President, National Partnership for Women & Families
- Khue Nguyen, Chief Operating Officer, C-TAC Innovations
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- Rebecca Anhang Price, Senior Policy Researcher, RAND Corporation
- Kathleen Puntillo, Professor Emeritus of Nursing, University of California, San Francisco
- Christine Ritchie, Professor of Medicine, University of California, San Francisco; and Medical Director of Clinical Programs in the UCSF Office of Population Health
- Phillip Rodgers, Associate Professor of Family Medicine and Internal Medicine, University of Michigan
- Andrew Ryan, Associate Professor, University of Michigan School of Public Health
- Justin Sanders, Attending Physician, Dana-Farber Cancer Institute; Instructor in Medicine, Harvard Medical School; and Associate Faculty with the Serious Illness Care Program at Ariadne Labs
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- Gwynn B. Sullivan, Project Director, National Coalition for Hospice and Palliative Care
- Joan Teno, Professor of Medicine, University of Washington
- James Tulsky, Professor, Harvard Medical School; Co-Director, Harvard Medical School Center for Palliative Care; Chair, Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute; and Chief, Division of Palliative Medicine, Brigham and Women's Hospital
- Martha L. Twaddle, Senior Vice President, Home Centered Care Institute; and Senior Medical Director, Aspire Health
- Tom Valuck, Partner, Discern Health

## Appendix B: Priority Next Steps and Research Needed

Domain	Priority
<b>Measurement</b>	Adapt CAHPS measure/module that examines key domains including communication and goal concordant care vs. CAHPS survey that is administered about 2-3 months post enrollment in community-based programs for persons with serious illness. As always with CAHPS instruments, the perspective of the patient and caregiver play a critical role in development.
	Improve public reporting by ensuring that information is presented to patients, caregivers, and providers that is timely, easily understood and actionable.
	Develop, test and validate a new approach to measure “goal concordant” care and examine whether bereaved family and patient reports of discordant care are valid and actionable.
	Convene stakeholders to propose enhanced functions that promote data exchange and interoperability of EHRs to allow actionable measurement for quality improvement and accountability.
	Conduct analyses to understand the reliability and validity of proxy responses for a patient throughout the disease trajectory.
	Conduct analyses to understand the responsiveness of measures to interventions.
<b>Denominator</b>	Examine the specificity, sensitivity and positive predictive value of utilization-based criteria to identify seriously ill persons at high risk for utilization and mortality against a “gold standard” needs assessment to identify persons who would benefit from enhanced community-based services.
	Assess the degree to which a utilization-based definition can be enhanced by inclusion of function and cognitive status measures, currently part of post-acute care assessments mandated by the IMPACT Act and what population is excluded from the denominator because of the lack of these assessments.
	Create a brief second-step telephone screen (after identifying patients based on claims and diagnostic criteria) to identify one’s need for enhanced services and evaluate how many persons would have to be screened to identify one who would benefit from these services.
	Translate these findings to a comprehensive EHR strategy that could identify the “denominator” and thus enhance access to services and ease measurement for accountability.
<b>Registry-Based Co-Creation Learning System</b>	Pilot test a co-creation learning system model using the following steps: 1) form a lead team that is part of current efforts to form a registry collaborative among the existing registries; 2) involve a range of stakeholders in the design process, including patients and families, care teams, clinicians, researchers and registry holders, and gather input from IT experts, health system leaders, payers and implementation scientists; and 3) Coordinate with other related efforts, including the American Academy of Hospice and Palliative Medicine and American Board of Family Medicine registries.
<b>Value-Based Payment</b>	Simulate various models for linking quality and spending information to identify potential unintended consequences.

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