Accountability for Community-Based Programs for the Seriously Ill

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Abstract

Innovation is needed to improve care of the seriously ill, and there are important opportunities as we transition from a volume- to value-based payment system. Not all seriously ill are dying; some recover, while others are persistently functionally impaired. While we innovate in service delivery and payment models for the seriously ill, it is important that we concurrently develop accountability that ensures a focus on high-quality care rather than narrowly focusing on cost containment. The Gordon and Betty Moore Foundation convened a meeting of 45 experts to arrive at guiding principles for measurement, create a starter measurement set, specify a proposed definition of the denominator and its refinement, and identify research priorities for future implementation of the accountability system. A series of articles written by experts provided the basis for debate and guidance in formulating a path forward to develop an accountability system for community-based programs for the seriously ill, outlined in this article. As we innovate in existing population-based payment programs such as Medicare Advantage and develop new alternative payment models, it is important and urgent that we develop the foundation for accountability along with actionable measures so that the healthcare system ensures high-quality person- and family-centered care for persons who are seriously ill.

Keywords: accountability system; community-based palliative care programs; value-based payment system

INDUSTRIALIZED NATIONS are faced with the challenge of a growing population of frail, older persons. In the United States, about two-thirds of Medicare beneficiaries have multiple chronic conditions, and one-third have functional limitations.^{1,2} At the same time, there are concerns about the growing proportion of U.S. gross domestic product devoted to healthcare, which is projected to hit 20% by 2025.³ In part, the volume-based incentives and absence of price controls in the healthcare system that resulted in this level of spending have also resulted in concerns over the quality of care provided to these persons. Providing value-based care—rather

than volume based—to people with serious illness while constraining the growth of healthcare costs is a critical policy challenge that presents significant opportunities for innovation in care delivery.

The National Academy of Medicine (NAM) has noted that by helping to clarify and honor patient values, goals, and preferences, quality could be enhanced by avoiding preventable and unnecessary medical interventions that will not help achieve patient goals and are unlikely to benefit or may even harm the patient.⁴ Patients generally prefer to receive home- and community-based palliative care when feasible,

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which studies show decreases costs.⁵ In addition, people with serious illness are typically receiving their care from multiple physicians in various settings of care, resulting in care fragmentation. Enhanced care coordination can reduce this fragmentation while improving the experience of care and decreasing avoidable complications.⁶

The changing incentives in the healthcare 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 19 states. At the same time, the federal Medicare Care Choices Model (MCCM) demonstration program allows over 140 participating hospices to provide services to hospice-eligible Medicare beneficiaries without forgoing disease-directed treatment.⁷

As we innovate, a word of caution should be noted. Not all seriously ill persons are dying. Among the costliest 5% of patients who account for 50% of all U.S. healthcare spending in a year, about half recover and have lower costs in subsequent years. Only about 10% of these patients have been, in retrospect, in their last year of life. The remaining 40% are patients with multiple chronic conditions, often accompanied with functional and cognitive impairment, that have persistently high costs year over year.⁸ As we move from volume-based incentives to value-based incentives, we need an accountability system to ensure that cost containment pressures do not lead to undertreatment or worse quality of care for this vulnerable population.

In May 2017, the Gordon and Betty Moore Foundation convened 45 participants 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 seriously ill population, and identify research needs and next steps.

There are three key components of an accountability system: (1) accreditation and certification; (2) public performance information; and (3) value-based payment. In establishing an accountability system, a key first step is defining high-quality care. The NAM proposed a set of evidence-based core com-

petencies for high-quality serious illness care (Table 1). Quality measures should be built around these core competencies. A second key component is defining who is in the denominator. At the convening, Dr. Amy Kelley led a working group that proposed a 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.” Operationalizing that definition with existing data is a challenge as discussed in her article in this special supplement. That article proposes an initial denominator using existing data and then outlines the needed research.

Guiding Principles for Measurement

At this time of innovation in the creation of new delivery models (e.g., Aspire Health, Aetna Compassionate Care Program, community-based palliative care programs),⁹ testing of a potential new Medicare benefit (e.g., the MCCM demonstration that allows hospices to provide palliative care services along with care for potentially extending life), and consideration of new payment programs under the Medicare Access and CHIP Reauthorization Act (MACRA),¹⁰ it is important that actionable quality measures guide the further development of these programs. 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. It should be noted these are a set of ideals, and it is not expected that a measure would fulfill all these criteria.

There are important tensions and trade-offs 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, and 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, such as those with cognitive impairment and persons near death, are unable to report on their experiences of care. Although not currently a standard of practice in the Consumer Assessment of Healthcare Providers and Systems (CAHPS) patient experience surveys and other assessments, family caregivers should be invited to serve as proxies when patients are unable to respond. In addition, it is important to consider the potential for unintended consequences from the choice of measures and how measures are defined and implemented. An example of an unintended consequence is forcing a process of care considered central to quality that the patient does not want. For example, many seriously ill patients and families welcome spiritual support from the healthcare team. Yet, not all people with serious illness want to discuss their religious beliefs with a healthcare professional or spiritual care provider.¹¹ A measure focused on ensuring access to spiritual counseling should not result in unintended consequences by forcing the patient to be seen by a spiritual care counselor.

TABLE 1. CORE COMPETENCIES FOR HIGH-QUALITY, COMMUNITY-BASED SERIOUS ILLNESS CARE PROGRAMS

- Identification of the target population
- Team-based care
- Caregiver training
- Attention to social determinants of health
- Communication training and supports
- Goal-based care plans
- Symptom management
- Medication management
- Accessibility (including 24/7 coverage)
- Transitional care
- Measurement of value for accountability and improvement

Adapted from: Cohn J, Corrigan J, Lynn J, Meier D, et al. Community-based models of care delivery for people with serious illness. National Academy of Medicine Discussion Paper. <https://nam.edu/wp-content/uploads/2017/04/Community-Based-Models-of-Care-Delivery-for-People-with-Serious-Illness.pdf>.

TABLE 2. GUIDING PRINCIPLES FOR MEASUREMENT

1. The unit of measurement is the patient and his or her 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 healthcare providers.
3. Measures should focus on the patient and caregiver experience and reinforce shared accountability across providers to address the current fragmentation of the healthcare 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 healthcare providers.
6. The patient is best source of information on his or her symptoms and quality of life, but many persons with a serious illness and the majority of persons 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 time frame within the disease trajectory that are 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 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.

The selection of process measures needs to be based on high-quality evidence that links that process to patient- and caregiver-reported 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 as an accountability measure of poor quality must carefully consider the fact that about one in five hospice patients either previously refused hospice or suffered a sudden medical event that resulted in a late hospice referral.¹²

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. This starter set 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 that already exists would need to be modified from an existing measure, or is a new measure. Several of these measures are already in use, as noted by National Quality Forum (NQF) endorsement status. Further work is needed to examine psychometric properties in a potential new population as modifications to the definition of serious illness change the denominator of the target population.

The starter measure set should be refined over time based on additional research and future developments in the field (Table 4). 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 (NCQA) 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 evidence, guidelines, and standards.

Measurement Challenge of Small N

A significant issue for quality measurement of serious illness care is small numbers. Many community-based palliative care programs enroll small numbers of patients. Small numbers of patients result in small sample sizes for quality measures, resulting in low measure reliability. The Medicare Payment Advisory Commission (MedPAC) highlighted this issue in its 2017 Report to the Congress, and suggested as a solution that Center for Medicare and Medicaid Services (CMS) move to population-based measures that assess performance for a group of providers, rather than at the individual provider level.¹³ 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.

Finally, in the absence of carefully focused accountability systems, seriously ill patients may be overlooked in larger models that encompass a broader population. For example, in an accountable care organization (ACO) model, the seriously

TABLE 3. PROPOSED MEASURE STARTER SET

Domain	Proposed starting measures and tools	Data source	Existing	Modified	new
Well-being of patients and caregivers	Integrated Palliative Care Outcome Scale-5 (Cicely Saunders Institute, United Kingdom) ^a	Patient, family, or clinician at time of visit	•		
Experience of care	Patient and Family Experience of Ongoing Care Survey (to be administered 2–3 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 members 2–3 months after patient death)	Bereaved family		•	
Clinical care	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	•		
Safety	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			•
Cost and Utilization	Total cost of care (NQF #1604): adapted for serious illness	Utilization data		•	
	Potentially avoidable ED visits	Utilization data	•		
	Rate of risk-standardized acute, unplanned hospital admissions among Medicare fee-for-service patients 65 years and older with multiple chronic conditions (NQF #2888)	Utilization data	•		
	Discharge to community (CMS Skilled Nursing Facility Quality Reporting Program measure) ^b	Utilization data	•		
Access	Hospice enrollment and enrolled more than 3 days before death (NQF #0216)	Utilization data	•		
	Community-based program for seriously ill offered	Utilization data			•

^aCicely Saunders Institute: IPOS-5 in English. <https://pos-pal.org/maix/ipos-5-in-english.php>.

^bCenters for Medicare and Medicaid Services: www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/NursingHomeQualityInits/Skilled-Nursing-Facility-Quality-Reporting-Program/SNF-Quality-Reporting-Program-Measures-and-Technical-Information.html.

ACO, accountable care organization; CAHPS, Consumer Assessment of Healthcare Providers and Systems; CMS, Center for Medicare and Medicaid Services; ED, emergency department; EHR, electronic health record; IPOS-5, Integrated Palliative Care Outcome Scale-5; NQF, National Quality Forum.

ill typically represent a small portion (5–10%) of the patient panel. The impact of care for the seriously ill portion of the population on overall quality measures can be so small that the ACO may conclude it is not 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. One solution is to apply different weights to quality measures for the seriously ill that will incentivize these models to improve the care of the seriously ill.

Measuring goal concordance

CAHPS surveys are used to assess patient experience for the purposes of assessing provider performance in a variety

of CMS quality and payment programs. In the development of a new 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, concerning is that a person may have said at an earlier time they want to die at home, but then have symptom distress that requires transfer to a hospital or general inpatient-level hospice care for appropriate treatment. Changes in circumstances result in changes in options that often cannot be anticipated in advance, which can result in a clinician being wrongly penalized for failure to provide goal concordant care based on an earlier advance care plan when the care was appropriate and necessary. Goal concordant care is not just about life sustaining care but also about what is important to the person

TABLE 4. PRIORITY NEXT STEPS AND RESEARCH NEEDED

<i>Domain</i>	<i>Priority</i>
Measurement	<p>Adapt CAHPS measure/module that examines key domains, including communication and goal concordant care vs. CAHPS survey that is administered about 2–3 months postenrollment in community-based programs for persons with serious illness. As always with CAHPS instruments, the perspective of the patient and caregiver plays 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.</p> <p>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.</p> <p>Convene stakeholders to propose enhanced functions that promote data exchange and interoperability of EHRs to allow actionable measurement for quality improvement and accountability.</p> <p>Conduct analyses to understand the reliability and validity of proxy responses for a patient throughout the disease trajectory.</p> <p>Conduct analyses to understand the responsiveness of measures to interventions.</p>
Denominator	<p>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.</p> <p>Assess the degree to which a utilization-based definition can be enhanced by inclusion of function and cognitive status measures, currently part of postacute care assessments mandated by the IMPACT Act, and what population is excluded from the denominator because of the lack of these assessments.</p> <p>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.</p> <p>Translate these findings to a comprehensive EHR strategy that could identify the “denominator” and thus enhance access to services and ease measurement for accountability.</p>
Registry-based cocreation learning system	<p>Pilot test a cocreation 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 information technology 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.</p>
Value-based payment	<p>Simulate various models for linking quality and spending information to identify potential unintended consequences.</p>

and what outcomes that they want to avoid. As recently noted by Teno et al., there are important challenges in measuring goal concordance of care as an accountability measure that should be taken into consideration.¹⁴ They include:

- (1) Patient and family readiness or lack of readiness for information and discussion of goals of care may result in distress if this conversation is forced to a time point when the patient and/or family are not ready. This has been termed “information toxicity.”^{15,16}
- (2) Prospective measurement of goals as they evolve over time requires time and resources with reflection on what is the right denominator.

Given the limitations of accurately assessing goal concordance in real time, the focus in the near term may need to 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?)

Measuring value

NQF 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 preferences should also inform assessments of value.¹⁷ Additional research is needed on how to most appropriately assess the patient preference-dependent component of value in serious illness care. Andrew Ryan, PhD, and Phillip Rogers, MD, as part of this special supplement outline the pros and cons of various models for linking quality and costs.¹⁸

Improving EHR and other data platforms

As Curtis et al. discuss, there are important barriers to electronic health record (EHR) functionality, including missing and inaccessible data elements, to measure the care of the seriously ill.¹⁹ With the implementation of the IMPACT Act, data elements and quality measures from postacute care patient assessments are being standardized across settings.²⁰ 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 establish genuine 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 require a means of identifying who should be offered enhanced services. For the seriously ill 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 who do not need the services (i.e., low specificity), reducing the value of the program. On the contrary, if the denominator is too narrow, too many individuals who would benefit will be excluded (i.e., low sensitivity). This trade-off 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-needs 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. An article by Kelley et al. proposes operationalization of the denominator and provides recommendation for future research to refine the denominator (Table 4).²¹

As noted, community-based programs for the seriously ill are growing rapidly in Medicare Advantage plans and some ACOs. At the convening in Banff, 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) development of a cocreation patient registry and (2) adoption of an advanced alternative payment model (APM) with downside financial risk for clinicians caring for persons with defined elements of serious illness. These scenarios are not mutually exclusive, and over the long term, a more population-based approach may be most feasible and impactful.

A cocreation registry creates a partnership between the care team and the patient and caregiver for eliciting patient priorities, concerns, and preferences for care. Patients provide information about their symptoms and quality of life, and these data are made available to clinicians in real time along with other clinical data to inform decision making at the point of care. An article by Kamal et al. lays the vision for cocreation registry. We will briefly discuss APMs.²²

The Affordable Care Act (ACA) established the Center for Medicare and Medicaid Innovation (CMMI) at CMS to develop and test new models of care delivery and value-based payment, also known as APMs. 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 MACRA of 2015 established the ability for organizations to propose advanced APMs for testing, requiring providers to accept some downside financial risk as well as accountability for quality. There are two advanced APMs that have been submitted by C-TAC and the

American Academy of Hospice and Palliative Medicine and are currently under consideration. As part of any APM for the seriously ill, it is very important that the accountability system is developed as these models are tested. If a new APM 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. In addition, engagement with the Learning and Diffusion Group at CMMI, which collects lessons learned from CMMI's APM development and implementation, may help inform the final design of these models. As these two serious illness advanced APMs move through the review process, efforts should be made to harmonize their approaches as much as possible.

Conclusion

Measurement is the foundation 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 feasible, valid, actionable, and meaningful quality measures is included. In this article, we have identified a set of guiding principles for measurement (Table 2) and a starter set of measures for use by an accountability system (Table 3) and its components. We have identified a series of research priorities (Table 4) for more fully defining the Proposed Starter Set. 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 seriously ill patients and their caregivers.

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