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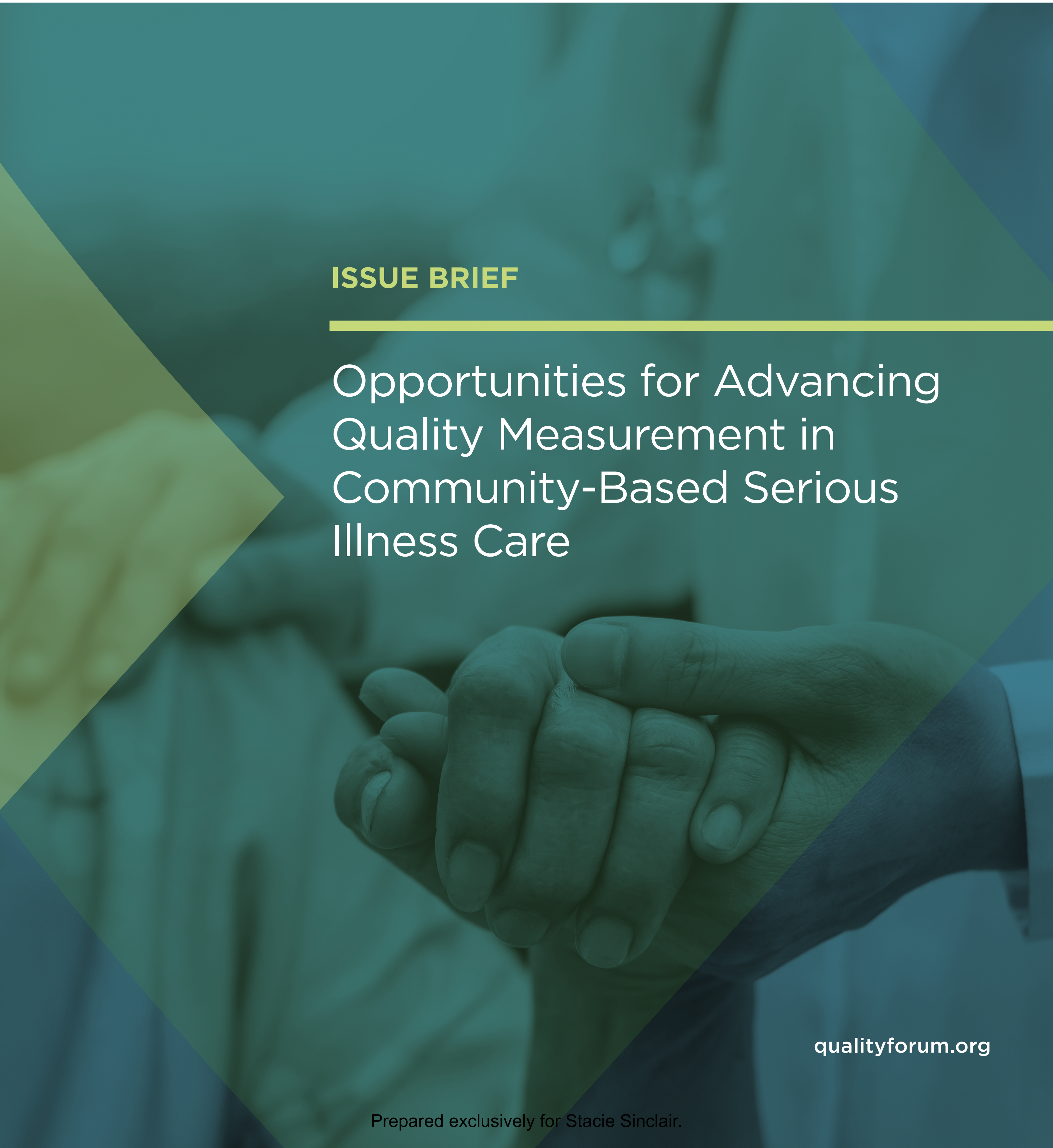

ISSUE BRIEF

Opportunities for Advancing Quality Measurement in Community-Based Serious Illness Care

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About National Quality Forum

The National Quality Forum (NQF) is the nation's resource driving measurable health improvement. NQF is an independent, not-for-profit, membership-based organization that brings healthcare stakeholders together to recommend quality measures and improvement strategies that reduce costs and help patients get better care. Driven by science, collaboration, and proven outcomes, NQF helps move multiple perspectives into action. Our mission improves our nation's healthcare quality, safety, and effectiveness by providing a forum where everyone has an equal voice advancing healthcare improvements that provide the greatest value to patients, caregivers, payers, providers, and policymakers alike.

ACKNOWLEDGEMENTS

This Issue Brief is funded by the Gordon and Betty Moore Foundation through Grant GBMF6889 to National Quality Forum.

The Gordon and Betty Moore Foundation fosters path-breaking scientific discovery, environmental conservation, patient care improvements, and preservation of the special character of the Bay Area. Visit Moore.org and follow @MooreFound.

NQF would like to thank the many organizations and individuals who contributed their technical expertise to this Issue Brief. In particular, NQF is grateful for the opportunity to have collaborated with the Center to Advance Palliative Care as part of the Serious Illness Quality Alignment Hub. NQF also acknowledges the participants and supporters of the Serious Illness Quality Alignment Hub Quality Measurement Committee. These key contributors (see Appendix A) laid the groundwork to help address quality improvements for people living with serious illness. Their efforts and strategic direction informed priority topics and guided the recommendations contained in this resource.

The conclusions, findings, and opinions expressed by individuals who contributed to this publication do not necessarily reflect the official position of any contributor's affiliated organization.

Contents

Introduction

Millions of Americans of all ages face the challenge of living with serious illnesses, such as advanced cancer, heart disease, Alzheimer's disease, and other chronic conditions.

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 his or her caregivers.[1]

An estimated 45 million Americans are living with one or more chronic conditions that limit personal function and are likely to worsen rather than get better.[2] Although representing only 14 percent of the population, those with serious illness account for 56 percent of all healthcare expenditures—almost $1 trillion.[3] This is a vulnerable, frail population at risk with important concerns regarding the safety and quality of care they receive.

Most people living with serious illness need both healthcare and social supports, such as access to food, housing, personal care, transportation, and financial support. In addition to disease-focused medical care, most people need relief from symptoms (e.g., pain, dyspnea, and depression), care coordination and communication over time and across settings, and information and assistance in making difficult decisions. This sort of expertise in symptom management, **shared decision making**, and care coordination are features of what is known as palliative care, which is now available in most hospital and hospice settings.[4] Yet, the proliferation of hospital-based palliative care and advanced illness care models will not fully meet the needs of the serious illness population, which is substantially broader than those who are hospitalized and those who qualify for hospice.

Increasingly, providers are delivering care to people living with serious illness in community settings, such as office practices, medical clinics, long-term care facilities, and patients' homes. Given the growth and diversity of serious illness care programs, consistent approaches to measuring quality and aligning incentives are important to ensure a high standard of care and to discern differences in provider performance. Aligning incentives—specifically payment, public reporting, accreditation, and certification—around a shared quality strategy is needed to promote care that is person-centered, safe, efficient, effective, and affordable.

We define community settings as including office practices, medical clinics, long-term care facilities, and patients' homes. A serious illness program delivering care in these settings should use a team approach to improving quality of life for people living with serious illness.[5]

Over the past decade, the National Quality Forum (NQF) has contributed to foundational work in this area, including the 2006 **National Framework and Preferred Practices for Palliative and Hospice Care**; the 2008 **National Priorities Partnership Palliative and End-of-Life** national priority; the **Geriatrics and Palliative Care Standing Committee** measure endorsement work; and the National Quality Partners (NQP) **Advanced Illness Care Action Team**. NQF is grateful for the opportunity to have continued this important work over the past several years through the Serious Illness Quality Alignment Hub, in collaboration with the Center to Advance Palliative Care (CAPC) and other leaders in the field, to promote high-quality serious illness care for current and future generations.

Issue Brief Overview

The content in this Brief is the result of input gathered from key experts convened over the past two years as part of the Serious Illness Quality Alignment Hub. This project established a Quality Measurement Committee (QMC) comprised of 15 multistakeholder experts (see Appendix A) who met regularly to steer the project work and prioritize key issues. The project convened three working meetings called strategy sessions to address priorities identified by the QMC. Each of those strategy sessions in turn were comprised of multistakeholder experts who met to address the QMC's high-priority topics:

1) *Guiding principles for identifying individuals with serious illness*
2) *Integrating functional assessments into care*
3) *Addressing caregiver strain and resilience in the context of serious illness*

This Brief summarizes the recommendations from the QMC and expert panels to drive improvements in the quality of care for those receiving community-based serious illness care services and their caregivers. It includes expert insights, strategies, approaches, tools, measures, and measure concepts, as well as highlights useful resources developed through various initiatives and efforts across the evolving field of quality in serious illness and palliative care.

Serious illness programs focus on providing relief from the pain, symptoms, and stress of serious illness for both the patient and family at any age and at any stage in the illness. Serious illness care can be provided along with curative treatment.[6]

At a minimum, a serious illness program should provide expert pain and symptom management; effective communication with patients and families to support autonomous decision making for medical treatment and care priorities; and screening and support for the emotional, social, and spiritual needs of patients and their families.[6]

A broad set of stakeholders may find value in this Brief. Clinicians and other practitioners delivering care in community settings may find value in the strategies, approaches, and tools described in the sections addressing functional assessment and caregiver strain and well-being. Health plans, federal agencies, and policy and regulatory bodies may find value in the overview of the current quality measurement landscape, which outlines existing measures, measures known to be under development, and recommendations on what might be needed in the future. Researchers and measure developers may find value in reviewing the measure concepts identified by expert panels to address quality measurement gaps in the topic areas addressed throughout this Brief.

This Brief does not replace guidance that professional societies, associations, and other organizations have produced. Rather, it builds on current efforts to provide additional resources and expert insights for all stakeholders focused on serious illness care delivered in community-based settings.

Measurement and Accountability for High-Quality Serious Illness Care

Healthcare organizations, including community-based programs, should build a culture that uses ongoing collection of data to drive rigorous and continual quality improvement. Mechanisms to measure progress and track care delivery help healthcare organizations identify opportunities to improve the quality of care they are delivering, health outcomes, and patient and family care experiences.

Patient- and family-centeredness is a core aspect of quality, particularly for the seriously ill population. The World Health Organization (WHO) definition of palliative care includes family as part of the care unit.[7]

Ideally, these quality improvement efforts are aligned across organizations through the use of standardized data collection tools and approaches, and a shared measurement strategy. This helps facilitate benchmarking and performance comparisons, and also forms the foundation for establishing accountability to ensure that patients with serious illness receive appropriate, beneficial, and high-value care. This concept of accountability generally refers to verification that high-quality care, informed by expert guidelines, is being delivered.

Accountability approaches vary in scope. They can tie rewards to performance on quality measures. Private reporting refers to reviewing quality measurement results among internal stakeholders only, such as among leaders and administrators within a single health system. This helps organizations understand their own performance and can reveal quality improvement opportunities. Public reporting means that measurement results are shared with the general public, such as through a website or printed report. In making measurement results public, it gives consumers information they can use to make decisions about where they seek care. Performance-based payment is payment for care that is contingent on performance measurement results. When incentives such as payment and market competition are on the line, measurement programs have more impact and also come under more scrutiny.

The mechanisms and entities for holding providers accountable for the care they deliver can depend on the program, setting, or audience. CAPC developed a framework to describe the various accountability systems for serious illness care. That framework outlines opportunities to improve access and quality across 10 accountability systems spanning federal, state, and private arenas and is available on the **Serious Illness Quality Alignment Hub website**.

Given the complexity and potential consequences for patients and providers, there is tremendous pressure to get quality measurement right, but that can be challenging for serious illness care. There is broad diversity in terms of the diseases, conditions, and settings to be assessed, as well as variation in individual patient and family priorities and preferences for care. For example, some individuals with serious illness and their families may opt for care that others believe is low value. There is also inherent variability in the growing number of community-based programs in terms of who they are administered by, how they are governed, how large they are, how robust their capabilities and depth of experience are, and in which settings they deliver care.

As illustrated in CAPC's accountability systems framework, many different entities play a role in holding providers accountable for the serious illness care they are delivering. These entities require guidance on which measures are appropriate to use and how they should be applied. This Brief provides a broad overview of the current quality measurement landscape, highlighting what quality measures exist today, what is known to be under development, and what experts recommend is needed in the future. It is important to note, however, that quality measurement in this space is emerging and evolving. While this Issue Brief does not recommend specific measures for accountability purposes, it provides guidance on what measures should be developed and tested to fill critical gaps in quality measurement for serious illness care.

As appropriate quality measures are developed, tested, implemented, and refined in the topic areas addressed in this Brief, stakeholders will have to consider how and where they might be applied and the implications and potential negative unintended consequences of applying the measures in accountability contexts. Regardless of the context in which measures are applied (i.e., in internal quality improvement or accountability contexts), it is critical to minimize measurement burden on clinicians and patients and families; ensure the feasibility of data collection and reporting, emphasizing measures where information is readily available; test the measures in the intended care setting, level of analysis, and target population; and select measures that are meaningful to patients, families, and providers.

Guiding Principles for Identifying Individuals with Serious Illness

Current approaches to identifying individuals with serious illness vary from program to program, which poses challenges to quality measurement for two reasons. First, an existing quality measure's specifications describe who is included in the measure's calculations, but if organizations are using different approaches to identify who should be included in the denominator and numerator of the measure, it will be challenging to determine whether the quality measure is being calculated appropriately and may not accurately reflect an organization's performance. Second, developing and testing new quality measures requires clearly defined measure specifications that align with identification approaches to facilitate comparisons in quality measure performance. Inconsistent identification approaches across programs prevents true performance comparisons. A clear and consistent approach to identifying individuals living with serious illness will address these issues and help provide a more consistent foundation on which to implement quality measurement in serious illness care.

Lessons from Current Identification Approaches

Lessons learned from the field have highlighted the various approaches programs use to identify those with serious illness and the challenges related to data collection. Most approaches use a specific program's inclusion criteria to identify individuals with serious illness, resulting in an approach driven by the program's purpose (e.g., reduce ER admissions) and resources (e.g., access to data, analytic capabilities). These *program-centric approaches* tend to focus on diagnoses, costs, and utilization, and may overlook individuals who have significant unmet needs but do not exhibit high utilization rates or costs.

Many other programs employ clinician referral as an approach to identifying individuals with illness. This approach helps promote access but can contribute to increased variability in which patients are included in the program in terms of diagnoses, functional status, and medical and social needs. This variation, in turn, makes it difficult to compare programs, particularly on quality measure performance. Many of these identification approaches rely heavily on claims data, which can provide information about the individual's diagnoses and utilization patterns but do not capture key information about an individual's unmet needs (e.g., functional status, caregiver needs).

A key opportunity to improve data collection is through standardized use of functional status, functional trajectory, and caregiver assessment tools, as well as guidance on how to store this data within a patient's health record. It is important to note that function refers not just to physical function, but to cognitive and social function as well.

With these lessons in mind, the guiding principles below are based on an understanding that it is not appropriate or feasible to have a single, standard approach to identifying individuals with serious illness. Because the population is so varied, using a single approach would likely result in excluding individuals who would benefit from palliative care or other supportive services. This set of guiding principles is meant to promote more consistency in approaches, but not mandate the use of specific data or tools.

Table 1. Guiding Principles for the Identification of Individuals with Serious Illness

Guiding Principle	Rationale
1. The approach should attempt to include data on health conditions, functional status, and caregiver strain.	The approach should attempt to capture data on each of the major components of the serious illness definition. If data on functional status or caregiver strain is not available for identification, programs should collect this information after identification and use it to inform the delivery of care.
2. The approach should consider the specific purpose of the program in which it is being applied.	A program may target a specific subset of the seriously ill population and the approach may be tailored to capture the needs of that subset. Additional data may be required to enhance the approach's specificity and identify individuals who would be appropriate for a specific program.
3. The approach should utilize data that can be used to identify individuals with serious illness and inform the delivery of their care.	To minimize the burden associated with a given approach, data (e.g., from Outcome and Assessment Information Set [**OASIS**] and Minimum Data Set [**MDS**]) collected and analyzed for identification purposes should also be used to inform the delivery of care to the individual identified as seriously ill.
4. The approach should be regularly examined to determine whether newly available data could enhance the approach's effectiveness.	New sources of data are likely to emerge over time, and data that is currently considered infeasible to collect (e.g., functional status) may be more easily accessed as new tools and technology are developed. Regularly examining the approach will allow for the identification and incorporation of these new data sources.
5. The approach should be monitored for unintended consequences.	Approaches may inadvertently exclude individuals who would be appropriate for services or incentivize undesirable behavior. Monitoring for these unintended consequences should be part of a regular maintenance process for the approach.
6. The approach should include the same components of the serious illness definition, regardless of the target patient population's age.	Senior, adolescent, and pediatric populations can all experience a serious illness. Regardless of the target population's age, the approaches should attempt to examine each of the major components of the serious illness definition.
7. The approach should use resources available to a wide range of settings and providers.	To promote access to care, the approach should incorporate data sources and measures that the majority of settings and providers can access.

These guiding principles highlight the need for approaches to reflect the multi-component nature of serious illness, while also recognizing the need for flexibility. Notably, the guiding principles recognize the need to assess approaches continuously to ensure the best and most appropriate data are used and the effects of the approach are assessed and addressed. This continuous assessment will help address questions related to the lack of data for each component of the serious illness definition (e.g., "How can we capture data on functional status and caregiver strain on a more consistent basis?"), dosing (e.g., "How can the approach help us determine what level of services this individual needs?"), and capacity (e.g., "What resources are required to care for the individuals identified by an approach?"). The greater clarity and consistency that comes from this continued refinement will be necessary for assessing where existing measures can be appropriately applied and inform the development of new quality measures that capture important aspects of care delivered to the seriously ill.

Integrating Functional Assessment into Serious Illness Care and Measurement Implications

Functional assessment is a component of the serious illness definition, and data on patient function is key to identifying individuals with serious illness. However, functional assessments are not routinely completed in practice, particularly in community-based settings. When functional assessment is completed, there is wide variation in the tools used and the approaches implemented to record and track function-related data. With many degenerative illnesses, the scope and frequency of functional assessment would need to be adjusted. Functional assessments can reveal significant unmet needs in an individual and can inform the development of a comprehensive care plan. Without function-related data, care plans may not address all of an individual's needs, which may result in continued declines in function and quality of life and increases in caregiver strain.

PREFERRED FUNCTIONAL ASSESSMENT TOOLS AND APPROACH

Tools used to assess function need to demonstrate psychometric soundness and apply to a broad population of individuals, given the many conditions or comorbidities that may be labeled a serious illness. To minimize provider and patient measurement burden, tools widely used in the current practice environment should be prioritized. The tools in this section have demonstrated ability for successful incorporation into clinical workflows. Lastly, these tools are available in different modes of administration, which may be important given the growing use of technology and telehealth services.

Ultimately, collecting function-related data should help to identify individuals who have a serious illness and help inform providers about the types of supports and services an individual requires.

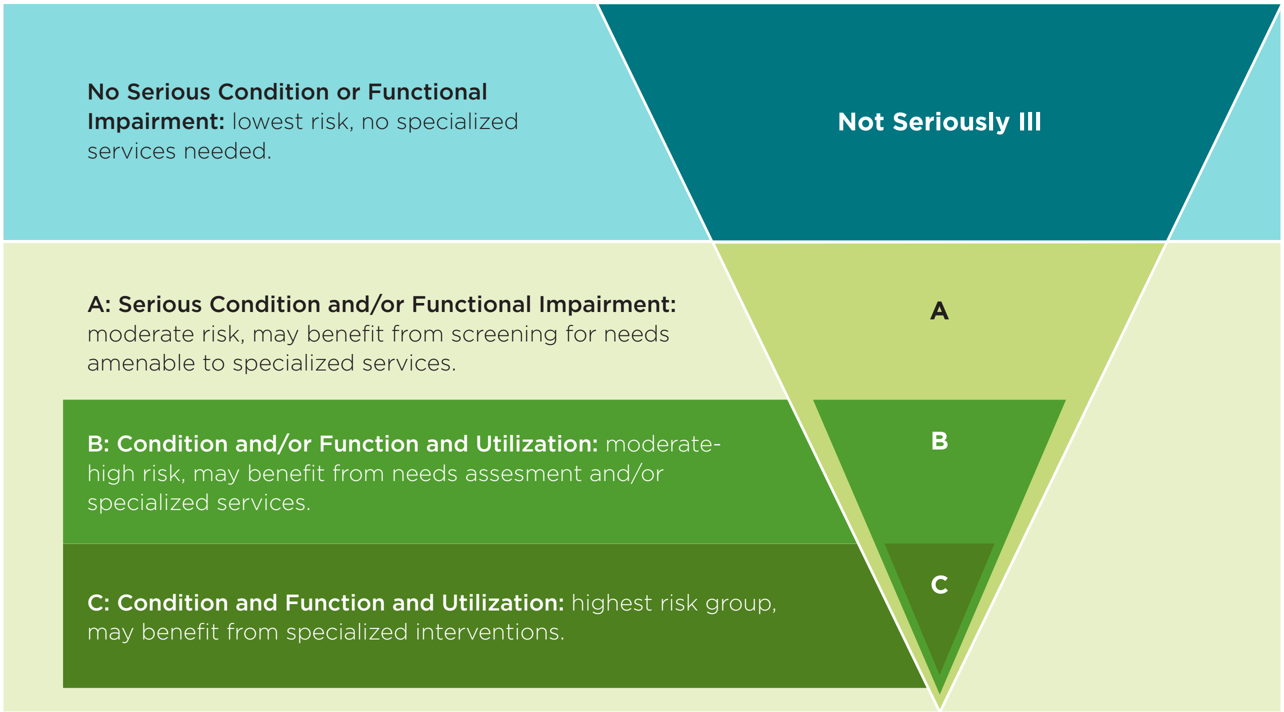
Tools that can identify individuals with serious illness need to be applied to a large group of patients and, therefore, must be short and easy to implement. Tools meeting this requirement, however, do not provide enough information to help providers understand the underlying causes of a functional impairment or determine needed supports and services. Tools providing detailed enough information to help inform care need to be longer and require more time to administer, making it difficult to use them with a large volume of patients. Given these competing demands, a stepped approach using different sets of tools is required.

A stepped screening and assessment approach to integrating functional assessments into care includes a set of tools for screening patients to identify those with serious illness, as well as a set of tools for assessment that helps inform care for those with serious illness.

To whom this approach is applied is another question to be considered given the heterogenous nature of serious illness. Thinking about a continuum of serious illness and different levels of risk for further decline in function and quality of life provides a helpful framework for who would be identified at each step of the screening and assessment approach (Figure 1). The initial screening could be applied to a large patient group, such as a primary care clinic's patient panel, and could help identify those who are either not seriously ill or those where there is moderate risk for decline in function or quality of life (i.e., those in Group A, Figure 1). The assessment approach could help differentiate the individuals in Group A from Group B, where there is moderate to high risk of decline in function or quality of life, or from Group C, where there is the highest risk of functional or quality of life decline.

The proposed screening and assessment approach (Figure 2) describes the purpose of each stage and identifies specific tools appropriate for use in a given phase for both the adult and pediatric populations, as serious illnesses can occur across the lifespan. The screening step aims to identify individuals who may need a more in-depth assessment by a provider, likely a primary care provider (e.g., internist, geriatrician, pediatrician). This screening could be done annually, at the time of a health event (e.g., hospitalization), or at the provider's discretion. For the first-level assessment, the identified tools are longer in length and aim to provide a general understanding of the functional impairment's cause, severity, and impact on the patient and caregivers. With this information, the primary care provider can determine whether referral to a specialist at a higher level of support is needed. The second-level assessment is geared towards assessment completed by specialists (e.g., palliative care providers, cardiologists, rheumatologists) who facilitate a detailed and in-depth understanding of the impairment and can inform the delivery of even more specialized services. The flow diagram illustrates the process of implementing this approach in practice and how the information from the selected tool is used to make decisions about additional assessments and care delivery.

Figure 1. Three Definitions of Serious Illness from Broad to Restrictive. Source: Kelley AS, Covinsky KE, Gorge RJ, et al. Identifying older adults with serious illness: A critical step toward improving the value of health care. *Health Serv Res.* 2017; 52(1).



No Serious Condition or Functional Impairment: lowest risk, no specialized services needed.

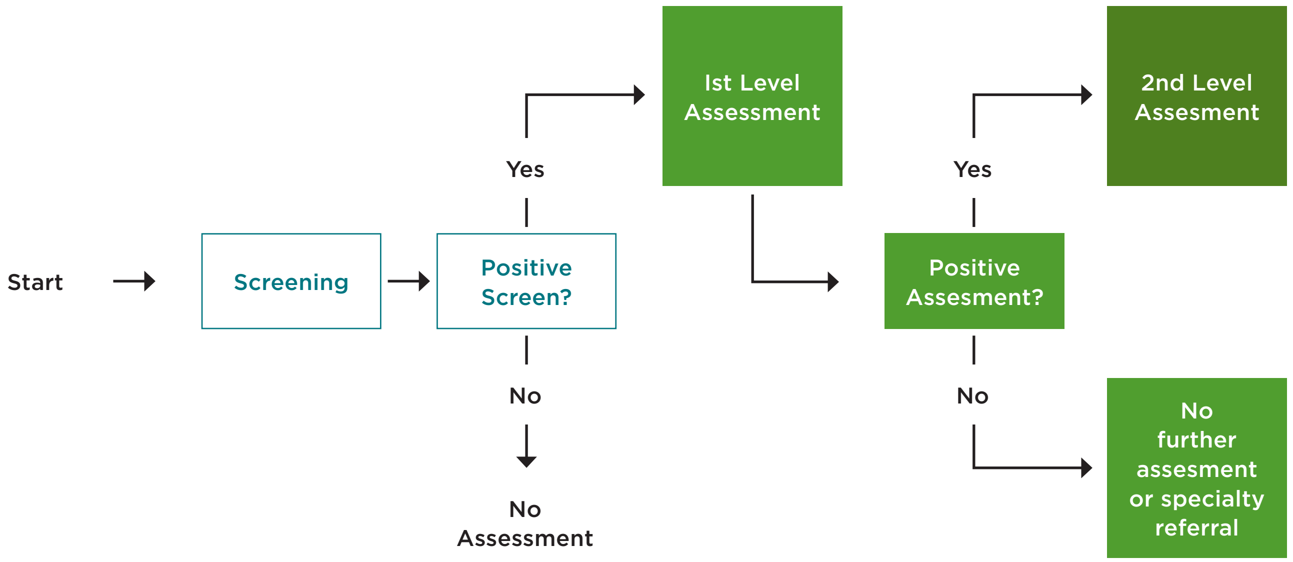
A: Serious Condition and/or Functional Impairment: moderate risk, may benefit from screening for needs amenable to specialized services.

B: Condition and/or Function and Utilization: moderate-high risk, may benefit from needs assesment and/or specialized services.

C: Condition and Function and Utilization: highest risk group, may benefit from specialized interventions.

Figure 2. Stepped Screening and Assessment Approach Flow Diagram and Preferred Tools

	Screening Tools	**First-Level Assessment Tools**	**Second-Level Assessment Tools**
Purpose	Identify individuals in Group A who may benefit from additional, more in-depth functional assessments.	Identify individuals in Group B who may have a higher risk for unmet needs and may benefit from specialized services or interventions. Specific goals of the assessment include obtaining a general understanding of the impairment's cause, severity, and impact on the patient and their caregiver.	Identify individuals in Group C who may be at highest risk for unmet needs and may need to be prioritized for specialized services or interventions. Specific goals of the assessment include obtaining an in-depth understanding of the impairment's cause, severity, and impact on the patient and their caregiver.
Age: Pediatrics	• PROMIS® 2-item Short Form: - Global Health Mental - Global Health Physical	• Lansky Play Performance Scale • Peds-Quality of Life • Pediatric FIM Tool • PROMIS® Longer Forms	• Tools recommended in each of the NCP Palliative Care Guidelines • Disease-specific assessment tools
Age: Adults	• PROMIS® 2-item Short Form: - Global Health Mental - Global Health Physical • Life Space Constriction (1-item version)	• Palliative Performance Scale • Karnofsky Performance Scale • PROMIS®- Physical, Cognitive, Social Short Forms • Barthel Index of Activities of Daily Living	• Tools recommended in each of the NCP Palliative Care Guidelines • Disease-specific assessment tools



ADDRESSING GAPS IN FUNCTION RELATED QUALITY MEASUREMENT

Many existing measures in this space are process measures focused on whether a functional assessment was completed. Most identified outcome measures capture whether an individual experienced an improvement in some aspect of function over a given period of time or episode of care. In a serious illness population, however, a lack of functional improvement is not necessarily an indicator of poor quality, and intervention may not be appropriate in every situation. When conducting functional assessments in this context, it is critical to capture how the impairment impacts the individual and caregiver and if any identified impairments are addressed within the care plan. Also of note is that physical function is not the only important aspect of function to capture; functional impairment may be cognitive as well, as in Alzheimer's disease. Capturing all those factors into a single measure is difficult. A set of measures and/or a composite measure that captures screening, assessment, and appropriate follow-up or intervention would provide a comprehensive view of whether function was assessed and whether the provider responded appropriately. Below we highlight high-priority quality measure concepts addressing this gap in quality measurement. Additional quality measure concepts for consideration are outlined in Appendix B.

High-Priority Functional Assessment Quality Measure Concepts

Functional Assessment and Care Plan	Social Function and Needs	Addressing Changes in Functional Status	Co-creation of Care Plan
Functional assessments with an appropriate action plan in place to address identified functional needs.	Assessment of social function and a documentation of a care plan that addresses identified social function needs.	Documentation of a plan for what to do when a change in functional status occurs.	Evidence of patient and/or caregiver involvement in the development of the care plan.

Addressing Caregiver Strain and Well-Being

Caregivers are critical partners in serious illness care and are vulnerable to physical, social, and mental health issues, which, in turn, affects patients receiving care. Caregivers of those with serious illness experience a higher risk of burden, strain, and poor quality of life than those who are not engaged in a caregiving role. While there are a variety of federal and state policies and programs that address caregivers, the healthcare system inadequately addresses caregiver identification, assessment, and referral to supportive services. A systematic and well-designed assessment can help identify a caregiver's needs and strengths and, in turn, contribute to a plan of care that ensures the well-being of both care partners—the caregiver and the seriously ill care recipient.

CAREGIVER ASSESSMENT TOOLS AND CONSIDERATIONS FOR ADDRESSING CAREGIVERS

There are a large number of caregiver assessment tools currently available for use by healthcare providers, researchers, and program developers. These tools have been captured in resource inventories such as the **Family Caregiver Alliance and Benjamin Rose Institute on Aging's Selected Caregiver Assessment Measures: A Resource Inventory for Practitioners, 2nd Edition**. Efforts by multistakeholder expert convenings have been made to categorize tools into conceptual domains, including: (1) context of caregiver; (2) caregiver's perceptions of health and functional status of care recipient; (3) caregiver values and preferences; (4) well-being of the caregiver; (5) consequences of caregiving; (6) skills/abilities/knowledge to provide care recipient with needed care; and (7) potential resources that caregiver could choose. While all of these domains are important, no single tool captures all critical information, and only a few of the available tools have been validated in serious illness or palliative care contexts (Appendix C).

Although these tools are helpful in efforts to address caregiver needs, it is important to take into consideration the context of the caregivers in question (i.e., whether there are multiple caregivers, availability and capacity to support the person with serious illness, caregiver access to financial and supportive services) and identified sources of caregiver strain. Additionally, there is a possibility of there being multiple caregivers playing different roles, or the person accompanying a patient at any given healthcare visit may not be the primary caregiver. This poses significant challenges to identifying caregivers—a critical first step in assessing and addressing strain and well-being.

Efforts underway to address caregiver identification include a new state law known as the Caregiver Advise, Record, Enable (CARE) Act, which requires that hospitals record the name of the family caregiver in medical records, inform the caregiver when the patient is discharged, and provide education and instruction of the medical tasks they will need to perform for the patient at home. Many of these tasks can be complex, such as managing multiple medications, providing wound care, managing special diets, giving injections, or operating monitors or other specialized medical equipment. Lack of confidence in preparedness to perform these types of tasks may be a significant source of anxiety and can contribute to a perceived inability to contend with role demands. It may be useful to assess caregivers' confidence in their ability to perform these types of tasks and connect them with educational resources if needed. It is also important to note that interactions with the healthcare system can be a significant source of frustration and tension for many caregivers. They may feel judged about the care they are providing or not providing.

Resilience, rather than well-being, may be a more helpful overarching concept to use when considering caregivers. Resilience includes well-being but also addresses confidence in performing tasks, ability to cope with worry about their loved one and their own health and well-being, and ability to deal with the anticipated or actual grief and loss that comes with caring for someone with serious illness. This concept of anticipatory grief reflects that there may be a sense of impending loss that begins long before bereavement and references not just the death of the person receiving care, but lifestyle changes that make it difficult to participate in desired activities and the potential loss of opportunities to pursue lifelong goals.

ADDRESSING GAPS IN CAREGIVER-RELATED QUALITY MEASUREMENT

The existing measurement landscape in this space focuses primarily on process and outcome measures to assess the care of the individual with serious illness and not the caregiver's well-being or strain. These measures use the caregiver as a proxy respondent to evaluate the experience of care, assess whether the caregiver received education, and assess whether plans were documented and shared with the caregiver. Given the dearth in appropriate measures that address caregivers as individuals, measure concepts should be developed to fill this critical gap in quality measurement for caregivers of those with serious illness.

Three measure concepts are proposed to support identifying, assessing, and addressing caregiver needs and resilience. The first is a measure concept focused on caregiver identification. Identification is a critical first step that must happen before any assessment or provision of support is possible. Often those who are identified as caregivers by the care team or by the person with serious illness do not self-identify as a caregiver. Concordance between who is identified as the caregiver and who self-identifies as a caregiver is critical to ensuring the care team is communicating with the correct person and addressing their caregiving needs. Lastly, while this measure concept should address whether a caregiver has been identified and documented in the care plan or electronic health record (EHR), it is important to connect those who do not have a caregiver with support services that may be able to fill this caregiving role.

The second proposed measure concept focuses on identifying and meeting caregiver needs. Specifically, it measures whether caregivers are being assessed, their needs and goals are being identified, they're being referred to services and supports to meet their needs, and their needs and goals are being met. This measure concept could be a composite measure that encompasses a stepwise assessment approach analogous to that suggested for integrating functional assessment into serious illness care. It is important, however, for programs to have a degree of flexibility in their approaches to account for the unique needs of the populations they serve, the resources available in their community, and the setting of care and context of the caregiver.

The final measure concept addresses caregiver strain and resilience and focuses on a single caregiver self-reported measure of distress. This could be a quick indicator that caregiver needs were adequately addressed, if, for example, the measure of distress is maintained below a given threshold. This measure approach allows flexibility for community-based programs to implement structures and processes tailored to their populations and resources in order to achieve the caregiver-reported outcome of interest. There is power in acknowledging caregivers as people and asking how they are doing in the context of caring for their loved one. Anecdotal evidence suggests that clinicians rarely ask caregivers how they are coping, what they are worried about, or when their last "good day" was. Even these simple questions, regardless of whether a clinician can connect them to a service, recognize caregivers as critical partners in the care of the person with serious illness.

High-Priority Caregiver Quality Measure Concepts

Caregiver Identification and Concordance

Percent of persons with serious illness with a caregiver(s) identified in the care plan/ record and percent of those identified who self-identify as the caregiver(s)

- *Of those with no identified caregiver, percent linked to supportive services*

Caregiver Needs Identified and Met

Percent of caregivers with a complete assessment with

1) needs and goals identified;
2) referral to appropriate services;
3) needs and goals met

Caregiver-Reported Resilience

Percent of caregivers reporting that:

- *They are asked about their worries or their last "good day"*
- *Their distress level is maintained below threshold*

These caregiver quality measure concepts, and the functional assessment quality measure concepts outlined above, address known gaps in serious illness quality measurement and should be prioritized for development. Additional gaps are outlined in the NQF's 2016 report, **Strategies for Change – A Collaborative Journey to Transform Advanced Illness Care**, and include measures of treatment burden, financial toxicity, caregiver support, and shared decision making. These measures were emphasized as priorities then and remain highly relevant and should still be considered for development and testing. These concepts help move the needle toward measuring what matters most to people living with serious illness and their families and, if fully developed, could be used in both quality improvement and accountability applications. Recognizing that providers are in need of quality measures available today, we outline the current state of quality measurement and highlight what is known to be under development below.

Current State of Quality Measurement

Since 2006, when NQF first developed a measurement framework for palliative and end-of-life care and endorsed 38 evidence-based preferred practices for high-quality palliative care programs, we have endorsed more than 30 measures in this topic area, many of which currently are used in federal quality improvement and public reporting programs.

In 2017, NQF expanded the scope of the Standing Committee charged with oversight of the palliative and end-of-life care measures portfolio by adding measures specifically relevant to older adults. While the scope of this new Geriatrics and Palliative Care Standing Committee is broader than serious illness, the portfolio of 36 measures it oversees (Appendix D) is a starting place for identifying measures that have been evaluated against **NQF's standard evaluation criteria**, which include importance to measure and report, scientific acceptability of measure properties, feasibility, usability and use, and related and competing measures.

Measures that may be particularly useful to reference include two new measures that received NQF endorsement in October 2019: (NQF3497) Evaluation of Functional Status (Basic and Instrumental Activities of Daily Living [BADLs and IADLs]) for Home-Based Primary Care and Palliative Care Patients and (NQF3500) Evaluation of Cognitive Function for Home-Based Primary Care and Palliative Care Patients. The Geriatrics and Palliative Care Standing Committee regularly convenes to review and maintain measures it oversees and to consider new measures for evaluation.

There are many other organizations and initiatives that have developed or are developing meaningful measure sets for serious illness care, which we highlight below. Some of these efforts have identified gaps in serious illness care quality measurement and are working to address those gaps, as have the Serious Illness Quality Alignment Hub strategy sessions addressing functional assessment and caregiver strain and resilience. There is a key opportunity for alignment in these efforts across stakeholders to work together and optimize coordination under a shared national strategy. This opportunity is addressed in detail under Goal 3 of the recently released **Serious Illness Quality Alignment Hub National Strategic Plan**, the culmination of more than two and half years of the Hub's work to identify the most feasible and impactful strategies to hold providers accountable for delivering high-quality care to people living with serious illness.

This National Strategic Plan recommends the creation of a sustainable body to continuously drive quality measure development and promote relevant quality measure adoption across accountability systems. The development and implementation of this body will be a key driver for improving quality measurement and accountability going forward. Also of note is the **Palliative Care Quality Collaborative (PCQC)**, convened by the American Academy of Hospice and Palliative Medicine (AAHPM), where leaders from national organizations hosting three palliative care quality registries are working to offer one unified registry to improve quality in palliative care. The PCQC seeks to support clinicians and programs to provide data-driven, high-quality, patient-centered care for people living with serious illness and their families.

Quality measurement in serious illness care is currently evolving. Until the realization of a collaborative effort to create and maintain an inventory of all relevant measures currently in use, measures under development, and identified gaps, providers can utilize existing measure starter sets and apprise themselves of known measures under development. Below we highlight select initiatives, with additional details on the measures referenced in each effort available in Appendix D.

- ***Banff Convening on Quality Measures for Serious Illness Care Starter Set:*** 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. Experts identified a starter set of quality measures categorized by well-being of patients and caregivers, experience of care, process measures of clinical care, advance care planning, safety, utilization, and cost and access.

- ***Merit-Based Incentive Payment System Fuctional Outcome Assessment Measure:*** The Centers for Medicare & Medicaid Services (CMS) Merit-Based Incentive Payment (MIPS) program includes a functional outcome and assessment measure that may be useful as a starter measure (CMIT ID# 641; NQF ID# 2624). It is important to note that this measure is not specific to serious illness.

- ***AAHPM and HPNA Measuring What Matters:*** The **Measuring What Matters** initiative proposed a set of 10 quality measures to use for program improvement, 5 which have since been applied as CMS requirements for hospices. Most of these measures are for the inpatient setting but may be helpful to reference in thinking about measurement in community settings.

- ***Palliative Care Measures Project:*** In 2018, the American Academy of Hospice and Palliative Medicine (AAHPM), in partnership with the National Coalition for Hospice and Palliative Care (Coalition) and the RAND Corporation developed **patient-reported quality measures for community-based palliative care**. some of which are patient-reported outcome measures.

- ***International Consortium of Health Outcomes Measurement:*** With increased attention on issues of aging and chronic disease, building on an existing international framework may be helpful. **The International Consortium for Health Outcomes Measurement** (ICHOM) is a nonprofit organization that seeks to transform healthcare systems globally by measuring and reporting patient outcomes using a standardized approach. Several ICHOM measure sets address selected areas identified in this Brief.

- ***Center to Advance Palliative Care Recommended Measures/Measure Areas:*** In 2019, the Center to Advance Palliative Care released a shortlist of recommended quality measures and measure areas for a palliative care or serious illness initiative. The shortlist also contains information about the intended purpose, considerations, and caveats for use.

- ***National Committee for Quality Assurance Person-Driven Measures for Accountability:*** In 2018, the National Committee for Quality Assurance (NCQA) released a report outlining its project to develop a suite of **performance measures suitable for use in serious illness accountability programs**. These measures are intended to evaluate the quality of care through the lens of patient goals, as well as address a quality gap and support processes for moving to person-driven measures for evaluating goal-concordant care.

- ***Additional Efforts Underway:*** There are a number of international efforts that may help to inform measure development and broaden our understanding of palliative and serious illness care. Hospice and nursing home efforts can also inform how we think about measurement in community settings. These include the **Palliative Care Outcome Scale**, Australia's **Palliative Care Outcomes Collaborative**, and the **Centers for Medicare & Medicaid Services Hospice Outcomes and Patient Evaluation** projects.

The Path Forward

Community-based serious illness care is an emerging care model and is rapidly growing as more and more health systems, hospices, medical groups, home health agencies, and other entities launch programs to address care for this vulnerable population. This growth is driven, in part, by an aging population, growing numbers of individuals with serious illness, and gaps in care for those with healthcare and support needs but do not require hospitalization and are ineligible for hospice care.

This Issue Brief outlines recommendations, preferred tools and approaches to help providers in community-based settings integrate functional assessment into care and identify and meet the needs of caregivers of those with serious illness. It also outlines current measures available for use, in development, or proposed to fill measurement gaps, including several high-priority measure concepts addressing functional assessment and caregiver strain and resilience.

While quality measurement in community-based serious illness programs is challenging, it is important for community-based organizations and providers to measure the care they are delivering in an effort to ensure patients receive care that is appropriate, beneficial, and high quality.

Moving forward, much work remains to be done in fully defining, developing, and testing measures to address known gaps in quality measurement in serious illness care. Moreover, all stakeholders need to come together to align around a common measurement strategy as the foundation for an accompanying, robust accountability system. There is a key opportunity to coordinate the various quality measurement efforts across stakeholders and support implementation of the Serious Illness Quality Alignment Hub National Strategic Plan to ensure that a defined population with serious illness receives care meeting measurable quality standards across diagnoses, populations, care settings, and geographies.

APPENDIX A:

Key Contributors

Asterisked contributors provided additional guidance and review for this Issue Brief.

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APPENDIX B:

Additional Recommended Measure Concepts from Strategy Sessions

Functional Assessment and Care Plan

Functional assessments with an appropriate action plan in place to address identified functional needs.

Functional Screening

Annual functional screening of individuals with a risk of serious illness using one of the preferred functional screening tools.

Sequential Functional Screenings

Functional screening of individuals with a risk for serious illness AND completion of a specialized functional screening if the initial screen is positive.

Functional Status Score

A combination of functional assessments that result in a score. A cutoff score identifies a person with a serious illness and is a flag for palliative care referral.

Appropriate Training

Staff appropriately trained to administer functional assessments to individuals who are or are at risk for being seriously ill.

Use of Functional Tools

Staff appropriately use functional tools to assess function and plan care.

Caregiver Assessment

Caregivers receive a caregiver assessment that identifies the caregiver's capacity and specific support needs.

Medication Management

Completion of a medication management process that includes medication justification, simplification, and reconciliation and assessment of the patient or caregiver's ability to manage medications.

Portability of the Care Plan

Accessibility of the care plan across providers, sites, health systems, etc.

Timely Entry into Specialized Services

Timely and appropriate referral to specialty services.

APPENDIX C:

Caregiver Assessment Tools Validated in Serious Illness or Palliative Care Contexts

Assessment Tool	BASC*	CBS-EOLC	CIS	CRA	ZBI - 6-item	ZBI-S 3-item	MCSI	FACQ-PC	CQOLC	QOLLTI-F	SF-36	CQLI-R
Consequences of Caregiving Subdomains												
Physical Health Strain		✓		✓			✓	✓		✓	✓	✓
Emotional Health Strain	✓	✓						✓	✓	✓	✓	✓
Family Relationship Strain	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	
Social Isolation			✓	✓				✓			✓	✓
Grief/Loss												
Work Strain			✓	✓			✓	✓			✓	
Financial Strain			✓	✓			✓	✓	✓			✓
Lifestyle/Scheduling	✓		✓	✓	✓		✓	✓	✓	✓	✓	
Caregiver Satisfaction w/ Helping Care Recipient	✓			✓				✓	✓	✓		
Well-being Subdomains												
Developing New Skills and Competencies			✓					✓				
Depression/ Emotional Distress	✓	✓					✓	✓	✓	✓	✓	
Life Satisfaction/ QoL	✓	✓			✓			✓	✓	✓	✓	
Self-Rated Health			✓	✓	✓	✓		✓			✓	
Health Conditions	✓											

*BASC: Brief Assessment Scale for Caregivers; CBS-EOLC: Caregiver's Burden Scale in End-of-Life Care; CIS: Caregiving Impact Scale; CRA: Caregiver Reaction Assessment; ZBI 6-item: Zarit Burden Inventory, 6-item; ZBI 3-item: Zarit Burden Inventory; MCSI: Modified Caregiver Strain Index; FACQ-PC: Family Appraisal of Caregiving Questionnaire for Palliative Care; CQOLC: Cancer, Quality of Life Index-Cancer; QOLLTI-F: Quality of Life in Life-Threatening Illness—Family Carer Version; SF-36; Medical Outcomes Study 36-item Short Form; CQLI-R: Caregiver Quality of Life Index-Revised

APPENDIX D:

Existing Quality Measure Starter Sets for Serious Illness Care

NQF Geriatrics and Palliative Care Standing Committee Portfolio of Quality Measures: Note that this portfolio of measures is regularly revisited and maintained as new measures are developed and evaluated.

NQF #	*Title*	*Federal Programs: Finalized or Implemented as of June 25, 2019*
0167	*Improvement in Ambulation and Locomotion*	• Home Health Value-Based Purchasing (Implemented)
0174	*Improvement in Bathing*	• Home Health Value-Based Purchasing (Implemented)
0175	*Improvement in Bed Transferring*	• Home Health Value-Based Purchasing (Implemented)
0176	*Improvement in Management of Oral Medications*	• Home Health Value-Based Purchasing (Implemented) • Home Health Quality Reporting (Implemented)
0177	*Improvement in Pain Interfering with Activity*	• Home Health Value-Based Purchasing (Implemented) • Home Health Quality Reporting (Implemented)
0209	*Comfortable Dying: Pain Brought to a Comfortable Level Within 48 Hours of Initial Assessment*	N/A
0383	*Oncology: Plan of Care for Pain – Medical Oncology and Radiation Oncology (paired with 0384)*	• Hospital Care (Implemented) • Prospective Payment System- Exempt Cancer Hospital Quality Reporting (Implemented) • Merit-Based Incentive Payment System Program (Finalized)
0384	*Oncology: Medical and Radiation - Pain Intensity Quantified (paired with 0383)*	• Merit-Based Incentive Payment System Program (Implemented) • Medicaid Promoting Interoperability Program (Proposed)
0420	*Pain Assessment and Follow-Up*	N/A
1617	*Patients Treated with an Opioid who are Given a Bowel Regimen*	• Hospice Quality Reporting (Implemented)
1628	*Patients with Advanced Cancer Screened for Pain at Outpatient Visits*	• Prospective Payment System-Exempt Cancer Hospital Quality Reporting (Considered)
1634	*Hospice and Palliative Care— Pain Screening*	Hospice Quality Reporting (Implemented)
1637	*Hospice and Palliative Care— Pain Assessment*	• Hospice Quality Reporting (Implemented)

NQF #	*Title*	*Federal Programs: Finalized or Implemented as of June 25, 2019*
1638	*Hospice and Palliative Care—Dyspnea Treatment*	• Hospice Quality Reporting (Implemented)
1639	*Hospice and Palliative Care —Dyspnea Screening*	• Hospice Quality Reporting (Implemented)
1647	*Beliefs and Values - Percentage of Hospice Patients With Documentation in the Clinical Record of a Discussion of Spiritual/Religious Concerns or Documentation that the Patient/Caregiver Did Not Want to Discuss*	• Hospice Quality Reporting (Implemented)
0326	*Advance Care Plan*	• Home Health Value-Based Purchasing (Implemented) • Merit-Based Incentive Payment System Program (Finalized) • Ambulatory Surgical Center Quality Reporting (Considered) • Hospital Outpatient Quality Reporting (Considered)
1626	*Patients Admitted to ICU who Have Care Preferences Documented*	N/A
1641	*Hospice and Palliative Care—Treatment Preferences*	• Prospective Payment System- Exempt Cancer Hospital Quality Reporting (Considered) • Hospice Quality Reporting (Implemented)
0210	*Proportion Receiving Chemotherapy in the Last 14 Days of Life*	• Merit-Based Incentive Payment System Program (Finalized) • Hospital Compare (Finalized) • Prospective Payment System – Exempt Cancer Hospital Quality Reporting: (Finalized)
0213	*Proportion Admitted to the ICU in the Last 30 Days of Life*	• Merit-Based Incentive Payment System Program (Finalized) • Hospital Compare (Finalized) • Prospective Payment System – Exempt Cancer Hospital Quality Reporting: (Finalized)
0215	*Proportion Not Admitted to Hospice*	• Merit-Based Incentive Payment System Program (Finalized) • Hospital Compare (Finalized) • Prospective Payment System – Exempt Cancer Hospital Quality Reporting: (Finalized)

NQF #	***Title***	***Federal Programs: Finalized or Implemented as of June 25, 2019***
0216	*Proportion Admitted to Hospice for Less Than 3 Days*	• Merit-Based Incentive Payment System Program (Finalized) • Hospital Compare (Finalized) • Prospective Payment System – Exempt Cancer Hospital Quality Reporting: (Finalized)
1623	*Bereaved Family Survey*	N/A
1625	*Hospitalized Patients Who Die an Expected Death with an ICD that Has Been Deactivated*	N/A
2651	*CAHPS Hospice Survey (Experience with Care): 8 PRO-PMs: (Hospice Team Communication; Getting Timely Care; Getting Emotional and Religious Support; Getting Hospice Training; Rating of the Hospice Care; Willingness to Recommend the Hospice; Treating Family Member with Respect; Getting Help for Symptoms)*	• Hospice Quality Reporting (Implemented)
3235	*Hospice and Palliative Care Composite Process Measure—Comprehensive Assessment at Admission*	• Hospice Quality Reporting (Implemented)

Banff Convening on Quality Measures for Serious Illness Care Starter Set

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. These experts identified a starter set of quality measures categorizedby well-being of patients and caregivers, experience of care, process measures of clinical care, advance care planning, safety, utilization, and cost and access. Some measures already exist, some would need to be modified from an existing measure, and others are proposed as new measures.

Domain	*Proposed Starting Measures and Tools*	*Existing*	*Modified*	*New*
Well-Being of Patients and Caregivers	• Integrated Palliative Care Outcome Scale (IPOS) - 5 (Cicely Saunders Institute, UK)	✓		
Experience of Care	• CAHPS Home- and Community-Based Services Measures (NQF #2967): Adapt for Serious Illness		✓	
Clinical Care	• Comprehensive Admission Assessment – % of Patient Stays During Which the Patient Received All Care Processes Captured by Quality Measures (NQF #1617, 1634, 1637, 1638, 1639, 1647, 1641 as applicable)	✓		
	• Caregiver Assessment			✓
	• Advance Care Plan (NQF #0326)	✓		
Safety	• Medication Reconciliation Post-Discharge (NQF #0097)	✓		
	Unwanted Care that Is Not Goal Concordant			✓
	Patient or Family Assessment of Goal Concordance			✓
Cost and Utilization	• Total Cost of Care (NQF #1604): Adapt for Serious Illness		✓	
	• Potentially Avoidable ED Visits	✓		
	• Potentially Avoidable Hospitalizations for Patients with Multiple Chronic Conditions (Yale/CMS measure)	✓		
	• Discharge to Community After SNF Stay (AHCA)	✓		
Access	• Hospice Enrollment and Enrolled More than 3 Days Before Death (NQF #0216)	✓		
	• Community-Based Program for Seriously Ill Offered			✓

Merit-Based Incentive Payment System Functional Assessment Measure

The Centers for Medicare & Medicaid Services (CMS) is required by law to implement a quality payment incentive program, referred to as the **Quality Payment Program**, which rewards value and quality outcome in two ways: Merit-Based Incentive Payment (MIPS) and Advanced Alternative Payment Models (APMs). Under the MIPS program, there is an existing functional outcome and assessment measure that may be useful as a starter measure (CMIT ID# 641; NQF ID# 2624). It is important to note that this measure is not specific to serious illness, but does capture current functional outcome assessment and documentation of a care plan based on identified functional outcome deficiencies.

This measure captures the documentation of a current functional outcome assessment using a standardized functional outcome assessment tool AND documentation of a care plan based on identified functional outcome deficiencies on the date of the identified deficiencies

AAHPM and HPNA Measuring What Matters

The **Measuring What Matters** initiative—led by the American Academy of Hospice and Palliative Medicine (AAHPM) and Hospice and Palliative Nurses Association (HPNA)—represents a major advancement in aligning performance measurement among healthcare professionals in the fields of hospice and palliative care. Through a consensus process[8], this effort proposed a set of 10 quality measures to use for program improvement, 6 which have since been applied as CMS requirements for hospices. Most of these measures are for the inpatient setting but may be helpful to reference in thinking about measurement in community settings.

- Comprehensive assessment of physical, psychological, social, spiritual, and functional needs
- Screening for pain, shortness of breath, nausea, constipation
- Pain treatment
- Shortness of breath treatment
- Discussion of emotional or psychological needs
- Discussion of spiritual/religious concerns*
- Documentation of surrogate decisionmaker and contact information
- Documentation of preferences for life-sustaining treatment
- Care consistency with documents preferences
- Global measure of patient and family experiences of care

*NQF-endorsed

Palliative Care Measures Project

In 2018, the American Academy of Hospice and Palliative Medicine (AAHPM), in partnership with the National Coalition for Hospice and Palliative Care (Coalition) and the RAND Corporation, was awarded a cooperative agreement from the Centers for Medicare & Medicaid Services to develop patient-reported quality measures for community-based palliative care. The measures are intended for use in CMS's

Quality Payment Program (QPP), including the Merit-Based Incentive Payment System and Alternative Payment Models. Two measures being developed in support of this project include patient-reported outcome performance measures (PRO-PMs) in the areas of pain/symptom management and communication for patients with serious illness who are receiving outpatient palliative care. The measures address if patients received desired help for pain, and whether they felt heard and understood by their palliative care provider and team.

International Consortium of Health Outcomes Measurement

With increased attention worldwide on issues of aging and chronic disease, building on an existing international framework may be helpful. **The International Consortium for Health Outcomes Measurement** (ICHOM) is a nonprofit organization that seeks to transform healthcare systems globally by measuring and reporting patient outcomes using a standardized approach. Over the past several years, ICHOM released several measure sets, including one focused on older persons, one focused on individuals with lung cancer, and one focused on dementia. These sets offer opportunities to align measurement in selected areas identified in this Brief and provide specifications to support data collection at an individual patient level. Collecting and aggregating this data could be highly valuable in monitoring person-centered outcomes in serious illness care and benchmarking progress internationally.

- Autonomy and control
- Loneliness and isolation
- Participation and decision making
- Mood and emotional health
- Caregiver burden
- Caregiver quality of life
- Activities of daily living
- Social
- Pain
- Frailty
- Place of death
- Fatigue and vitality
- Health-related quality of life
- Overall quality of life and well-being
- Shortness of breath
- Duration of time spent in hospital at end of life
- Acute complications of treatment

Center to Advance Palliative Care Recommended Measures/Measure Areas

Category	*Type*	*Quality Measure/ Measurement Area*	*Related NQF #*	*Purpose/Considerations/ Caveats*
Access	Structure	Availability of interdisciplinary palliative care team, with 24/7 response of some kind in selected facility(ies) (yes/no)		Structure measure that demonstrates palliative care capabilities; can be assessed through survey or achieving accreditation/certification.
Satisfaction	Patient Experience	CAHPS (Consumer Assessment of Health Providers and Systems)	#0009	Different versions of CAHPS available based on setting/ audience.
Satisfaction	Outcome	Likelihood to recommend the services or program (i.e., Net Promoter Score)		Practice-level reporting or plan can choose to send out surveys for all provider programs. Consider standardizing the surveys or asking for a copy of the surveys providers use in order to determine how to aggregate the data to display to department leaders and above.
Advance Care Planning	Process	Rates of patients who have an advance care plan or surrogate decision maker documented in the medical record or documentation in the medical record that an advance care plan was discussed but the patient did not wish or was not able to name a surrogate decision maker or provide an advance care plan	#0326	Specified for patients 65+, but consider application to younger patients.
Clinical Quality	Process	Proportion of patients with pain screening or assessment (and/or with pain plan of care)	#1634 #1637 #0420	Ideally it would be important to assess for other symptoms (e.g., breathlessness, nausea, fatigue, etc.), but scalable quality measures are not yet available.

Category	*Type*	*Quality Measure/ Measurement Area*	*Related NQF #*	*Purpose/Considerations/ Caveats*
Clinical Quality	Process	Proportion of patients with functional assessment (ability to perform activities of daily living and instrumental activities of daily living)	#2631	Functional information systematically captured in Medicare post-acute care settings due to IMPACT Act requirements; identify opportunities to leverage this information where possible.
Clinical Quality	Process	Proportion of patients with their caregiver burden formally assessed		Not yet commonly collected.
Utilization	Outcome	Rates of avoidable hospital and/or emergency department utilization; risk-adjusted as appropriate		Pull from claims data. Develop a plan to determine unwanted/unnecessary utilization. Set appropriate targets for consumer behavior/demographics (i.e., target should not be zero as this could disincentivize appropriate and necessary utilization).
Utilization	Outcome	Days at home: number of days a patient remains outside of an institutional care setting during a standardized time period		Pull from claims data. CMS level currently in development, recommend use of standard measure once available.
Utilization	Process	Appropriate hospice utilization (e.g., hospice referral rate or hospice length of stay (LOS) for those referred or proportion of hospice LOS less than seven days or more than 180 days for those referred)		LOS can be pulled from claims data.

National Committee for Quality Assurance Person-Driven Measures for Accountability

In 2018, the National Committee for Quality Assurance (NCQA) released a report outlining its project to develop a suite of **performance measures suitable for use in serious illness accountability programs**. These measures are intended to evaluate the quality of care through the lens of patient goals, as well as address a quality gap and support processes for moving to person-driven measures for evaluating goal-concordant care.

- **Comprehensive assessment**
  - Symptoms
  - Physical health
  - Behavioral health
  - Cognitive function
  - Physical function
  - Spiritual needs
  - Activities/independent activities of daily living
  - Caregiver strain and capabilities
- **Goal documentation**
- **Comprehensive care plan**
- **Person-driven measures of goal-concordant care, which could take several forms**
  - Goal concordance with the care plan
  - Goal concordance with care delivered
  - Goal concordance with care outcomes
  - Goal attainment
  - Processes associated with improved alignment between goals and outcomes or attainment
- **Patient engagement in serious illness and goal setting conversations (potentially a modified CAHPS survey for serious illness care)**

Additional Efforts Underway

There are a number of international efforts that may help to inform measure development and broaden our understanding of palliative and serious illness care. Hospice and nursing home efforts can also inform how we think about measurement in community settings.

The **Palliative Care Outcome Scale (POS)** is a body of work developed by a multidisciplinary team based in the United Kingdom. It was first developed in 1999 for use with patients with advanced disease and to improve outcome measurement by evaluating many essential and important outcomes in palliative care. The POS measures are continuously updated and contain validated instruments that can be used in clinical care, audit, research, and training. They are widely used globally, including in Europe, Asia, Africa, and America.

Australia's **Palliative Care Outcomes Collaborative (PCOC)** is a national voluntary program that is producing information to be used by clinicians and by local, state, and national providers of palliative care to continuously improve care for patients and their families. PCOC measures outcomes for pain, including physical symptoms; psychological well-being; spiritual needs; and family and carer outcomes.

The **Centers for Medicare & Medicaid Services Hospice Outcomes and Patient Evaluation (HOPE)** aims to develop quality measures that are meaningful to stakeholders and reflect critical outcomes of care throughout hospice stays. The measures will meet the **Meaningful Measures Initiative** objectives to identify high-priority areas for quality measurement while reducing the burden on hospice providers.

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NOTES

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