Serious Illness Strategies

Driving Value in High-Need Populations

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Introduction

Between 5 and 12 percent of U.S. adults live with serious illness and are at risk for preventable suffering and crisis utilization of health care services. As health care organizations drive toward value, improving care for this high-cost, high-needs population becomes a top priority. Yet what exactly does it take to ensure quality while improving the cost-effectiveness of care?
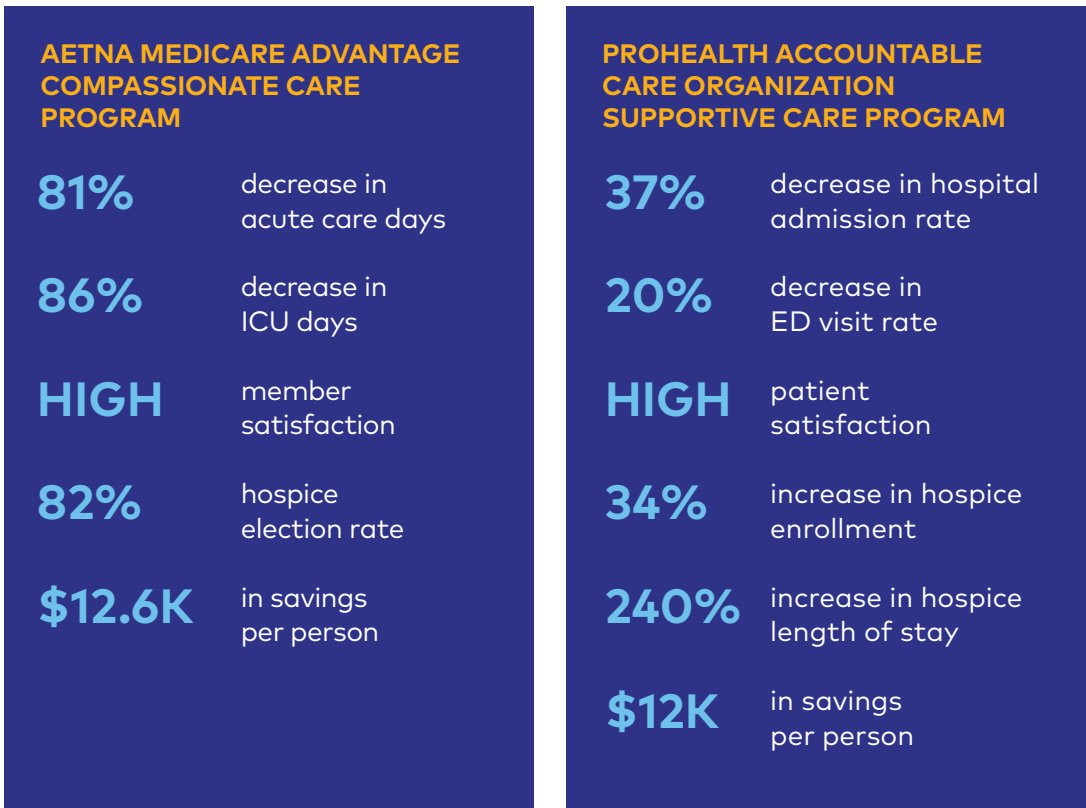
The Center to Advance Palliative Care (CAPC) has worked with health plans, ACOs (accountable care organizations), and population management entities across the country to define a core set of feasible strategies that make a significant difference in both quality of life and health care spending for people with serious illness.

The three key strategies are these: proactively identify rising-risk patients; engage with these individuals and assess their needs; and provide home-based supports to avert emergencies. These strategies align with the principles of Age-Friendly Health Systems, and many organizations have used this guidance to advance Age-Friendly principles. Payers can also add network quality management strategies to encourage their network to adopt serious illness strategies.

Serious Illness Strategies

Proactive Identification	Engagement and Assessment	Home-Based Supports
01	02	03

Combining the three serious illness strategies produces impressive results for a variety of health care organizations, as well as patients and families, as these two examples show:

AETNA MEDICARE ADVANTAGE COMPASSIONATE CARE PROGRAM

81%	decrease in acute care days
86%	decrease in ICU days
HIGH	member satisfaction
82%	hospice election rate
$12.6K	in savings per person

PROHEALTH ACCOUNTABLE CARE ORGANIZATION SUPPORTIVE CARE PROGRAM

37%	decrease in hospital admission rate
20%	decrease in ED visit rate
HIGH	patient satisfaction
34%	increase in hospice enrollment
240%	increase in hospice length of stay
$12K	in savings per person

The serious illness strategies are outlined in the following sections. They are accompanied by links to tools and resources, as well as recommended practical action steps and cautions from successful organizations that will facilitate your implementation.

Strategy 1

Proactively Identify the Seriously Ill Population

The Goal:

Identify medically complex patients who could benefit from an extra layer of responsiveness and support.

To have an impact on health care quality and cost, additional services and supports must be targeted to those with "high burden"—be it symptom burden, caregiver burden, and/or poor function—which can result in crisis use of care services. However, finding the right population for intervention continues to challenge many organizations. Clinician opinion is not a reliable screening mechanism, because clinicians often recognize such burdens too late, if at all. On the other hand, diagnosis data alone often indicate too large a population for action, including many people who may not be facing significant difficulties.

Recommended Strategy:

Combine Diagnosis with Evidence of Additional Need

Use a two-factor approach. Start with a short list of diagnoses or use a tool such as the Charlson Comorbidity Index.

Narrow down the list by incorporating additional data that indicate unmet need, impaired function, or high symptom burden—for example, a recent ED (emergency department) visit or hospitalization, orders for home oxygen or durable medical equipment, or any social risk factors that are captured in your data system.

Data-derived patient lists are most effective when reviewed and validated by the treating clinician, both to hone accuracy and strengthen relationships with network providers.

The "surprise question" (asking clinicians "How surprised would you be if this patient died in the next year?") has proven to be an unreliable identifier of patients with unmet need. However, asking a similar question directly of patients or their loved ones has been reported to work well: **How likely do you think it is that you'll find yourself in the hospital or emergency room in the next month or two?**

Two-Factor Algorithms Enhance Specificity

Adding an indicator of unmet need helps organizations distinguish between these patients:

Patient A:
Stage IV breast cancer with intermittent pain and growing weakness, relying on distant caregivers

Patient B:
Stage IV breast cancer actively employed and fully functional, equipped with knowledge and strong family support

Two-Factor Population Identification

First, a qualifying diagnosis must include at least one of these:	• Advanced cancer • End stage or stage V renal disease • Advanced dementia • Advanced lung disease • Advanced heart failure • Advanced liver disease • Diabetes (with severe complications) • Advanced Parkinson's disease • ALS, Huntington's, progressive supranuclear palsy, or other neurodegenerative disease • Hip fracture, over age 70 • Stroke requiring hospital admission

AND

At least one of these indicators of unmet need, impaired function, and/ or high symptom burden:	• One or more ED visits within the past six months • One or more hospital admissions within the past six months • Use of home oxygen • Home health episode with date of admission not following a hospital discharge (i.e., community referral) • Sequential home health episodes • Durable medical equipment claims consistent with impaired function or high symptom burden • Documented difficulty with activities of daily living, either captured in ICD-10 codes[*] or documented in post-acute data • Documented social needs (e.g., unsafe housing, food insecurity) captured in ICD-10 codes or documented in a social needs screen such as in the Accountable Health Communities program

*The full list of relevant ICD-10s is available in the Resources of the Kelley Laboratory.

# Practical Action Steps and Cautions from Successful Organizations

Clinician Control	Clinicians can still be in control, even if the initial identification process is data-driven. For example, use the data to prompt clinicians to assess for unmet needs with "Best Practice Alerts."
Polypharmacy Caution	Polypharmacy is a poor discriminator for need, since most patients are on too many medications. Instead, consider using anticholinergic burden to identify high-risk patients from within a population
Target Home Health	Targeting patients/members using home health benefits, especially those with community referrals, has been a successful tactic used by both plans and ACOs.
Racial Bias in the Data	EHR (electronic health record) and claims algorithms have been demonstrated to have implicit racial bias. To address this problem, some organizations have implemented a lower cut-point for the risk score for non-white populations.
Health Plan Information Sources	For health plans, useful information about patients' unmet needs is everywhere! Leverage all the conversations that your organization is having with patients—through customer service, pharmacy, utilization management, etc.—as these can reveal unknown burdens and barriers. Best practice is to funnel identified members to complex care managers (see more below).
Identifying Hospitalized Patients	Data-driven identification processes are also invaluable in connecting appropriate inpatients to needed expertise, such as specialty palliative care, in hospital settings.

> **PALLIATIVE CARE** is specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a specially trained team of doctors, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support. Palliative care is based on the needs of the patient, not on their prognosis.

Strategy II

The Role of Care Management: Engage with Patients and Assess Their Distress
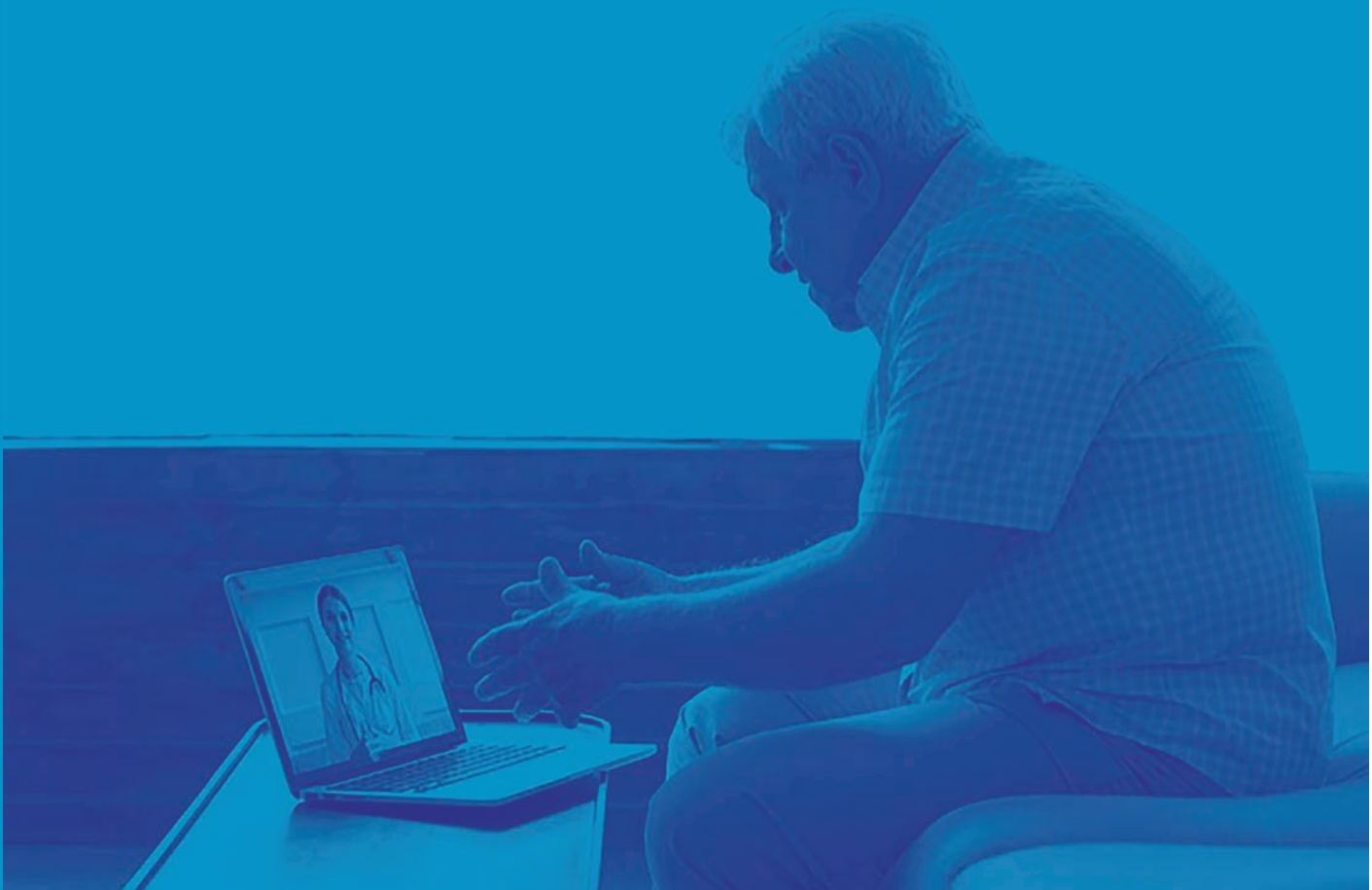
The Goal: Ensure true shared decision-making, eliciting what matters to patients and families, which typically includes relief from suffering.

While data can get you started on the road to addressing gaps in care, a skilled human connection is also necessary to uncover missing information, engage patients and families in shared decision-making, and triage to appropriate supports. Success lies in changing the role of care management—turning the focus from treatment adherence to uncovering and addressing potential suffering.

Early assessment for patient symptoms, worsening functional dependency, and high caregiver burden successfully identifies the population at risk for unnecessary emergency department and hospital utilization. It also facilitates timely triage to the most appropriate services, including palliative care team consultation, psychological services, social supports, and/or home-based care. At the same time, skilled care managers can engage in meaningful patient and family education and communication—ensuring that families know what to expect, can articulate their values and goals, understand resources and services available to them, and can plan ahead for what to expect and the often difficult decisions to come.

Organizations that excel in care management for serious illness reap significant reputational and financial benefits, with some reporting a three-to-one return on investment.

Typical Care Management	Improved Care Management
• Assess for unmet needs	• Assess for symptom burden, including pain, anxiety, depression, constipation, fatigue, and weakness • Assess for caregiver burden • Work with care team to preemptively address symptoms and other needs
• Educate patient and family on the disease and self-care	• Ensure that patient and family understand prognosis, what to expect, and what to do as the disease progresses • Clarify patient's values, goals, and preferences in the context of a realistic understanding of what to expect
• Support treatment adherence	• Work with clinical team to align treatment plan to the goals and values articulated by patient/family

Assess for Distress

The assessment should prioritize these three things: pain and other symptoms of illness; caregiver burden; and function. We know that many ED visits are caused by distressing symptoms and caregiving crises. The goal is to avert these with early detection and effective management.

High levels of burden should be reported to the treating team, and patients should be referred for additional supports as appropriate (e.g., palliative care or long-term services and supports; see next section).

Clarify What Matters

Equip care managers to hold meaningful conversations with patients and families facing serious illness, helping them to understand what to expect with their illness and think through what's important to them in this context. This is not about linkage to services—the conversation *is* the intervention. The first step is to help patients identify a surrogate decision-maker. Then, continuing conversations should help the patient and family clarify their goals and values, and carefully consider the range of care options available, without judgment or influence.

Some successful organizations use dedicated teams of care managers with lower caseloads who focus specifically on complex and high-need patients. This allows sufficient time and resources for building meaningful member/patient relationships and trust, as well as stronger shared decision-making skills within the team; some organizations have noted that palliative-informed care management pays for itself and much more. However, if such a staffing strategy is not feasible, strong relationships with specialty palliative care teams for expert communications are a must.

THIS IS NOT ABOUT LINKAGE TO SERVICES—THE CONVERSATION *IS* THE INTERVENTION.

Practical Action Steps and Cautions from Successful Organizations

Communication Skills Training Required	Care managers need sufficient training in communication skills specific to working with people facing serious illness, especially in responding to emotion. Online training is available, and should be reinforced with role play, case conferences, and/or ongoing supervisory feedback on recorded calls.
Actually Making a Connection	Getting patients and families to engage in initial care manager conversations can be difficult, especially with an overload of outreach targeted to high-need individuals, as well as the growing national concern over telephone scams. Send a letter or text first to alert them of future outreach by other team members, and follow other outreach best practices to optimize engagement. Follow a script during the enrollment process to reduce variation and standardize best practices.
Emotional Support for Staff	Working with seriously ill patients and their families is emotionally difficult. Make sure to provide your workforce with support and opportunities to process emotion, such as through debriefing sessions or events that allow space for grieving.
Always Assess for Symptom Distress	Programs focused on cancer, heart failure, and COPD, at minimum, should regularly assess for symptom burden. This can also begin to address long-standing racial disparities in the treatment of pain and other symptoms.
Additional Health Plan Advice	Health plan care managers should have the ability to expedite access to recommended services for their members with serious illness, and health plans should waive cost-sharing for palliative care consultations.

Strategy III

Provide Home-Based Care and Support for the Highest-Need Patients

The Goal: Bring services and supports to the patient, and match the intensity of care to patient need.

Once unmet needs have been assessed and meaningful conversations have begun, care managers should triage patients to appropriate supports that will optimize quality of life while preventing crises and exacerbations. Most successful organizations provide 24/7 access to additional supports in the home, although the intensity of services can—and should—vary with patient needs and circumstances.

Recommended Strategy:

Supply Required Services with Demonstrated Competency

Eligible patients and families facing serious illness should receive:

→ Interdisciplinary care from team members with demonstrated communications and symptom management competency

→ Care plans based on comprehensive assessment (including symptom burden, caregiver burden, and functional ability as described above) and coordinated with treating providers

→ 24/7 access to a trained clinician, with access to the patients' medical records, to provide timely and meaningful clinical support during crises

→ Medication review, reconciliation, and de-prescribing when warranted

→ Shared decision-making, with patient and family education on what to expect (coordinated with care management conversations to avoid duplication and conflicts)

→ Mental health services when warranted

→ Access to pharmacists, chaplains, and other professionals easily available

Agile Service Intensity

Triage patients to different levels of support via warm handoff, and reassess periodically for needed transitions. Some portion of the high-need population will require only short-term services to stabilize their situation and develop a sustainable care plan. Others will require intermittent services as illness waxes and wanes, and still others will require a complete handoff to a new team, such as home-based primary and palliative care or a Program of All-Inclusive Care for the Elderly (PACE).

Short-term and intermittent approaches require coordination with other services, including complex care management, certified home health services, and primary care medical homes. Some successful approaches include:

→ Two-phase programs, with an initial period of more frequent visits and services—and thus a higher price—during the "active phase," followed by periodic phone check-ins and after-hours access during a lower-priced "monitoring" phase

 • *In one pioneering program, the monitoring phase is facilitated with automated texts; patient responses indicating concerns trigger prompt outreach from the care team*

→ Time-defined (30–60 day) episodes of specialty palliative care consultations to stabilize patients and align treatment to care goals, provided through home visits and/or telehealth

→ Community paramedicine, in coordination with prescribers, that can respond promptly and meaningfully to urgent issues (e.g., administer IV medications at home), especially after-hours

Persistent needs—such as functional or cognitive impairment—will require ongoing supportive services. This can include home-based primary and palliative care and/or long-term services and supports.

**Dial Up or Down
the Intensity of
Home-Based Care**

SHORT-TERM
• Consults
• Stabilization
• Hospital at Home

INTERMITTENT
• Stabilization with ongoing monitoring

ONGOING
• Primary/palliative care at home
• Mental health care
• Personal care

Practical Action Steps and Cautions from Successful Organizations

Careful Service Coordination	Home-based care programs should coordinate closely with other providers and services involved in the patient's care. Regularly scheduled case conferences are recommended.
Six to Eight Weeks	There seems to be a natural point at six to eight weeks where patients either stabilize, move to hospice, or wind up needing longer-term in-home care. Test if this holds true in your own population, and if so, use this pattern to design your home-based strategy.
"Friday Processes"	To prevent crises when services are less available over the weekend, home-based programs can use "tuck-in calls" on Fridays to make sure all patients have what they need.
Post-Acute Care Opportunities	Specialty teams should be deployed to post-acute settings to ensure appropriate communication and symptom management during admission, as well as to facilitate discharge to home-based services.
Pay Attention to Culture	Culturally sensitive and responsive care is essential for patients coping with serious illness; monitor through patient and family feedback and provide clinician education as appropriate.
Staff Credentialing and Quality Assurance	To ensure high-value home-based care, carefully vet providers and their clinical team for certifications and/or demonstrated competencies, and then monitor appropriate quality indicators.

An Additional Strategy for Payers

Training and Incentives to Improve Palliative Care Capabilities and Outcomes

The Goal:

Strengthen the broader health care delivery system for the care of the population living with serious illness. Avoid bolt-on approaches, which ignore sustainable changes to the existing network, so that care is truly transformed.

The strategies described above have been used to improve both quality of life and cost-effectiveness across a broad range of organizations. Some payer organizations have also deployed strategies that encourage acquisition of skills and palliative care capabilities in their network practices and hospitals. Attention to these capabilities in the network is the foundation of a comprehensive approach to care transformation.

Recommended Strategy:

Palliative Care Quality Incentives

Two leading health plans—Anthem and Highmark—include measures of access to specialty palliative care in their hospital quality programs. Anthem rewards hospitals for the availability of a specialty palliative care team and a process to identify patients for their services, while Highmark rewards hospitals for reaching or exceeding a target proportion of patients in need of palliative care. Not only do these plans report positive member experiences from these efforts, but their network hospitals also value the programs.

In addition to these simple indicators, other process and outcome measures can be used to assess the quality of care delivered to the population with serious illness. Consider choices from a curated menu and adapt for data availability and feasibility in your own organization.

Recommended Quality Measure Concepts to Ensure High-Quality Care for People Living with Serious Illness

- Patient-reported outcome: "I feel heard and understood by this provider and team"

- Proportion of patients with documented symptom, function, and caregiver burden assessments completed

- Proportion of patients who have a documented surrogate decision-maker or declined to name one

- Proportion of decedents with any hospice utilization; and proportion receiving hospice for greater than seven days

Skills-Building Initiatives

Improving care quality for people living with a serious illness is everybody's job—every clinical interaction with the patient is an opportunity to recognize and address unmet need and prevent crises. This requires a network-wide commitment to train all clinicians in core skills, including communication, pain and symptom management, and caregiver support. Safe, high-quality care is much more likely when all physicians, nurses, and others demonstrate competency in:

→ Assessing the needs and concerns of patients and their caregivers

→ Strengthening the clinician-patient relationship

→ Managing pain and symptoms

→ Preventing crises and planning ahead

[Specific competencies by discipline and role](#) **have been defined through expert consensus and can be applied to network quality initiatives.**

Organizations have reported measurable quality improvement through training initiatives directed toward primary care clinicians, oncologists, nephrologists, and others.

THIS REQUIRES A NETWORK-WIDE COMMITMENT TO TRAIN ALL CLINICIANS IN CORE SKILLS, INCLUDING COMMUNICATION, PAIN AND SYMPTOM MANAGEMENT, AND CAREGIVER SUPPORT.

Practical Action Steps and Cautions from Successful Organizations

Advance Care Planning Is Far from Sufficient	Avoid advance directive completion rates as the basis for financial incentives or quality reporting. Focusing on form completion too often results in a "check-box mentality" and can actually lead to poorer communication between patients and clinicians. Moreover, [there is little data supporting the ability of advance care planning to subsequently influence](#) actual care at the bedside. Consider instead using the selection of a surrogate decision-maker for all adult patients as a reporting measure.
Provider Contracts Remain As-Is	Health plans do not need to modify or negotiate new provider contracts to implement these incentives. Palliative care measures and training completions can be incorporated into any existing value-based program.
Clinician Engagement	For optimal clinician engagement, target the training to where there is already a champion, or when a glaring problem is apparent in the data and training can be used to catalyze quality improvement.
Drive Training Completion	Ideas to drive completion include compensating clinicians for their time spent in training, and using reports and dashboards to encourage friendly competition among colleagues.

"Health care leaders have a tremendous opportunity at hand—to help families through a difficult experience while simultaneously optimizing value in health care delivery. With a growing consensus on the highest impact strategies, new standards of care are being set for care of our sickest and most complex patients."

Diane E. Meier, MD
Founder, Director Emerita, and Strategic Medical Advisor
Center to Advance Palliative Care

Whether you are a health plan, an ACO, or a health system, CAPC resources can help you identify patients for additional support, match services to patient needs, develop programs for home-based support, and train clinicians in core skills needed to care for patients with serious illness.

Learn more and take advantage of CAPC resources. capc.org/strategies
capc.org/toolkits/resources-for-health-plans

The strategies outlined in this publication are being implemented by a growing number of organizations across the country. From 2019 to 2020, CAPC convened 43 Medicare Advantage and Medicare Accountable Care Organizations— covering nearly 3.5 million Medicare beneficiaries—and culled their lessons learned to create this guide. These organizations recognized the opportunity to strengthen their businesses through shared exploration of best practices and new ideas to ensure high-value care for their members and patients facing serious illness. Additional guidance and continuing peer conversations are available through CAPC.

Contact membership@capc.org to learn more.