America's Care of Serious Illness
A STATE-BY-STATE REPORT CARD ON ACCESS TO PALLIATIVE CARE IN OUR NATION'S HOSPITALS
2019
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Preface

The 2019 *State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals* provides an analysis of whether patients living with a serious illness in the United States are receiving equitable access to palliative care services in hospitals. The goal is both to inform and to help the public and policymakers increase the availability of palliative care for the millions of people in need.

This report, an update of the 2015 edition, is the result of a collaboration between the Center to Advance Palliative Care (CAPC) and the National Palliative Care Research Center (NPCRC).

The report draws on the expertise of a research team led by R. Sean Morrison, MD, director of the National Palliative Care Research Center, Diane E. Meier, MD, director of the Center to Advance Palliative Care, and Maggie Rogers, MPH, Allison Silvers, MBA, Stacie Sinclair, MPP, and Rachael Heitner, MA, CHPCA, of CAPC.

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Introduction: Living with Serious Illness in America

America’s health care delivery system does not currently meet the needs of patients and families living with a serious illness. Our nation’s focus on disease-specific treatments, rather than on the needs of the whole person and their family, has resulted in unnecessary suffering, fragmented, burdensome—often futile—and costly interventions, untreated pain and symptoms, lengthy and repeated hospitalizations and emergency department visits, overwhelmed family caregivers, and clinician burnout. This is an unsustainable system in terms of both poor quality and high cost. Sweeping changes in standards of care for the most seriously ill are required if we are to provide appropriate and effective, value-driven care.

Health care costs are rising every year, and the United States continues to maintain its status as the highest per-capita spender on health care in the developed world. The current fee-for-service structure favors high-volume, quantity, and technical intervention and limits reimbursement for so-called cognitive services such as time-intensive care coordination, counseling, and comprehensive management of complex and multiple medical illnesses. As in most high-income nations, health care spending in the U.S. is appropriately—concentrated on the sickest and neediest patients: the top 5% of spenders account for nearly 50% of all health care costs. This group is characterized not only by the presence of one or more serious medical illnesses, but also by functional dependency (needing another person to get through the day), cognitive impairment, frailty, and heavy reliance on family and other caregivers. Contrary to common belief, the majority of people in this highest-cost, highest-need group are living with a serious illness. Only 11% of them are in the last twelve months of life.¹
Current expenditure is unsustainable and will worsen as the baby boomers age. At present, at least twelve million adults and 400,000 children are living with a serious illness, such as cancer, heart disease, kidney disease, or dementia. By 2035, the number of people over age sixty-five, 81% of whom live with multiple chronic conditions, will approach seventy-eight million and, for the first time, will eclipse the number of people eighteen years old or younger and the number of women age eighteen to fifty-five—the traditional caregiver workforce. For those over age eighty-five, the fastest-growing segment of the American population, one in three will have Alzheimer’s disease or a related dementia, and most will spend the last two years of their lives requiring assistance with at least one activity of daily living—eating, dressing, bathing, transferring, or toileting.

Due to unmet needs and unresolved symptoms, people living with a serious illness are heavy users of the health care system: 911 calls, emergency department visits, hospitalizations, and skilled nursing facility admissions are commonplace. In its recent report, “Being Seriously Ill in America Today,” The Commonwealth Fund reported consistently poor-value care for people with the most need:

**Patient Experience:** Twenty-two percent of people with a serious illness reported that hospital staff were not responsive to their needs, 23% reported receiving conflicting information from different health professionals, 21% would not recommend their hospital to someone else who has the same illness, and less than 50% were asked what their personal preferences would be if a critical situation should arise.

**Health Care Costs:** Thirty-seven percent reported having used up all or most of their savings dealing with their health and medical condition, even though 91% reported having health insurance. Twenty-three percent reported being unable to pay for necessities like food, heat, or housing.

**Caregiver Distress:** More than one-third of those who received help from a family caregiver noted strains and burdens on their caregivers, including emotional stress, physical stress, financial issues, and poorer health.
Palliative care offers a meaningful, high-value approach to the existing costly and often undesirable care options.

Palliative care offers a high-value approach to combating the existing costly and often undesirable care options (repeated and unwanted hospitalizations and skilled nursing facility admissions, unnecessary emergency department visits, and panicked 911 calls). As outlined below, the evidence is clear: to deliver high-quality, responsive care for our most complex patients, investment in reliable access to palliative care in America’s health care system is required.

What Is Palliative Care?

Palliative care is specialized team care that focuses on improving quality of life for patients and families in the setting of a serious illness. Palliative care is provided by a specially trained team of physicians, nurses, social workers, and others who work together with a patient’s other doctors to furnish an added layer of support. Many elements of palliative care—such as skilled communication about what to expect in the future and safe management of pain and other symptoms—can and should be delivered by all frontline clinicians, assuming they have adequate training. Palliative care is appropriate at any age and any stage in a serious illness, and it can be provided along with curative treatment. Because palliative care services are based on patient and family need, not prognosis, palliative care teams respond to the episodic, complex, and long-term nature of serious illness.

Palliative care improves care quality.

Most serious illness is present over many years. Although most serious illness progressively worsens over time, the trajectory is rarely predictable or continuous: patients experience periods of relative stability intermixed with shorter periods of crisis or disease exacerbation. Palliative care addresses the needs of patients and families over time and across stages of illness by providing continuous, coordinated, and quality care in the setting of a serious illness. By supplying expert medical care—specifically, treatment of pain and other symptoms, skilled communication, and aligning treatment to patient needs and goals—palliative care teams help patients and
families preempt or manage predictable complications, thus avoiding unwanted and often expensive crisis care.

Recent studies have shown that palliative care reduces symptoms and improves quality of life for both the patient and their family caregivers. This reduces unnecessary emergency department visits, hospitalizations, and time spent in the intensive care unit.\textsuperscript{9,10,11} For some patient populations, studies suggest that patients receiving palliative care live longer than those receiving only traditional medical care.\textsuperscript{12} Recent studies of symptom burden among cancer patients found not only reduced crisis care utilization, but also improved quality of life and better survival as compared to the control group of those without palliative care.\textsuperscript{13,14,15}

**Palliative care lowers costs.**

Investment in palliative care is repaid through the cost savings associated with the prevention of health crises that palliative care programs provide. On average, palliative care consultation is associated with reductions in direct hospital costs of more than $3,000 per admission, and for the sickest patients with four or more diagnoses, these cost savings are closer to $4,800 per admission.\textsuperscript{16} Incorporating standardized access to palliative care services for patients with serious illness in our nation’s hospitals has the potential to save hospitals and health systems hundreds of millions of dollars per year.

**People want what palliative care provides.**

AA national poll conducted in 2019 by Public Opinion Strategies (POS)\textsuperscript{17}, revealed broad nationwide support for palliative care services. Although most respondents did not have a strong understanding of what palliative care had to offer, once informed about palliative care services, 90% said that they would be likely to consider palliative care for a loved one if they had a serious illness. Additionally, 94% stated it is important that palliative care services be made available at all hospitals for patients with a serious illness and their families, while 90% agreed that it should be covered by health insurance.
Findings and Analysis: A National and State-by-State Review and Report Card

As of 2019, 72% of hospitals with fifty or more beds report a palliative care team.

As in our prior reports (2001, 2008, 2011, and 2015), this report describes the prevalence and locations of hospital palliative care programs across the fifty states and the District of Columbia using data from the American Hospital Association (AHA) Annual Survey Database™, the National Palliative Care Registry™, and CAPC’s Mapping Community Palliative Care initiative.

This Report Card demonstrates continued linear growth in the number of hospital palliative care teams in the United States. As of 2019, 72% of hospitals with fifty or more beds report a palliative care team, up from 67% in 2015 and 7% in 2001. These hospitals currently serve 87% of all hospitalized patients in the U.S., an increase from 82% in 2015. Significant regional variation persists, with penetration highest in New England and lowest in the south-central states. Large nonprofit hospitals in urban centers remain the institutions most likely to provide access to a palliative care team.

Where you live matters.

Geographic location and regional characteristics influence the availability of palliative care services. People living with a serious illness who reside in the northeastern United States have access to significantly more hospital palliative care programs than those living in other regions. The Mid-Atlantic and east north-central regions increased an entire letter grade since 2015, joining New England as ‘A’ regions, with more than 80% of their hospitals now reporting a palliative care team. A significant change was also observed in the west south-central region of the U.S., where the number of hospitals with palliative care teams improved from 42% in the last Report Card to 50% in 2019 (Graph A).
Three-quarters of states now have a grade of A or B.

Graph A. Growth in the prevalence of hospital palliative care by region, from 2015 to 2019

Growth in palliative care prevalence varies greatly by region.

Graph B. Number of states by grade (2008, 2011, 2015, 2019)

Three-quarters of states now have a grade of A or B.
In the 2019 Report Card, three-quarters of states receive a grade of either A or B, with more than 60% of hospitals in those states reporting a palliative care program; no state received an F grade (Graph B).

- **Four states** (Delaware, New Hampshire, Rhode Island, and Vermont) have palliative care teams in all of their hospitals with fifty or more beds.

- **Four additional states** (Connecticut, the Dakotas, and Utah) and the District of Columbia are one hospital shy of 100% penetration.

- Alabama, Mississippi, New Mexico, Oklahoma, and Wyoming were the lowest-performing states, with fewer than 40% of hospitals reporting palliative care teams.

The Appendix Table presents detailed results by state, including hospital palliative care counts and prevalence by hospital ownership type (nonprofit, for-profit, and public), sole community provider hospitals, and larger hospitals with 300 or more beds. These data are limited to hospitals with fifty or more beds. The Appendix Table separately presents the prevalence of palliative care programs among small hospitals with fewer than fifty beds.
Hospital Palliative Care Grades by Region 2019

Region grade by color:

- **A**: 80% or more
- **B**: 60%–79%
- **C**: 40%–59%

**Pacific**
- Alaska: C
- California: B
- Hawaii: B
- Oregon: A
- Washington: A

**Mountain**
- Arizona: B
- Colorado: A
- Idaho: B
- Montana: C
- Nevada: A
- New Mexico: D
- Utah: A
- Wyoming: D

**West South Central**
- Arkansas: C
- Louisiana: B
- Oklahoma: D
- Texas: C
Source: Center to Advance Palliative Care (CAPC)
At a state level, fourteen states increased a letter grade, half of them moving from a B to an A between 2015 and 2019. Two states, Montana and Nebraska, dropped down a grade, although this resulted from an increase in the overall number of hospitals (the denominator) rather than a significant decrease in or closure of palliative care teams (the numerator).

Access to palliative care for people living in rural America remains limited. Ninety percent of hospitals with palliative care are in urban areas. Only 17% of rural hospitals with fifty or more beds report palliative care programs.

**Access to palliative care depends on hospital characteristics.**

Hospital characteristics associated with a higher likelihood of having a palliative care team remain consistent since we began our reports. The likelihood of a hospital having a palliative care team increases with hospital size (Graph C). Ninety-four percent of U.S. hospitals with more than 300 beds now have a palliative care team, compared to 62% of hospitals with fifty to 299 beds.

→ **TAX STATUS** remains a strong significant predictor of the presence of a palliative care team. For-profit hospitals of any size are significantly less likely to provide palliative care services than nonprofit or public hospitals. Eighty-two percent of nonprofit hospitals, 60% of public hospitals, and only 35% of for-profit hospitals (up from 23% in 2015) report palliative care programs. In larger hospitals with 300 or more beds, nearly all public and nonprofit hospitals, 98% and 97%, respectively, have palliative care teams, whereas only 63% of for-profit hospitals report a palliative care program (Graph D). Reasons for differences in palliative care availability by tax status are unknown. However, differential adoption of palliative care by for-profit hospitals is consistent with overall lower investment in high-value services.18
Graph C. Percentage of hospitals with a palliative care program by hospital size and region, 2019

Prevalence of palliative care programs increases with hospital size across regions.

Graph D. Proportion and percent of hospitals with palliative care by tax status, 2019

Access to palliative care is lower in for-profit hospitals regardless of hospital size.
PUBLIC AND SOLE COMMUNITY PROVIDER HOSPITALS are often the only option for people lacking health care coverage (10% of the population) or for those who are geographically isolated. Only 40% of sole community provider hospitals reported a palliative care team in 2019, a number that was not statistically different from our finding in 2015. The situation is slightly better for patients at public hospitals, which typically provide care for immigrants, the indigent, and the uninsured. Sixty percent of public hospitals report palliative care programs, but this number has remained unchanged over the past four years.

FREESTANDING CHILDREN’S HOSPITALS with fifty or more beds are included for the first time in the 2019 Report Card. Children's hospitals are overwhelmingly nonprofit (95%) and located in urban areas (100%) and contain, on average, 268 beds. Of the fifty-six freestanding children's hospitals with fifty or more beds in the United States, forty-eight (86%) report a pediatric palliative care team. In the Pacific region, all eleven children's hospitals (100%) report pediatric palliative care teams.

HOSPITALS WITH FEWER THAN FIFTY BEDS make up more than two-thirds of our nation's hospitals but account for only 1.2 million patient admissions (4% of all admissions). Small hospitals are typically in rural areas. In sparsely populated states, like Iowa, Kansas, Montana, and the Dakotas, three-quarters or more of all hospitals have fifty or fewer beds. The small number of annual patient admissions at small hospitals and the even smaller number of admissions that could benefit from palliative care may make it difficult for many of these hospitals to support a full palliative care team. Nevertheless, 36% of small hospitals did report a palliative care program of some type. Further research is needed to identify affordable models of palliative care that can provide high-value care for people living with a serious illness who are served by small hospitals. While not included in the overall Report Card state grades, more detail on small hospitals with palliative care can be found in the Appendix Table.
Meeting the need requires more than just access.

Clinicians, hospitals, and health systems have recognized palliative care as indispensable to the delivery of high-value care to people living with a serious illness—those in the highest-cost and highest-need 5% of U.S. patients. Over the past decade, the number of hospitals with palliative care in the United States has increased significantly since the first national findings were published in 2001. Despite this steady and impressive growth, millions of people living with a serious illness still do not have access to hospitals that provide palliative care; access is determined not by patient need but by where a patient lives or the type of hospital (factors such as hospital size or tax status) to which they are admitted. Hospital palliative care programs are often understaffed and therefore not likely to meet the needs of the ever growing number of referrals.\textsuperscript{20} Equitable and reliable access to quality palliative care services must improve across the nation.

America’s sickest patients are admitted to every hospital in the United States, and yet, not all clinicians are appropriately equipped to care for them. Patient ranking of the quality of communication with their clinicians is an independent predictor of hospital readmissions; on average a hospital could reduce its readmission rate by 5% if it prioritized training clinicians in good communication with patients.\textsuperscript{21} Improving care for our nation’s patients and families requires all current and future clinicians, primary care physicians, and palliative care and other specialists alike to receive training in skilled communication, safe and effective symptom management, and psychosocial assessment and support, and in understanding when to refer patients to specialist-level palliative care. Ensuring that all clinicians who care for complex and seriously ill patients are trained in these competencies is essential to improving the quality of patient care, reserving access to specialist palliative care teams for the most complex patients and their families.

Equitable and reliable access to quality palliative care services must improve across the nation.
A Call to Action: Accelerating Progress in Palliative Care Policy

Leaders in the public and private sectors can take specific actions to standardize access to timely and high-quality palliative care services and move U.S. health care to a system that reliably meets the needs of people living with a serious illness, and their families.

Since the 2015 *State-by-State Report Card* was published, the palliative care field has made steady progress across multiple domains, thanks in part to supportive policies from Congress, federal agencies, and state governments, as well as generous private sector investments. However, prevalence varies based on geography and hospital characteristics such as size and tax status. Leaders in the public and private sectors can take specific actions to standardize access to timely and high-quality palliative care services and move U.S. health care to a system that reliably meets the needs of people living with a serious illness, and their families.

**Policy Progress over the Past Four Years**

**WORKFORCE GROWTH**

Since the formal recognition of palliative care as a medical subspecialty in 2008, the field has grown to include 7,618 board-certified palliative care physicians, and more than 18,000 palliative care–certified nurses. The Social Work Hospice & Palliative Care Network (SWHPN) released a palliative care certification program in 2018, and specialty training and certification opportunities now exist for chaplains, physician assistants, and pharmacists.

**PAYMENT REFORM**

In the last three years, Medicare has made changes to allow specific payment for advance care planning and complex chronic care management. The Center for Medicare and Medicaid Innovation (CMMI) began testing new models that expand access to palliative care specialists, including the Oncology Care Model and the Medicare Care Choices Model.
The Creating High-Quality Results and Outcomes Necessary to Improve Chronic (CHRONIC) Care Act, passed as part of the Bipartisan Budget Act of 2018, will allow Medicare Advantage (MA) plans to pay for social supports as well as in-home palliative care services for specific populations. Value-based insurance design may also provide a payment platform for non-hospital palliative care.

QUALITY, STANDARDS, AND RESEARCH ADVANCES

In 2015, the National Quality Forum (NQF) established a Palliative and End-of-Life Care Standing Committee (changed to the Geriatrics and Palliative Care Standing Committee in 2018) to rigorously scientifically review and endorse quality measures for older adults and those with a serious illness. In 2018, the Centers for Medicare and Medicaid Services (CMS) contracted with the American Academy of Hospice and Palliative Medicine (AAHPM) to develop new palliative care quality metrics to help fill measurement gaps identified by NQF. In 2018, the fourth edition of the National Consensus Project (NCP) *Clinical Practice Guidelines for Quality Palliative Care* was published, updating existing guidelines and establishing new standards and expectations for all health care professionals caring for people living with a serious illness, and their families. In the areas of research, the National Palliative Care Research Center and the National Institutes of Health (NIH) published white papers on palliative care research funding priorities, followed by a series of NIH program announcements encouraging submission of palliative care research projects. Concurrently, the Patient-Centered Outcomes Research Institute (PCORI) directed roughly $100 million to palliative care research, comparing the effectiveness of different delivery strategies across providers, settings, and modalities.
ENHANCED CLINICIAN SKILLS
Recognizing that nearly all clinicians care for patients living with a serious illness, several states passed laws for continuing education requirements in pain management, safe opioid prescribing, and palliative care. Several private health plans are beginning to require clinician training in core palliative care knowledge and skills as a component of their incentive programs for hospital quality.

INCREASED PUBLIC AWARENESS AT THE STATE LEVEL
As of publication, twenty-eight states have established Palliative Care Advisory Councils (or similar bodies) that are charged with increasing awareness of palliative care. Activities include developing websites to provide palliative care information to state residents, analyzing state-level access to palliative care, and providing state governments with recommendations for future policy action.

Remaining Gaps
Despite this progress, people living with a serious illness still do not have reliable access to palliative care. To ensure this access, policymakers must overcome persistent gaps and challenges.

WORKFORCE
Inadequate workforce and workforce pipeline to meet the needs of patients living with a serious illness, and their families

PAYMENT
Insufficient financing and financial incentives to ensure equitable and reliable access to palliative care for all people living with a serious illness
QUALITY, STANDARDS, AND RESEARCH
Lack of accountability for access to high-quality care delivery for patients with a serious illness; gaps in the evidence base to build the science guiding clinical practice

CLINICIAN SKILLS
Insufficient clinician training in communication; pain and symptom management; family assessment and support; and care over time and across settings

PUBLIC AND CLINICIAN AWARENESS
Continued lack of knowledge about the benefits of palliative care and who can benefit from it

Leaders in both the public sector (particularly those who oversee Medicare and Medicaid) and private sector (private health plans, purchasers, and accountable care organizations) can take specific actions to address these issues.
Policy Recommendations

Federal Legislation

Workforce

PASS the Palliative Care and Hospice Education and Training Act (PCHETA), which—among other things—establishes:

- grants to medical schools and teaching hospitals for career development awards
- workforce development and fellowships for doctors, nurses, and social workers
- career incentive awards for nurses, social workers, chaplains, and others

On July 23, 2018, the full House of Representatives passed the Palliative Care and Hospice Education and Training Act (PCHETA) by voice vote. This was the result of years of education by stakeholders in the field, as well as leadership by members of Congress and their staffs. PCHETA (H.R. 647) was reintroduced in the 116th Congress in 2019.

audience: CONGRESS

ESTABLISH loan forgiveness programs for clinicians who work as palliative care specialists.

audience: CONGRESS

EXPAND Medicare-funded graduate medical education (GME) slots to train medical professionals, with provisions specifically for palliative care fellowships.

audience: CONGRESS
Payment

**ELIMINATE** Medicare beneficiary cost sharing for patient-centered services such as advance care planning and chronic care management, and evaluate the impact of these changes.

Beneficiary copayments have been identified by clinicians and patients alike as a barrier to accessing necessary services. Previous legislation has successfully removed beneficiary cost sharing for high-value services such as evidence-based screenings and immunizations and could be replicated for services such as advance care planning.

**audience:** CONGRESS

**REVISE** Medicare Conditions of Participation for hospitals and skilled nursing facilities to incorporate the availability of specialty palliative care teams meeting quality standards. Alternatively, incentivize palliative care team availability for these facilities.

**audience:** CONGRESS

**CREATE** and expand existing Medicare alternative payment models driving improved quality of care, quality of life, and health outcomes in patients with a serious illness. Ensure that all models allow concurrent palliative care and disease treatment.

**audience:** CONGRESS

**MODIFY** the Medicare home health benefit eligibility—which currently requires that patients be “homebound” and have a “skilled need”—to include patients with certain characteristics (such as functional or cognitive impairment) to improve access to home health services.

**audience:** CONGRESS
**Policy Recommendations**

**Remove** restrictions on telehealth for Medicare beneficiaries with a serious illness.

**Audience:**
- CONGRESS

**Quality, Standards, and Research**

**Pass** PCHETA, which enhances the National Institutes of Health (NIH) research in palliative care.

In 2018, the Labor and Health and Human Services (L/HHS) Appropriations bill urged the NIH to develop and implement a trans-Institute strategy to expand and intensify national research programs in palliative care to address quality of care and quality of life for the rapidly growing population of individuals in the United States living with a serious illness.

**Audience:**
- CONGRESS
- NATIONAL INSTITUTES OF HEALTH (NIH)

**Clinician Skill Building**

**Create** a grant program to fund targeted clinical training in the care of people with a serious illness.

**Audience:**
- CONGRESS

**Public and Clinician Awareness**

**Pass** PCHETA, which establishes a national palliative care education and awareness campaign to educate patients, caregivers, and providers about the benefits of palliative care.

In 2018, the L/HHS Appropriations bill encouraged the Agency for Healthcare Research and Quality (AHRQ) to consult with relevant stakeholders to develop and disseminate information to patients, families, and health professionals about palliative care as an essential part of the continuum of quality care for people living with a serious illness.

**Audience:**
- CONGRESS
- AGENCY FOR HEALTHCARE RESEARCH AND QUALITY (AHRQ)
Federal Regulation

Payment

**ELIMINATE** Medicare beneficiary cost sharing for patient-centered services such as advance care planning and chronic care management and evaluate the impact of these changes.

**audience:**

CENTER FOR MEDICARE AND MEDICAID SERVICES (CMS)

**CREATE** and expand existing Medicare alternative payment models driving improved quality of care, quality of life, and health outcomes in patients with a serious illness. Ensure that all models allow concurrent palliative care and disease treatment.

In April, 2019, CMMI released the Seriously Ill Population option under a new primary care alternative payment model.

**audience:**

CENTER FOR MEDICARE AND MEDICAID INNOVATION (CMMI)

**MODIFY** the Medicare home health benefit eligibility—which currently requires that patients be “homebound” and have a “skilled need”—to include patients with certain characteristics (such as functional or cognitive impairment) to improve access to home health services.

**audience:**

CENTER FOR MEDICARE AND MEDICAID SERVICES (CMS)

**INCLUDE** functional and cognitive status as a distinct element in premium risk adjustments in Medicare Advantage (MA).

Understanding a patient’s functional status is a crucial factor in identifying who is appropriate for palliative care and in developing a care plan that best meets their individual needs. In 2018, the Government Accountability Office (GAO) released a report showing the relationship between functional status and actual spending for MA members. This GAO report called for functional abilities to be factored into MA risk adjustment.

**audience:**

CENTER FOR MEDICARE AND MEDICAID SERVICES (CMS)
EXPLORE additional regulatory flexibility to expand telehealth access for people with a serious illness who are in the traditional Medicare program. Telehealth can significantly expand access to palliative care for people living with a serious illness. Recent policy changes to advance telehealth include the CY19 Physician Fee Schedule, which allows for two new services—brief virtual check-ins with patients, and remote evaluation of recorded video and images.

**audience:**

[CENTERS FOR MEDICARE AND MEDICAID SERVICES (CMS)]

### Quality, Standards, and Research

**IMPLEMENT** legislative direction from the 2019 Labor and Health and Human Services Appropriations bill to expand research funding in palliative care.

**audience:**

[NATIONAL INSTITUTES OF HEALTH (NIH)]

**BOLSTER** patient experience measures in current and future Medicare value-based purchasing programs.

**audience:**

[CENTERS FOR MEDICARE AND MEDICAID SERVICES (CMS)]

**IMPLEMENT** Medicare Access and CHIP Reauthorization Act (MACRA)—funded measures for specialty palliative care within the relevant clinician payment programs and explore adoption for other Medicare payment programs.

In 2018, CMS awarded the American Academy of Hospice and Palliative Medicine (AAHPM)—with support from the National Coalition for Hospice and Palliative Care (NCHPC) and RAND Corporation—$5.5 million to develop at least two new quality measures specific to communication skills and symptom management skills.

**audience:**

[CENTERS FOR MEDICARE AND MEDICAID SERVICES (CMS)]
ENSURE that professionals with palliative care expertise are included on relevant Center for Scientific Review (CSR) study sections within the NIH, and that appropriate ad hoc reviewers are involved in relevant reviews when standing study section expertise is lacking.

**audience:**
NATIONAL INSTITUTES OF HEALTH (NIH)

ADD quality incentives for selected entities (e.g., hospitals, skilled nursing facilities, home health agencies, and dialysis centers) that reward both clinician training programs and access to palliative care teams.

Experience from the private sector can inform public efforts to incentivize high-quality palliative care. For instance, one national payer incorporated palliative care as a measure in its hospital quality incentive program; hospitals earn credit by achieving Advanced Certification for Palliative Care, or by meeting four core standards that include access to a specialty team along with an all-staff training program.

**audience:**
CENTERS FOR MEDICARE AND MEDICAID SERVICES (CMS)

ENSURE that any policies designed to address the opioid epidemic do not restrict necessary access to these medications for people with a serious illness and those receiving palliative care.

**audience:**
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS)
U.S. DRUG ENFORCEMENT ADMINISTRATION (DEA)

**Public and Clinician Awareness**

UNDERTAKE, support, and share communication and behavioral research aimed at assessing public perceptions and actions concerning care for people living with a serious illness, developing and testing effective messages and tailoring them to appropriate audience segments, and measuring progress and results.

**audience:**
AGENCY FOR HEALTHCARE RESEARCH AND QUALITY (AHRQ)
State Policy

Workforce

**ESTABLISH** or expand loan forgiveness programs for clinicians who work as palliative care specialists.

Federal and state governments can support growth in the palliative care workforce by helping cover the costs of training. For instance, Maryland maintains the Maryland Loan Assistance Repayment Program (MLARP). This program provides financial support that can be applied toward higher-education loans to certain physicians, physician assistants, and medical residents who work in eligible care sites.

**audience:** STATE LEGISLATURES | STATE HEALTH DEPARTMENTS

Payment

**PAY** for services beneficial to people with a serious illness by using existing codes, such as advance care planning, interdisciplinary team consults, and respite for family caregivers.

States can support palliative care through traditional Medicaid by adding specific billing codes to their Medicaid benefits. For instance, both Delaware and Virginia added codes that pay for advance care planning services, interdisciplinary care team consults, and respite services.

**audience:** STATE LEGISLATURES | STATE MEDICAID DIRECTORS

**INCLUDE** home-based palliative care as a benefit under Medicaid Managed Care (MMC) and/or Managed Long-Term Services and Supports (MLTSS).

**audience:** STATE LEGISLATURES

**CREATE** opportunities to support pediatric palliative care, including embedding within existing programs and structures, such as Medicaid Health Homes or Early and Periodic Screening, Diagnostic, and Treatment (EPSDT).

**audience:** STATE LEGISLATURES
REVISE state exchange requirements to allow palliative care to be included as a benefit in any on-exchange plan.

audience:

STATE REGULATORY BODIES

INCLUDE functional and cognitive status as a distinct element in premium risk adjustments in Medicaid Managed Care (MMC).

audience:

STATE MEDICAID DIRECTORS

INCENTIVIZE provision of palliative care services to beneficiaries with serious illness under MMC and Managed Long-Term Services and Supports (MLTSS) through improved risk adjustment and quality incentives.

MMC plans provide a significant opportunity to expand palliative care to states’ most vulnerable residents. In 2014, California passed SB 1004, which required that all Medi-Cal plans cover palliative care for members with a serious illness.

audience:

STATE LEGISLATURES

STATE MEDICAID DIRECTORS

Quality, Standards, and Research

INSERT licensure requirements that hospitals and skilled nursing facilities with fifty or more beds provide access to specialty palliative care teams, as well as staff training on palliative care, communication, and symptom management.

Maryland, informed by findings from a legislatively mandated pilot study on hospital palliative care, updated its regulations to require that hospitals with fifty or more beds establish an active, hospital-wide palliative care program that provides consultation services to patients living with a serious illness.

audience:

STATE LEGISLATURES

STATE REGULATORY BODIES
INSERT a definition of and minimum standards for palliative care in the state code and relevant regulations, outside of hospice regulations.

Formalizing a clear definition and standards for palliative care can ensure quality and consistency. Colorado has a detailed definition in its health facility licensure, which provides clarity on the settings in which palliative care can be offered and establishes a foundation for palliative care activity in the state and a future framework for accountability.

audience:

| STATE LEGISLATURES | STATE REGULATORY BODIES |

ESTABLISH separate licensure for home-based palliative care and modify existing licensure for hospices and home health agencies based on existing practice standards.

To clarify that licensed hospices can provide non-hospice palliative care services to people with a serious illness, California passed SB 294. The state will monitor and evaluate the effects of hospice providers offering palliative care services and review findings by 2021.

audience:

| STATE LEGISLATURES | STATE REGULATORY BODIES |

REQUIRE providers, accountable care organizations, and managed care plans to report on relevant metrics or include palliative care in performance improvement projects to relevant oversight bodies.

Texas included palliative care as one of the projects in its Delivery System Reform Incentive Payment (DSRIP) program. By the program’s end, twenty projects were reporting on one or more outcomes related to palliative care, including pain management and treatment preferences, with most reporting improvement over their baseline.

audience:

| STATE LEGISLATURES | STATE REGULATORY BODIES |
ENSURE that any policies designed to address the opioid epidemic do not restrict necessary access to these medications for people with a serious illness and those receiving palliative care.

While a majority of states are passing new laws and regulations to reduce the harm caused by the opioid epidemic, several states have simultaneously recognized the need to balance policy proposals and preserve access to necessary medications for people living with a serious illness. Maine, Vermont, and Indiana are examples of states that have included such exemptions.

**Clinicin Skill Building**

CREATE a grant program to fund targeted clinical training in the care of people with a serious illness. This can include the implementation of state cancer control plans.

Nebraska established a separate 501(c)(3) to implement its cancer control plan, which includes palliative care in the survivorship section. It has used Comprehensive Cancer Control Program funding to provide palliative care training to targeted cancer programs and clinicians and has leveraged national surveys to capture palliative care availability in the state.

**REVISE** state health professional licensure and continuing education requirements to include a minimum number of hours of instruction in both communication skills and symptom management skills.

Georgia requires that physicians working in pain management clinics demonstrate coursework in palliative care. Other states with pain management or palliative care continuing education requirements include New Jersey, Oregon, and Rhode Island.

**STATE POLICY**

**STATE LEGISLATURES**

**STATE REGULATORY BODIES**
Public and Clinician Awareness

**ESTABLISH**, in states that have not already done so, a multidisciplinary palliative care advisory board and task force.

Palliative Care Advisory Councils or similar bodies have been established in twenty-eight states, including Kansas, Ohio, Oklahoma, South Carolina, and Texas.

**audience:**

STATE LEGISLATURES

**INCLUDE** access to patient-centered services such as palliative care in state patients' bills of rights.

A patient's bill of rights can be a consequential tool for empowering patients to demand high-quality care. Recognizing this, Vermont inserted a section on palliative care and pain management in its Bill of Rights for Hospital Patients in 2009.

**audience:**

STATE LEGISLATURES, STATE REGULATORY BODIES

**INCREASE** the role of state public health agencies in promoting palliative care, developing referral resources and educational materials, and possibly delivering these services directly.

**audience:**

STATE HEALTH DEPARTMENTS
Purchasers, Health Plans, and Accountable Care Organizations (ACOs)

Workforce

IDENTIFY clinicians in the existing network who are certified in palliative care to understand network capacity, and to classify them as high-value providers. Because palliative care is a subspecialty, additional research through professional societies is needed to identify these clinicians.

audience: health plans, ACOs

Payment

REDUCE or eliminate cost sharing for all encounters with members of a specialty palliative care team, as well as for all advance care planning conversations.

One pioneering health plan has been covering unlimited advance care planning conversations during any provider appointment.

audience: purchasers, health plans

COVER interdisciplinary team care in home and office settings, with 24/7 clinical response to crises, for eligible individuals. Consider changing the hospice policy to allow concurrent disease treatment while enrolled in hospice.

The Bipartisan Budget Act of 2018 enables Medicare Advantage (MA) plans to offer supplemental benefits to subsets of their members, based on member characteristics such as diagnosis. Centers for Medicare and Medicaid Services (CMS) guidance specifically highlighted home-based palliative care services as an example of the type of supplemental benefit that can be offered.

audience: purchasers, health plans
**BUILD** and operate programs of in-home interdisciplinary team care, with 24/7 clinical response to crises.

The impact on avoidable utilization by a New York–based ACO that provides home-based palliative care was recently published in the Journal of Palliative Medicine.\(^24\)

**Audience:**

ACOs

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**Quality, Standards, and Research**

**DEVELOP** and implement standing processes to screen for unmet palliative care needs by leveraging data analytics to proactively identify people living with a serious illness, functional impairment, and/or memory loss.

**Audience:**

HEALTH PLANS, ACOs

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**REQUIRE** or incentivize network hospitals, home health agencies, and skilled nursing facilities to demonstrate the availability of specialty palliative care teams who meet national guidelines. Consider requiring or incentivizing advanced certification in palliative care from an available accrediting body.

One national payer incorporated palliative care as a measure in its hospital quality incentive program; hospitals earn credit by achieving Advanced Certification for Palliative Care, or by meeting four core standards that include access to a specialty team, along with an all-staff training program.

**Audience:**

HEALTH PLANS, ACOs

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**REQUIRE** plans and ACOs to demonstrate sufficient specialty palliative care capacity in their provider network facilities and services.

Tools and templates to help purchasers evaluate the abilities of their health plans and ACOs to adequately care for people with serious illness are available in Catalyst for Payment Reform’s Purchaser Toolkit for Serious Illness Care Strategies.

**Audience:**

PURCHASERS
Clinician Skill Building

ENSURE that case managers working with people with a serious illness or complex needs are trained in key areas such as communication skills and conducting comprehensive family needs assessments.

One national payer offers specially trained complex care management to members with serious illness. Nurses and social workers support members and their family caregivers, providing needs assessment, education, shared decision making, and goals-of-care discussions, as well as psychosocial care, resulting in reductions in inpatient days and emergency department visits, as published in 2009 in the Journal of Palliative Medicine.25

audience:
PURCHASERS HEALTH PLANS ACOs

PROVIDE financial incentives for selected network clinicians to acquire communication and symptom management skills. Consider targeting oncology, cardiology, neurology, nephrology, and pulmonology departments.

audience:
HEALTH PLANS ACOs

EDUCATE all network providers about palliative care, including instruction on when to refer to a palliative care specialty team for consultation.

One California payer helps its network serve seriously ill patients by offering training, tools, and resources on palliative care.

audience:
HEALTH PLANS ACOs
Public and Clinician Awareness

**PROMOTE** information on the benefits of palliative care to all populations.

**audience:**
- PURCHASERS
- HEALTH PLANS
- ACOs

**ESTABLISH,** in areas where these do not yet exist, a multi-stakeholder coalition to continuously identify and advance opportunities that improve quality of life for people living with a serious illness, and their families.

The Massachusetts Coalition for Serious Illness Care gathers plans, providers, patient advocates, professional associations, and others to strategize on the implementation of statewide campaigns that improve advance care planning, clinician skills, and more.

**audience:**
- PURCHASERS
- HEALTH PLANS
Appendix

Data Sources and Methodology

Data on hospital characteristics were obtained from the American Hospital Association (AHA) Annual Survey Database™ for the data year 2017 and supplemented with data from 2016 for nonresponders. Additional data on hospital palliative care programs were obtained from the National Palliative Care Registry™ (registry.capc.org) and CAPC’s Mapping Community Palliative Care initiative (mapping.capc.org). All hospitals identified as having palliative care programs but not participating in the Registry or Mapping were validated through existing databases, state palliative care directories, CAPC faculty, and web searches to verify reporting.

Analyses were limited to nongovernmental, general medical and surgical, children’s general medical and surgical, cancer, children’s cancer, heart, and obstetrics and gynecology hospitals within the fifty states and the District of Columbia. Analyses were also limited to hospitals that either responded to the AHA Annual Survey or participated in the Registry or Mapping initiatives. Where analyses are limited to hospitals with fifty or more beds, the final sample included a total of 2,409 hospitals. Of these, 2,348 completed the AHA survey; this number includes hospitals that also participated in the National Palliative Care Registry™ or CAPC’s Mapping Community Palliative Care initiative. An additional sixty-one hospitals that participated in the Registry but did not submit data to the AHA were also included.

Comparisons across Report Cards should be made with caution, as previous Report Cards did not include children’s general medical and surgical hospitals or children’s cancer hospitals. As with our previous Report Cards, the 2019 State-by-State Report Card did not examine timeliness, reach, or quality of hospital-based palliative care programs. The grades represented in the Report Card are based solely on the existence of palliative care teams in hospitals.
Glossary

Alternative payment model (APM)
The method of paying for services in which providers choose to receive rewards and penalties for quality and cost outcomes. It differs from the standard fee-for-service schedules for each defined encounter or procedure in one of two ways: a) the provider’s ultimate earnings are enhanced or reduced by their quality and/or cost outcomes; or b) the provider’s ultimate earnings are dependent upon the difference between actual costs and target costs.

Accountable Care Organization (ACO)
An Accountable Care Organizations is a group of providers organized to take responsibility for the overall quality of care and the total cost of all the health care services needed by a group of patients over a period of time. An Accountable Care Organization is not a payment model; it is an organizational structure designed to accept accountability for care delivery quality and costs.

Hospital categories
For-profit: Run by individuals, partnerships or corporations.
Nonprofit: Run by a charitable organization (including church-operated).
Public: Nonprofit institutions run by a state, county, city, district or other government authority.
Sole community provider: Hospitals that are designated by Medicare because they are located more than thirty-five miles from other hospitals, or they are the sole providers of health care services for a region due to limitations in local topography or prolonged severe weather conditions. thirty-five miles from other hospitals, or they are the sole providers of health care services for a region due to limitations in local topography or prolonged severe weather conditions.

Medicare Advantage (MA)
Also known as, Medicare Part C, a private health insurance plan that enrolls Medicare beneficiaries and covers their health professional and facility costs in exchange for a premium paid by the federal government. Medicare beneficiaries who enroll in a Medicare Advantage plan agree to have their health care payments determined by this private plan, and so waive their rights to participate in traditional Medicare.

Palliative care, palliative medicine
Specialized medical care for people with serious illnesses. It focuses on giving patients relief from the symptoms and stress of a serious illness no matter what the diagnosis. The goal is to improve quality of life for both the patient and his or her family. Palliative care is provided by a team of palliative care specialists, including doctors, nurses and social workers, who work together with a patient’s other physicians to provide an added layer of support. Palliative care is appropriate at any age and at any stage of a serious illness and can be administered at the same time as curative treatment.

Prevalence
In the Report Card, prevalence is the proportion of hospitals that report a palliative care program during the reporting period. Presented as a percentage, prevalence is calculated by taking the number of hospitals with palliative care and dividing that by the total number of hospital.

For additional terminology related to palliative care payment, please visit the CAPC Payment Glossary of Terms at capc.org.


## TABLE

Prevalence and Distribution of Palliative Care Programs in U.S. Hospitals by State and U.S. Census Region

<table>
<thead>
<tr>
<th>State</th>
<th>Letter Grade</th>
<th>Number Grade</th>
<th>Total Programs/Hospitals</th>
<th>By Hospital Type</th>
</tr>
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*Limited to U.S. Hospitals with 50 or More Beds*
Limited to U.S. Hospitals with 50 or More Beds

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<th>State</th>
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<tr>
<td>MOUNTAIN</td>
<td>B</td>
<td>72.8</td>
<td>(107/147)</td>
<td>81.4 (79/97)</td>
<td>60.0 (21/35)</td>
<td>46.6 (7/15)</td>
<td>47.6 (10/21)</td>
</tr>
<tr>
<td>Alaska</td>
<td>C</td>
<td>42.9</td>
<td>(3/7)</td>
<td>60.0 (3/5)</td>
<td>0.0 (0/0)</td>
<td>0.0 (0/2)</td>
<td>0.0 (0/2)</td>
</tr>
<tr>
<td>California</td>
<td>B</td>
<td>77.3</td>
<td>(170/220)</td>
<td>90.5 (144/159)</td>
<td>10.7 (3/28)</td>
<td>69.6 (23/33)</td>
<td>50.0 (2/4)</td>
</tr>
<tr>
<td>Hawaii</td>
<td>B</td>
<td>66.7</td>
<td>(6/9)</td>
<td>75.0 (6/8)</td>
<td>0.0 (0/0)</td>
<td>0.0 (0/1)</td>
<td>50.0 (1/2)</td>
</tr>
<tr>
<td>Oregon</td>
<td>A</td>
<td>88.9</td>
<td>(24/27)</td>
<td>95.6 (22/23)</td>
<td>0.0 (0/2)</td>
<td>100.0 (2/2)</td>
<td>0.0 (0/0)</td>
</tr>
<tr>
<td>Washington</td>
<td>A</td>
<td>84.0</td>
<td>(42/50)</td>
<td>97.2 (35/36)</td>
<td>50.0 (1/2)</td>
<td>50.0 (6/12)</td>
<td>75.0 (3/4)</td>
</tr>
<tr>
<td>PACIFIC</td>
<td>B</td>
<td>78.3</td>
<td>(245/313)</td>
<td>90.9 (210/231)</td>
<td>12.5 (4/32)</td>
<td>62.0 (31/50)</td>
<td>50.0 (6/12)</td>
</tr>
<tr>
<td>NATIONAL</td>
<td>B</td>
<td>71.5</td>
<td>(1723/2409)</td>
<td>81.8 (1408/1720)</td>
<td>34.7 (135/389)</td>
<td>60.0 (180/300)</td>
<td>40.0 (56/140)</td>
</tr>
</tbody>
</table>

*Hospitals with less than 50 beds were not validated and are as reported in the AHA Annual Survey.
Acknowledgments

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www.npcrc.org
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