

Palliative Care in Illinois

Palliative Care Need and Infrastructure in Illinois

Between five and twelve percent of the U.S. population is living with a serious illness such as cancer, COPD, advanced dementia, or heart failure. Many of these high-need individuals could benefit from palliative care: specialized, team-based medical care, which is focused on providing relief from the symptoms and stress of the illness. Palliative care is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment. It has been shown to improve quality of life for both patients and caregivers, helping them avoid health crises and reducing avoidable utilization of emergency departments and hospitals.

There are numerous opportunities at the state level to improve palliative care access and quality. This report provides information on the availability of specialty palliative care and other indicators that impact outcomes for people facing serious illness. Both policymakers and palliative care champions can use the report to inform decision-making and prioritization on state-level activities.

Palliative Care Structures in Illinois

	STATUS ^a	NAME OF ORGANIZATION
Active, Legislatively-Established Palliative Care Advisory Council (or Similar Body)	Yes	Illinois Hospice and Palliative Care Advisory Committee Board
State Hospice and Palliative Care Association	Yes	Illinois Hospice and Palliative Care Organization
State Hospice and Palliative Nurses Association Chapter	Yes	Chicagoland Chapter of HPNA Rockford Stateline Chapter of HPNA
Adult Serious Illness (or Other Relevant) Coalition	No	N/A
Pediatric Serious Illness (Or Other Relevant) Coalition	Yes	Greater Illinois Pediatric Palliative Care Coalition
State-Level Capacity Assessment	No	N/A

Availability of Hospital Palliative Care in Illinois

The availability of palliative care services in U.S. hospitals has grown rapidly in recent decades, but varies widely by state and U.S. Census Division. The following table compares availability of inpatient palliative care programs in your state to regional and national palliative care availability, by hospital size.^b Nationally, the majority of large hospitals—those with 300 or more beds—now report availability of palliative care.

Prevalence of Hospital Palliative Care by Facility Size

LOCATION	BY HOSPITAL SIZE			
	<50 BEDS	50-149 BEDS	150-299 BEDS	300+ BEDS
Illinois	37.2% 16/43	73.1% 19/26	92.6% 25/27	100.0% 26/26
East North Central	49.3% 113/229	72.9% 86/118	89.2% 83/93	93.8% 90/96
National	40.3% (532/1319)	70.3% (502/714)	85.5% (523/612)	96.2% (634/659)

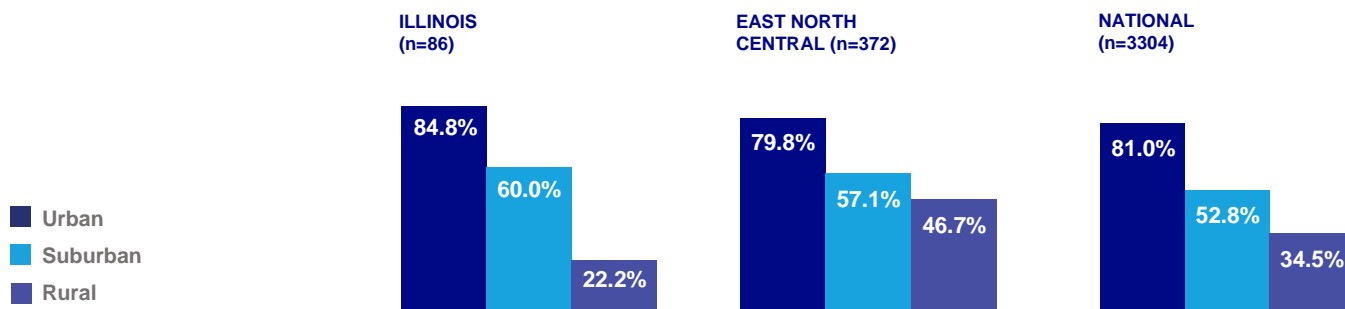
East North Central = IL, IN, MI, OH, WI

Based on total reported hospital admissions in this state, an estimated 94.4% of inpatients may have access to hospital-based palliative care.

Prevalence of Hospital Palliative Care by Type of Community

Hospital-based palliative care is most commonly available in urban communities. The graph below (figure 1) compares hospital palliative care availability in your urban, suburban, and rural communities against the regional and national prevalence, and includes hospitals of all sizes.^c

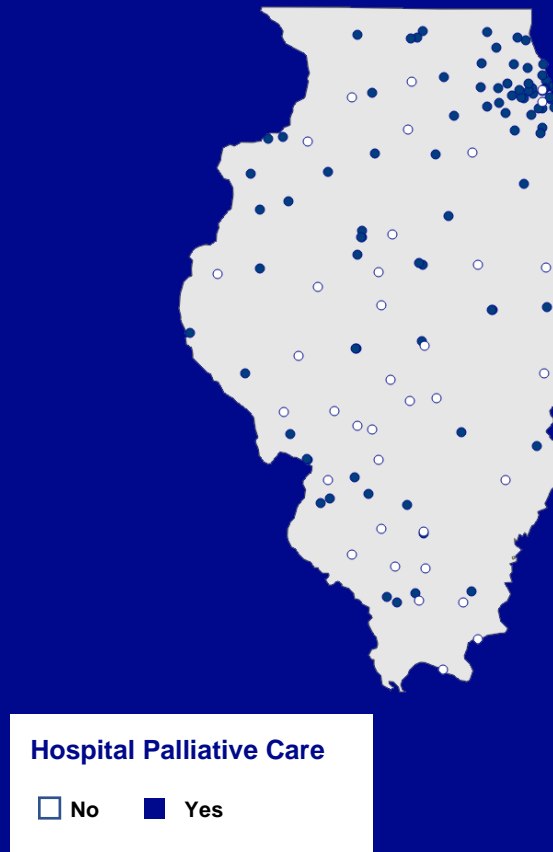
Figure 1. Percentage of Hospitals with a Palliative Care Program by Geographic Type



Hospital Palliative Care by Location

The map below (figure 2) shows all Illinois hospitals that report inpatient palliative care availability and includes hospitals of all sizes.^d Solid dots represent hospitals that report having a palliative care program or unit, and empty dots represent hospitals that do not currently report inpatient palliative care.

Figure 2. Availability of Hospital Palliative Care in Illinois



Availability of Community Palliative Care in Illinois

At least **15** programs providing palliative care in the community have been identified in your state; this is likely an undercount, based on self-reported data only. Visit [Get Palliative Care](#) for information on palliative care programs that have listed themselves on the Palliative Care Provider Directory. If you are aware of community-based palliative care programs that are not yet listed, please encourage them to participate at the [Provider Directory submission site](#).

The Center to Advance Palliative Care (CAPC) works to collect information on palliative care programs serving patients in community settings, including office practices/clinics, long-term care facilities, and/or patient homes. Availability of community-based palliative care is essential to patients receiving support over the course of their illness, and can reduce crises and avoidable hospital utilization.^e

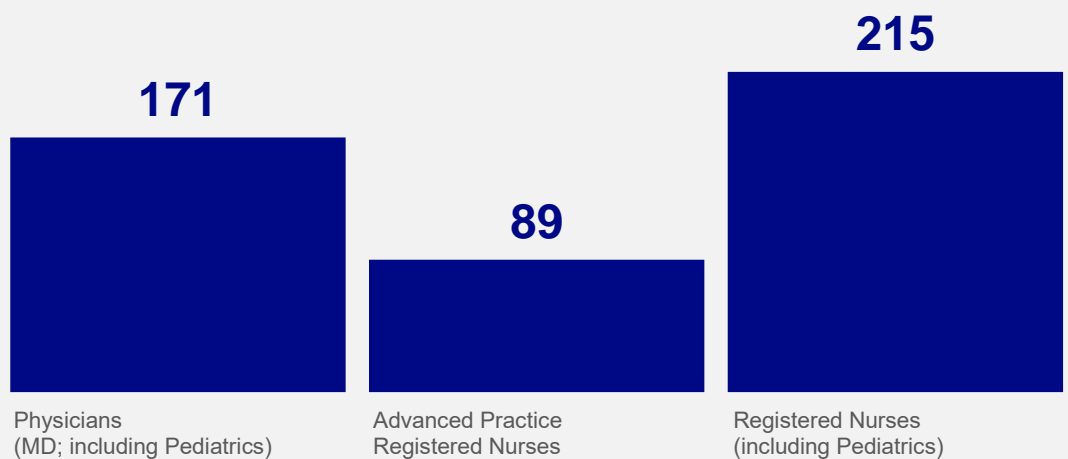
Specialty Palliative Care Workforce in Illinois

Certified Clinicians

Physicians (MDs), advanced practice registered nurses (APRNs), physician associates (PAs), registered nurses (RNs), licensed practical/vocational nurses, social workers, and chaplains can all pursue specialty certification in palliative care. Not all clinicians who work on palliative care teams have received palliative care certification, though professional certification is the gold standard for quality palliative care.

The graph below (figure 3) shows the numbers of MDs, APRNs, and RNs that have received specialty certification in palliative care or pediatric palliative care in Illinois.^f (Palliative care-certified Doctors of Osteopathy (DOs), PAs, social workers, and chaplains may be providing palliative care in your state, but these numbers were either unavailable or too low to be included at the state level.) Additional members of the interprofessional palliative care team may include pharmacists, home health aides, therapists, and other health professionals, although specialty palliative care certification does not currently exist in these fields.

Figure 3. Count of Palliative Care Certified Physicians, Advanced Practice Registered Nurses, and registered Nurses in Illinois



Certified Prescribers

There are at least 260 certified prescribing palliative care providers in your state, resulting in at least 2.1 per 100,000 residents in your state (this includes MDs and APRNs only; data for DOs and PAs is currently unavailable at the state level).^g This capacity is likely insufficient to meet the needs of your state, but training non-palliative care prescribers in the basics of caring for people with serious illness can be an important strategy to complement your state's specialty palliative care workforce.

Figure 4. Prescribers Certified in Specialty Palliative Care per 100,000 Population



Certified Pediatric Clinicians

While the pediatric population (i.e., neonates, perinates, infants, children, adolescents, and young adults) living with serious illness is small—approximately 500,000-700,000 children nationwide—it is critical to ensure qualified attention to their and their families' needs. In your state, 14 pediatricians have been board-certified in Hospice and Palliative Medicine (HPM).^h There are also 7 certified pediatric nurses.

Medical Fellowship Programs in Illinois

Future access to high-quality palliative care depends on the availability of a robust training pipeline for specialists. HPM fellowship programs provide an accredited learning experience to ensure graduates meet the core competencies of palliative care. There are 6 HPM fellowship programs in your state.ⁱ

Palliative Care Payment in Illinois

A growing number of states are exploring options to pay for specialty, community-based, interprofessional palliative care through Medicaid, through the establishment of new benefits or directives to managed care plans to cover palliative care services. In your state, the following payment actions have been taken:†

ADULT PAYMENT ACTIVITY	STATUS	SUPPORTING INFO (ADULTS)
Separate payment/standalone Medicaid or other benefit for palliative care	No	N/A
Directive to Medicaid Managed Care Plans (or similar entities)	No	N/A
Directive to private payers	No	N/A

PEDIATRIC PAYMENT ACTIVITY	STATUS	SUPPORTING INFO (PEDS)
Separate payment/standalone Medicaid or other benefit for palliative care	Yes	https://hfs.illinois.gov/content/dam/soi/en/web/hfs/medicalproviders/cc/documents/011920231915iSPAPedPalliativeCareProgramFinal.pdf
Directive to Medicaid Managed Care Plans (or similar entities)	No	N/A
Directive to private payers	Yes	https://www.ilga.gov/legislation/billstatus.asp?DocNum=3819&GAID=16&GA=102&DocTypeID=SB&LeqID=138882&SessionID=110

The supporting information is the most current at the time of this report publication. Please check your relevant state agency's website for more information.

Continuous Improvement Efforts in Illinois

Center to Advance Palliative Care Membership

In Illinois, 61 organizations—including hospitals, home care agencies, medical practices, payers, long-term care facilities, and more—are active CAPC members and have access to tools, clinical training, consulting, and technical assistance to improve care quality for people living with a serious illness, and their caregivers.^k Membership is used to design and grow high-quality specialty palliative care programs, and to train non-palliative care clinicians in core skills.

This means that thousands of clinicians in your state already have access to training in communication skills, pain and symptom management, supporting family caregivers, preventing crises, and reaching more patients in need with specialty palliative care programs. Nationwide, CAPC has trained close to 150,000 clinicians. Contact membership@capc.org to discuss how to leverage these resources.

Professional Continuing Education Requirements

Many states have topic-specific continuing education (CE) requirements that are relevant to palliative care. These include required topics such as pain and symptom management, opioid prescribing, geriatrics, and ethics. It is possible for palliative care champions to leverage these requirements to advance palliative care training and/or awareness initiatives. View [CE requirement aggregators](#) for physicians, nurses, and social workers for more information.

In addition, note that the federal Drug Enforcement Administration now requires completion of an 8-hour training for all clinicians who register to prescribe controlled substances. [CAPC training](#) can fulfill this requirement.

In addition to specialty palliative care indicators, champions should consider additional indicators that can inform their efforts to improve care for residents living with a serious illness. The following state indicators contain some of the most relevant information to support action or measure state-level progress.

Illinois Payment Mix

Across the total state population, 53.0% have employer-sponsored insurance, 20.0% are covered by Medicaid with Medicaid Managed Care, 14.0% are covered by Medicare, with roughly 38.7% enrolled in Medicare Advantage, and 7.0% are un-insured.^{l-n} This impacts where financial support for palliative care services—along with quality incentives to drive quality and access—might come from.

Cancer Mortality by Race/Ethnicity

Nationwide, there are significant disparities in cancer mortality. In Illinois, the death rate per 100,000 is as follows: 184.7 for Black residents; 95.6 for Hispanic residents; and 156.5 for white residents.^o Due to state variations in population, Asian, American Indian/Alaska Native, Native Hawaiian/Other Pacific Islander, and those of multiple races are not consistently available. Visit your state's Cancer Control Plan to learn more.

Advanced Care Transformation (ACT) Index

The Coalition to Transform Advanced Care (C-TAC) developed the ACT Index to allow health care leaders, policymakers, regulators, communities, and consumers to track progress towards improving quality of life for people living with a serious illness. The most recent version of the ACT Index includes 26 measures in the following four domains: Care; Costs; Community and Caregivers; and Communication.

[As of the most recent ACT Index Report, your state was ranked 35 out of 51.^p](#)

AARP Long-Term Services and Supports (LTSS) Scorecard

AARP's LTSS State Scorecard is a compilation of data and analysis that provides a comprehensive picture of how states, through their LTSS systems, are supporting older adults, people with physical disabilities, and family caregivers. Rankings are based on metrics that capture the following elements: Affordability and Access; Choice of Setting and Provider; Safety and Quality; Support for Family Caregivers; and Community Integration.

[As of the most recent LTSS Scorecard, your state was ranked 25 out of 51.^q](#)

Palliative Care State Policy

State champions can make a number of changes to improve the care of people living with a serious illness in the areas of workforce, payment, clinician skill-building, or public awareness. Organizations like the [National Academy for State Health Policy \(NASHP\)](#) have been compiling more information on individual state policy activity. Opportunities for policy action include:

- Use state policies and regulations to define palliative care services and standards.
- Incorporate essential components of palliative care into relevant Medicaid programs (such as Health Homes, Managed Long-term Care Plans, or Home and Community Based Services). This can include revising enrollee assessments to include functional impairment, symptom distress, and caregiver burden, or inserting communication training requirements for care managers and other clinicians.
- Create a process to involve multiple interested parties, in conjunction with the state department of health, to inform the development of Medicaid reimbursement policies and quality control measures for interdisciplinary, community-based palliative care.
- Establish or expand loan forgiveness programs for certified clinicians who work as palliative care specialists in your state.
- Create a state-level awareness campaign to educate the public and providers on what palliative care is and who can benefit.
- Revise state health professional licensure and continuing education requirements to include a minimum number of hours of instruction in both pain/symptom management skills and serious illness communication skills, with particular attention to best practices in equitable care. There are now five states requiring implicit bias training for their physicians, and others may follow.
- Provide grants and other supports to enable palliative care teams to provide remote consultations to rural hospitals and federally qualified health centers.
- Add a palliative care module to the state Behavioral Risk Factor Surveillance System (BRFSS) questionnaire to better understand palliative care delivery from the consumer perspective.

Palliative care leaders in your state may have more targeted recommendations to improve access and quality, and should be consulted before embarking on any new initiative.

Methodology and Resources

This report was prepared on April 25, 2024 using the most recently available data at that time, which may include prior years' information. Details on the sources and calculations for each section are below and available at the Serious Illness Scorecard [Data and Methodology page](#).

CAPC also maintains [resources](#) to support state policymakers and palliative care champions. For more information, please contact paymentandpolicy@capc.org.

Sources

- a. CAPC gathered information on state structures between February 13-29, 2024, based on publicly reported data found on the internet, as well as from professional associations
- b. Internal CAPC analysis based on data from the American Hospital Association Annual Survey Database 2022, based on hospital self-report of palliative care program or unit; no validation was done on the responses
- c. CAPC analysis from AHA Annual Survey Database 2022 (as above)
- d. CAPC analysis from AHA Annual Survey Database 2022 (as above)
- e. [Palliative Care Ensures Value](#)
- f. Physician count from the [American Board of Medical Specialties \(ABMS\) Board Certification Report 2022-23](#); Advanced Certified Hospice and Palliative Nurse and Certified Hospice and Palliative Nurse counts from the Hospice and Palliative Credentialing Center (HPCC) Certification Verification Tool, accessed February 7, 2024
- g. CAPC analysis from the ABMS and HPCC certified professionals by state, together with state population numbers from the U.S. Census, Vintage 2022 data, accessed February 2, 2024
- h. Physician count from the ABMS Board Certification Report 2022-23 (as above), specific to the count of American Board of Pediatrics subspecialists in Hospice and Palliative Medicine
- i. Data on fellowship programs from the [American Association of Medical Colleges](#), accessed February 12, 2024
- j. CAPC gathered information on state-level payment activity between February 13-29, 2024, based on state legislation, the Center for Medicare and Medicaid Services Waiver List, and State Department of Health websites
- k. Internal CAPC data on its organizational members and users, accessed February 7, 2024
- l. Data from [KFF State Health Facts, Health Insurance Coverage of the Total Population 2022](#), accessed February 13, 2024
- m. Medicare Advantage penetration: CMS Statistics and Reports, Monthly Medicare Advantage Enrollment by State, January 2024; accessed February 13, 2024
- n. Medicaid Managed Care "With/Without" based on [KFF Total Medicaid MCOs](#), using 2023 CMS Enrollment Reports, based on 2021 data, accessed February 13, 2024
- o. Data from [KFF State Health Facts, Total Cancer Deaths by Race/Ethnicity 2021](#), accessed February 13, 2024
- p. State ranking based on the [Advanced Care Transformation Report 2023](#), a product of the Coalition to Transform Advanced Care (C-TAC), shared with CAPC staff January 10, 2024
- q. State ranking based on the 2023 AARP report, [Innovation and Opportunity: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregiver](#)