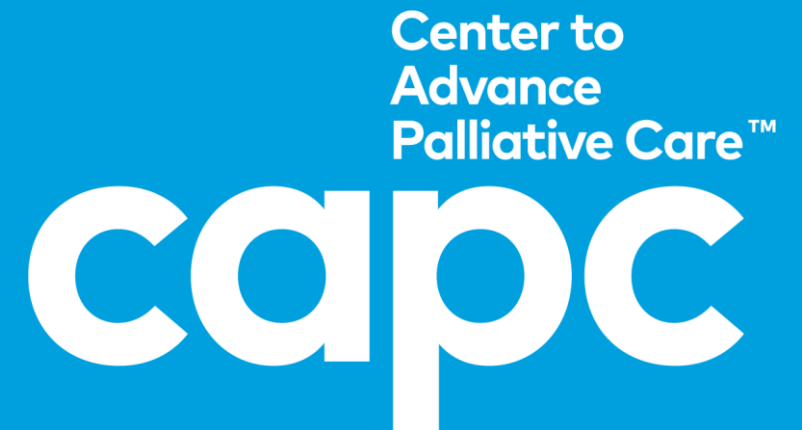


# The Serious Illness Scorecard 2024

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An abstract, colorful geometric pattern composed of various shapes like circles, triangles, and rectangles in shades of blue, red, yellow, and black, some with textured or woven patterns.

Save the Date

Center to Advance Palliative Care

# National Seminar 2025



September 15-17, 2025 • Philadelphia, PA  
[capc.org/seminar](https://capc.org/seminar)

# Today's Session

A review of America's readiness to meet the needs of people living with serious illness

- ❑ Why Evaluate State Capacity?
- ❑ How the States Performed
- ❑ A National Picture of Palliative Care and Skill-Building
- ❑ Now What? Recommendations to Strengthen Capacity

# Why a Serious Illness Scorecard?

# Serious Illness in America

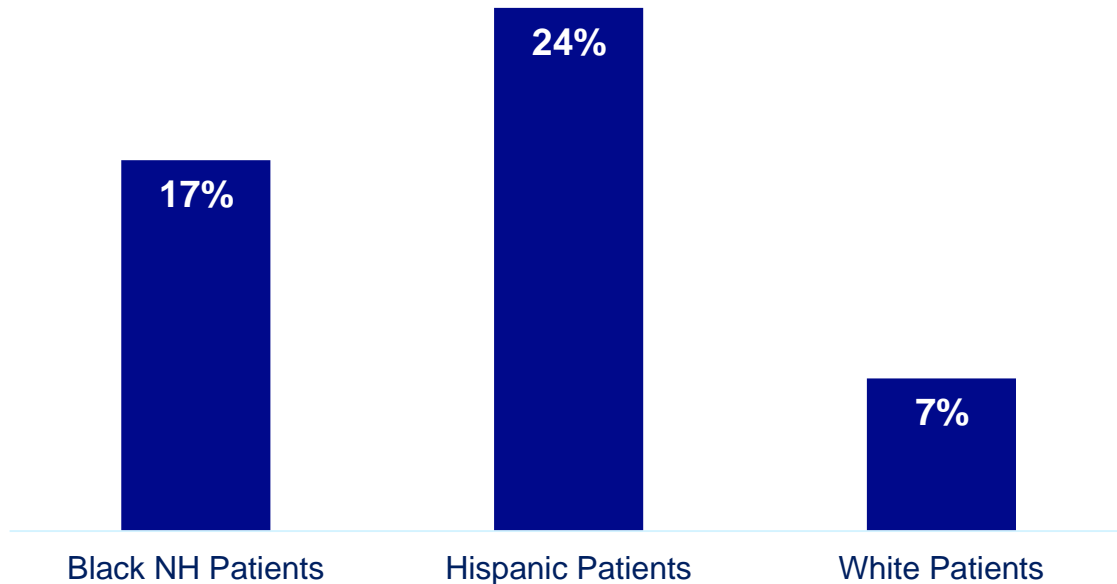
- Serious illness is a health condition that carries a high risk of mortality AND either negatively impacts a person's daily function or quality of life, OR excessively strains their caregivers (Kelley, 2018)
- Examples include metastatic cancer, heart failure, kidney failure, advanced dementia, and frailty
- At least 13 million adults and approximately 700,000 children are living with a serious illness today

# Families facing serious illness often do not get what they need from the US health care system

- **Poor communication with clinicians**
  - Misunderstanding of prognosis
  - Little information on 'what to expect' with their illness
  - Treatment decisions not informed by patient values and goals
- **Poor pain and symptom management**
  - Pain and other symptoms drive the majority of emergency department visits
- **Significant burden on family caregivers**
  - More than 1/5 of Americans are caregivers
  - Impacts physical health, psychological well-being, and financial circumstances

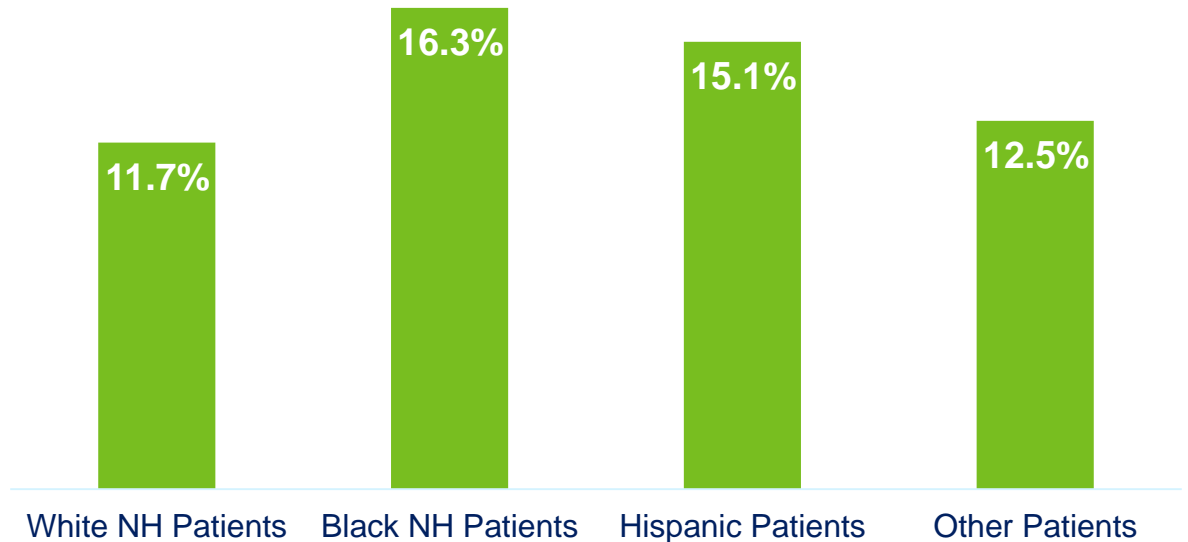
# Care Experiences for People Living with Serious Illness are Inequitable

Older Adults Reporting Never Having Their Preferences Considered



Source: Community Catalyst 2022

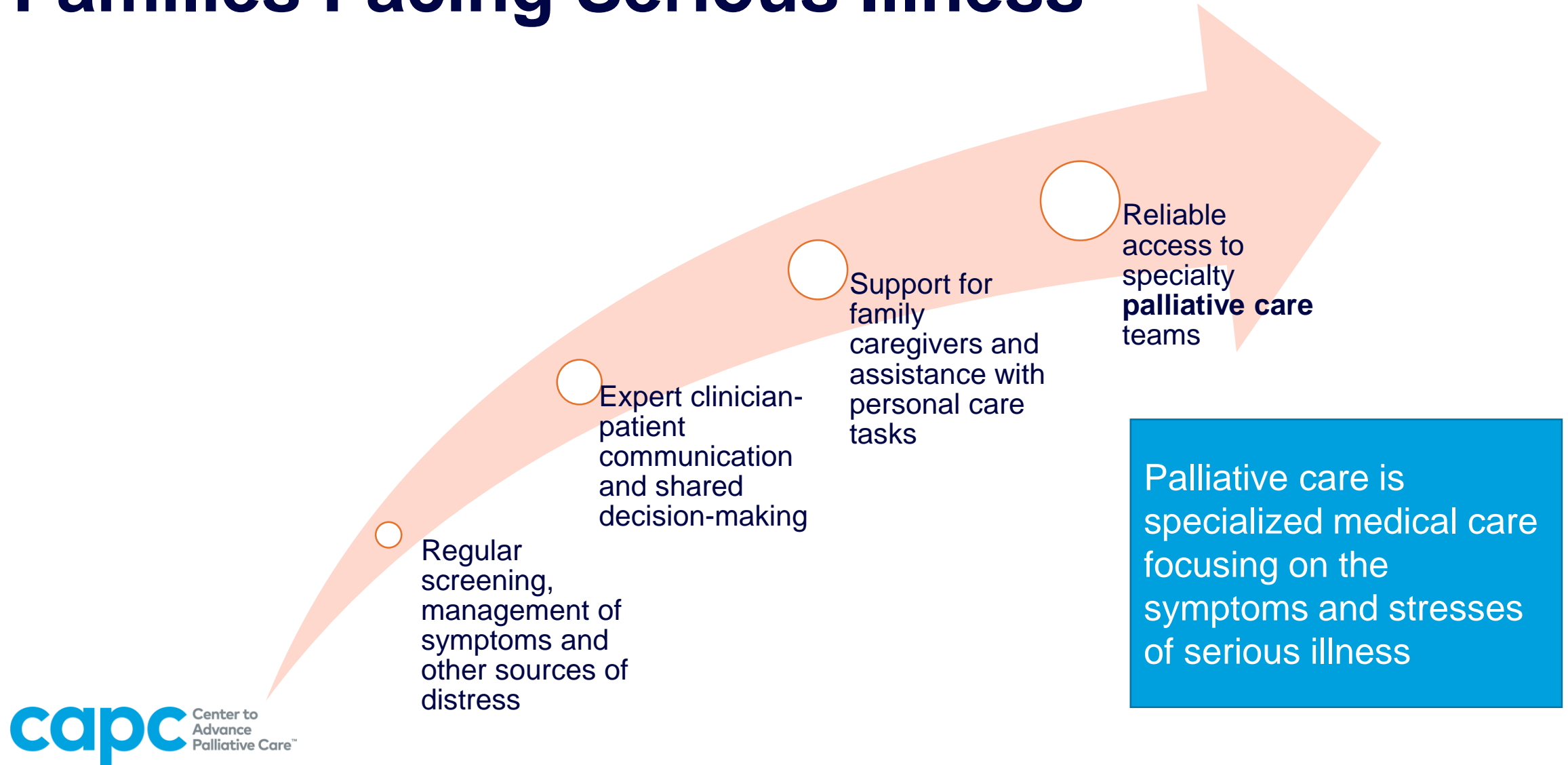
More than 1 ED Visit, Last Month of Life One Year Post-Diagnosis



Source: Karanth J Thorac Onc 2018

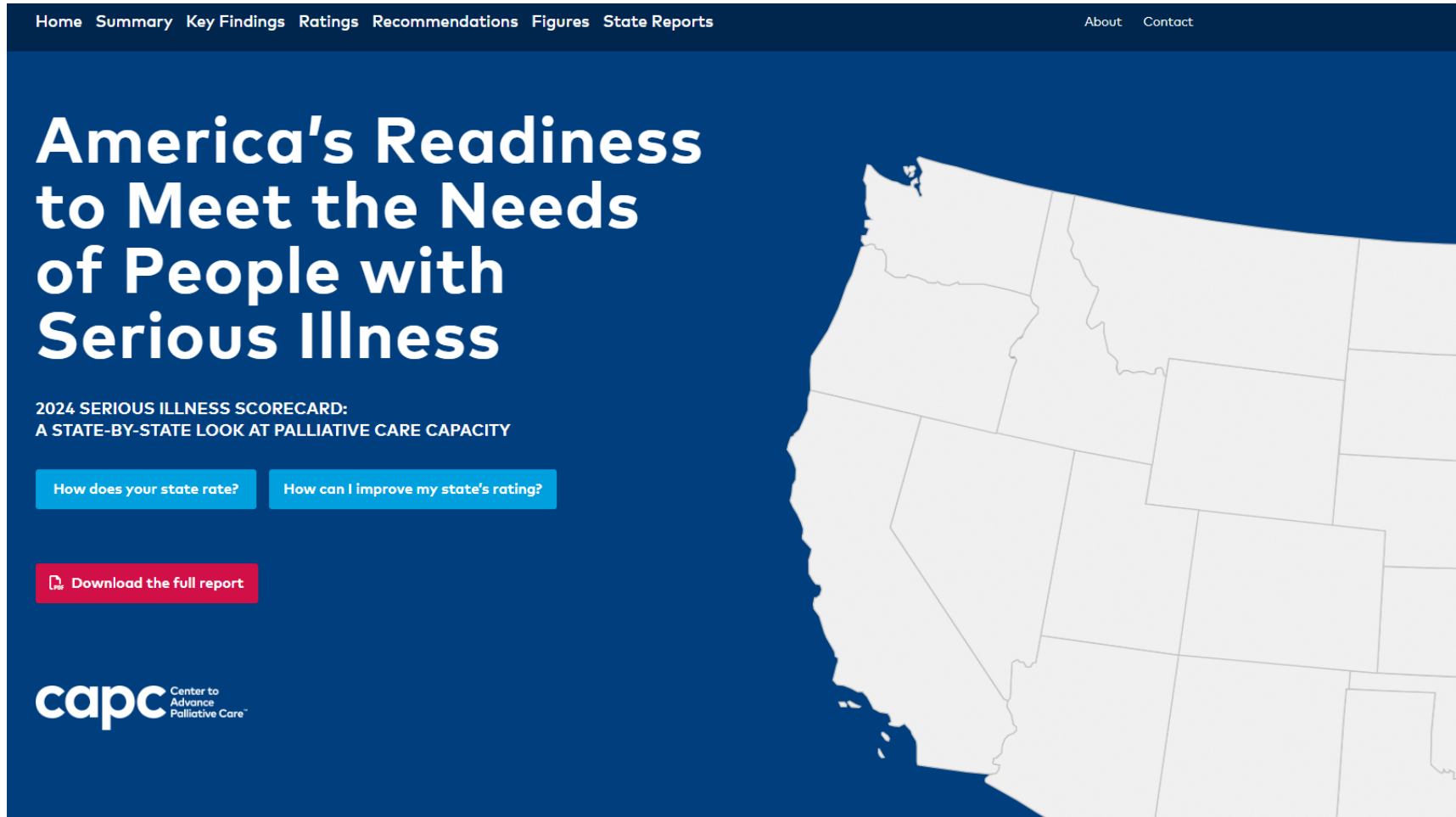


# Key Factors in High-Quality Care for Families Facing Serious Illness



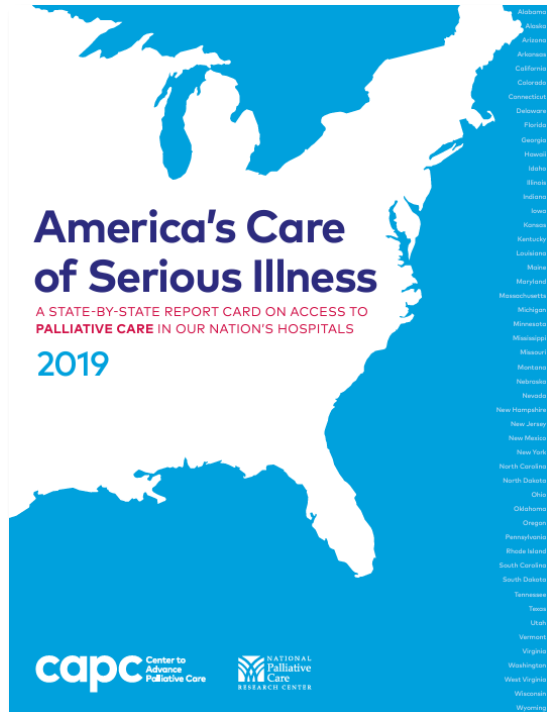


# CAPC has evaluated each state's capacity to deliver high-quality care to people with serious illness



# The Serious Illness Scorecard Builds on the prior CAPC “State by State Report Card”

- The Report Card measured prevalence of hospital-based palliative care programs in each state
- Four editions between 2006 and 2019
- Inpatient palliative care access had grown dramatically, but is now leveling off
- Palliative care now extends well beyond the 4 hospital walls
- The broader health care system continues to adopt palliative care principles and practices



# User Feedback Helped Us Create a New Product



# The Serious Illness Scorecard Uses Ten Variables Across Five Domains

## Specialty Palliative Care Availability

- Proportion of state's hospitals (> 50 beds) with self-reported palliative care program or unit
- Count of state's certified hospice and palliative care professionals per 100,000 population

## Payment for Palliative Care Services

- Existence of state legislation or regulation expanding payment for specialty palliative care (adult or pediatric)
- Existence of unique services for enrollees with serious illness at the state's largest health insurance provider

## Structured Champions, Advocacy, and Support

- Existence of active state palliative care advisory council
- Existence of regional, state, or local palliative care coalition (adult or pediatric)

## Building Skills Outside Specialty Palliative Care

- Existence of relevant medical and/or nursing continuing education requirements
- Count of clinicians who completed at least one CAPC course per 10,000 clinicians in the state

## Foundation for Functional and Caregiver Support

- Existence of Medicaid Waiver for Children with Serious Illness
- AARP Long-Term Services and Supports (LTSS) Scorecard ranking

# The Serious Illness Scorecard includes individual state reports with much more detail to consider state-level opportunities for continued improvement

## Palliative Care in Alabama

### Palliative Care Need and Infrastructure in Alabama

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.

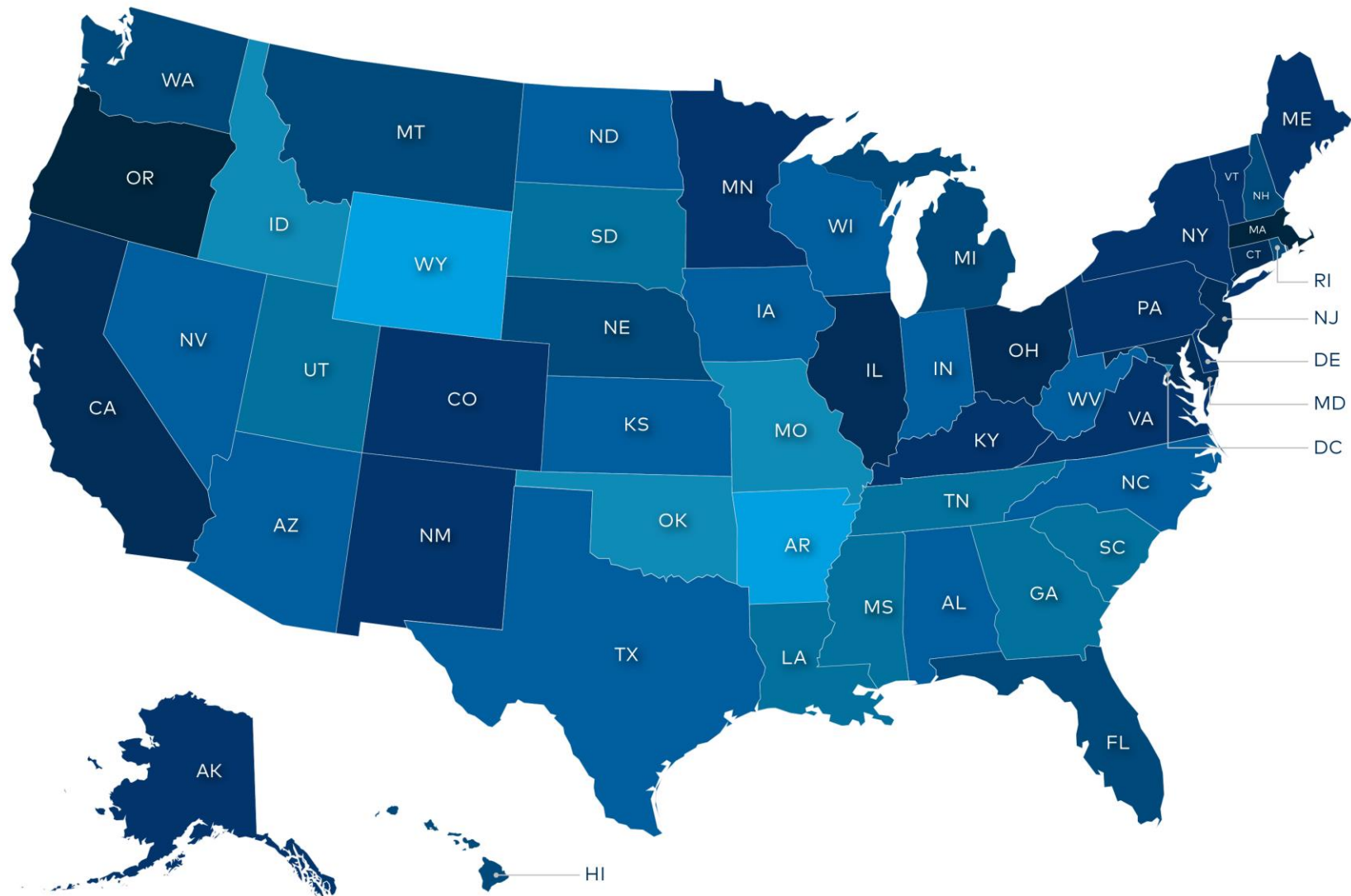
There are numerous opportunities at the state level to improve palliative care access and quality. This report provides information on the availability of specialty palliative care and other indicators that impact outcomes for people facing serious illness. Both policymakers and palliative care champions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

### Palliative Care Structures in Alabama

|  | STATUS* | NAME OF ORGANIZATION   |
|--|---------|--|
| Active, Legislatively-Established Palliative Care Advisory Council (or Similar Body) | Yes     | <a href="#">Alabama State Advisory Council on Palliative Care and Quality of Life</a>    |
| State Hospice and Palliative Care Association  | Yes     | <a href="#">Alabama Hospice and Palliative Care Organization</a>                         |
| State Hospice and Palliative Nurses Association Chapter                              | Yes     | <a href="#">The Central Alabama Chapter of HPNA</a>                                      |
| Adult Serious Illness (or Other Relevant) Coalition                                  | Yes     | <a href="#">The Southeast Institute for Innovation in Palliative and Supportive Care</a> |
| Pediatric Serious Illness (Or Other Relevant) Coalition                              | No      | N/A  |
| State-Level Capacity Assessment  | No      | N/A  |

# How the States Performed in 2024





## Scorecard Ratings by State 2024

CAPC Serious Illness Scorecard | [scorecard.capc.org](https://scorecard.capc.org)

State rating by color:





# State Ratings Ranged from 1.0 to 4.5

## Top-Rated States

**4.5**

- Massachusetts
- Oregon

**4.0**

- California
- Connecticut
- Illinois
- Maryland
- New Jersey
- Ohio

## Bottom-Rated States (1.0 – 1.5)

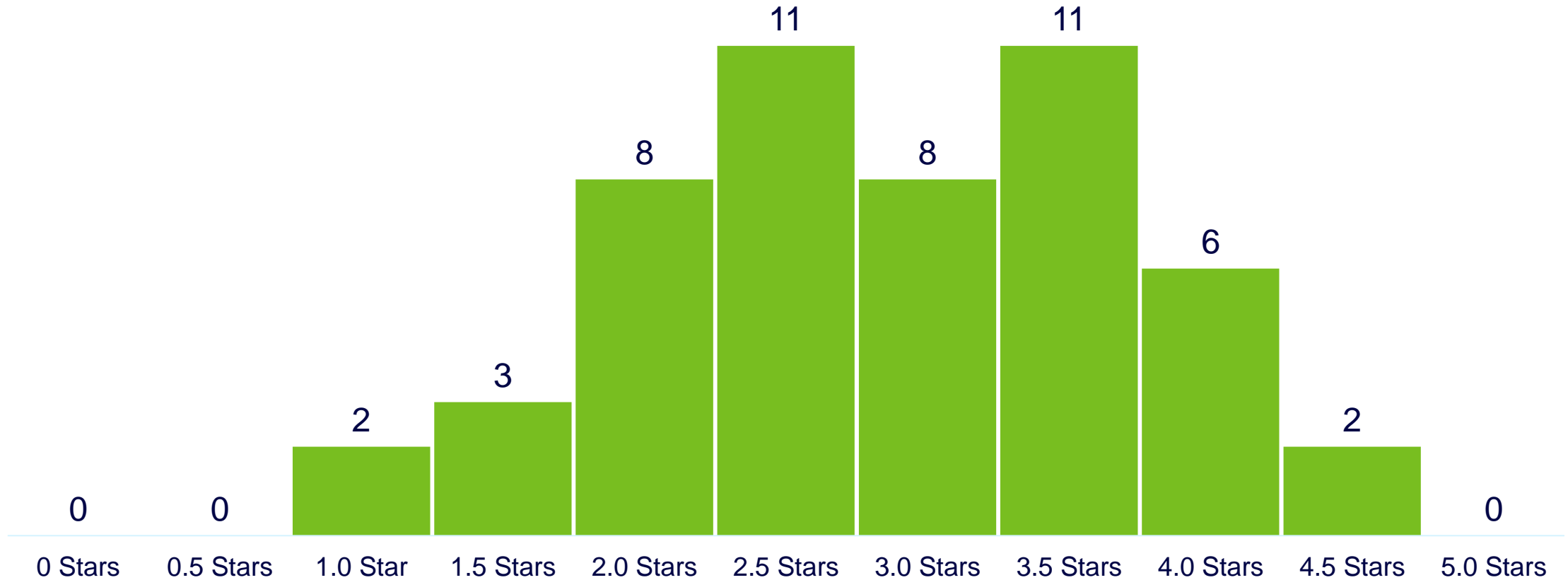
**1.5**

- Idaho
- Missouri
- Oklahoma

**1.0**

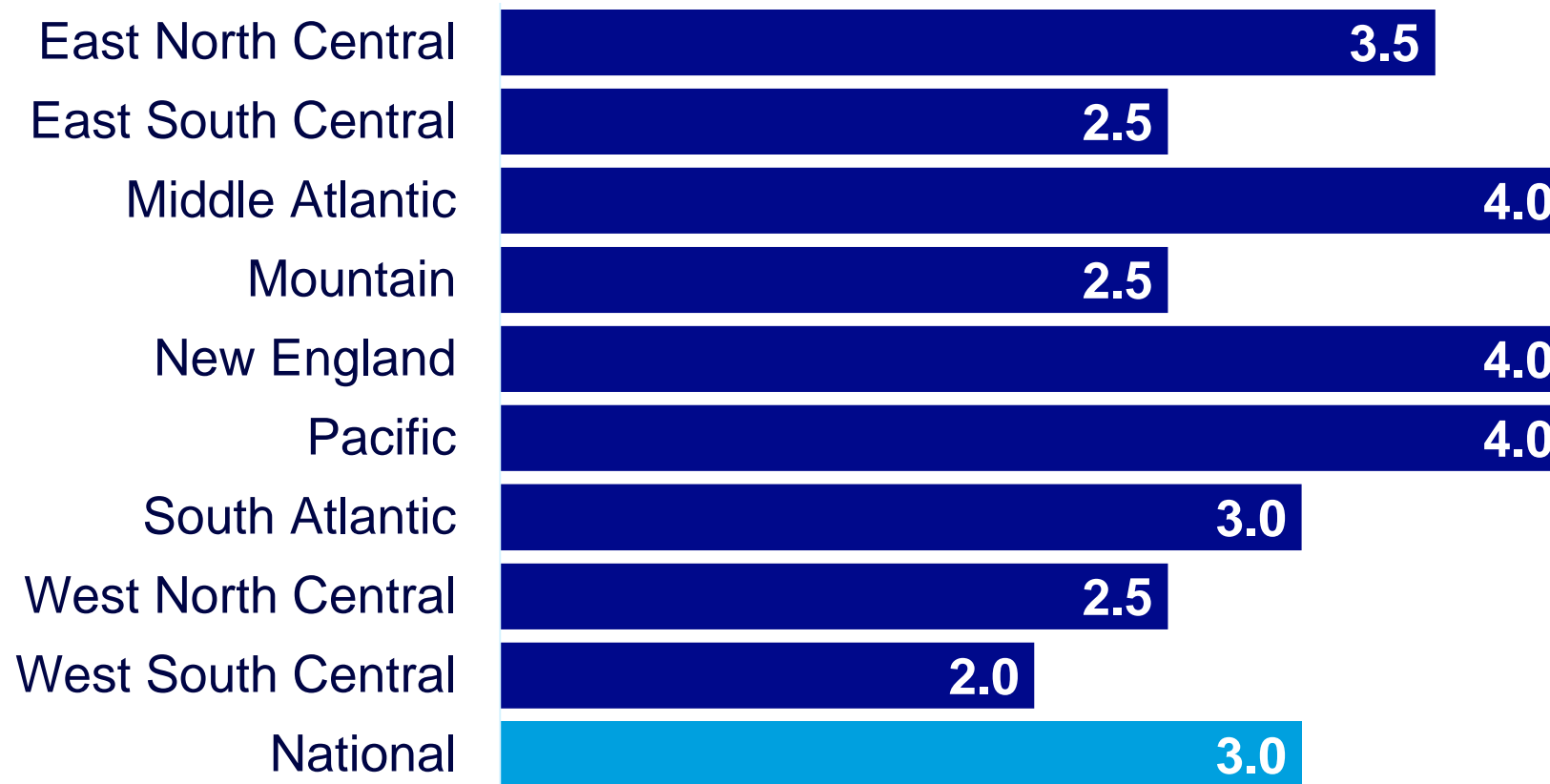
- Arkansas
- Wyoming

# 2024 Distribution of Star Ratings



# Capabilities for High-Quality Care for Serious Illness Vary with Geography

Average Census Division Star Rating 2024



# Performance by Domain

| Domain  | # Highest Performing States | # Lowest Performing States |
|---|-----------------------------|----------------------------|
| Specialty Palliative Care Availability            | 19                          | 17                         |
| Payment for Palliative Care Services              | 6                           | 21                         |
| Structured Champions, Advocacy, and Support       | 10                          | 11                         |
| Building Skills Outside Specialty Palliative Care | 15                          | 19                         |
| Foundation for Functional and Caregiver Support   | 16                          | 9                          |

Highest Performing = Both measures above the median  
Lowest Performing = Neither measure above the median

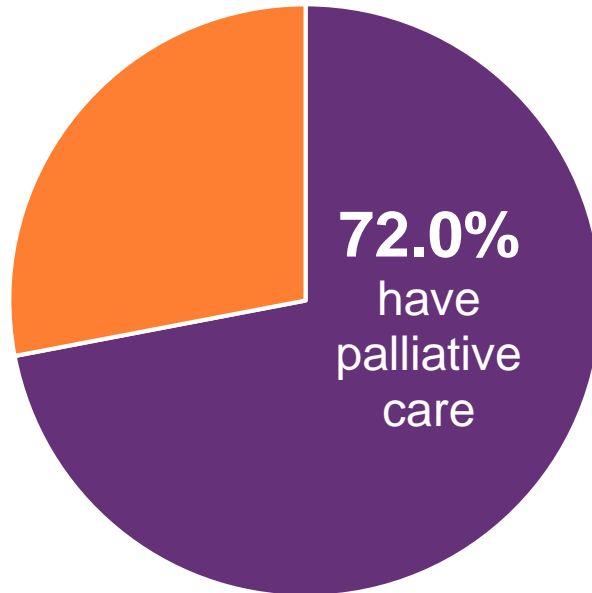
# Reflections on State Performance in 2024

- Encouraging to see more high performers than low performers
- In many cases, states with structures for advocacy and/or education performed better
- Unsurprisingly, payment for palliative care services was the worst-performing domain
  - Certain large private payers, such as Elevance and CVS/Aetna, helped to bolster some states
- Long-term services and supports for both adults and children are getting stronger in some states

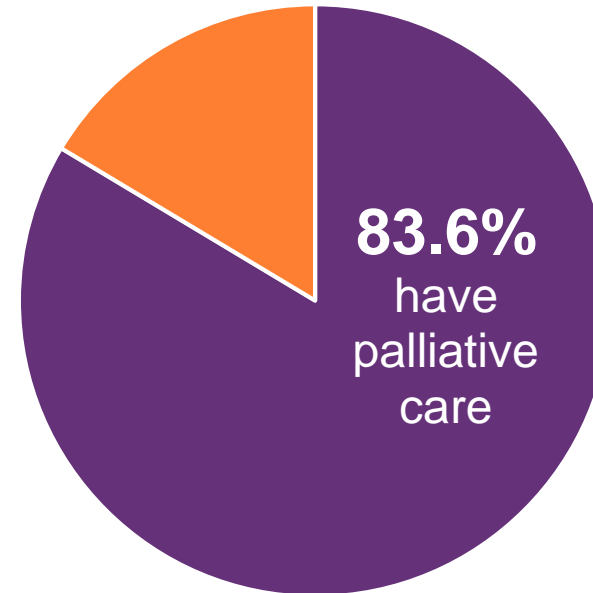
# A National Picture of Palliative Care and Palliative Skill-Building

# Hospital Palliative Care Continued to Grow

Hospitals with 50+ Beds  
2019 Report Card



Hospitals with 50+ Beds  
2024 Scorecard

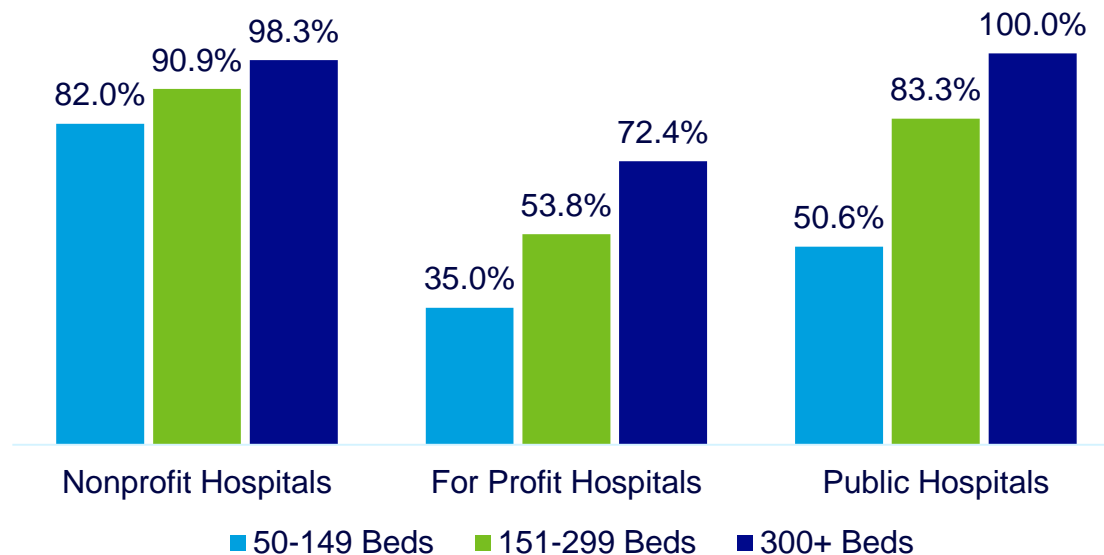


91.2% of all hospital admissions happen at a hospital with palliative care

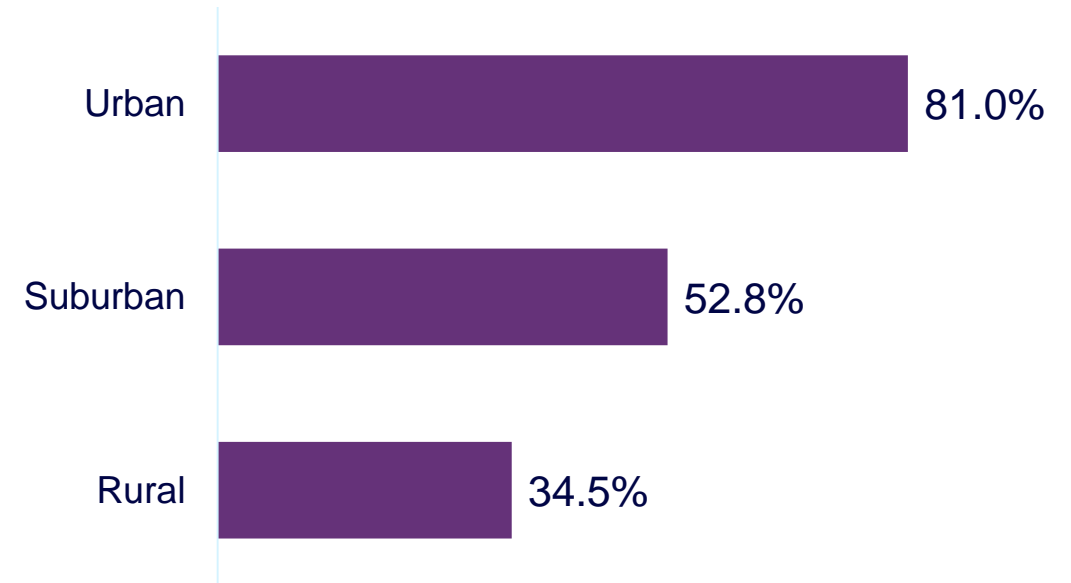


# Hospital Palliative Care Access Still Varies Widely

Hospital Palliative Care Prevalence by Bed Size and Tax Status



Hospital Palliative Care Prevalence by Geographic Type



# Community-Based Palliative Care Access

| Palliative Care Program by Setting               | Total Reported  |
|--|---|
| Medical offices and long-term care facilities    | 994 identified nationwide by palliative care programs |
| Home-based programs                              | Serving 80.2% of all US counties                      |
| Home-based palliative care supplemental benefits | Available in 205 Medicare Advantage plans             |

*Note: Does not characterize the capacity (max census) of community-based programs*

# Building Skills Among All Clinicians: By the Numbers

Over 3,000 organizations have used CAPC education

136,000 clinicians have completed courses in basic palliative care skills

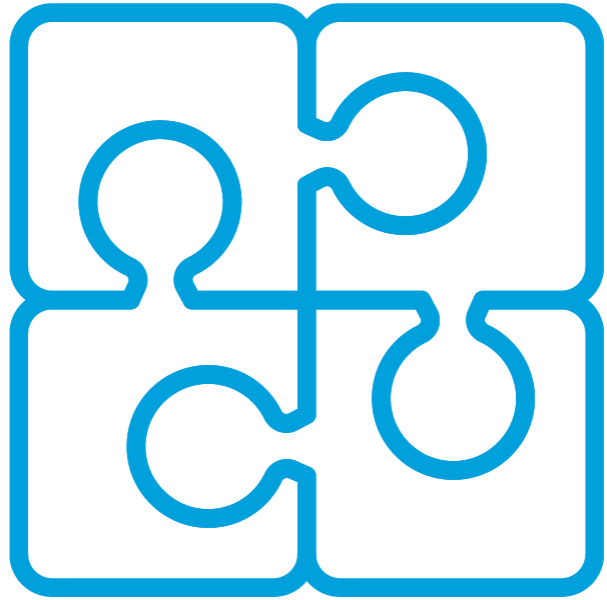
21 states require clinical education in clinical skills relevant to serious illness

# Now What? Suggestions to Strengthen Capacity

# Each State Report Reviews Strengths and Opportunities for Advancement



# Coalitions Can be a Powerful Force for Change



**Active Legislatively  
Established Palliative  
Care Advisory Council**

20 states

**Local Coalition  
Specific to Palliative  
Care**

29 states

# State Policy Recommendations

- ❑ Define palliative care in state policies
- ❑ Incorporate palliative assessments into existing Medicaid programs
- ❑ Explore Medicaid reimbursement for community-based palliative care
- ❑ Establish/expand loan forgiveness for palliative care professionals
- ❑ Incorporate palliative skills in continuing education requirements
- ❑ Provide grants to enable palliative care consultations to rural hospitals and FQHCs
- ❑ Add a palliative care module to the state risk surveillance system (BRFSS)



# Success Factors

- Meaningful coordination across all interested parties
- Prioritize! What is the most pressing problem to solve?
- Understand current resources
  - Some states collect information on palliative care programs and specialists via survey
  - CAPC and NASHP have useful resources – no need to reinvent the wheel
- Plan for implementation

**States can develop creative solutions to improve care for families facing serious illness. Some examples include:**

- Washington Rural Palliative Care Initiative
- The Southeast Institute for Innovation in Palliative and Supportive Care
- West Virginia law to create content and educational materials on palliative care
- Oregon requiring Medicaid accountable care organizations to provide interdisciplinary, in-home palliative care
- Goals of Care Coalition of New Jersey payment and awareness advocacy

# Need Input or Ideas? Join the State Palliative Care Forum

## State Palliative Care Forum

This forum is a free, centralized place for people who are interested in advancing palliative care at the state- and local levels. Feel free to post resources that you're working on, share progress on any legislative/regulatory/other initiatives, or ask questions of each other. The more you participate, the more meaningful it will be!




Email [paymentandpolicy@capc.org](mailto:paymentandpolicy@capc.org) to join

# Get the Word Out!

## Serious Illness Scorecard Social Media Kit

### 2024 Serious Illness Scorecard

A State-by-State Look at Palliative Care Capacity



#### Social Media Kit

The Center to Advance Palliative Care's (CAPC) [Serious Illness Scorecard](#) rates each state's capacity to deliver high-quality care to people living with a serious illness. Use the posts below to share your state's rating, in-depth information about access to palliative care in your state, and recommendations for improvement—and encourage others to explore their state's rating.

#### Posts


[X / Twitter](#)

**POST 1**  
(STATE NAME) rates a (INSERT RATING) in its capacity to deliver high-quality care to people living with a serious illness. Explore @capcpalliative 2024 Serious Illness Scorecard for our state's full report and recommendations to improve: <https://scorecard.capc.org/> #hpm #hpc

**POST 2**  
2024 Serious Illness Scorecard: A State-By-State Look at Palliative Care Capacity from @capcpalliative >> <https://scorecard.capc.org/>

- ✓ Find out your state's rating
- ✓ Read the key findings
- ✓ Review the actions #palliative care champions and federal and state policymakers can take

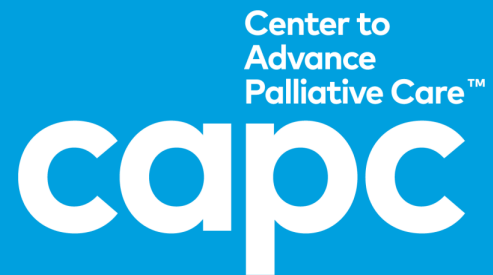
#hpm #hpc



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[https://docs.google.com/document/d/1j4g3rb2UZzNZgOfFNOeqZxSCglcxyx\\_79gZTL24lp\\_g/edit?usp=sharing](https://docs.google.com/document/d/1j4g3rb2UZzNZgOfFNOeqZxSCglcxyx_79gZTL24lp_g/edit?usp=sharing)

# Questions?



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