

The Status of Palliative Care in the United States: An Update

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<https://reportcard.capc.org/>



America's Care of Serious Illness

2015 STATE-BY-STATE **REPORT CARD** ON ACCESS
TO PALLIATIVE CARE IN OUR NATION'S HOSPITALS

Alabama
Alaska
Arizona
Arkansas
California
Colorado
Connecticut
Delaware
Florida
Georgia
Hawaii
Idaho
Illinois
Indiana
Iowa
Kansas
Kentucky
Louisiana
Maine
Maryland
Massachusetts
Michigan
Minnesota
Mississippi
Missouri
Montana
Nebraska
Nevada
New Hampshire
New Jersey
New Mexico
New York
North Carolina
North Dakota
Ohio
Oklahoma
Oregon
Pennsylvania
Rhode Island
South Carolina
South Dakota
Tennessee
Texas
Utah
Vermont
Virginia
Washington
West Virginia
Wisconsin
Wyoming

Today's Agenda

- Who are the high risk high cost patients?
- The needs of the seriously ill and their families
- Why palliative care is the solution
- How is our nation doing?

Audience Polling Question

Who is in the audience? (Select your primary role):

- A. Palliative care team member
- B. Administrator
- C. Advocate
- D. Researcher
- E. Other

What is Palliative Care?

- Specialized medical care for people with serious illness.
 - Doctors, nurses, social workers, chaplains
- Improves quality of life
- Provides an added layer of support
- Accompanies life-prolonging and curative treatments for as long as patients need it.

What Do Palliative Care Teams Do?

Relieve

- Pain and other symptoms
- Distress- emotional, spiritual, social, practical
- Uncertainty

Communicate

- What to expect
- Treatments that match person and family priorities

Coordinate

- Medical and practical needs across settings

Why is Palliative Care the Solution? Many studies show:

- Improved quality of life for patients
 - Reduces pain and other symptoms
 - Addresses patient-family goals
- Improved family satisfaction/well-being
- Prevention of crises that drive hospitalizations and costs

Temel et al, NEJM 2010; Wright AA et al, JAMA, 2008; JCO, 2010; Nelson et al, Perm J, 2011; Enguidanos, JPM 2012, Adelson et al, ASCO 2013

Americans Want Palliative Care*

Telephone survey of 800 Americans

- **92%** of respondents say they would seek palliative care for a loved one if they had a serious illness.
- **92%** of respondents say palliative care services should be available at all hospitals.
- **BUT...** Only 8% were knowledgeable about palliative care at the start of the survey

*Public Opinion Strategies/CAPC/ACS Consumer Poll, 2011

Why a Report Card?

- To determine adequacy of access to palliative care services.
- To understand gaps in access to palliative care delivery to inform policy change

Audience Polling Question

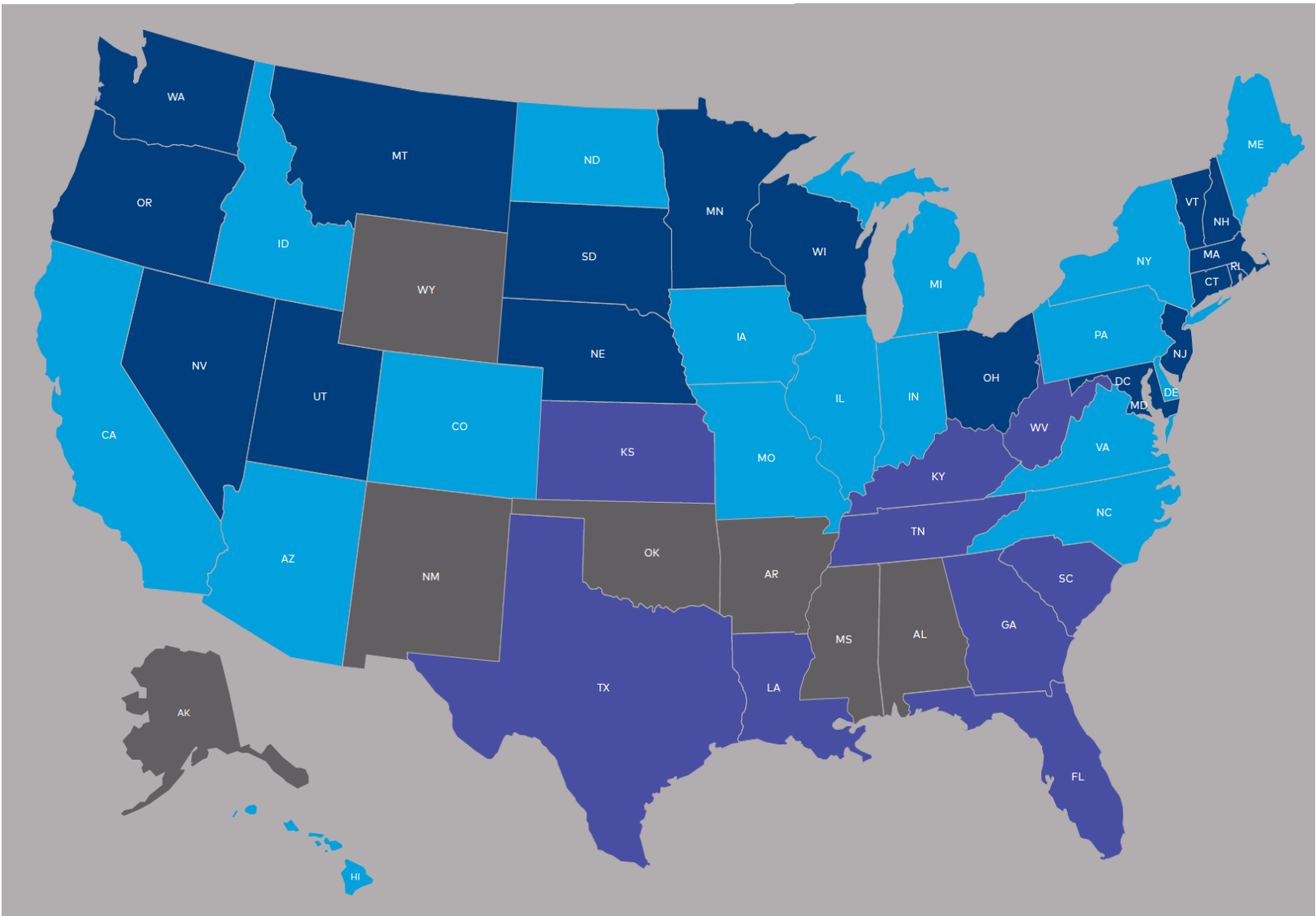
How have you used the report card up to this point?


- A. Forwarded to someone
- B. Met with someone to discuss
- C. Planned follow-up activities based on the findings
- D. All of these activities
- E. None of these activities


Methods


- National survey of all hospitals in the United States providing medical/surgical care to adults
- Data linked to American Hospital Association Annual Survey, Dartmouth Atlas of Healthcare, U.S. Census Data
- Full methods available at:
 - <http://online.liebertpub.com/toc/jpm/0/0>


Did your state make the grade?



>80% of hospitals with palliative care programs 

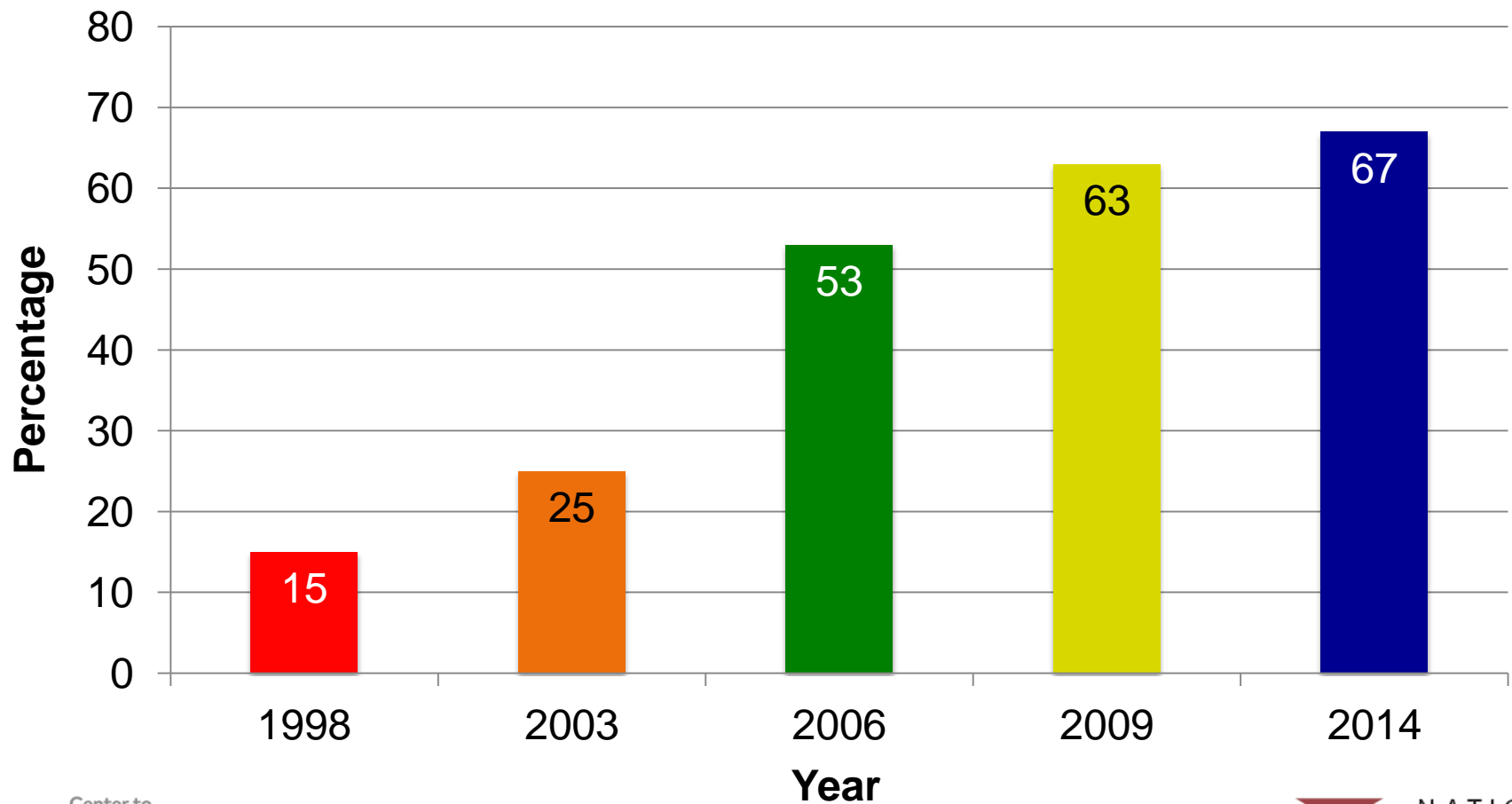
61-80% of hospitals with palliative care programs 

41-60% of hospitals with palliative care programs 

21-40% of hospitals with palliative care programs 

The Good News...

Palliative Care Has Grown Dramatically in U.S. Hospitals



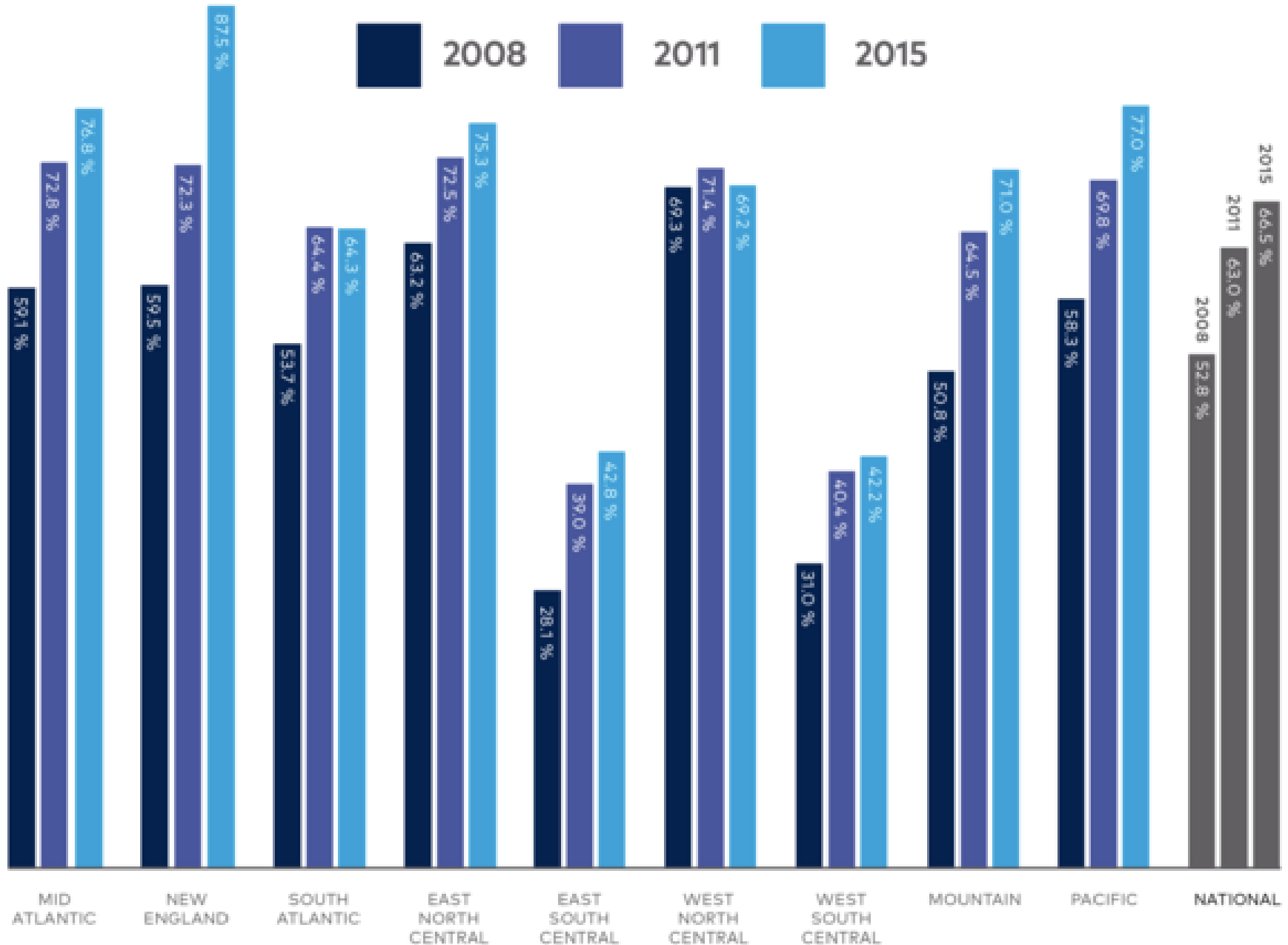
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Advance
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 NATIONAL
Palliative
Care
RESEARCH CENTER

Graph B. Percent of hospitals with a palliative care program by census region (2008, 2011, 2015)

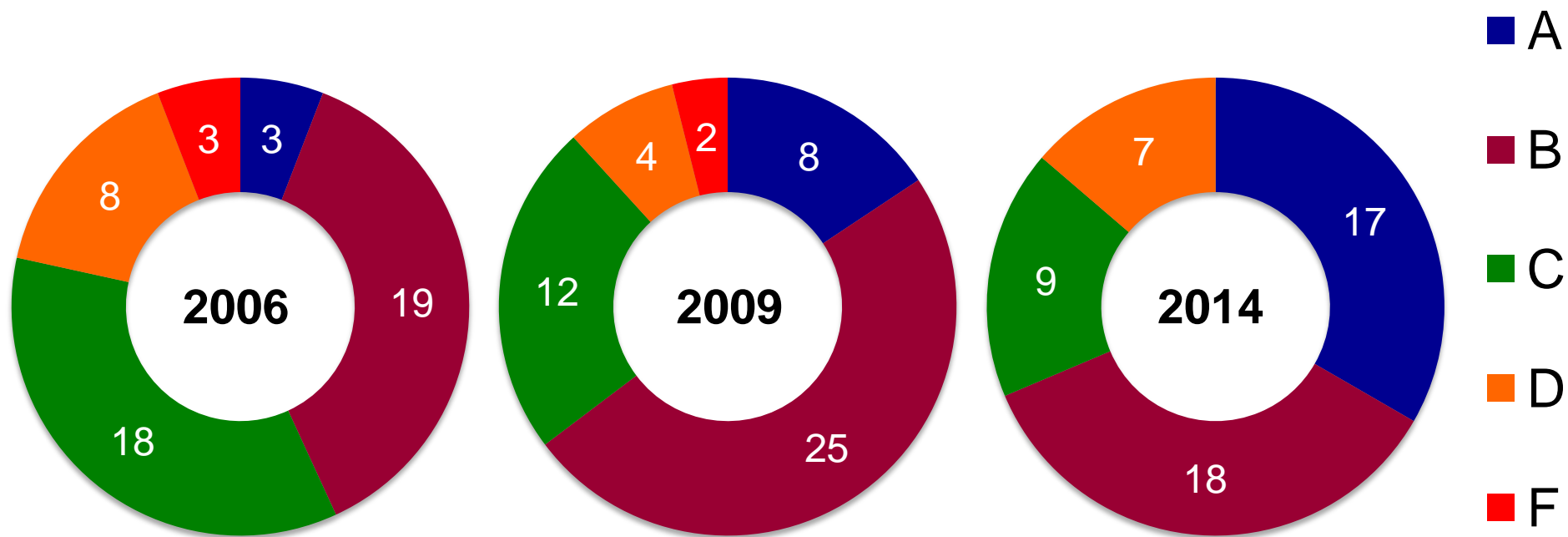
Most regions continue to see growth in palliative care programs.



Who's Providing Palliative Care?

- 90% of hospitals with 300 or more beds
- 97% of teaching hospitals
- 90% of Catholic Church operated hospitals
- 77% of nonprofit hospitals

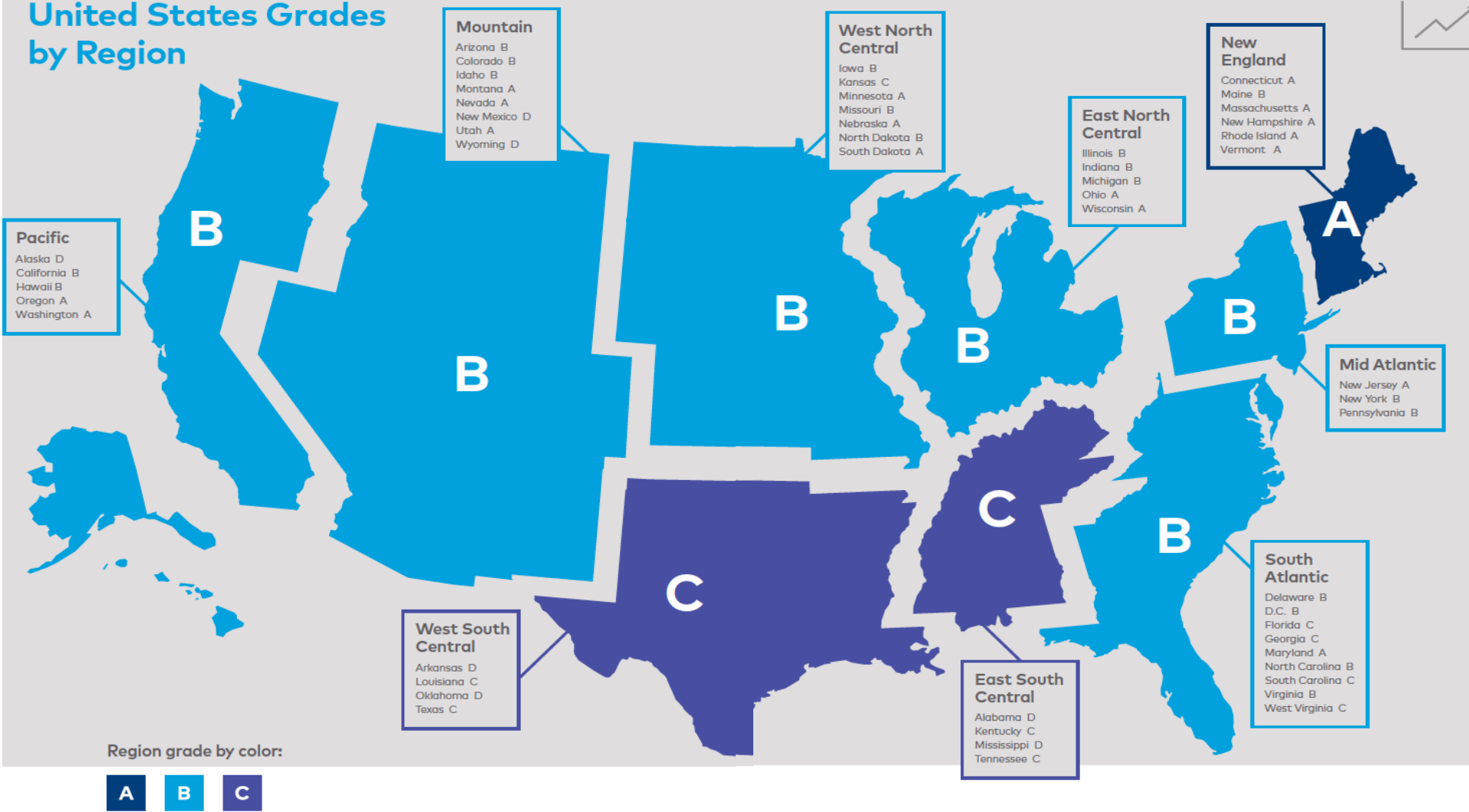
Two-Thirds of States Have a Grade of A or B in 2015



Gaps

One-third of U.S. hospitals with fifty or more beds report no palliative care services, and one-third of the states received a grade of C or D.

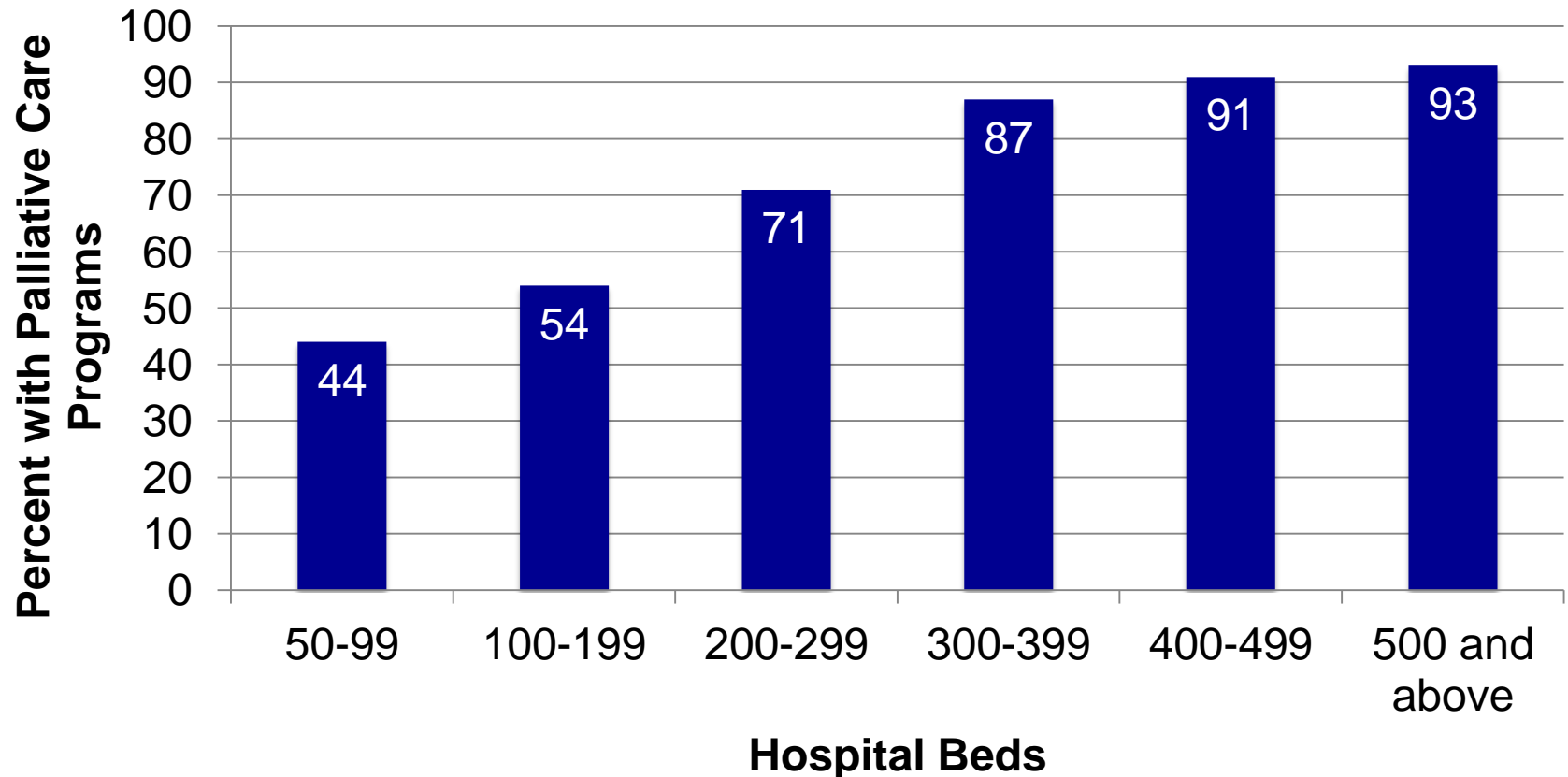
United States Grades by Region



Where are the gaps?

- **Geography:** the South
- **Ownership:** For Profits
 - All hospitals: 23% of for-profits vs. 67% of nonprofits
 - 300 or more bed hospitals: 54% of for-profits vs. 94% of nonprofits
- **Hospital size:** Smaller hospitals
 - <100 beds: 44% vs. >300 beds: 90%

Percent of Hospitals with Palliative Care Teams by Size



Graph C. Percentage of hospitals with a palliative care program by hospital beds and regions, 2015

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

MID ATLANTIC



NEW ENGLAND



SOUTH ATLANTIC



EAST NORTH CENTRAL



EAST SOUTH CENTRAL



WEST NORTH CENTRAL



WEST SOUTH CENTRAL



MOUNTAIN



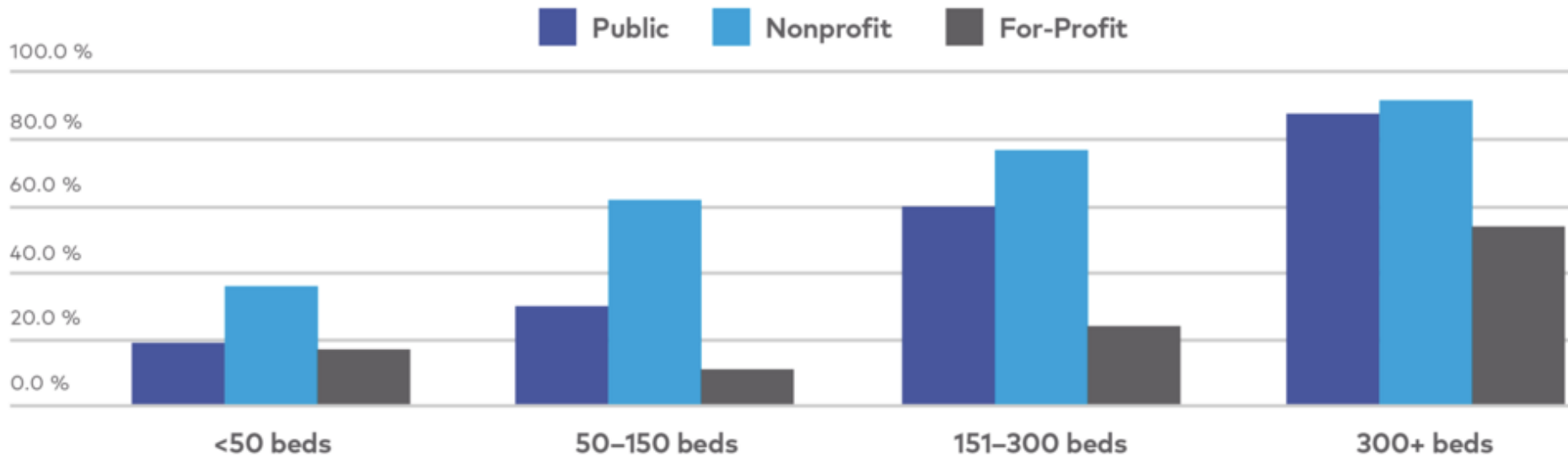
PACIFIC



Number of beds, by color: <50 50-150 151-300 300+

Graph D. Percentage of hospitals with a palliative care program by hospital ownership and hospital beds, 2015

Lower rates of palliative care program prevalence persist in for-profit hospitals across all hospital sizes.



Interpreting Your Grade

Grade	Definition	Have Program?	Next Steps/ Interpretation
A/B	>80 percent or >60 percent of hospitals in your state have a PC program	Yes	Congratulations – you’re part of a movement to increase access to palliative care in your state! Next step: Continue to examine the quality of your program.
		No	You are behind many of the other hospitals in your state in delivering this service. Next step: Think about how you would set up a program
C/D	>40 percent or >20 percent of hospitals in your state have a PC program	Yes	Congratulations – you’re leading the way in your state! Next step: Encourage others to do the same and continue to examine the quality of your program.
		No	Your state is behind other states in making this service available. Next step: Think about how you would set up a program

The next 5 years

- Support southern, smaller, and for-profit hospitals to develop palliative care programs
- Enhance access for patients in need
 - <50% of patients who could benefit typically receive palliative care even when it's available!
- Develop new models of palliative care delivery outside of hospice and hospitals
 - Home, nursing home, office practices

Deficits that need addressing

- Infrastructure
- Workforce
- Evidence

Infrastructure

- Not enough access to palliative care in hospitals with existing programs
- Most illness occurs outside of hospitals
 - Models need to be developed and disseminated without regard to prognosis
- Poor or no quality metrics for complex patients with multiple medical problems moving across multiple care settings.

What is Needed?

- Regulatory and accreditation requirements
- Quality measures linked to payment incentives
- Clinician training in core skills
- System redesign – checklists and pathways
- Insurance benefit design

Quality and Payment

recommendation:

Allocate funding to develop quality address communication, concordance

recommendation:

Direct CMS to include palliative care measures in

recommendation:

As CMMI is selecting and piloting new care models, ensure that palliative care is a component of care, quality measurement and payment for those with serious illness.

ed programs, untable Care e Five-Star re Advantage ty reporting and uld include, where ome measures uate resources ous illness.

who should act:

CMS

CONGRESS

Work Force

- 1 palliative medicine MD for every 1,700 persons with serious illness
- Most fellowship programs in academic medical centers are supported through *philanthropy*, not GME
- No mandatory training for front-line doctors and nurses

What Is Needed?

- Palliative care fellowship training
- Training in core palliative medicine knowledge and skills for *all clinicians*
- Quality measures, transparency, and public reporting

Workforce

recommendation:

Establish palliative care centers that would develop and disseminate curricula related to

recommendation:

Reform Graduate Medical Education (GME) funding to support residency slots in high-value specialties like palliative care, and explore a GME quality-improvement program to create incentive for skills training in patient-centered communication, team-based care and pain and symptom management for all physicians, regardless of specialty.

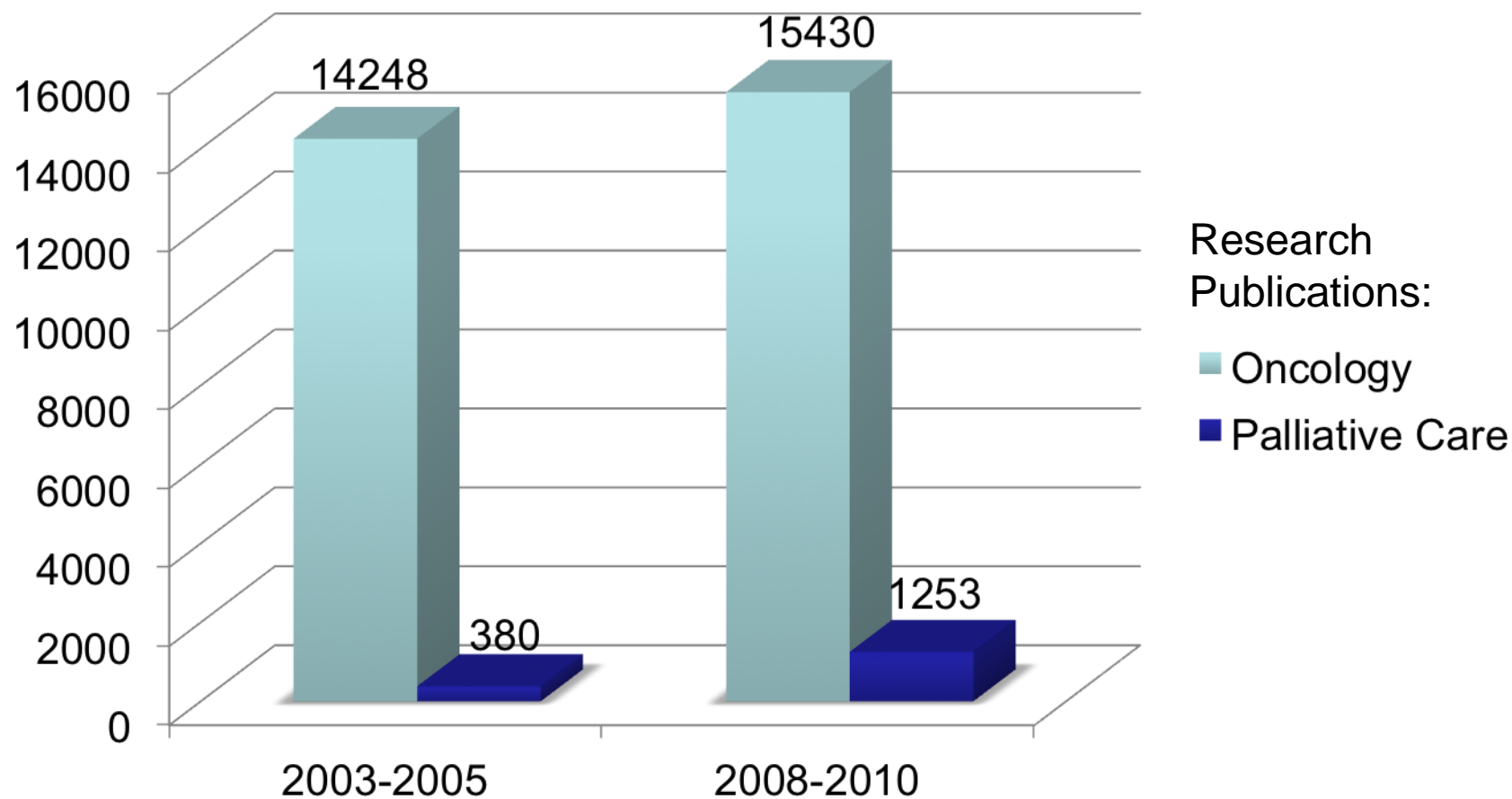
who should act:

CONGRESS

wards for palliative care workers and chaplains to the field of palliative care, educators who can integrate nursing school and

CONGRESS

Evidence Base



Research Funding

- 0.2% of all NIH grants focus on palliative care
- By institute
 - NCI: 0.4% of all grants funded
 - NIA: 0.8% of all grants funded

The Result:

- Current palliative care practice is guided by:
 - Data from other populations
 - Results from small series of patients from single institutions
 - Anecdote and hearsay
- Is this the type of care that we really want for ourselves and our loved ones?

Research

recommendation:

Support PCORI, NIH and AHRQ research on symptom relief, care for patients with serious illness, and

recommendation:

Develop specific program announcements and requests for applications targeted to palliative care research priorities. These studies should include research on functional and cognitive outcomes, implementation studies and large scale translation into practice.

recommendation:

Develop a Center for Scientific Review (CSR) study section that focuses on serious illness, beyond disease and biology-specific topic areas. Existing study sections that currently review research grant applications related to palliative care should have at least three members with content and methodological expertise in palliative care.

who should act:

NIH

AHRQ

PCORI

CMMI

NIH

AHRQ

What can you do to influence Federal policy?

Talk to your representatives about **HR 3119: Palliative Care and Hospice Education and Training Act (Engel/Reed)**

- Expands federal research
- Supports training for health professionals
- Establishes a national public education and awareness campaign.
- <http://patientqualityoflife.org/policy-and-advocacy-materials/>

Recommendations for State Policymakers

- **State leadership should create a multidisciplinary** advisory board and/or task force to conduct a landscape analysis of available resources and determine state priorities and needs.
- **State legislatures should appropriate funding** to establish palliative care training institutes in their states, ideally within an existing university health system, to develop appropriate curriculum, create requirements for training and provide opportunities for hands-on professional development. The institute should integrate this curriculum into undergraduate and graduate courses in medicine, nursing, social work and chaplaincy. The institute should also provide continuing education for practicing midcareer health care professionals.

How to Leverage the Report Card?

Establish Goals	<ul style="list-style-type: none">• Develop a palliative care program in a hospital that does not have one• Expand your palliative care program in the hospital/into the community• Increase recognition of/funding for palliative care at state level• Support passage of the Palliative Care and Hospice Education and Training Act (H.R. 3119)
Identify Audience	<ul style="list-style-type: none">• Hospital administrators• State legislatures• State health departments• Federal legislators
Take Action	<ul style="list-style-type: none">• Schedule meetings with hospital administrators/C-suite to share findings• Bring to state coalition or organization to develop state strategy• Reach out to state Medicaid department to share information on PC cost/quality• Work with local American Cancer Society-Cancer Action Network chapter on passing state advisory board legislation• Reach out to Federal legislators (letter writing/in-person meeting)

Community Health Needs Assessment

If your hospital is nonprofit, IRS tax code requires conduct of a community health needs assessment (CHNA) to maintain tax exempt status. Therefore, find out who is responsible for conducting the CHNA in your hospital: <https://www.irs.gov/Charities-&-Non-Profits/Charitable-Organizations/New-Requirements-for-501%28c%29%283%29-Hospitals-Under-the-Affordable-Care-Act>

Community Health Profile Resources

- County Health Rankings
 - <http://www.countyhealthrankings.org/>
- Community Health Status Indicators
 - <http://wwwn.cdc.gov/communityhealth>
- Kaiser State Health Facts
 - <http://kff.org/statedata/>

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www.cambiahealthfoundation.org



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Questions and Comments

- Do you have questions for the presenter?
- Click the hand-raise icon (🙋) on your control panel to ask a question out loud, or type your question into the chat box.

