

State Policy Windows of Opportunity: Palliative Care and Advance Directives- How to Harness State Data to Improve Palliative Care

Speakers:

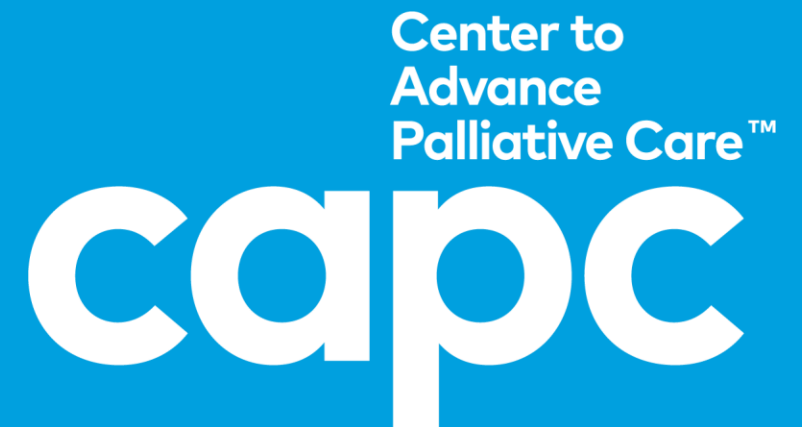
- Marisette Hasan, RN, BSN, VP of Community Action & Policy, C-TAC
- Stacie Sinclair, MPP, Associate Director, Policy and Care Transformation, Center to Advance Palliative Care (CAPC)



Collecting Data on Your Local Palliative Care Landscape

A New State Survey Template

Stacie Sinclair, MPP
October 21, 2024



Project Origins: C-TAC-CAPC 2023 Summit

- Mapping allows leaders to comprehend the landscape of palliative care; assess the need and capacity of care providers in a given state
- Environmental scans help identify the various ways that palliative care is delivered

Several Initiatives Completed or Underway

Palliative Care in California: Narrowing the Gap

Issue brief and interactive maps describe capacity of palliative care programs in 2017

JUNE 12, 2018

The Need for Palliative Care

Inpatient Services

Community-Based Services

County Summaries

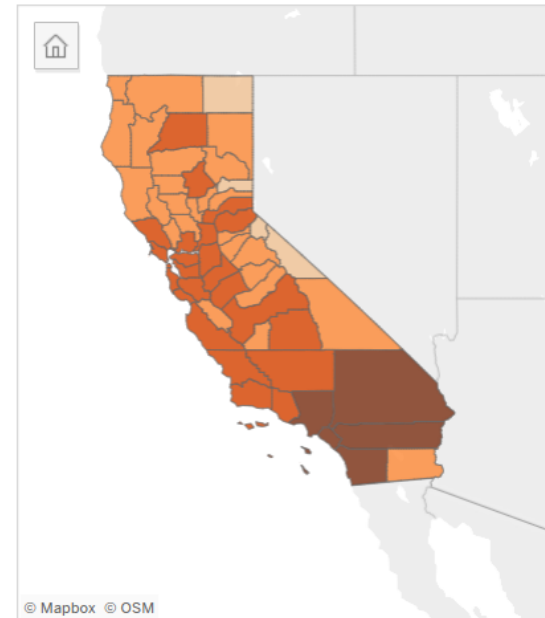
COMMUNITY-BASED SERVICES

Community-based programs provide palliative care in clinics, at patient homes, or over the phone. This research identified 380 community-based PC programs sponsored by home health agencies, hospices, medical groups, health systems, and social service organizations — more than double the number identified in 2014.

For this research, many programs provided data on the number of patients seen annually; when actual data were not available, estimates based on the average caseload reported by similar programs were used.

The 380 community-based PC programs can serve approximately 76,730 patients annually, about 40% of the estimated 191,000 Californians who need PC in the last year of life. While capacity has increased dramatically in recent years, supply is still insufficient. Community-based PC is nonexistent in 6 counties. Of the other 52 counties, 18 have limited supply, and are able to meet less than 30% of the estimated need. In Sacramento County, for example, the 16 identified programs can serve 2,610 patients annually. In 8,385 patients in

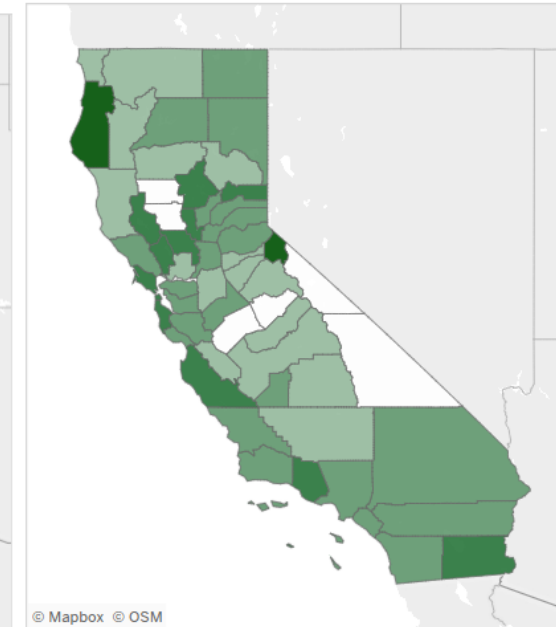
Estimated Palliative Care Need Patients Needing PC in the Last Year of Life



Patients # Counties

<= 100 4

Estimated Community-Based PC Sufficiency Community-Based PC Capacity as % of Need



Est. Sufficiency # Counties

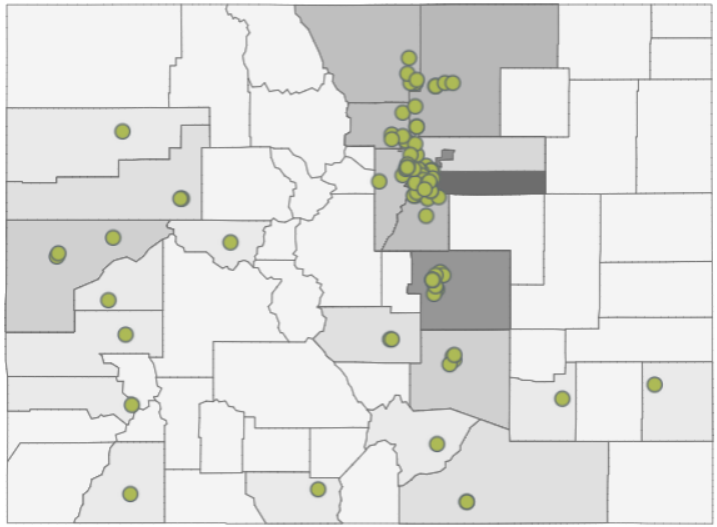
0% 6
1-25% 16



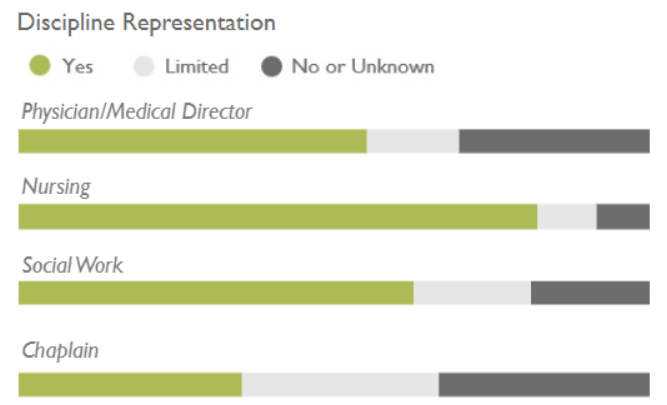
Palliative Care Map and Report

CENTER FOR IMPROVING
VALUE IN HEALTH CARE

County: (All) Available 24/7: (All) Treats Pediatrics: (All) Setting: (All)



97 total sites



Select a site to filter the table below

Hover for contact details:

Abode Hospice and Home Health of Color...	5465 Mark Dabling Blvd	Colorado Springs	80918	
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Palliative Care Provider Questionnaire

The Department of Health Care Policy and Financing is interested in the structure of your palliative care team, and how you bill for services. We will use this information to inform our research on developing a potential palliative care benefit through Health First Colorado (Colorado Medicaid). Thank you for your time and expertise!

Note: We're discussing palliative care here as a separate and distinct array of services. This survey is **not** referring to hospice care.

paymentandpolicy@capc.org [Switch account](#)

Not shared

* Indicates required question

What is your role related to palliative care: *

- Nurse
- Physician
- Advanced Practice Provider
- Social Worker
- Case Manager
- Behavioral Health Professional
- Nurse Aide or CNA
- Chaplain or Clergy
- Dietary or Nutritional Support
- Pharmacist
- Hospital or Clinic Administration
- Other:

Goals of Care Coalition of New Jersey Survey

November 2023
Palliative Care Provider Survey
Introduction

****PLEASE NOTE THIS SURVEY IS TO BE COMPLETED BY PALLIATIVE CARE PROGRAM ADMINISTRATORS****

Goals of Care Coalition of New Jersey (GOCC)
Cancer Research (NJCCR) to:

Get an accurate understanding of state capacity
care teams and programs.
Develop a directory of specialty palliative care

PLEASE NOTE this survey is intended to collect

New Mexico Medicaid Stakeholder Survey

January 2024
https://docs.google.com/forms/d/e/1FAIpQLSdQ6vWbWnCSITKQOCsebiyBnad5CDqp3nZCRluG_mSOjKW8uw/formResponse

Hospice-like community palliative care benefit through NM Medicaid stakeholder survey [WINTER CONFERENCE]

The New Mexico Human Services Department (HSD) is interested in exploring a hospice-like community palliative care benefit through New Mexico Medicaid. We have been tasked with providing appropriate team composition (core and supplemental), included services, inclusion and exclusion criteria, and payment methodology. We want to know your thoughts on these topics to better inform our recommendations to HSD. Questions on this form are called out as "adult" or "pediatric".

What is your role within palliative care? (e.g., providers, MCO, caregiver, etc.)

Your answer

QUESTION 1: PALLIATIVE CARE TEAM

HB 378 (2022) Palliative Care Services in Maryland: Final Report

Appendix A

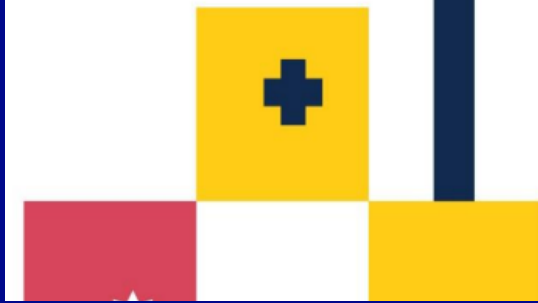
Inpatient Palliative Care Survey

On behalf of Kōkua Mau, we would like to invite you to participate in our research study that aims to learn more about the state of palliative care in Hawai'i.

The purpose of this project is to assess the state of palliative care in Hawai'i. We hope to learn more about the available resources pertinent to palliative care, as well as the gaps in our

ing to compare the status of inpatient and

*part of a hospital setting which may already
o improve palliative care services in the*



Sample State Palliative Care Survey

Note: This sample survey was generously provided by the Tennessee Department of Health, building off work done by the Florida Department of Health. Users are encouraged to modify the survey as appropriate for your specific state needs.

[Email message]

Dear [Recipient],

The [insert survey lead] is working to gather specific information on palliative care across the state. We would greatly appreciate your help by taking approximately 10 minutes to complete a survey to help the [insert survey lead] better understand the capacity of palliative care in [insert state]. Your answers are valuable and will assist us in identifying gaps in service, as well as provide recommendations to address any unmet needs. Your answers will remain confidential and the results of the survey will be reported in a summary format.

National Palliative Care Registry™

The National Palliative Care Registry, a joint project of the Center to Advance Palliative Care (CAPC) and the National Palliative Care Research Center (NPCRC), was active from 2008-2020, and its goal was to build a profile of palliative care teams, operations, and service delivery. During that time, more than 1,000 palliative care programs received at least one comparative performance report.



The National Palliative Care Registry™ is building a profile of palliative care teams, operations and service delivery.

884

Palliative Care Programs

1031

Care Settings

1.46M

Initial Patient Consultations

The Registry is FREE and open to all palliative care programs across the continuum



2016 data entry is always open! If you haven't entered your data already, do it today!
(Sign in and start submitting)

Participate in the Registry



Access Metrics & Resources

What's New for the Home Survey

Based on feedback from participating palliative care programs, the CAPC home-based palliative care workgroup and the field, we have made some changes to the home-based palliative care survey. This version of the survey will be available starting **January 1, 2019** for annual data entry. Below is an outline of those changes.

- 1. Focused Scope:** The new Home Survey has strengthened focus on actionable structure and process measures that are feasible for programs to collect.
- 2. Length and Question Changes:** The new Home Survey is shorter than our previous version. Questions were removed for a series of reasons, including low participation rates, too burdensome for programs to collect, requires chart review/custom reporting from the EMR, non-reliable answers from participants, and/or outside of the process and structure scope.
- 3. One of Many Data Resources:** While patient reported outcomes and clinical data are extremely important for programs to collect to show program value and impact, the Registry is not the correct venue to collect it. Data collection for quality improvement purposes are better met by other systems, such as participating in a palliative care quality improvement



► J Palliat Med. 2019 Sep 3;22(9):1026–1031. doi: [10.1089/jpm.2019.0262](https://doi.org/10.1089/jpm.2019.0262)

The National Palliative Care Registry: A Decade of Supporting Growth and Sustainability of Palliative Care Programs

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PMCID: PMC6735315 PMID: [31329016](https://pubmed.ncbi.nlm.nih.gov/31329016/)

Mapping

COMMUNITY PALLIATIVE CARE

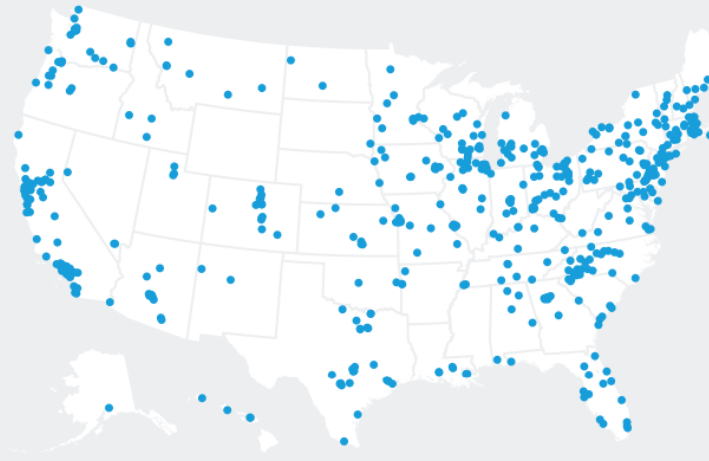
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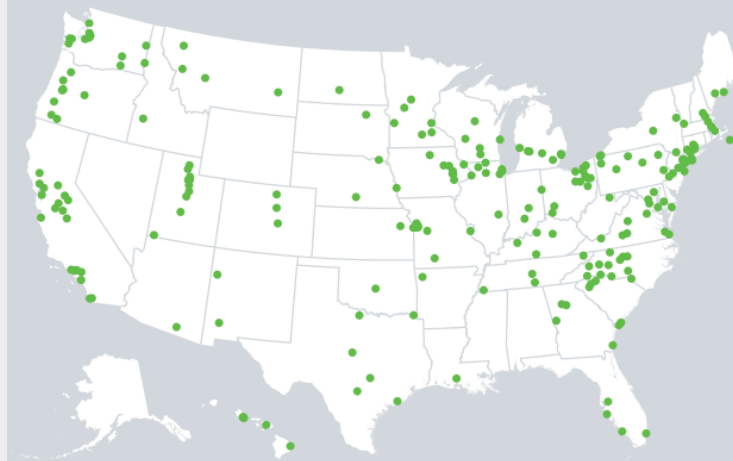
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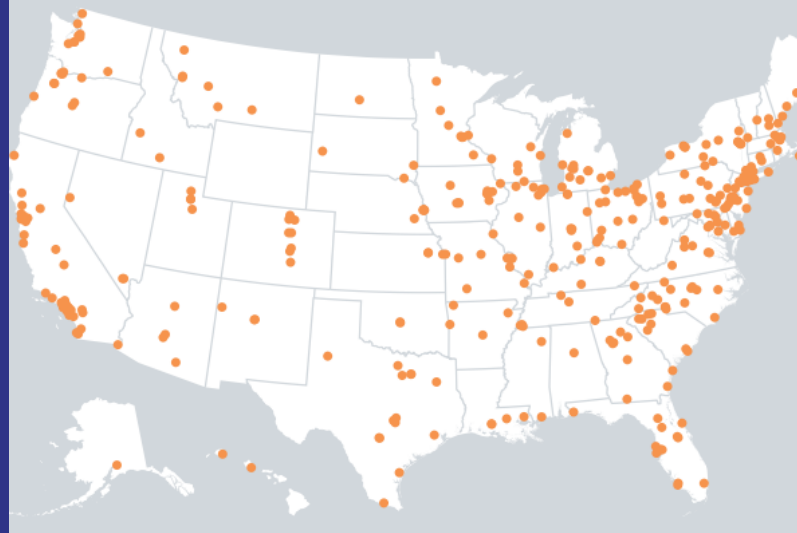
Respondents Who Provide Palliative Care in Patients' Homes



Respondents Who Provide Palliative Care in Long-Term Care Facilities



Respondents Who Provide Palliative Care in Office Practices or Clinics



Appendix I: Mapping Community Palliative Care Survey

Are you a community-based palliative care program? Put yourself on the map!

Add your program to the Palliative Care Provider Directory on GetPalliativeCare.org - the top palliative care website for patients and families and the ONLY comprehensive online directory of palliative care programs nationwide. Make it easier for patients, families, and providers to locate your program. Completing the survey takes less than five minutes and is free.

By listing your program, you will also make your mark on our growing map of community-based palliative care programs across the country. Your participation will help us expand, fortify, and support this growing cohort of community-based palliative care programs across the country.

Mapping Community Palliative Care is a project of the Center to Advance Palliative Care, in collaboration with the National Coalition for Hospice and Palliative Care. Funding is provided by the Gordon and Betty Moore Foundation.

Survey Questions

What is Palliative Care?

Palliative care is a team approach to improving quality of life for people living with serious illness. It focuses on providing relief from the pain, symptoms, and stress of a serious illness for both the patient and family. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

At a minimum, a palliative care program should provide:

- Expert pain and symptom management
- Effective communication with patients and families to support autonomous decision-making for medical treatment and care priorities
- Screening and support for the emotional, social, and spiritual needs of patients and their families

<https://www.capc.org/mapping-community-palliative-care/>



PCQC Registry Stats

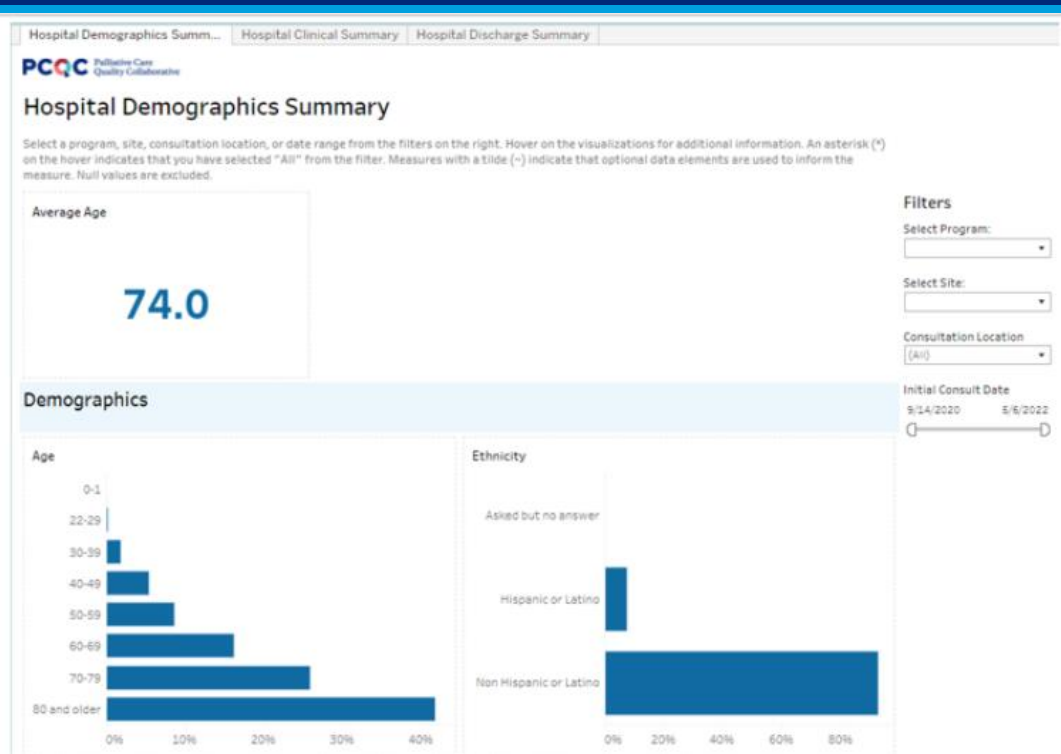
Patient

- 175k Encounters
- 49k Unique Patients
- 1.2k Active Users
- 4.8m+ Data Points Completed

Program

- 450 Program Surveys Completed
- Reporting on 6k Survey Responses

<https://www.palliativequality.org/>



Document Last Revised January 23, 2023

Community Annual Survey

Annual Program Surveys and Reports provide actionable data that programs can use to secure, expand and retain resources for delivery of high-quality palliative care, and to support the establishment of new palliative care programs where none exist. Data is collected on all service settings across the continuum of care, including hospital, long-term care, office/clinic, and home-based palliative care.

With the move to PCQC, we took this opportunity to review and refine our surveys to align with best practices. The following pages show the community survey questions for 2022. The survey is broken down into five sections:

- Program-level questions to be completed by all palliative care programs that provide care in the community
- Home: questions specific to programs that provide care in patient's homes
- Office: questions specific to programs that provide care in office practices and/or clinics
- Long-term Care: questions specific to programs that provide care in long-term care facilities
- Staffing questions specific to each community setting (Home, Office, and Long-term Care)

<https://www.capc.org/provider-directory/>

Get Listed on the Palliative Care Provider Directory

Finding palliative care services should be easy and convenient, not only for patients living with a serious illness, and their families, but also for their medical teams. CAPC's national [Palliative Care Provider Directory](#) on GetPalliativeCare.org provides a quick and easy way for patients, families, and referring clinicians to locate and contact palliative care programs in their area.

Add Your Palliative Care Program to the Provider Directory

Specialty palliative care programs in both hospital and community settings can be listed in the Provider Directory by filling out [this short questionnaire](#). Your program may already be listed on the Directory. If it is, claim your listing and update it. If it's not, you can add it! Listing your program is **free and open to all** palliative care programs in the U.S. You *do not* have to be a CAPC member to list your program.

[LIST YOUR PROGRAM](#)

More about GetPalliativeCare.org

The Palliative Care Provider Directory is a feature of GetPalliativeCare.org, CAPC's website for patients and families. With more than 1.2 million visits per year, GetPalliativeCare.org is the go-to website for patients and families seeking



GET PALLIATIVE
CARE

Menu

Palliative Care Provider Directory

Palliative Care Provider Directory

Search Results: 3 results found

ENTER ADDRESS, ZIP CODE OR CITY & STATE

district of columbia

RADIUS

Closest 20 results

CHECK THE ONE THAT APPLIES:

Hospital Nursing Home Office/Clinic Home

[Search](#)

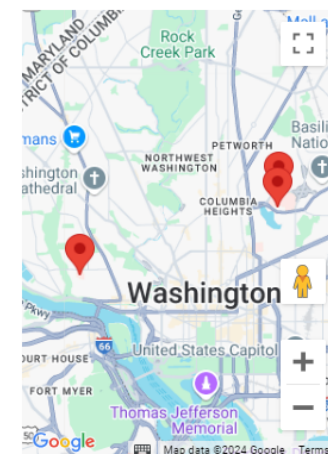
The Palliative Care Provider Directory is a resource to help you or a loved one locate palliative care in your area. It includes all programs that have listed themselves with us. Please contact the palliative care program directly to confirm eligibility.

Children's Hospital Nmc

MedStar Georgetown University Hospital

MedStar Washington Hospital Center

<https://getpalliativecare.org/provider-directory/>



Challenges in Tracking Care for SI

- No universal agreement on core features
- No clear denominator for community based palliative care
- Survey development and administration is costly

This is not a comprehensive list of challenges.

Partial Solution: Survey Template

- Identify core themes across previously administered surveys
- Reduce the opportunity cost of developing a draft survey for new states undertaking this work
- Increase alignment with other states

October 2023

- C-TAC-CAPC Summit State Pre-Conference

November 2023

- C-TAC State Coalition Call: Review pre-summit session takeaways

January 2024

- C-TAC State Coalition Call: Confirm interest in state template, plan workgroup

February-May 2024

- Thematic analysis of existing survey materials

May 2024

- Survey Workgroup Meeting #1 – summarized findings and gathered initial feedback

July 2024

- Survey Workgroup Meeting #2 – reviewed draft template

October 2024

- Survey Workgroup Meeting #3 – reviewed final draft template
- C-TAC National Leadership Summit 2024

CAPC Team



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Palliative Care Physician & Assistant Professor of Clinical Medicine at New York Presbyterian-Lower Manhattan Hospital/Weill Cornell Medical Center

Physician Fellow, Hospice and Palliative Care, Mt. Sinai (2022-2024)



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- Ellen Byrne
- Nichole Davis
- Kari Degerness
- Jennifer Driscoll
- Jeannette Koijane
- Michele Snyders

Guiding Questions

- Why are we collecting this information? What kind of information do we need to know?
- What are we trying to achieve with this survey? What is the purpose of this survey?
- Who are the target participants for this survey?
- Who are the target audiences for the survey data?
- What types of data are integral to advocating for and implementing a Medicaid palliative care benefit? (may vary by state)

Thematic Analysis

- Program basics: contact information, location, capacity, [NCP Guideline](#) adherence, financing structure
- Care settings: in what setting(s) is care being delivered
- Patient characteristics: program eligibility criteria, demographic information, diagnoses
- Structure and process: organizational and staffing structure, service provision
- Monitoring and quality outcomes: metrics to track quality of care, quality improvement initiatives

Survey Purposes

- Inform public policy
- Inform payers and referral sources about access/available supply
- Inform the public where to go for help
- Assist surveyors and regulators in ensuring quality

Challenge/Decision Points

- Matching survey to audience need
- Estimating current vs. future capacity
- Multiple care settings
- Overlap with existing national surveys
- Comprehensive tool – customization and completion burden
- Need for supplemental implementation materials

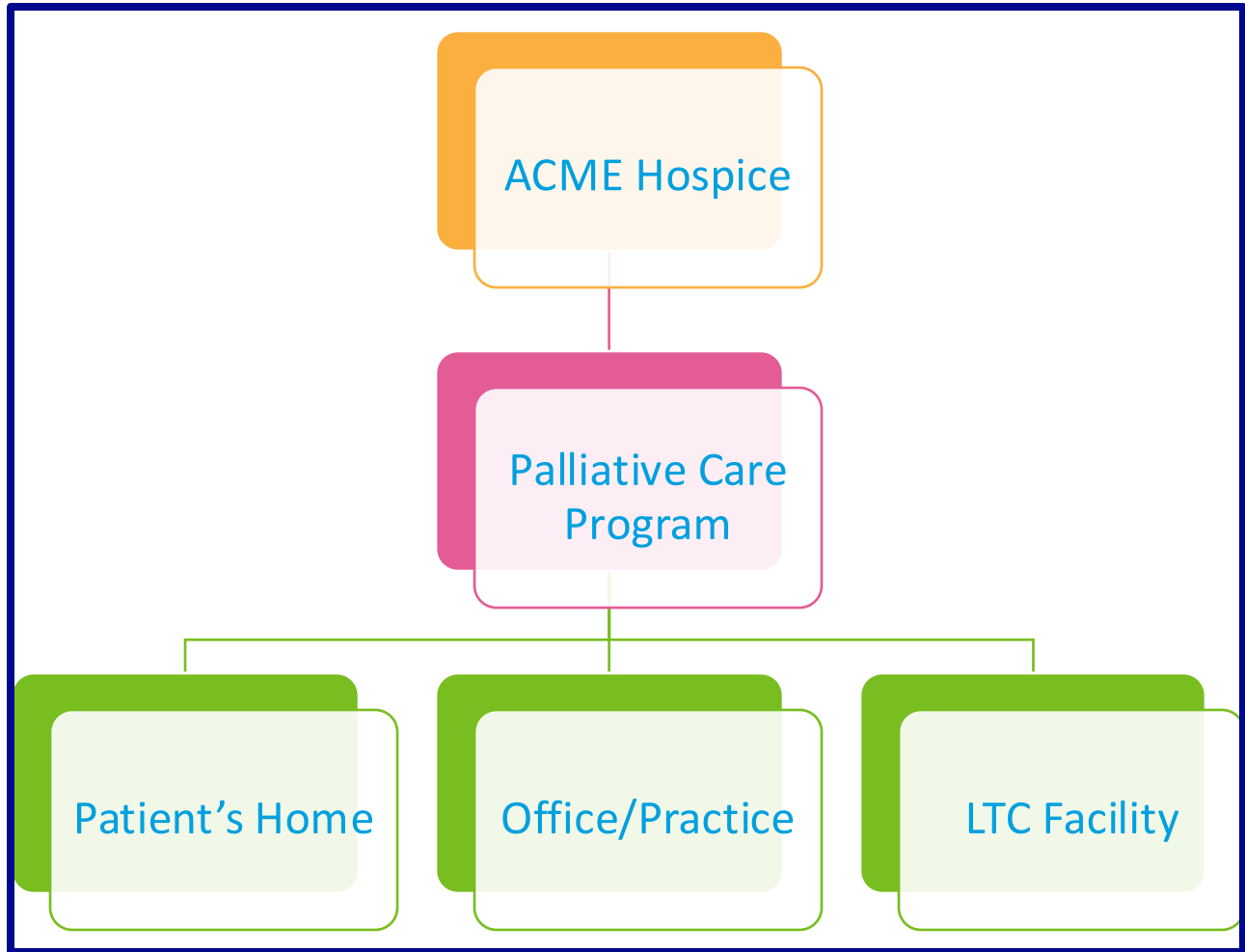
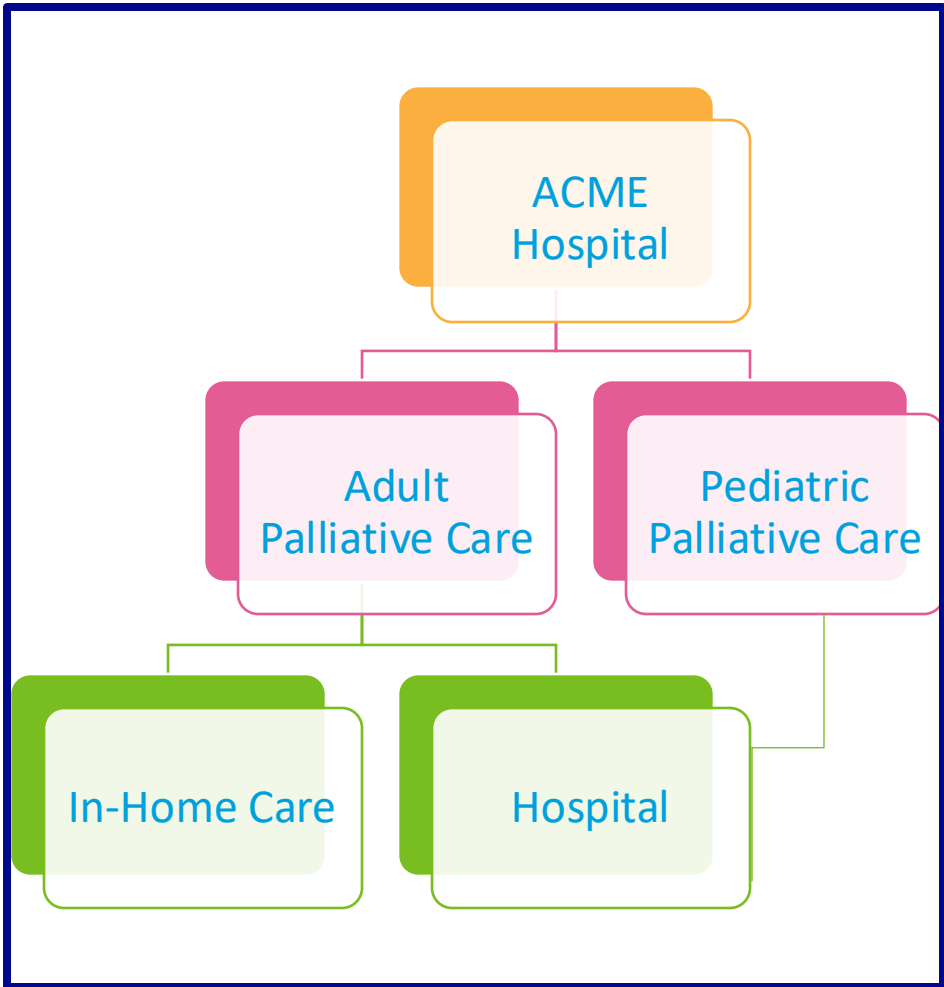
Final(ish) Draft

- Minimum viable product
- Freely available
- Supplement to PCQC and the Palliative Care Provider Directory

Domain 1 – Program Information

- Subsection 1: Respondent Information
- Subsection 2: Program Information
 - Administrative home
 - Contact information
 - General patient population
 - Clinician employment
 - Funding sources



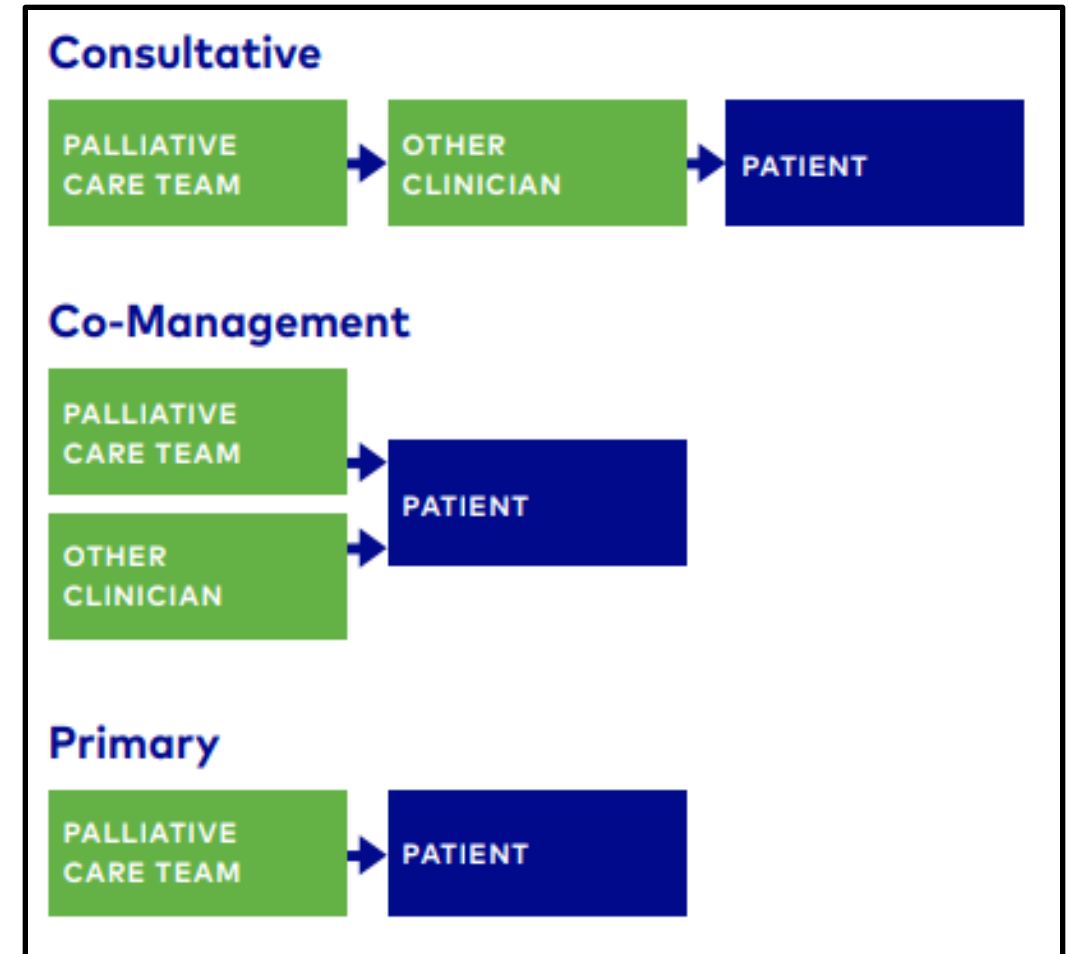


Domain 2 – Care Settings

- Subsections for each setting:
 - Hospital
 - Outpatient, Office Practice, or Clinic
 - Patient's Home
 - Long-Term Care Facility
- Consistent items collecting:
 - Patient volume
 - Eligibility criteria
 - Telephone support

Domain 3 – Structure and Process

- Subsection 1: Service Delivery
 - Licensure type(s)
 - Management model
 - Palliative care services
- Subsection 2: Staffing Structure
 - Head count and FTE
 - Number with specialty palliative care certification



Domain 4 – Monitoring and Quality Outcomes

- Quality measures collected
- Participation in other registries or data collection efforts
- Program certification – current or planned

In Progress – “Cheat Sheet”

Palliative Care Survey Draft - Additional Information

Domain/ Subsection/ Item	Question	Survey Programming	Operational Definitions/ Other Considerations
Domain 1, Subsection 2, Item 1	What type of entity administers or operates the palliative care program?	<ul style="list-style-type: none"> • Beneficial if drop down menu • Should have option to say “Add another program” (or something similar) 	If your organization has more than one palliative care program, complete a separate form for each one. For each program you add, you will have the opportunity to add one or more hospitals, office practices, or long-term care facilities. If you have an in-home palliative care program, you will be able to add multiple U.S. counties.
Domain 2	Hospital Referrals		Provide the total number of annual inpatient initial consults referred from the following locations. The sum of all primary categories should equal the total number of initial consults reported during the reporting period. Secondary categories (e.g. for the ICU) are not required but provide a deeper level of information and should sum to the primary category. If you do not track this information or are not able to access it, please check off “I cannot answer this question.”
Domain 4, Subsection 1, Item 3	Which of the following palliative care services does your organization provide?		This item has been included in most surveys, and so has been retained in this template. However, at least one survey implementer has noted that the data from this item have not typically been very useful, since - for instance - few palliative care programs are going to say that they don't offer caregiver support

Implementation Considerations – Beyond Initial Scope

- Funding
- Customization
- Survey Messaging
- Rolling Out
- Data Collection and Analysis

Breakouts/Template Worksheet

- What is your interest in the state palliative care survey?
- Do you have questions/need additional clarification on any of the items?
- What supplemental resources would be beneficial as you implement this survey?
- Any other feedback?

Please return these worksheets to me!

Report Back





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!

Set up people

1WR AD AW A AEM AM AT AC AE AG AR AK AP BHH BO BH + 6 just follow

Message Board

- Civic Health Alliance Webinar - 9/23**
* This is a post to the State Palliative Care Forum
- CAPC Briefing - Findings from First Annual Pulse Survey (September 19)** 1
- Tomorrow! How Palliative Care Can Support Caregivers in Policy and Practice**
- ATI/CAPC Report: Opportunities for Improving Access to Palliative Care for Duals with Serious**
- Congrats to Hawai'i on SPA Approval!** 5
On May 7, 2024, the Centers for Medicare and
- OB Rulemaking - CCOs to Deliver Palliative Care**

State Pal Care Resources

Key State Pal Care Events



Set important dates on a shared schedule and subscribe to events.

Schedule an event

Campfire

LS **Laura Shoemaker** 11:19am
Hello! Thank you, Zach, for the invitation to this fo...

Final Thoughts

- Opportunity to review previous palliative care surveys
- Template survey can help harmonize data collection efforts, reduce the opportunity cost for states with fewer resources
- Template is the tip of the iceberg

BRIEFING: The 2024 Serious Illness Scorecard (December 10, 4:30-5:30pm ET)

The new Scorecard reviews each state's readiness and capacity to meet the needs of people living with a serious illness, and their families and caregivers. This briefing will highlight national trends and provide practical, actionable recommendations for state policymakers, palliative care champions, and advocates to improve care within their own state or organization.



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<https://www.capc.org/events/webinars/briefing-americas-readiness-to-meet-the-needs-of-people-with-serious-illness-the-2024-serious-illness-scorecard/>

Additional Questions/ Discussion

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