Drivers of California's Progress in Advancing Palliative Care

California Health Care Foundation

HEALTH CARE THAT WORKS FOR ALL CALIFORNIANS

About the Author

Transforming Care Partners is a consulting firm focused on improving the experience of aging and serious illness care by partnering with leading and growing organizations on strategy development, implementation, and evaluation/learning. For additional information about the authors, contributors, and other acknowledgments, please visit www.chcf.org/resource-center/californias-palliative-care-evolution.

About the Project

As the California Health Care Foundation (CHCF) winds down its work in palliative care after 15 years, this project examines and celebrates the collective successes achieved by the many stakeholders responsible for the growth of palliative care in California, and considers opportunities to build on and accelerate this growth to meet future needs.

For this project, Transforming Care Partners engaged with and synthesized insights from in-depth interviews with over 30 leaders across five segments of the field (i.e., health plans, health systems/providers, community-based organizations, policymakers / government agencies, and membership organizations). The authors also facilitated a cross-discipline working session with over 200 participants at the Coalition for Compassionate Care of California Annual Summit in May 2023 to solicit more input.

About the Foundation

The California Health Care Foundation is an independent, nonprofit philanthropy that works to improve the health care system so that all Californians have the care they need. We focus especially on making sure the system works for Californians with low incomes and for communities who have traditionally faced the greatest barriers to care. We partner with leaders across the health care safety net to ensure they have the data and resources to make care more just and to drive improvement in a complex system. For more information, visit www.chcf.org.

Introduction

Many Californians living with serious illness now benefit from palliative care. This significant progress resulted from years of dedicated efforts led by multiple people and organizations including palliative care providers and clinicians, advocacy and education organizations, health systems, health plans, policymakers, and philanthropic organizations throughout the state and the nation. Although coming from different perspectives, these leaders pursued the common goal of improving care for people with serious illness. A subset of these leaders and organizations had a particular and important focus on people with low incomes and the diverse communities served by the state's safety-net health care systems.

Thanks to the visionary efforts of these leaders and organizations, many more Californians now have access to palliative care services. Although capacity data across all settings and payer types remain unavailable, the data that do exist show that 88% of California's public hospitals have inpatient palliative care programs, 71% of California's public hospitals offer outpatient palliative care services, and California's Medi-Cal managed care plans (MCPs) are required by law to provide palliative care services to a specific member population.[1] Also, four of the largest health plans in California — Kaiser, Anthem Blue Cross (Elevance), Blue Shield of California, and Health Net — provide home-based palliative care to qualifying members.[2]

IN THE FIELD

Seven medical specialty organizations endorse palliative care:

- ►American Association for the Study of Liver Disease[4]
- ►American College of Cardiology[5]
- ►American College of Emergency Physicians[6]
- ►American College of Surgeons[7]
- ►American Society of Clinical Oncology[8]
- ►American Thoracic Society[9]
- ►National Comprehensive Cancer Network[10]

To support this growing capacity, California has more specialty palliative care providers, and providers with generalist palliative care training, compared to previous years. Currently, the state has 13 fellowship programs accredited by the Accreditation Council for Graduate Medical Education, and professionals from seven disciplines can obtain specialty certifications in palliative care.[3]

Palliative care has transitioned from a relatively unknown specialty to one well recognized within the health care community. As a result, seven prominent health care specialty organizations now endorse palliative care as the standard of care for seriously ill patients (see "In the Field" Box).

Five key drivers played a critical role in advancing palliative care (PC) in California. These drivers were identified through interviews with experts in the field and through the California Health Care Foundation's knowledge of particular initiatives that have contributed to advancement of the field. These drivers of progress are meant to inspire reflection and to offer insights for future strategic planning endeavors. Note that they do not constitute an exhaustive list.

Key Drivers of Progress in California

1. Policy Change
Policy changes facilitated payment for palliative care for both adults and children, and enhanced end-of-life care communication and preference documentation practices.

2. Collaboration
Peer learning communities, payer-provider partnerships, and regional coalitions encouraged knowledge sharing, joint problem-solving, and maximizing program effectiveness.

3. Focus on Quality
The availability of technical assistance, data registries for quality improvement, national consensus guidelines, and accreditation and certification programs enabled palliative care programs to focus on quality.

4. Demonstrating Value
The evidence base and value case for PC continued to strengthen, showing that palliative care improves patient symptoms, quality of life, and patient and family satisfaction; promotes greater clarity in patient goals of care; reduces unnecessary hospitalizations and emergency department visits; and mitigates overall health care costs.

5. Workforce Development
Pathways to becoming a certified specialty palliative care practitioner increased substantially, as did avenues for gaining generalist palliative care training.

Driver of Progress 1: Policy Change

California has been a leader in implementing public policy that fosters equitable access to quality palliative care. Five key policy changes have been instrumental in laying the groundwork for scaling palliative care services and for supporting goal-aligned treatment (see "Statewide Policy Changes Driving Progress in California").

Statewide Policy Changes Driving Progress in California

Date	Policy Change	Contributions to Progress
2006	**Assembly Bill 1745** **(Nick Snow Children's Hospice and Palliative Care Act)**	Required California to pursue a Medi-Cal waiver to enable children with serious illness, regardless of prognosis, to receive palliative care concurrently with curative treatment. The requirement served as a precursor to Senate Bill 1004.
2008	**Assembly Bill 3000**	Establishes Physician Orders for Life-Sustaining Treatment (POLST) in law and requires clinicians to honor the form.
2014	**Senate Bill 1004**	Requires the Department of Health Care Services (DHCS) to set standards and provide technical assistance for Medi-Cal managed care plans to ensure delivery of palliative care services to eligible members. Law was effective in 2018 and updated in 2019 to include children.
2021	**Assembly Bill 133** **(California POLST eRegistry Act)**	Authorizes the California Emergency Medical Services Authority to establish a statewide POLST electronic registry system.
2023	**DHCS D-SNP Requirement**	Requires Dual Eligible Special Needs Plans (D-SNPs) to provide access to palliative care services for eligible members (effective 2024).

Sources: Author analysis of Assembly Bill (AB) 1745 (Cal. 2006); AB 3000 (Cal. 2008); Senate Bill 1004 (Cal. 2014); AB 133 (Cal. 2021); and CalAIM Dual Eligible Special Needs Plans: Policy Guide (PDF), Dept. of Health Care Services, January 2023.

"I never thought I'd see the day that I would combine 'palliative care' and 'benefit' together. It just lets me know that this is a movement that is growing and moving forward."

—Kim Beverly, MSW, MSG, Palliative Care Clinical Program Manager, Blue Shield of California

Statewide Policy Changes to Support Specialty Palliative Care

California's legislation supporting specialty palliative care began with the passage of Assembly Bill (AB) 1745, known as the Nick Snow Children's Hospice and Palliative Care Act of 2006. AB 1745 established a Medi-Cal waiver program to provide home-based palliative care for publicly insured children with serious illness, regardless of prognosis. The program was implemented in 11 counties and offered services such as nursing visits, respite care, psychosocial support, massage, and expressive therapies like art and music.

AB 1745 laid the foundation for Senate Bill (SB) 1004, passed in 2014 and implemented in 2018, which mandated the California Department of Health Care Services (DHCS) to set standards and provide technical assistance for Medi-Cal managed care plans (MCPs) to ensure the provision of palliative care services to eligible members. Soon afterward, AB 1745 was sunset and the provision of children's palliative care was included as part of SB 1004. In 2023, five years after the implementation of SB 1004, the Medi-Cal requirements of MCPs served as the basis for the requirement that all Dual Eligible Special Needs Plans (D-SNPs) offer palliative care beginning in 2024. D-SNPs are Medicare Advantage plans that provide care to people enrolled in both Medicare and Medicaid ("dually eligible" enrollees).

LESSONS FROM THE FIELD

Teri Boughton, policy consultant to the California State Senate Committee on Health, who worked on development of SB 1004, highlighted three reasons the legislation passed successfully without opposition:

► Pediatric palliative care had demonstrated high satisfaction rates among caregivers and providers, decreases in hospitalization rates, and either cost savings or cost neutrality.

► The proposed legislation would not cost the state any money and was assumed to be budget neutral to Medi-Cal plans.

► Many policymakers had experienced serious illness within their families and, as a result, could understand and support the benefits of quality palliative care.

Policy Changes to Support POLST

In 2008, AB 3000 was signed into law, establishing Physician Orders for Life-Sustaining Treatment (POLST) in California. The law enabled use of POLST forms in the state, which direct health care providers in the use of specific medical interventions aimed at resuscitation or sustaining life if

patients cannot speak for themselves. This policy expanded access to information and processes that give people approaching the end of life more control over their medical treatment.

In 2021, AB 133 required the California Emergency Medical Services Authority to establish a statewide electronic registry system for POLST. The purpose of the registry is to help ensure that patients' completed POLST forms are available wherever the patient receives care. That same year, the Coalition for Compassionate Care of California contracted with the State of California to provide subject matter expertise and stakeholder management to assist and guide the state through the research, planning, and implementation of a secure electronic POLST registry.

Palliative Care in Statewide and National Initiatives

Palliative care has also been incorporated into several of California's statewide health initiatives, significantly increasing its visibility (see "Statewide Initiatives That Incorporate Palliative Care").

Statewide Initiatives That Incorporate Palliative Care

Date	Initiative	Contributions to Progress
2012	**Let's Get Healthy California Framework**	Establishes a framework for assessing and monitoring the health of Californians; includes access to palliative care as one of the indicators for monitoring health across the lifespan.
2021	**Master Plan for Aging**	California's blueprint for navigating changing demographics over the next 10 years, it includes access to palliative care and POLST as priority initiatives.
2022	**CalAIM (California Advancing and Innovating Medi-Cal) Initiative — Enhanced Care Management (ECM)**	ECM requires comprehensive health assessments including a screening process for assessing the need for palliative care.

Sources: Author analysis of Let's Get Healthy California Task Force Final Report (PDF), Let's Get Healthy California Task Force, December 19, 2012; Master Plan for Aging (PDF), California Dept. of Aging, January 2021; and CalAIM (PDF), Dept. of Health Care Services.

In addition to statewide policy changes, national policy changes have contributed to the increase in palliative care capacity across California (see "National Policy Changes Driving Progress in California"). Although statewide policies have been the primary driver of increased palliative care capacity in Medi-Cal, national policies impacting Medicare Advantage and accountable care organizations have helped drive expansion across other payer types.

National Policy Changes Driving Progress in California

Date	Policy Change	Contributions to Progress
2010	**Affordable Care Act**	Created new mechanisms to pay for or provide incentives for incorporating palliative care, including accountable care organizations, bundled payments, concurrent care demonstration program, and penalties for preventable readmissions.
2018	**CHRONIC (Creating High-Quality Results and Outcomes Necessary to Improve Chronic) Care Act**	Paved the way for Medicare Advantage plans to cover home-based palliative care and other nonmedical services that benefit people with serious illness.
2024	**Value-Based Insurance Design Hospice Carve In**	Requires advance care planning support for all enrollees with serious illness, provision of access to timely and appropriate palliative care services, and provision of transitional concurrent care (disease-modifying treatment delivered after hospice enrollment).

Sources: Hannah Crook et al., "Improving Serious Illness Care in Medicare Advantage: New Regulatory Flexibility for Supplemental Benefits" (PDF), Duke Margolis Center for Health Policy, December 2019; and "VBID Model Hospice Benefit Component Overview," Centers for Medicare & Medicaid Services, last updated September 6, 2023.

Driver of Progress 2: Collaboration

The collaboration of dedicated and passionate leaders, learning from one another, has been instrumental in implementing, strengthening, and sustaining inpatient, outpatient, and home-based palliative care across the state.

Peer Learning Communities

Several formal and informal peer learning communities across the state have supported progress. Regular meetings with colleagues doing the same or similar work helped participants see their work as part of a larger system-change effort. It also enabled them to reach out to colleagues for information, problem-solving, and support.

The California Health Care Foundation (CHCF) funded learning communities aimed at increasing access to palliative care for the safety net (see "Peer Learning Communities Supported by California Health Care Foundation"). These learning communities contributed to progress by helping participants make the business case for palliative care, track and report operational and outcome measures, and focus on program sustainability.

Peer Learning Communities Supported by the California Health Care Foundation

Date	Learning Community	Contributions to Progress
2008–13	**Spreading Palliative Care in California Public Hospitals**	The leaders of 15 public hospitals developing or expanding palliative care programs participated in a peer learning and support network. Analysis of program structures conducted in 2021 showed that the public hospital services were more interdisciplinary and just as effective as their private hospital peers.
2013	**Palliative Care Action Community**	Twenty-one organizations participated in a one-year learning collaborative that supported and strengthened participants' existing efforts to build effective, sustainable clinic- and home-based palliative care services. Participants shared implementation strategies and experiences with different clinical models, and had access to tools and technical assistance for assessing operational and fiscal outcomes. Analyses of fiscal outcomes for two participating sites led to peer-reviewed manuscripts that helped strengthen the value proposition for such services.
2015–19	**Spreading Community-Based Palliative Care in California Public Hospitals**	Leaders and staff from nine public hospitals created a supportive learning environment as five sites established new clinic- or home-based palliative care services and four expanded existing services. Information from program leaders about staffing practices and other processes were shared in a peer-reviewed publication, a significant addition to the literature on safety-net community-based palliative care.

Date	Learning Community	Contributions to Progress
2017–18	Senate Bill (SB) 1004 Implementation Technical Assistance Series	Medi-Cal managed care plans (MCPs) and home-based palliative care providers engaged in technical assistance and peer learning about developing palliative care partnerships and services before implementation of SB 1004's Medi-Cal palliative care requirements. Tools and information developed for the series were provided in a PC in Medi-Cal online resource center.
2019–21	Medi-Cal Palliative Care Community	MCPs and providers responsible for operationalizing SB 1004 were supported with ongoing webinars, an annual convening, and an annual survey. Activities encouraged the spread of promising practices in operationalizing Medi-Cal palliative care as dozens of MCPs and providers gained experience with the benefit. Key lessons were curated in a Medi-Cal PC services online resource center.
2020–21	Generalist Palliative Care in California Public Hospitals	Nine public health care systems put into practice generalist palliative care interventions including advance care planning, goals of care clarification, pain assessment and management, and end-of-life and comfort care orders. Descriptions of these programs, and resources to support replicating such work, were distributed via a generalist PC online resource center.
2021–23	Medi-Cal Palliative Care MCP Learning Community	CHCF supported regular webinars and discussion forums for MCPs, annual surveys of MCPs and contracted palliative care providers, and continued the annual convenings of MCPs and contracted palliative care providers. Information shared in these forums supported the spread of promising practices and collaborative problem-solving.

Sources: Carin van Zyl et al., "Doing More with the Same: Comparing Public and Private Hospital Palliative Care within California," Journal of Palliative Medicine 25, no. 7 (July 2022): 1064–71; Colin Scibetta et al., "The Costs of Waiting: Implications of the Timing of Palliative Care Consultation Among a Cohort of Decedents at a Comprehensive Cancer Center," Journal of Palliative Medicine 19, no. 1 (Jan. 2016): 69–75; J. Brian Cassel et al., "Effect of a Home-Based Palliative Care Program on Healthcare Use and Costs," Journal of the Amer. Geriatrics Society 64, no. 11 (Nov. 2016): 2288–95; Michael W. Rabow et al., "Staffing in California Public Hospital Palliative Care Clinics: A Report from the California Health Care Foundation Palliative Care in Public Hospitals Learning Community," Journal of Palliative Medicine 24, no. 7 (July 2021): 1045–50; "Palliative Care in Medi-Cal (SB 1004) Resource Center," California Health Care Foundation (CHCF), accessed September 8, 2023; Hunter Gatewood and Kathleen Kerr, "Essential Elements of Medi-Cal Palliative Care Services: A Toolkit for Medical Manged Care Plans and Palliative Care Providers," CHCF, August 2021; "Essential Skills and Supports for All Clinicians Treating Serious Illness: Building Generalist Palliative Care Capabilities Across Services and Settings," CHCF, February 2022; and "MCP Learning Community Resources," Coalition for Compassionate Care of California.

"When I think about palliative care in California, one of the things that I love most is that it feels that I am part of a community who works together, regardless of what health system we work for, to be able to create better systems to care for patients and families."

—Matthew Gonzales, MD, Associate Vice President, Chief Medical and Operations Officer, Providence Institute for Human Caring

Payer-Provider Partnerships

Passing SB 1004 was an important step in making palliative care available to Medi-Cal enrollees. By itself, however, it could not ensure health plans and palliative care providers could effectively and collaboratively deliver high-quality services to the people who would benefit from them. Field leaders formed several initiatives that gave health plans (including those not offering Medi-Cal products) and provider organizations support and tools to develop and sustain community-based palliative care (CBPC), including home-based palliative care (HPBC) and outpatient (clinic-based) palliative care. (See "Example California Payer-Provider Partnership Initiatives.")

Payer-provider partnerships highlighted the importance of open communication between payers and providers and a shared commitment to consistency, quality, and standards in the delivery of effective, sustainable, patient- and family-centered palliative care services.

"I think palliative care has grown in California because there are so many passionate experts and people who really see that this type of care makes a difference."

—Kim Bower, MD, Medical Director, Blue Shield of California

Example California Payer-Provider Partnership Initiatives

Date	Payer-Provider Partnership	Contributions to Progress
2014–17	**Payer-Provider Partnerships for Palliative Care**	Identified practices for payers and providers to maximize effectiveness of health plan–funded community-based palliative care services. Key lessons were distributed via a payer-provider partnerships online resource center.
2016–22	**California Advanced Illness Collaborative**	Developed and evaluated a set of standards to facilitate contracting for CBPC services.
2017–19	**Increasing Access to Palliative Care in Rural California**	Identified potential solutions for common challenges experienced by health plans and providers delivering palliative care in rural settings.

Sources: "Payer-Provider Partnerships for Palliative Care," CHCF, October 2018; "Consensus Standards for Community-Based Palliative Care in California," CCCC, October 2017; and Kathleen Kerr, Monique Parrish, and Lyn Ceronsky, Home on the Range: Plans and Providers Team Up to Bring Palliative Care to Rural Californians, CHCF, May 2020.

Coalitions

Formal, structured coalitions have played a pivotal role in supporting the progress of palliative care in California, including the Coalition for Compassionate Care of California (CCCC), the Chinese American Coalition for Compassionate Care (CACCC), and local collaborative efforts.

Founded in 1998, CCCC's mission is to promote and enhance quality palliative and end-of-life care in California. Over time, CCCC has adeptly convened a diverse group of stakeholders, ranging from health care professionals to community-based organizations and patient advocates, foundations to policymakers. Serving as the backbone organization for the field in California, CCCC has played a vital role in fostering and facilitating collaboration, learning, and action through peer learning communities, payer-provider communities, policy advancement, and POLST implementation.

Established in 2005, CACCC emerged to address the lack of linguistically and culturally appropriate end-of-life information and training available within the Chinese community. Among other things, CACCC actively promotes advance care planning across California and spearheads hospital-based patient ambassadorship programs in Northern California.

In addition to statewide coalitions, several active local coalitions help drive progress. For instance, the San Diego Coalition for Compassionate Care maintains affiliations with CCCC and the California State University Shiley Haynes Institute for Palliative Care. It conducts monthly member meetings, hosts an annual conference, and provides a speakers bureau for community organizations. Another example is the San Francisco Palliative Care Workgroup, which operates under the San Francisco Department of Disability and Aging. Its membership includes local leaders from various sectors, such as health systems, community-based organizations, payers, family and patient advocates, and foundations. The workgroup developed a strategy for the City of San Francisco to expand palliative care, advocated for a resource directory (currently being implemented), and organized annual advance care planning workshops in commemoration of National Health Care Decisions Day. Notably, the workgroup adopts a community-driven, racial equity lens in its work, as evidenced by its three Learning Journeys with the Black, Chinese, and Latino/x communities.[11]

These statewide and local coalitions mobilize diverse stakeholders and lead initiatives that transcend the scope or capacity of any one organization. Coalitions have played, and will continue to play, a critical role in propelling the advancement of palliative care.

Technical Assistance and Centers of Excellence

State and national organizations established centers of excellence and provided free or low-cost toolkits to help health plans, health systems, and palliative care provider organizations make the business case for, pay for, design, and implement specialist and generalist palliative care services.

In California, CCCC and CHCF have created and distributed multiple toolkits to help all members of the palliative care ecosystem implement generalist and specialist palliative care and advance care planning in multiple settings. Nationally, the Coalition to Transform Advanced Care, the National Hospice and Palliative Care Organization, and the Center to Advance Palliative Care (CAPC) have all created toolkits to help payers and providers design and implement home-based palliative care. CAPC also created multiple tools to help health systems make the case for investing in palliative care more broadly and to help employers and other health care purchasers support palliative care. As of April 2023, 135 California-based organizations have CAPC member-ships, giving their employees full access to all CAPC training and tools.[12]

Since 2002 the Palliative Care Leadership Center (PCLC) at UCSF — one of nine such centers launched by CAPC — has provided training and support to health care organizations aiming to establish or expand their palliative care program. Each of the PCLCs across the country provides support for participants to conduct a comprehensive needs assessment and engage in strategic planning to clarify goals, set priorities, and enhance operations, and a year of ongoing mentoring, guidance, and troubleshooting. The establishment of the PCLC at UCSF notably increased access to these supports for California providers. As of April 2023, 134 California-based organizations have completed PCLC training.[13]

RESOURCES FROM THE FIELD

► Up Close: A Field Guide to Community-Based Palliative Care in California (CHCF)[14]

► Home on the Range: Plans and Providers Team Up to Bring Palliative Care to Rural Californians (CHCF)[15]

► Lessons Learned from Payer-Provider Partnerships for Community-Based Palliative Care (PDF) (CHCF)[16]

► Palliative Care in Medi-Cal (SB 1004) Resource Center (CHCF)[17]

► Community-Based Palliative Care Resource Center (CHCF)[18]

► Essential Elements of Medi-Cal Palliative Care Services (CHCF)[19]

RESOURCES FROM THE FIELD (continued)

➤ Tools for Making the Case for Palliative Care (CAPC)[20]

➤ Palliative Care Resources for Health Plans (CAPC)[21]

➤ Designing and Implementing Community-Based Palliative Care: A Guide for Payers (PDF) (Coalition to Transform Advanced Care)[22]

➤ Palliative Care Resources for Employers and Other Health Care Purchasers (Catalyst for Payment Reform)[23]

➤ POLST Tools and Resources (CCCC)[24]

Driver of Progress 3: Focus on Quality

As inpatient, outpatient, and home-based palliative care expanded within the safety net and beyond, California's palliative care leaders saw the opportunity and increasing need to assess the quality of palliative care programs. Thanks to the work already happening in the state and across the nation, California had access to palliative care consensus guidelines and standards, measures to support assessments, benchmarking and quality improvement initiatives, and certification and accreditation options for provider organizations.

Consensus Guidelines and Standards

The essential elements of quality palliative care have been identified, maintained, and updated through the National Coalition for Hospice and Palliative Care's *Clinical Practice Guidelines for Quality Palliative Care* (National Consensus Project [NCP] Guidelines).[25] Now in its fourth edition, the NCP Guidelines describe gold-standard palliative care and offer suggestions for incorporating best practices into care delivery in a range of settings and for multiple populations. Over the years, the NCP Guidelines have served as a touchstone for health systems and providers when designing new specialty and generalist palliative care programs. They also informed the development of the California Advanced Illness Collaborative Standards, which sought to translate the recommendations in the NCP Guidelines into specific requirements that could inform contracting for community-based palliative care services.[26]

Measures

Multiple national efforts have sought to identify and test measures that can assess quality of care delivered by palliative services across settings. In 2012 the National Quality Forum, at the request of the federal Department of Health and Human Services, endorsed 14 measures suitable for accountability and quality improvement for palliative and end-of-life care.[27] In 2014, the American Academy of Hospice and Palliative Medicine and the Hospice and Palliative Nurses Association, through the Measuring What Matters project, endorsed a top-10 list of valid, clinically relevant measures for assessing care quality in hospice or palliative care, appropriate for any patient population and care setting.[28]

As the field evolved and more care was being delivered in outpatient and home settings, new measures were developed and distributed. The Palliative Care Quality Measures Project, led by the American Academy of Hospice and Palliative Medicine in collaboration with the RAND Corporation and the National Coalition for Hospice and Palliative Care, developed and tested two patient-reported outcome performance measures that evaluate quality of care.[29] The measures, which assess how much patients felt heard and understood and if patients got the help

they wanted with pain, were designed for outpatient settings and were endorsed by the National Quality Forum in 2021. In 2021 RAND released its Serious Illness Survey for Home-Based Programs, a validated tool for assessing the experiences of patients in communication, help with symptoms, and care coordination, among others.[30]

Today, the field has access to validated tools for assessing patient and family experience of care and other key processes and outcomes across inpatient, outpatient, and home settings. The Center to Advance Palliative Care has compiled measure sets, which include many of the measures described above, as well as an array of technical assistance materials to assist provider, health system, and payer organizations in selecting measures.

Although having valid measures has been a tremendous boon to understanding and improving quality, developing structures and processes that support and encourage their use, and reducing variation in what is measured across organizations, remain significant challenges for the field.

Data and Quality Improvement

The Palliative Care Quality Network (PCQN), started by UCSF, played a pivotal role in elevating the significance of data collection and quality improvement in California and beyond. PCQN operated a national quality improvement database, which stored and analyzed information about patient characteristics, care processes, and treatment outcomes from specialty palliative care teams in hospitals and various community settings across California and other states. PCQN also functioned as a quality improvement collaborative, letting members track their own performance, compare outcomes with other member programs, and identify and share best practices in core areas such as pain management, advance care planning, and screening for spiritual care needs. In 2019, PCQN was folded into a new national entity, the Palliative Care Quality Collaborative (PCQC). According to PCQC administrators, 257 California-based organizations belong to PCQC, providing benchmarking for palliative care in multiple settings: inpatient, clinic, and home.[31]

In another national effort, the National Hospice and Palliative Care Organization (NHPCO) Quality Connections Program supports and recognizes members' efforts to improve care quality.[32] Participants must achieve milestones within defined time frames by focusing on four pillars: education, application of education, performance measurement, and innovation. Success in the program is measured quarterly, based on activities completed in each pillar. Quarterly, NHPCO publishes a national Achievement Map and celebrates participating organizations' progress throughout NHPCO publications, including press releases and social media.

Organizational Certification/Accreditation

Since 2016, national credentialing organizations such as The Joint Commission and Community Health Accreditation Partner have developed palliative care credentials and standards for services operating in inpatient or community settings. Currently, 79 California organizations are certified in home-based palliative care by The Joint Commission or Community Health Accreditation Partner, and six California hospitals have palliative care certification for inpatient services from The Joint Commission.[33]

RESOURCES FROM THE FIELD

▶ Clinical Practice Guidelines for Quality Palliative Care, 4th Ed. (National Coalition for Hospice and Palliative Care)[34]

▶ Palliative Care Quality Measures Project (National Coalition for Hospice and Palliative Care)[35]

▶ RAND Serious Illness Survey (RAND Corporation)[36]

▶ Palliative Care Quality Collaborative[37]

▶ Defining and Measuring Quality (Center to Advance Palliative Care)[38]

Driver of Progress 4: Demonstrating Value

Demonstrating value requires a strong evidence base to describe the full range of palliative care impacts on patients, families, providers, and health care systems. The ability to show value was one of the key drivers for passing SB 1004 and is still a persuasive lever that can motivate nonmandated payers to offer palliative care. The value case is also critical for palliative care programs operating in health systems and medical groups to secure the resources they need to sustain, improve, and expand services.

Palliative care leaders in California and across the nation have worked thoughtfully and diligently to contribute to the evidence base for inpatient, outpatient, and home-based palliative care. Multiple studies show palliative care improves patient symptoms, quality of life, and patient and family satisfaction. It promotes greater clarity in patient goals of care, helps reduce avoidable hospitalizations and emergency department visits, and moderates overall health care costs. Selected studies that have measured these impacts are presented in "Selected Literature Demonstrating the Effectiveness of Palliative Care Programs."

Selected Literature Demonstrating the Effectiveness of Palliative Care Programs

Domain	Impact	Sources
Inpatient Palliative Care		
Health/Clinical Outcomes	Patients cared for by consultation services in public and private hospitals had improvements in pain, nausea, dyspnea, and anxiety.	Carin van Zyl et al., "Doing More with the Same: Comparing Public and Private Hospital Palliative Care Within California," *Journal of Palliative Medicine* 25, no. 7 (June 29, 2022): 1064–71.
Patient/Family Experience	Almost all family caregivers (95%) surveyed by phone said they would recommend the palliative care (PC) service.	Sean O'Mahony et al., "The Benefits of a Hospital-Based Inpatient Palliative Care Consultation Service: Preliminary Outcome Data," *Journal of Palliative Medicine* 8, no. 5 (Oct. 20, 2005): 1033–39.
Cost of Care	Costs were 28% lower among PC recipients, compared to usual care.	Peter May et al., "Economics of Palliative Care for Hospitalized Adults with Serious Illness: A Meta-Analysis," *JAMA Internal Medicine* 178, no. 6 (June 1, 2018): 820–29.
Outpatient Palliative Care		
Health/Clinical Outcomes	Patients receiving early PC along with standard oncologic care had better quality of life, fewer depressive symptoms, less aggressive end-of-life care, and longer lives than similar patients receiving usual care.	Jennifer S. Temel et al., "Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer," *New England Journal of Medicine* 363, no. 8, (Aug. 19, 2010): 733–42.

Domain	Impact	Sources
Patient/Family Experience	Palliative care was associated consistently with improvements in patient and caregiver satisfaction, along with improvements in advance care planning and lower health care utilization.	Dio Kavalieratos et al., "Association Between Palliative Care and Patient and Caregiver Outcomes: A Systematic Review and Meta-Analysis," *JAMA* 316, no. 20 (Nov. 22/29, 2016): 2104–14.
Cost of Care	Cancer patients receiving early (mostly clinic-based) PC had lower rates of emergency department, hospital, and intensive care unit use, and hospital costs were lower, compared to patients who received later PC.	Colin Scibetta et al., "The Costs of Waiting: Implications of the Timing of Palliative Care Consultation Among a Cohort of Decedents at a Comprehensive Cancer Center," *Journal of Palliative Medicine* 19, no. 1 (Jan. 2016): 69–75.
Home-Based Palliative Care		
Health/Clinical Outcomes	Patients cared for by a home-based palliative care service showed improvement in anxiety, appetite, dyspnea, well-being, depression, and nausea.	Christopher W. Kerr et al., "Clinical Impact of a Home-Based Palliative Care Program: A Hospice-Private Payer Partnership," *Journal of Pain and Symptom Management* 48, no. 5 (Nov. 2014): 883–92.
Patient/Family Experience	Patients randomized to home-based palliative care reported greater improvement in satisfaction with care at 30 and 90 days after enrollment, compared to those who received usual care.	Richard Brumley et al., "Increased Satisfaction with Care and Lower Costs: Results of a Randomized Trial of In-Home Palliative Care," *Journal of the Amer. Geriatrics Society* 55, no. 7 (July 2007): 993–1000.
Cost of Care	Total costs of care for patients who received home-based PC were 49% to 59% lower than costs for a matched cohort of patients that received usual care.	J. Brian Cassel et al., "Effect of a Home-Based Palliative Care Program on Healthcare Use and Costs," *Journal of the Amer. Geriatrics Society* 64, no. 11, (Nov. 2016): 2288–95.

RESOURCES FROM THE FIELD

➤ Evaluating Fiscal Outcomes for Inpatient Palliative Care (CHCF)[39]

➤ Making the Case for Inpatient Palliative Care (CHCF)[40]

➤ Evaluating Fiscal Outcomes for Outpatient Palliative Care (CHCF)[41]

➤ Making the Case for Outpatient Palliative Care (CHCF)[42]

➤ The Case for Community-Based Palliative Care (Center to Advance Palliative Care)[43]

➤ Studies of Home-Based Palliative Care Economic Outcomes (PDF) (Coalition for Compassionate Care of California)[44]

Driver of Progress 5: Workforce Development

The expansion of palliative care relies on a robust and skilled interdisciplinary workforce, including medical providers, nurses, social workers, and chaplains, all with the necessary capacity, capability, and competencies. Note that palliative care only officially gained recognition as a distinct medical specialty in 2006. Since then, leaders in palliative care have recognized that the size of the specialty workforce is likely to remain insufficient to meet the needs of people with serious illness. This underscores the significance of implementing continued and diverse approaches to support the growth of a well-trained workforce including specialty palliative care and generalist palliative care.

Specialty Palliative Care Fellowship and Certification Programs

The pathways to becoming a certified specialty palliative care practitioner have increased substantially. Today, California offers a total of 13 accredited medical fellowship programs, and specialty certification programs are available for registered nurses, nursing assistants, advanced practice registered nurses, licensed/vocational nurses, physicians, social workers, and chaplains.[45] (See "Resources from the Field.")

Generalist Palliative Skills Training

Generalist palliative care (also known as "primary palliative care") has emerged as an important strategy for ensuring comprehensive care for all people facing serious illness. The generalist palliative care model began gaining traction over a decade ago as a practical response to the increasing demand for palliative care services and supports while reserving limited palliative care specialists for patients with more complex needs. Generalist palliative care skills let non-palliative care specialists administer basic palliative care comfortably and competently. More options exist for training in generalist palliative care now than ever before, including in-person, online synchronous, and online asynchronous training. (See "Resources from the Field.")

WORKFORCE DEFINITIONS

Specialty palliative care. Specific area of medical practice that focuses on providing specialized care and support to those with serious illness. Specialty palliative care clinicians have specialized training and certification.

Generalist palliative care. Basic level of care provided by health professionals who may not have specialized training or expertise in palliative care but have general skills in managing pain and symptoms, discussing prognosis and goals of care, and identifying unmet social, emotional, or spiritual needs of patients with serious illness. When necessary, generalist palliative care providers refer patients to specialty palliative care for more complex interventions. Generalist palliative care is also called primary palliative care or basic palliative care.

RESOURCES FROM THE FIELD

➤ Accreditation Council for Graduate Medical Education[46]

➤ California State University Shiley Haynes Institute for Palliative Care[47]

➤ Center to Advance Palliative Care[48]

➤ End-of-Life Nursing Education Consortium[49]

➤ Evidence-Based Communications Skills Training (VitalTalk)[50]

➤ Essential Skills and Supports for All Clinicians Treating Serious Illness: Building Generalist Palliative Care Capabilities Across Services and Settings (CHCF)[51]

➤ Serious Illness Care: Tools for Clinicians and Health Systems (Ariadne Labs)[52]

➤ Essentials of Palliative Care (Stanford School of Medicine)[53]

Endnotes

1. Hospital palliative care leaders, personal communication with author, April–May 2023; and "Palliative Care Policies," California Dept. of Health Care Service (DHCS), accessed September 8, 2023.

2. Plan representatives who participated in palliative care projects sponsored by the California Health Care Foundation (CHCF) between 2014 and 2023, personal communication with authors.

3. Author analysis of "Accreditation Council for Graduate Medical Education (ACGME) – Public," Accreditation Council for Graduate Medical Education, accessed October 1, 2023; and Connie Dahlin (former consultant to Hospice and Palliative Nurse Assn.), personal communication with authors on the year specialty palliative care certifications by discipline were available, May 1, 2023. These certifications were made available by the Hospice and Palliative Care Credentialing Center (HPCC) — registered nurse (1994), nursing assistant (2002), advanced practice nurse (2003), and licensed/ vocational nurse (2003). The Amer. Board of Family Medicine recognized the Hospice and Palliative Medicine board-certifying exam for physicians in 2008, the Natl. Hospice and Palliative Care Organization added social work certification (2009), and the Natl. Assn. of Catholic Chaplains approved certification for chaplains (2013) with support from the Assn. of Professional Chaplains.

4. Shari S. Rogal et al., "AASLD Practice Guidance: Palliative Care and Symptom-Based Management in Decompensated Cirrhosis," *Hepatology* 76, no. 3 (Sept. 2022): 819–53.

5. Larry A. Allen et al., "Decision Making in Advanced Heart Failure: A Scientific Statement from the American Heart Association," *Circulation* 125, no. 15 (Apr. 17, 2012): 1928–52.

6. "Palliative Care in the ED," Amer. College of Emergency Physicians, November 21, 2022.

7. "Statement of Principles of Palliative Care," American College of Surgeons (ACS), August 1, 2005; and Halle B Ellison et al., "Surgical Palliative Care: Considerations for Career Development in Surgery and Hospice and Palliative Medicine," ACS, October 1, 2021.

8. Betty R. Ferrell et al., "Integration of Palliative Care into Standard Oncology Care: American Society of Clinical Oncology Clinical Practice Guideline Update," *Journal of Clinical Oncology* 35, no. 1 (Jan. 2017): 96–112.

9. Paul N. Lanken et al., "An Official American Thoracic Society Clinical Policy Statement: Palliative Care for Patients with Respiratory Diseases and Critical Illnesses," *Amer. Journal of Respiratory and Critical Care Medicine* 177, no. 8 (April 15, 2008): 912–27.

10. Maria Dans et al., "NCCN Guidelines Insights: Palliative Care, Version 2.2021," *Journal of the National Comprehensive Cancer Network* 19, no. 7 (July 28, 2021): 780–88.

11. *Learning Journey 2023 Report,* San Francisco Palliative Care Work Group, 2023.

12. Allison Silvers (chief health care transformation officer, Center to Advance Palliative Care [CAPC]), personal communcation with authors, April 25, 2023.

13. Allison Silvers, personal communication with authors, April 26, 2023.

14. Kate Meyers, Kathleen Kerr, and J. Brian Cassel, *Up Close: A Field Guilde to Community-Based Palliative Care in California*, CHCF, September 2014.

15. Kathleen Kerr, Monique Parrish, and Lyn Ceronsky, *Home on the Range: Plans and Providers Team Up to Bring Palliative Care to Rural Californians*, CHCF, May 2010.

16. Kathleen Kerr and Kate Meyers, *Lessons Learned from Payer-Provider Partnerships for Palliative Care* (PDF), CHCF, October 2018.

17. "Palliative Care in Medi-Cal (SB 1004) Resource Center," CHCF.

18. "Community-Based Palliative Care," CHCF.

19. Hunter Gatewood and Kathleen Kerr, "Essential Elements of Medi-Cal Palliative Care Services: A Toolkit for Medi-Cal Managed Care Plans and Palliative Care Providers," CHCF, August 2021.

20. "Tools for Making the Case," CAPC, last reviewed June 24, 2020.

21. "Resource for Health Plans," CAPC, last reviewed June 3, 2020.

22. Torrie Fields et al., *Designing and Implementing Community-Based Palliative Care: A Guide for Payers* (PDF), Coalition to Transform Advanced Care.

23. "Palliative Care Resources for Employers and Other Health Care Purchasers," Catalyst for Payment Reform.

24. "Physician Orders for Life-Sustaining Treatment (POLST)," Coalition for Compassionate Care of California.

25. *Clinical Practice Guidelines for Quality Palliative Care*, 4th ed., Natl. Coalition for Hospice and Palliative Care (NCHPC), 2018.

26. "Consensus Standards for Community-Based Palliative Care in California," Coalition for Compassionate Care of California (CCCC), last updated October 2017.

27. "Endorsement Summary: Palliative Care and End-of-Life Care Measures," National Quality Forum, February 2012.

28. "Measuring What Matters," Amer. Academy of Hospice and Palliative Medicine, accessed September 8, 2023.

29. "Palliative Care Quality Measures Project," NCHPC, December 7, 2021.

30. "RAND Serious Illness Survey," RAND Corporation, November 2, 2021.

31. Fred Friedman (registry manager, Palliative Care Quality Collaborative), personal communication with authors, April 25, 2023.

32. "Quality Connections Program," Natl. Hospice and Palliative Care Organization, accessed October 13, 2023.

33. "Certification and Verification Data," The Joint Commission (TJC), accessed October 11, 2023; Jennifer Kennedy (vice president, Community Health Accreditation Partner), personal communication with authors, April 26, 2023; and "Advanced Certification, California Hospitals," TJC, accessed September 26, 2023.

34. *Clinical Practice Guidelines for Quality Palliative Care*, NCHPC.

35. "Palliative Care Quality Measures Project," NCHPC.

36. "RAND Serious Illness Survey," RAND Corporation.

37. Palliative Care Quality Collaborative.

38. "Defining and Measuring Quality," CAPC, last reviewed October 19, 2020.

39. J. Brian Cassel and Kathleen Kerr, *Evaluating Fiscal Outcomes for Inpatient Palliative Care*, CHCF, March 2023.

40. J. Brian Cassel and Kathleen Kerr, *Making the Case for Inpatient Palliative Care*, CHCF, August 2022.

41. J. Brian Cassel and Kathleen Kerr, *Evaluating Fiscal Outcomes for Outpatient Palliative Care*, CHCF, March 2023.

42. J. Brian Cassel and Kathleen Kerr, *Making the Case for Outpatient Palliative Care*, CHCF, August 2022.

43. *The Case for Community-Based Palliative Care*, Center to Advance Palliative Care.

44. *Studies of Home-Based Palliative Care Economic Outcomes* (PDF), CCCC, October 2022.

45. Author analysis of "ACGME – Public"; and Dahlin.

46. Accreditation Council for Graduate Medical Education.

47. California State University Shiley Haynes Institute for Palliative Care.

48. Center to Advance Palliative Care.

49. "End-of-Life Nursing Education Consortium," Amer. Assn. of Colleges of Nursing.

50. "Evidence-Based Communication Trainings," VitalTalk.

51. *Essential Skills and Supports for All Clinicians Treating Serious Illness: Building Generalist Palliative Care Capabilities Across Services and Settings*, CHCF, February 2022.

52. "Serious Illness Care: Tools for Clinicians and Health Systems," Ariadne Labs.

53. "Essentials of Palliative Care," Stanford School of Medicine.