

# **California Health Care Foundation**



**Issue Brief** 

# Palliative Care in California: Narrowing the Gap

Paliative care is specialized medical care that provides patients with relief from the symptoms, pain, and stress that often occur with serious illness. Palliative care (PC) is appropriate at any age and at any stage of a serious illness, and can be provided alongside curative treatment. In recent years the availability of specialty palliative care programs has increased dramatically, as payers, providers, and consumers have come to appreciate its benefits.

In 2014 the California Health Care Foundation sponsored research that catalogued the prevalence of palliative care services across the state, and considered the supply of such services relative to the estimated need among individuals in the final year of life. Results of that research indicated that services available in acute care hospitals were sufficient to meet 33% to 50% of estimated need, and that programs serving patients in clinics, patient homes, or across both settings — community-based PC were able to meet 24% to 37% of need. Services were unevenly distributed across the state, with many counties not having access to inpatient palliative care, community-based palliative care, or either type of service. The 2017 update of this research found dramatic increases in the number of programs, the number of individuals being served, and broader availability across the state.

# Types of Specialty Palliative Care

For this research two types of specialty palliative care services were inventoried: *inpatient* and *community-based* services.

**Inpatient palliative care (IPPC)** is delivered to seriously ill hospitalized patients, usually by an interdisciplinary team (typically, but not always, composed of physician, nurse, social worker, and chaplain) that provides consultation to other hospital staff.

**Community-based palliative care (CBPC)** is delivered to seriously ill patients outside of the hospital setting — in clinics, patient residences, and through video visits and phone contacts. Service staffing and care delivery models are highly variable and

can range from home visits provided by nurse and social worker teams with direction from a physician, to clinic-based services where most care is delivered by a physician. CBPC services are sponsored by and affiliated with many types of organizations, including health systems, hospices and home health agencies, medical groups, and social service organizations.

#### What About Hospice?

This research does not address need or sufficiency of hospice services. Hospice is a specific type of PC reserved for patients with terminal illness. In the United States, hospice is a formal benefit available through government and commercial payers and commonly requires that recipients forgo further curative treatments and have a prognosis of six months or less.

The National Hospice and Palliative Care Organization reports<sup>1</sup> that in 2016, only 48% of people with Medicare insurance who died elected to receive hospice care. Among those who used hospice, 54% did so for fewer than 30 days, including 28% who were enrolled for a week or less. Because many individuals do not elect to use hospice, or do so very late in the disease course, optimal end-of-life care requires availability of both palliative care and hospice services — the availability of hospice does not eliminate the need for palliative care. Therefore, the prevalence and capacity figures exclude hospice services but do include non-hospice PC services that are sponsored by hospice organizations.

## **Methods**

This analysis examines the prevalence, capacity, and sufficiency of inpatient and community-based palliative care programs in California in 2017 — that is, the number of programs (prevalence), the number of people typically served by those programs (capacity), and how the number served compares to the need for palliative care services in that region (sufficiency). A full description of methods used to identify programs, determine need, and calculate sufficiency is available in Appendix A.

## Results

Current inpatient palliative care capacity for the entire state is estimated to be sufficient to meet between 43% and 66% of need (mid-point estimate = 52%), and current community-based capacity is estimated to be sufficient to meet between 33% and 51% of need (mid-point estimate = 40%). This represents significant increases in the prevalence of IPPC and CBPC services, and in the number of patients served by such programs, compared to 2014 (see Table 1).

#### Table 1. Need, Capacity, and Sufficiency of Palliative Care Services, 2014 vs. 2017

	2014	2017	DIFFERENCE	TREND
People needing palliative care (PC) in final year of life*	183,937	191,343	7,406	Stable
Inpatient palliative care (IPPC) capacity	72,394	99,013	26,619	Increase
Community-based palliative care (CBPC) capacity	53,570	76,730	23,160	Increase
IPPC sufficiency <sup>†</sup>	39%	52%	33%	Increase
CBPC sufficiency <sup>†</sup>	29%	40%	38%	Increase
Counties with no IPPC	19	18	-1	Reduction
Counties with no CBPC <sup>‡</sup>	22	6	-16	Reduction
Counties with no specialty PC	15	4	-11	Reduction
Counties with ≥50% sufficiency IPPC	8	21	13	Increase
Counties with ≥50% sufficiency CBPC	5	14	9	Increase
Counties with $\geq$ 50% sufficiency IPPC and CBPC	1	6	5	Increase

\*Mean of high and low estimates of need for palliative care among individuals in final year of life.

<sup>†</sup> Reflects capacity divided by the mean of high estimate of need and low estimate of need for palliative care.

<sup>‡</sup> In 2018, after data collection for this project ended, the number of counties with no community-based palliative care shrank to zero. Source: Analysis conducted by Kathleen Kerr, 2018. While need for PC has remained relatively stable, capacity has grown significantly for both inpatient and community-based services. Increased capacity in the inpatient setting reflects a modest (9%) increase in the number of programs, but a more significant increase in the number of patients being cared for by programs (up 37.5%). Significant gaps still exist among small hospitals and (especially) among for-profit hospitals, of which only 11% have services. Prevalence of community-based services more than doubled, with the most significant growth seen among hospice organizations that are now offering PC in addition to hospice care.

## Inpatient Palliative Care Prevalence, Capacity, and Sufficiency

Among 356 acute care hospitals, the analysis validated the presence of 202 active IPPC programs (57% of sites). The net addition of 16 programs since 2014, a 9% increase, reflects the launching of 22 new programs, less the 6 that are no longer active. Programs are available in 40 of 58 counties (69%). In California, 55 of 58 counties have short-stay acute care hospitals — the type of facilities where the research team looked for IPPC services. Forty of those 55 counties (73%) have at least one hospital with an IPPC program. Among the counties with 10 or more hospitals, the proportion of sites with IPPC services ranged from 38% (Riverside and San Bernardino) to 92% (San Francisco). See Table 2.

#### Table 2. Prevalence of Inpatient Palliative Care Services in Counties with 10 or More Hospitals, 2017

	SHORT-STAY ACUTE CARE HOSPITALS	HOSPITALS WIT PC SERVICES	
Los Angeles	83	43	52%
Orange	27	12	44%
San Bernardino	21	8	38%
San Diego	20	14	70%
Riverside	16	6	38%
Alameda	15	11	73%
San Francisco	13	12	92%
Santa Clara	12	10	83%
Sacramento	10	8	80%

Note: PC is palliative care.

Source: Analysis conducted by Kathleen Kerr, 2018.

Looking at Health Service Areas — multi-county regions used in Office of Statewide Health Planning and Development reporting — prevalence ranged from a low of 31% in Northern California, which includes the 14 sparsely populated counties in the far northern area of the state, to 91% in the West Bay, which includes San Francisco and surrounding counties (see Table 3).

There were significant differences in prevalence of IPPC based on facility size. While 88% (79 of 90) of hospitals with 300 or more beds have IPPC programs, there were only six IPPC programs among the 46 sites with fewer than 50 beds (13%.) This is not entirely surprising, since smaller hospitals have insufficient volume to support a dedicated interdisciplinary program.

#### Table 3. Prevalence of Inpatient Palliative Care Services by California Region, 2017

OSHPD HEALTH SERVICE AREA*	SHORT-STAY ACUTE CARE HOSPITALS	HOSF W PC SE	PITALS ITH RVICES
04 - West Bay⁺	23	21	91%
07 - Santa Clara	12	10	83%
05 - East Bay	23	18	78%
02 - Golden Empire <sup>‡</sup>	21	16	76%
03 - North Bay	12	9	75%
14 - San Diego/Imperial	22	14	64%
08 - Mid-Coast	11	7	64%
10 - Santa Barbara/Ventura	13	8	62%
06 - North San Joaquin	18	11	61%
11 - Los Angeles	83	43	52%
13 - Orange	27	12	44%
09 - Central	23	10	43%
12 - Inland Counties	39	14	36%
01 - Northern California§	29	9	31%

\*Office of Statewide Health Planning and Development.

<sup>†</sup> West Bay: San Francisco and surrounding counties.

<sup>‡</sup> Golden Empire: Sacramento and surrounding counties.

<sup>§</sup> Northern California: Butte, Colusa, Del Norte, Glenn, Humboldt, Lake, Lassen, Mendocino, Modoc, Plumas, Shasta, Siskiyou, Tehama, and Trinity Counties.

Note: PC is palliative care.

Source: Analysis conducted by Kathleen Kerr, 2018.

There were also significant differences in prevalence based on the type of entity that owns the hospital or health system (see Table 4). All seven federally owned hospitals have inpatient programs, along with 89% of hospitals operated by the University of California, 72% operated by nonprofits, and 68% operated by cities and counties. Conversely, only 11% (7 of 66) of investor-owned sites were found to have programs.

#### Table 4. Prevalence of Inpatient Palliative Care Service by Ownership Type, 2017

	HOSPITALS	HOSPITA PC SE	ALS WITH RVICES
Federal	7	7	100%
University of California	9	8	89%
Nonprofit	219	158	72%
City and/or county	19	13	68%
District	36	9	25%
Investor	66	7	11%

Note: *PC* is palliative care.

Source: Analysis conducted by Kathleen Kerr, 2018.

There are significant differences in prevalence of inpatient palliative care based on the type of entity that owns the hospital or health system. As a group, the 202 IPPC programs are providing care in more than 99,000 inpatient admissions each year. The increased capacity compared to 2014 (up by 27,000, or 37.5%) reflects the increased number of programs and an increase in the number of patients served annually by each program.

Current inpatient palliative care capacity for the entire state is estimated to be sufficient to meet between 43% and 66% of need.

## Community-Based Palliative Care Prevalence, Capacity, and Sufficiency

The analysis identified 380 CBPC programs, double the 189 programs found in 2014 (see Table 5). Programs include 270 that offer services in patient homes or that follow patients across settings, and 110 specialty PC clinics. Programs are sponsored by health systems (31.6% of identified services), hospices and home health agencies (56.6%), medical groups including specialty palliative care practices (9.2%), and other types of organizations (2.6%) such as church-based groups or social service entities. By far the greatest increase in program sponsorship occurred among hospices and home health agencies; while the 2014 analysis identified only 42 hospices / home health agencies with PC programs, the 2017 scan found 215 such programs.

# Table 5. Community-Based Palliative Care Programsby Type of Organization, 2014 vs. 2017

	2014	2017	NET C	HANGE
Hospital or health system	108	120	12	11%
Hospice or home health	42	215	173	412%
Medical group / specialty palliative care practice	27	35	8	30%
Other	12	10	-2	-17%
Overall	189	380	191	101%

Source: Analysis conducted by Kathleen Kerr, 2018.

Community-based programs are available in 52 of 58 counties (90%), a significant increase since 2014, when only 36 of 58 counties (62%) had such services. With the January 2018 implementation of SB 1004, the California law that requires Medi-Cal managed care plans to provide access to PC to qualifying members, it is expected that in 2018 all California counties will be served by at least one CBPC program, through in-person or telemedicine services.

It is expected that in 2018 all California counties will be served by at least one community-based palliative care program, through in-person or telemedicine services. Clinic-based services are now available in all of the state's 10 most populous counties (see Table 6). As most PC clinics are affiliated with health systems and are located close to acute care hospitals, the same regions of the state that lack IPPC services also tend to lack PC clinics.

This analysis estimates that the 380 clinic, homebased, and cross-setting CBPC programs are caring for approximately 76,700 people each year. The increased capacity compared to 2014 (up by 23,200, or 43%) reflects the substantial increase in the number of programs, particularly those that deliver care in patient homes. That the increase in number of patients served (43%) does not correlate directly with the increase in the number of programs (100%) is not unexpected, given that most new programs will have relatively smaller patient panels in the first years of operation, and that many of the new programs are operating in rural areas, where relatively smaller volumes will be the norm, even among mature programs.

Current community-based palliative care capacity for the entire state is between 33% and 51% of need.

The least populous counties are much less likely to have access to inpatient or clinic-based PC, often because there is no acute care hospital in the county. Even so, residents of these counties do have access to home-based services, which are more often sponsored by specialty practices and hospice organizations that have expanded to also deliver palliative care. As such, while IPPC services are more prevalent in populous counties, many small counties actually have comparable or greater sufficiency of CBPC (see Table 7 on page 6).

#### Table 6. Presence of Palliative Care Clinics in Most Populous Counties, 2017

						ATIVE CARE CLI	NICS
	POPULATION	ALL DEATHS	Low	High	Number	Capacity*	$Sufficiency^\dagger$
Los Angeles	10,082,664	60,023	30,012	55,821	27	4,320	10%
San Diego	3,214,279	20,447	10,224	19,016	8	1,280	9%
Orange	3,125,833	18,826	9,413	17,508	10	1,600	12%
Riverside	2,294,333	15,380	7,690	14,303	5	800	7%
San Bernardino	2,096,123	13,082	6,541	12,166	5	800	9%
Santa Clara	1,871,516	9,713	4,857	9,033	7	1,120	16%
Alameda	1,582,119	9,583	4,792	8,912	4	640	9%
Sacramento	1,461,174	10,961	5,481	10,194	4	640	8%
Contra Costa	1,095,476	7,434	3,717	6,914	4	640	12%
Fresno	969,338	6,499	3,250	6,044	2	320	7%
California	38,548,204	250,121	125,061	232,613	110	17,600	10%

\*Estimated number of patients served annually.

<sup>†</sup> Capacity divided by the mean of high and low estimates of palliative care need among individuals in the final year of life.

Source: Analysis conducted by Kathleen Kerr, 2018.

#### Table 7. Capacity and Sufficiency of Palliative Care Services, by Population, 2017

COUNTY	POPULATION	ALL DEATHS	ESTIMATED PC NEED*	CBPC CAPACITY	IPPC CAPACITY	CBPC SUFFICIENCY	IPPC SUFFICIENCY		
High-population counties									
Los Angeles	10,082,664	60,023	45,918	21,850	27,145	48%	59%		
San Diego	3,214,279	20,447	15,642	6,315	6,489	40%	41%		
Orange	3,125,833	18,826	14,402	6,885	6,505	48%	45%		
Riverside	2,294,333	15,380	11,766	3,678	2,007	31%	17%		
San Bernardino	2,096,123	13,082	10,008	3,490	3,729	35%	37%		
Low-population o	ounties								
Mono	14,440	50	38	0	0	0%	0%		
Trinity	13,782	163	125	25	0	20%	0%		
Modoc	9,395	106	81	25	0	31%	0%		
Sierra	3,267	32	24	15	0	61%	0%		
Alpine	1,243	6	5	5	0	100%	0%		

\*Mean of high estimate of need and low estimate of need for palliative care (PC) among individuals in the final year of life.

Notes: CBPC is community-based palliative care. IPPC is inpatient palliative care.

Source: Analysis conducted by Kathleen Kerr, 2018.

# Factors That Have Encouraged Program Development

In part, the increase in the number of identified PC programs reflects a more robust search strategy in 2017 compared to 2014, but there are also a number of factors that have encouraged the development and expansion of programs, particularly in CBPC.

## Systemwide Strategies

While integrated health care delivery organizations such as Kaiser Permanente and the Department of Veteran's Affairs have longstanding initiatives promoting delivery of PC in both the inpatient and outpatient setting, this was not the norm for most health systems in 2014. Since then, more health systems have adopted initiatives aimed at ensuring the presence of inpatient PC services across all system sites. As inpatient PC programs have matured, some sites and entire systems have adopted strategies, such as triggers embedded in electronic health records, designed to promote referrals among hospitalized patients who would likely benefit from PC. These efforts to promote greater use of inpatient services have contributed to an increase in the number of people cared for by each program, an important avenue for increasing service sufficiency when most hospitals now have IPPC services. Since the overwhelming majority of PC clinics are affiliated with health systems that have inpatient PC services, it seems likely that the increase in PC clinic prevalence is at least partially an extension of the increase in inpatient services.

## **Health Plans**

A growing body of literature that demonstrates the positive impact that CBPC can have on patient, family, and utilization/cost outcomes has led several payers, notably Health Net and Blue Shield of California, to offer PC across many or all business lines. In March 2018, Blue Shield announced that it is offering PC as a standard medical service to all members with primary health coverage from Blue Shield of California and to Medi-Cal beneficiaries served by their affiliate, Care1st Health Plan. SB 1004, the California law that requires Medi-Cal managed care plans to provide access to palliative care to qualifying beneficiaries, has played an enormous role in promoting spread of CBPC across the state, in particular in rural areas. The increase in payers advancing PC has created more reliable revenue streams, which has allowed more providers to offer services to at least of a subset of the patients who need such care.

#### SB 1004: Palliative Care for Medi-Cal Beneficiaries

Signed into law in 2014 and implemented in January 2018, SB 1004<sup>2</sup> requires the state's Medi-Cal managed care plans (MCPs) to offer palliative care to qualifying beneficiaries. PC services are available to MCP members with specific advanced illnesses (cancer, congestive heart failure, chronic obstructive pulmonary disease, end-stage liver disease) who are open to participating in advance care planning and to a trial of home-based care. The law specifies that eligible patients can receive PC concurrently with all other appropriate medical care. Members who qualify for the SB 1004 palliative care benefit are eligible to receive seven core palliative care services, including advance care planning support, palliative care assessment and consultation, a comprehensive plan of care, access to an interdisciplinary palliative care team, care coordination, pain and symptom management, and mental health and medical social services. Spiritual care is recommended but not required, as is 24/7 access to symptom management support. As a result of this bill, all qualifying Medi-Cal beneficiaries in all of the state's 58 counties should have access to PC.

## **Changing Financial Models**

The increased focus on value-based payments and population-based revenue models, such as accountable care organizations, likely have promoted development of community-based PC services. Inpatient PC programs, which have been shown to be effective in reducing the cost of acute care hospital stays, were able to proliferate in a predominantly fee-for-service (FFS) payment environment. Because most hospital admissions among PC-appropriate patients are paid for on a fixed case-rate basis, hospitals are the primary fiscal beneficiary of the changes in costs and utilization that flow from inpatient PC; the hospital is paid a fixed amount for an admission, and the PC team helps keep the cost of care delivery below (or closer to) that amount. As a result, many health systems and hospitals stepped up to cover the cost of inpatient PC programs. Conversely, home-based and clinic-based programs, which cannot cover the cost of care delivery with traditional FFS billings, reduce cost of care by preventing

hospitalizations, not reducing the cost of an existing hospitalization. Thus, the fiscal benefit of CBPC accrues to the health plans, ACOs, or health systems or medical groups that carry fiscal risk for a population over time. Increasingly, these types of entities are developing networks that ensure access to PC, as well as policies and practices that promote use of these services.

# **Remaining Challenges**

While much progress has been made, many challenges remain. Not every program identified in 2014 survived into 2017. While PC has gained acceptance generally, many programs are still fragile and are at risk of shutting down when faced with changes in administrative and clinical leadership, loss of critical clinical team members, and changes in system or organizational priorities.

# Need to Educate Providers and Patients

In community settings, many PC programs have found that having capacity does not necessarily translate into immediate referrals. Much work still needs to be done to educate referring providers about how palliative care can help them and their patients, and particular emphasis needs to be placed on teaching providers about the difference between hospice and palliative care. Similarly, patients and families need to be oriented to the benefits of PC, again with an emphasis on distinguishing PC from hospice. Workforce shortages are also a persistent challenge, and many provider organizations that wish to hire certified or experienced staff are unable to do so. As a result, there is an ongoing need for training programs, in particular for midcareer providers of all disciplines.

# Challenges Associated with Scaling and Sustainability

As community-based programs evolve from small pilots to established services, many are navigating challenges associated with scaling and sustainability. Workflows and administrative processes that worked well for a small pilot need to be revisited and revised as programs develop the capacity to care for hundreds versus dozens of patients a year. The absence of standardization in billing practices, care delivery models, and methods for assessing quality can create enormous burdens on both providers and the entities that pay for care. A hospice and palliative care organization may have succeeded in securing six contracts to delivery home-based PC, but too often that also means the organization must contend with six different sets of requirements related to

#### California Advanced Illness Collaborative Consensus Standards

In spite of the growing body of evidence supporting the benefits of palliative care, the spread of CBPC programs has been hindered in part by an incremental approach of creating contracts one by one, sometimes with wide variation in the target population or services. In 2015, to address these challenges, the Coalition for Compassionate Care of California and Blue Shield of California created the California Advanced Illness Collaborative<sup>3</sup> (CAIC), a group of health plans, CBPC providers, and other stakeholders who developed consensus standards to inform CBPC payer-provider contracts for patients in a late stage of illness. The CAIC standards, which are aligned with the current specifications of SB 1004 (the California law that requires Medi-Cal managed care plans to provide access to palliative care), provide minimum standards regarding eligible patients, care team composition, clinical services, payment models, and metrics. With funding from the California Health Care Foundation, these standards are being piloted in Los Angeles and Sacramento Counties.

staffing, care models, service delivery requirements, metrics, billing and authorization processes, and payment amounts.

## Meeting the Specific Needs of Different Populations

While the absence of standardization creates a set of challenges, so too does the need to accommodate the variation in needs seen across geographic areas and patient populations. As programs are becoming more prevalent, it is also becoming apparent that there is no one-size-fits-all model for PC. A care model developed to serve a Medicare Advantage population in a largely suburban area will not necessarily work well for an urban Medi-Cal population. Both program leaders and their payer partners will need to be prepared to adjust expectations and assumptions related to payment methods and amounts, care delivery models, methods and frequency of care encounters, and even expectations about outcomes as they expand into different regions and care for more varied populations.

# **Remaining Questions**

While just knowing the number and location of services is useful, there are many questions about the state of palliative care in California that this research does not address.

## **Detail About Scope and Quality**

Perhaps most importantly, this analysis did not endeavor to learn exactly what these programs do, the nature of their staffing and clinical models, or how prepared staff are to deliver quality care. Given the absence of regulations and state or federal standards addressing palliative care, an analysis of program characteristics with an eye to assessing indicators associated with care quality (staff training, use of standardized protocols, etc.) would be a critical complement to the existing examination of prevalence.

## Uneven Access Based on Insurance Coverage

Further, while it is possible to estimate the number of people who might need palliative care in the final year of life, this analysis did not assess the types of insurance these individuals have, which is becoming the most relevant variable in determining access. Currently, people with Medi-Cal managed care, Medicare Advantage, and some types of commercial insurance are likely to have CPBC services covered. Others, notably those with traditional Medicare feefor-service coverage, would likely only be able to access home-based palliative care if they had the resources to pay for it out of pocket. The palliative care terrain remains uneven but in a new way, as now a community might have ample PC capacity, but not everyone in that community will have the same access to these programs.

## Appendix A. Methods

## Estimating IPPC Prevalence and Capacity

To determine the availability of IPPC, the research team began by looking at the California Office of Statewide Health Planning and Development (OSHPD) Utilization Report of Hospitals<sup>4</sup> (URH), a survey completed annually by all nonfederal licensed hospitals in California that includes questions about the presence of an IPPC program. The assessment was limited to nonspecialty, short-stay, acute care hospitals, as these facilities are the most likely to offer IPPC. A variety of methods were used to validate responses to the palliative care questions in the 2016 URH, including comparison to findings of the 2014 California Health Care Foundation prevalence study and direct outreach to system or PC program leaders. When no contact with a program or system leader was made, or if the project team did not have direct knowledge about the status of IPPC at a given site, the team cross-checked information about the presence or absence of an IPPC with information included in the palliative care provider directory<sup>5</sup> maintained by the Center to Advance Palliative Care, and reviewed hospital and health system websites and other public sources for evidence of IPPC.

IPPC service volumes were obtained from many system and PC program leaders. When actual volume data were not available, volume was estimated based on the median service volume for hospitals with similar numbers of general acute care beds. For this research, *IPPC capacity* was defined as the number of admissions that the PC team sees annually. It was assumed that most IPPC programs are seeing as many patients as possible given staffing levels.

Capacity for hospital-based programs was attributed to the county in which the hospital is located.

### **Estimating CBPC Prevalence and Capacity**

Because CBPC programs are sponsored by many types of provider organizations, the analysis used a layered approach to identify programs. The research team began with the list of CBPC programs identified in 2014, and revised or supplemented these data with information from the following sources:

- Review of data submitted to OSHPD by health systems describing the presence of PC clinics and delivery of nonhospice palliative care<sup>6</sup> by hospices and home health agencies
- Direct outreach to the leadership of health systems with established CBPC programs
- Review of programs listed in the Center to Advance Palliative Care provider directory, as well as sites that belong to the Palliative Care Quality Network
- Review of organizations that have received Advanced Certification in Palliative Care from The Joint Commission

- Review of organizations participating in the Medicare Care Choices Model and the Oncology Care Model, two federal programs that promote delivery of CBPC
- Review of information from various CHCF projects that included CBPC providers
- Direct outreach to health plans that are known to offer palliative care benefits to their members

CBPC service volumes were obtained directly from many programs. When actual volume data were not available, volume was estimated based on the median service volume for similar types of programs (clinic-based, home-based, and programs that see patients across care settings).

For this research, *CBPC capacity* was defined as the number of patients that the service sees annually. The research team assumed that most CBPC services are seeing as many patients as possible given staffing levels.

Capacity for clinic-based PC services was attributed to the county in which the clinic is located. Homebased and cross-setting PC services often care for patients in multiple counties. If a service leader indicated that a program serves multiple counties, then program volume was apportioned to each county based on population. For example, CBPC program XYZ sees 100 patients per year and serves County A, with a population of 50,000, and County B, with a population of 100,000. Here, 33% of PC program XYZ's volume would be attributed to County A and 67% of the volume would be attributed to County B.

### **Estimating Need and Sufficiency**

It is useful to conceive of palliative care as being delivered in three types of situations: over the duration of a chronic progressive illness, during an acute health crisis that eventually resolves, and in the last year of life. While patients in all three groups may need palliative care, *this research estimates the need* for PC only among patients in the last year of life.

The estimate of the number of individuals in the last year of life was based on the 2018 County Health Status Profiles,<sup>7</sup> which includes data describing annual deaths in each California county.

Several studies estimating population-based need for PC have been done in Europe and Australia. To determine the proportion of people in the last year of life that might need PC, the research team used an approach similar to that endorsed by Murtagh et al.,<sup>8</sup> which defines PC need as a range. The "low estimate of need" is the number of people dying of seven conditions specified in the County Health Status Profiles that commonly need PC:

- ► Alzheimer's disease
- ► Cancer (all types)
- Cerebrovascular diseases (stroke)
- Chronic liver disease and cirrhosis
- Chronic lower respiratory diseases
- Coronary heart disease
- Diabetes

In 2017, these seven conditions accounted for 60% of deaths statewide.

The "high estimate of need" is the number of all deaths excluding those caused by accidents, homicides, or suicides. In 2017, this corresponded to 93% of deaths statewide.

*Sufficiency* is defined as PC service capacity divided by the estimated need.

**Example.** County C has 100 deaths each year. The data from the County Health Status Profiles indicate that 60 of those deaths were from the identified seven conditions (low estimate of need) and 93 of those deaths were from natural causes (high estimate of need). County C has two CBPC programs that together serve 50 patients a year (capacity). The maps would therefore report sufficiency of CBPC services as being between 54% (50  $\div$  93) and 83% (50  $\div$  60).

COUNTY	POPULATION	ALL DEATHS	PC NEED*	IPPC PROGRAMS	IPPC CAPACITY	CBPC PROGRAMS	CBPC CAPACITY	IPPC SUFFICIENCY	CBPC SUFFICIENCY
Alameda	1,582,119	9,583	7,331	11	4,788	14	2,830	65%	39%
Alpine	1,243	6	5	0	0	1	5	0%	100%
Amador	37,017	425	325	1	168	1	50	52%	15%
Butte	224,518	2,219	1,698	2	1,481	5	977	87%	58%
Calaveras	45,508	480	367	1	68	1	50	19%	14%
Colusa	22,254	139	106	0	0	0	0	0%	0%
Contra Costa	1,095,476	7,434	5,687	7	2,849	11	2,173	50%	38%
Del Norte	28,477	283	216	0	0	1	50	0%	23%
El Dorado	184,320	1,436	1,099	2	546	2	379	50%	35%
Fresno	969,338	6,499	4,972	5	3,375	4	795	68%	16%
Glenn	28,868	258	197	0	0	0	0	0%	0%
Humboldt	136,779	1,295	991	3	446	5	777	45%	78%
Imperial	183,154	1,027	786	0	0	2	438	0%	56%
Inyo	19,244	184	141	0	0	0	0	0%	0%
Kern	878,356	5,727	4,381	3	1,451	1	50	33%	1%
Kings	153,601	795	608	0	0	1	219	0%	36%
Lake	65,465	836	640	1	119	2	338	19%	53%
Lassen	35,038	205	157	0	0	1	50	0%	32%
Los Angeles	10,082,664	60,023	45,918	43	27,145	91	21,850	59%	48%
Madera	154,829	1,054	806	1	514	1	90	64%	11%
Marin	257,792	1,901	1,454	3	802	7	904	55%	62%
Mariposa	18,091	183	140	0	0	0	0	0%	0%
Mendocino	88,795	858	656	1	238	1	160	36%	24%
Merced	266,444	1,644	1,258	1	692	0	0	55%	0%
Modoc	9,395	106	81	0	0	1	25	0%	31%
Mono	14,440	50	38	0	0	0	0	0%	0%
Monterey	426,670	2,493	1,907	3	1,024	7	1,215	54%	64%
Napa	141,172	1,193	913	1	259	3	657	28%	72%
Nevada	98,453	982	751	1	156	1	219	21%	29%
Orange	3,125,833	18,826	14,402	12	6,505	33	6,885	45%	48%

## Appendix B. Table of Need, Capacity, and Sufficiency of Palliative Care Services, by County, 2017

COUNTY	POPULATION	ALL DEATHS	PC NEED*	IPPC PROGRAMS	IPPC CAPACITY	CBPC PROGRAMS	CBPC CAPACITY	IPPC SUFFICIENCY	CBPC SUFFICIENCY
Placer	369,460	2,992	2,289	3	1,887	5	977	82%	43%
Plumas	19,416	225	172	0	0	1	25	0%	15%
Riverside	2,294,333	15,380	11,766	6	2,007	18	3,678	17%	31%
Sacramento	1,461,174	10,961	8,385	8	6,726	13	2,611	80%	31%
San Benito	58,222	308	236	1	159	1	50	67%	21%
San Bernardino	2,096,123	13,083	10,008	8	3,729	15	3,490	37%	35%
San Diego	3,214,279	20,447	15,642	14	6,489	29	6,315	41%	40%
San Francisco	840,391	5,580	4,269	12	4,400	13	2,434	103%	57%
San Joaquin	713,961	5,215	3,989	5	1,386	4	825	35%	21%
San Luis Obispo	272,941	2,274	1,740	2	515	3	657	30%	38%
San Mateo	747,334	4,648	3,556	6	1,770	9	1,853	50%	52%
Santa Barbara	435,999	3,015	2,306	2	1,588	5	1,095	69%	47%
Santa Clara	1,871,516	9,713	7,430	10	5,415	14	2,953	73%	40%
Santa Cruz	272,210	1,739	1,330	1	455	3	657	34%	49%
Shasta	179,305	2,173	1,662	1	338	2	438	20%	26%
Sierra	3,267	32	24	0	0	1	15	0%	61%
Siskiyou	45,290	561	429	1	27	1	50	6%	12%
Solano	428,705	3,073	2,351	4	1,371	2	379	58%	16%
Sonoma	497,260	4,001	3,061	4	1,408	6	1,078	46%	35%
Stanislaus	532,344	4,042	3,092	3	2,283	10	1,412	74%	46%
Sutter	97,257	757	579	0	0	5	350	0%	60%
Tehama	64,827	633	484	0	0	1	50	0%	10%
Trinity	13,782	163	125	0	0	1	25	0%	20%
Tulare	461,703	2,932	2,243	1	1,049	2	384	47%	17%
Tuolumne	54,592	658	503	0	0	1	50	0%	10%
Ventura	844,833	5,531	4,231	6	3,033	15	2,817	72%	67%
Yolo	208,069	1,254	959	2	351	3	657	37%	68%
Yuba	74,258	587	449	0	0	1	219	0%	49%
California	38,548,204	250,121	191,343	202	99,013	381	76,730	52%	40%

\*Need reported as mean of low estimate of need and high estimate of need.

Notes: PC is palliative care. IPPC is inpatient palliative care. CBPC is community-based palliative care.

Source: Analysis conducted by Kathleen Kerr, 2018.

## Endnotes

- 1. Facts and Figures: Hospice Care in America, National Hospice and Palliative Care Organization, March 2018, www.nhpco.org (PDF).
- For more information about SB 1004 see "Palliative Care and SB 1004," California Department of Health Care Services, last modified February 7, 2018, www.dhcs.ca.gov.
- 3. For more information about the CAIC and the CAIC Standards, see "California Advanced Illness Collaborative (CAIC)," Coalition for Compassionate Care of California, coalitionccc.org.
- "Hospital: Data Sets and Data Products," Office of Statewide Health Planning and Development, last modified March 28, 2018, www.oshpd.ca.gov.
- 5. "Palliative Care Provider Directory," Center to Advance Palliative Care, getpalliativecare.org.
- 6. "Home Health Agencies and Hospice Facility Annual Utilization Data," Office of Statewide Health Planning and Development, www.oshpd.ca.gov.
- "County Health Status Profiles 2018," California Department of Public Health, last modified April 5, 2018, www.cdph.ca.gov.
- 8. F. E. Murtagh et al., "How Many People Need Palliative Care? A Study Developing and Comparing Methods for Population-Based Estimates," *Palliative Medicine* 28, no. 1 (January 2014): 49–58, doi:10.1177/0269216313489367.

## About the Author

Kathleen Kerr is a health care consultant. Her work is focused on promoting the development of sustainable, quality palliative care programs.

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