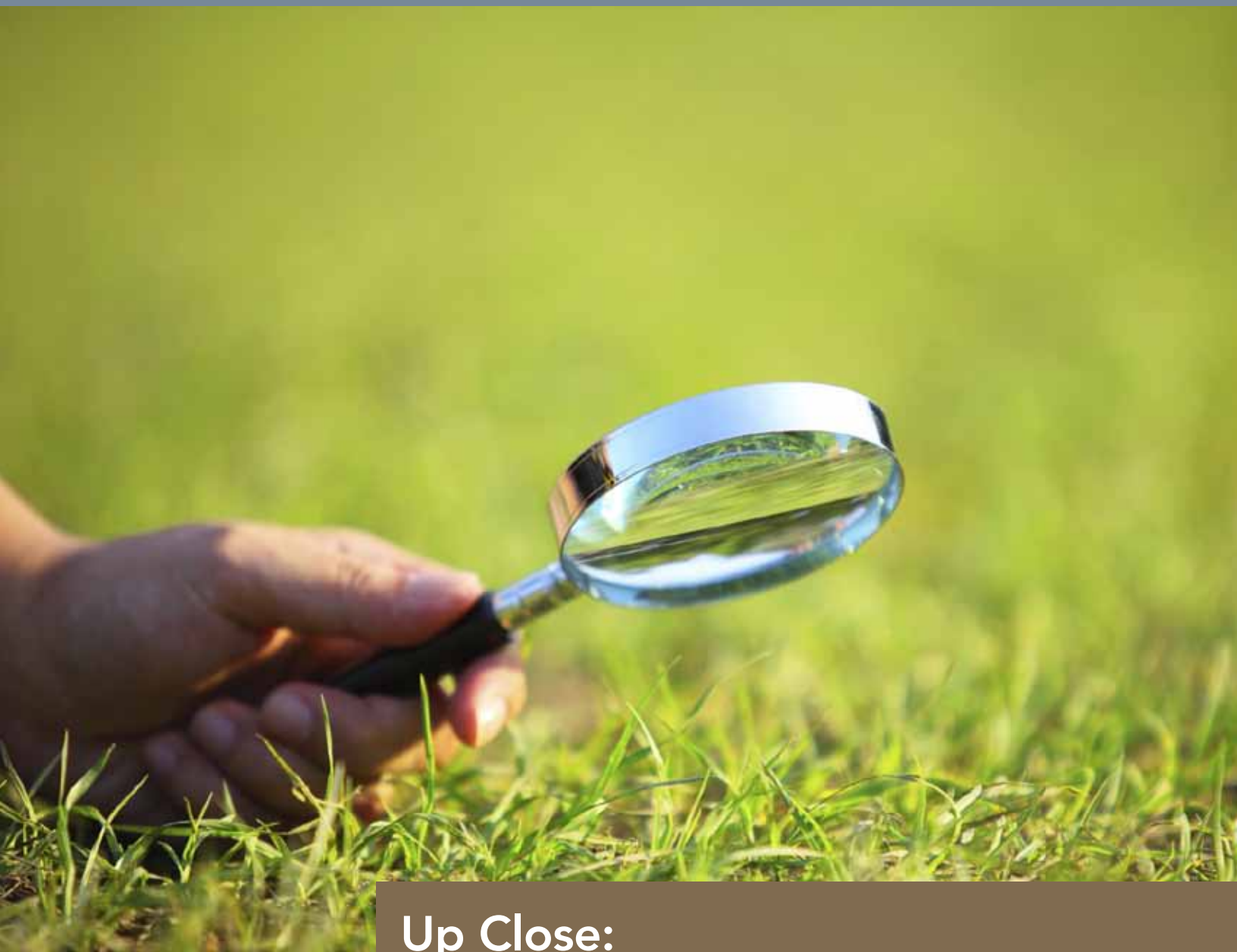




CALIFORNIA HEALTHCARE FOUNDATION



Up Close:
A Field Guide to Community-Based
Palliative Care in California

SEPTEMBER 2014

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Acknowledgments

The authors would like to acknowledge Mike Rabow, MD, professor of clinical medicine in the Division of General Internal Medicine, Department of Medicine, at UCSF for his contributions to this field guide and for his participation as faculty of the Palliative Care Action Community.

The authors would also like to acknowledge the contributions of the Palliative Care Action Community teams, who shared their experiences, knowledge, successes, and challenges with us and with each other. Their generosity made the production of this field guide possible.

About the Foundation

The **California HealthCare Foundation** works as a catalyst to fulfill the promise of better health care for all Californians. We support ideas and innovations that improve quality, increase efficiency, and lower the costs of care. For more information, visit www.chcf.org.

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Introduction

Increasingly, health systems across the United States are recognizing the importance of palliative care: specialized, interdisciplinary care that attends to the physical, psychological, emotional, and spiritual needs of people with serious illnesses, and their family members. Over the past two decades, many hospitals have established inpatient palliative care services for patients with complex or progressive illnesses. Although these inpatient programs have proliferated, community-based palliative care (CBPC) programs — those that offer services at a clinic, in a patient's residence, or over the phone — are far less prevalent.¹ Of the CBPC services that do exist, many have developed in relative isolation, with little opportunity for program leaders to network with peers, share promising practices and lessons learned, or compare staffing structures, benchmarks, and clinical and utilization outcomes.

In 2013 the California HealthCare Foundation (CHCF) launched the Palliative Care Action Community (PCAC)

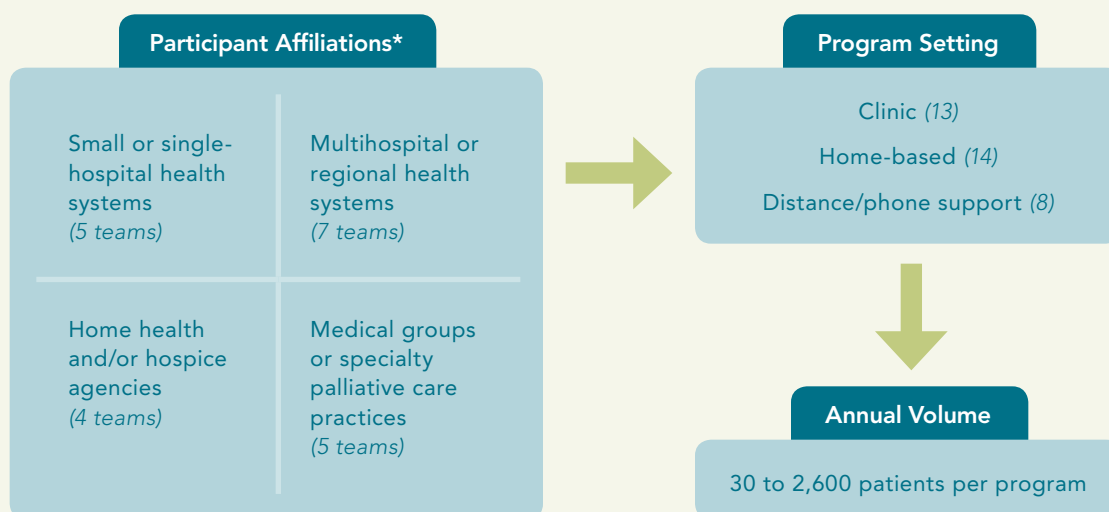
to promote collaboration among organizations working to strengthen or expand their CBPC services. Twenty-one California-based provider teams participated. They represented diverse types of organizations, provided services in a variety of settings, and came with varying levels of CBPC experience. Despite these differences, the teams faced some common challenges in program planning, operations, and evaluation.

Up Close: A Field Guide to Community-Based Palliative Care in California describes the common approaches and characteristics of these programs, the challenges they faced, and the promising practices they've developed. It also includes the opinions and experiences of many of the experts who interacted with the action community participants. The field guide is intended for providers interested in starting new CBPC programs as well as those who want to sustain, strengthen, or expand existing ones.

Palliative Care Action Community

The Palliative Care Action Community enabled participants to share promising practices and challenges with each other and to learn from other experts in the field.

Participating organizations were selected through a competitive Request for Proposals process. Administrative and clinical leaders from CBPC teams participated in monthly in-person and virtual learning sessions. Meetings were attended by the full cohort or by subsets based on discipline or geography. The full action community was active for just over one year; however, two discipline-specific workgroups continued meeting for an additional three months.



*See Appendix A for a list of participating organizations.

Features and Models of Community-Based Palliative Care

This section reviews the core features of community-based palliative care (CBPC) as implemented by the Palliative Care Action Community (PCAC) members, including the types of patients that can benefit from these services, typical staffing models and activities, options for structuring services, and examples of how teams engage with patients.

What Is Palliative Care?

There are many definitions of palliative care. The Center to Advance Palliative Care uses this one:

Palliative care is specialized medical care for people with serious illnesses. It focuses on providing patients with relief from the symptoms, pain, and stress of a serious illness — whatever the diagnosis. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.²

This definition emphasizes layering palliative care with ongoing disease-focused care; palliative care should

be thought of as a supplement to, rather than mutually exclusive of, ongoing treatment of the underlying disease. This is especially true of community-based palliative care, which is usually initiated months, if not years, before the end of life.

What Is Community-Based Palliative Care?

CBPC is nonhospital, nonhospice palliative care provided in clinics, in patient homes (including private residences as well as nursing homes and assisted living facilities), or over the phone.³ When connected to inpatient palliative services, CBPC programs provide care continuity for patients once they are discharged from the hospital.

How Are Patients Identified?

Teams use a variety of strategies to identify patients who might benefit from CBPC:

- ▶ Targeting patients with specific conditions or symptoms (for example, patients with cancer or chronic obstructive pulmonary disease, or those with pain scores over a certain threshold)
- ▶ Focusing on patients in particular settings (for example, offering CBPC to all long-stay nursing home residents)
- ▶ Utilization triggers (for example, patients with multiple hospitalizations in a given period)
- ▶ Referrals from inpatient palliative care services

Abbreviations

ACO	Accountable care organization
ACP	Advance care planning (or plan)
AHCD	Advance health care directive
APN	Advanced practice nurse
CAPC	Center to Advance Palliative Care
CBPC	Community-based palliative care
CC	Care coordinator
CHCF	California HealthCare Foundation
CHF	Congestive heart failure
CM	Case manager, care manager
DO	Doctor of osteopathic medicine (physician)

FTE	Full-time equivalent
IPA	Independent practice (or physician) association
LCSW	Licensed clinical social worker
NP	Nurse practitioner
PA	Physician assistant
PCAC	Palliative Care Action Community
POLST	Physician Orders for Life-Sustaining Treatment
PC	Palliative care
PCP	Primary care provider, primary care physician
RVU	Relative value units

Many PCAC teams reported that the need for outpatient palliative care exceeds their programs' current staffing and clinic space capacities. These limitations underscore the importance of clearly defining the most appropriate patients for the CBPC service, and selecting populations that the team can have the greatest impact on.

What Types of Services Are Offered?

Community-based palliative care is delivered by interdisciplinary teams that focus on anticipating, preventing, and reducing suffering for patients with serious illness and their family members. Assessments and treatments typically address physical, emotional, existential, and spiritual distress. Communication about disease progression, prognosis, and the benefits and burdens of various treatments are a major focus of CBPC, along with eliciting and documenting patient goals, values, and preferences.

While CBPC programs share common features, the scope of services differs across programs and settings. A 2013 survey of PCAC members shows the program-to-program variation in where, how, and by whom services are delivered (see Table 1).

Table 1. Palliative Care Services Offered by PCAC Members, by Setting

	CLINIC n=10	HOME-BASED n=11	DISTANCE n=5
Advance care planning	100%	100%	60%
Symptom management	100%	100%	80%
Emotional support	100%	82%	100%
Spiritual support	63%	55%	40%
Medication management	100%	91%	80%
Information about disease/prognosis	100%	91%	80%
Referrals to community services	88%	100%	60%
Case management	38%	64%	40%

Source: Survey of Palliative Care Action Community members, 2013.

How Are Services Structured, and Where Are Patients Seen?

CBPC programs can be supported by a variety of organizations including large health systems, small community hospitals, multispecialty medical groups, specialty palliative care practices, and home health or hospice agencies. The structure and focus of many CBPC programs, especially new services, are often shaped by organizational priorities and availability of staff and of clinic space or home visit resources.

Each service structure has its advantages and challenges. Being embedded in a specialty clinic can help strengthen relationships between CBPC team members and specialty clinic providers, enable palliative care to be seen as part of routine treatment in that specialty, and make it easier for patients to access palliative care services by coordinating appointment times. On the other hand, being embedded in one specialty clinic may limit the service's ability to grow, as it may be difficult to build embedded palliative care practices across multiple specialties.

While home-based palliative care services can fill a gap for patients who are not well enough to come into a clinic, some teams feel that the staff travel time involved in home visits could be better spent reaching more patients in a clinic setting.

From Concept to Practice: PCAC Member Approaches

The teams deliver services in different ways: Some are strictly clinic-based, some are strictly home-based, and others blend these approaches.

- ▶ One team visits patients in the location of their choice — at their home, in a nursing home, or in the clinic. This team sees patients in the hospital if they are admitted. By following patients across settings of care, this mobile team is able to ensure care continuity and to greatly enhance access during transitions.
- ▶ A medical center-based team follows patients across settings within the center during their visits. For example, the team may start a palliative care consultation in a clinic room, walk with the patient to the chemotherapy infusion center, and continue the conversation there.

- ▶ A clinic-based team embedded in an oncology clinic offers patients joint visits with palliative care team members and their oncologist. Joint visits help ensure the delivery of consistent messages about care goals and reinforce the idea that palliative care is offered simultaneously with, and as a complement to, oncology care.

PROMISING PRACTICE Embedded in Huntington Hospital's Chronic Disease Management Clinic, the Ambulatory Care Palliative Care Clinic serves congestive heart failure and chronic obstructive pulmonary disease patients early in their disease process. Scheduling patients to see palliative care providers on days when they are already coming in to the clinic helps minimize appointment attrition, and supports care continuity and collaboration between chronic disease management physicians and the palliative care team.

What Is the Palliative Care Team's Role in Relation to Other Providers?

The role of the CBPC team can vary, depending on the other primary or specialty care providers involved:

- ▶ **Consultation services.** The CBPC team offers recommendations to the referring provider but does not implement them.
- ▶ **Co-management services.** The CBPC team partners with the primary provider(s) to care for the patient, typically assuming total care for particular clinical issues.
- ▶ **Primary caregiver role.** The CBPC team is responsible for all of the referred patient's care needs.
- ▶ **Mixed model.** The CBPC team assumes different roles, depending on the patient's needs and desires, the referring provider's needs and capacity, and the setting. The team's approach can change as care needs change.

From Concept to Practice:

PCAC Member Approaches

- ▶ One team uses a consult model for much of their care, but provides co-management services when the palliative care team's expertise in managing specific symptoms or medications is needed.
- ▶ Another team designed their CBPC service as a medical specialty consult service, feeling this structure

allows them to see more patients because they are not involved in direct management of patient care. This team encourages primary providers to gain the skills to address less complex palliative care issues independently, and they reinforce the message with patients that their primary providers are responsible for their overall care.

What Happens Before the First Visit?

Once a patient has been referred to a CBPC service, the palliative care team prepares the patient and the team itself for the first visit. Pre-visit patient outreach helps to improve the patient's understanding of what palliative care is and what to expect, since some referring providers may not adequately describe palliative care or the reasons they are referring the patient.

Before the first visit, the palliative care team gathers information from the referring provider or patient record to better understand the patient's physical, emotional, and spiritual needs. This information helps the team decide which team members should take part in the first visit and what the focus of that visit should be. A pre-visit conversation with the referring provider helps the palliative care team understand and respond to that provider's goals for the patient and strengthens the provider-to-provider relationship.

From Concept to Practice:

PCAC Member Approaches

- ▶ After a referral has been made but before the first visit, a palliative care team member calls the patient to provide basic information about the service and discuss the patient's expectations for the initial visit.
- ▶ A palliative care team member administers a wellness screening survey before or at the beginning of the initial visit.
- ▶ A palliative care team member calls the referring provider or other involved providers to learn about the patient's needs and family dynamics, to clarify the referring provider's expectations, and to confirm the communication process. If further information is needed, a social worker looks at the patient's records, calls the patient, and shares the gathered information with the team.

CASE STUDY

Stanford Health Care

Setting and Structure

This academic medical center based in Stanford, California, has multiple outpatient clinics in three counties. In 2007, Stanford launched an inpatient palliative care service. Outpatient services began in 2012 with a palliative care clinic in the cancer center, followed by a freestanding palliative care clinic for non-cancer patients in 2014. Palliative care resides within the Clinical Support Services department, and provides consult, co-management, or primary caregiver services depending on the patient's needs and desires, capacity and needs of the referring provider, and setting. About half of the program's funding comes from physician billing and half from institutional support.

AT-A-GLANCE METRICS

Patients and Staffing

- **Patient population:** estimated as 80% oncology, 10% hematology, 10% other (cardiac, pulmonary, neurology)
- **Primary referral sources:** physicians (typically primary oncologist) and inpatient palliative care team
- **Unique outpatients per year:** 412
- **Outpatient encounters per year:** 1,075
- **Staffing (FTE):** 1.2 physician, 1.0 advanced practice nurse, 0.5 care coordinator, 0.5 licensed clinical social worker (total of 3.2 FTEs)

Measuring Results

Impact Measures

- **Patient-related:** results from Edmonton Symptom Assessment System and a palliative screening tool, patient and family satisfaction scores from across cancer center (plan to start monitoring)
- **Financial:** PCAC Supportive Care Calculator results (see page 27)

Selected Outcomes

- Primary reason for consultation: symptom management (49%) or goals of care (34%)
- Steady increase in volume of patients (80 to 100 patients/month) and number of referring providers since initiation of program

The team provides care in the palliative care clinic five days a week, plus a large number of visits in other settings when convenient for the patient, such as during infusion treatments or oncology visits.

The palliative care team provides a full spectrum of services, including assessing and addressing pain and other physical symptoms as well as psychosocial, emotional, and spiritual issues; discussing and documenting goals of care; counseling on and completing advance care planning documents; supporting family members; reconciling medications; educating patients about their disease and prognosis, including information on what to expect as the end of life approaches; and assisting with hospice enrollment and management when appropriate.

Successes, Challenges, and Aspirations

Stanford's palliative care team leaders include among their successes:

- The development of an interdisciplinary, responsive service available five days a week in multiple settings
- Increasing support and referrals from outpatient oncology providers
- The strong support from cancer center and hospital leaders

Challenges, and approaches for managing them, include:

- **Limited capacity and reach.** The team is considering ways to improve referrals to reach the most appropriate patients, address inefficiencies of their current cross-setting model, and increase palliative care knowledge among other providers.
- **Late referrals.** The team is piloting a palliative screening and assessment tool to understand opportunities for earlier referrals.
- **Time-consuming data collection.** The team is looking at opportunities to use their electronic medical record system for real-time data collection related to quality metrics and research projects.

In the future, the team would like to integrate palliative care with cancer care and other medical departments so that this concurrent care is viewed as the norm, develop home-based palliative care services or create partnerships to meet the needs of patients at home, and track data in real time to assess outcomes, make changes to the practice model, and support clinical trials.

What Is the Typical First Visit Like?

Referrals to CBPC are typically driven by complex physical, emotional, or spiritual issues resulting in the patient's need for extra support. It is essential that the team builds a trustful relationship with the patient, and the initial visit is a key opportunity to begin this process. During the first visit, it is usually not urgent that every need is addressed, as the team will typically be working with the patient over time. The team can discuss basic information about the patient which will be explored in more depth in subsequent visits, such as:

- ▶ Patient and family member priorities (e.g., top three concerns)
- ▶ Distressing pain and symptoms
- ▶ Emotional or spiritual issues
- ▶ Identification of a family member or friend to be involved in discussions about care

PCAC members reported that it can be helpful to define the CBPC team's goals for what patients should know by the end of the first visit, such as:

- ▶ General understanding of palliative care and how the team will work with the patient's primary provider
- ▶ Short-term plan, including who will see the patient next, where the patient will be seen, and goals for the next visit

From Concept to Practice: PCAC Member Approaches

The teams described a typical initial visit, including which providers are involved, the length of the visit, and the main goals of that first visit. Table 2 illustrates the diversity of approaches used across settings.

Table 2. Examples of Initial Visit Structures, by Setting

	PROVIDERS	LENGTH	GOALS
Mobile team sees patients across settings (part of a medical group)	Physician, social worker	90 minutes	Assess: <ul style="list-style-type: none"> ▶ Care goals ▶ Symptom management needs ▶ Advance care planning ▶ Psychosocial and spiritual issues
Embedded clinic in oncology (part of a multihospital, regional health system)	Joint visit with primary oncologist and CBPC team (physician, nurse, social worker)	60 to 90 minutes	Introduce advance care planning (to address fully during future visits) Give patient understanding of roles and responsibilities of palliative care team Assess: <ul style="list-style-type: none"> ▶ Physical issues ▶ Emotional/psychological issues (often leads to discussions on goals of care, patient's understanding of illness) ▶ Psychosocial and spiritual issues
Home-based (specialty palliative care practice)	Nurse, social worker	2 hours	Assess patient needs Provide education and consultation on symptom management Assist with long-range planning Help patient navigate care system No medical interventions provided

Source: In-person meetings and webinars of the Palliative Care Action Community, 2013-14.

PROMISING PRACTICE At Community Memorial Hospital, all interdisciplinary palliative care team members see the patient and family members together for the first meeting to assess understanding of the patient's condition, family dynamics, goals, and expectations. This allows each team member to process the same information and provide feedback through their discipline's unique lens.

PROMISING PRACTICE At Motion Picture & Television Fund, the interdisciplinary team, which includes a nurse, a social worker, and a chaplain, meets with the patient prior to their appointment with the palliative care provider — a physician or advanced practice nurse (APN). This meeting allows patients to raise the issues of greatest importance to them and enables team members to look collectively for any unspoken concerns. Team members describe this interdisciplinary sensitivity as “invaluable.” Team members communicate the salient points with the palliative care provider before the provider's first visit with the patient. This way, the provider can focus on key concerns right away.

What Happens During Follow-Up Visits?

The nature of a CBPC team's ongoing involvement in patient care varies based on the type of service provided (consult, co-management, or assuming role of primary provider), the staffing and availability of the CBPC team, and the needs and priorities of the patient and family members. For ongoing patient visits, teams typically focus on:

- ▶ Assessing and addressing physical, emotional, and spiritual distress to improve the quality of life of the patient and family members.
- ▶ Identifying goals and developing a care plan (often in collaboration with a patient's primary providers) that is informed by a robust understanding of the patient's and family members' needs and concerns.
- ▶ Communicating and collaborating with the patient's primary providers to ensure the care plan is implemented and adapted as needed over time, to ensure concordance between patient preferences and the care that is delivered.

From Concept to Practice: PCAC Member Approaches

Members provided examples of how their teams structure follow-up care in diverse settings (see Table 3, page 10).

PCAC members shared their different approaches to scheduling:

- ▶ One clinic-based service aims to see no more than three to four patients per half-day session. Their new-patient visits routinely include 1 to 1.5 hours with the provider plus some time in advance with the rest of the team, and follow-up visits last an hour.
- ▶ Another clinic plans for two new patients and three follow-up visits per half-day.
- ▶ Another clinic-based service plans for a maximum of three new patients or five follow-up visits in a five-hour session.
- ▶ One home-based service conducts three to four visits per full day, due to the travel time required.

PROMISING PRACTICE Sutter Care at Home has developed tools to help patients understand and engage in their own care. STOPLIGHT tools are condition-specific, paper-based forms designed to help patients manage their own care safely at home. These forms help patients gauge for themselves when they are doing well (in the green zone), when they should call their provider within the next 24 hours (in the yellow zone), and when they should call their provider right away (in the red zone). The STOPLIGHT tools are used throughout Sutter Health's hospitals, clinics, and home care services. Sutter Care at Home's Personal Health Record is a paper booklet that patients can use to track their current medications, care plan, and emergency contacts. It empowers patients to prepare for physician appointments, set personal goals, manage their own care, and plan ahead. These tools were developed with clinical content experts and field tested with patients.

PROMISING PRACTICE To help manage the increasing volume in their social worker-led Telephonic Care Management program, Hoag Hospital's palliative care team includes a first-year master of social work (MSW) intern who makes routine follow-up phone calls with relatively stable patients. This gives the team's licensed clinical social worker more time to work with patients who have more critical needs, and provides palliative care training to new social workers.

Table 3. Examples of Follow-Up Visit Structures, by Setting

STRUCTURE	
Embedded clinic in oncology (multihospital, regional health system)	<p>Team sees patients wherever they are in the clinic: in the oncologist's office, in the infusion center while getting chemotherapy, or after radiation treatments. This practice helps the patient avoid extra appointments and travel.</p> <p>Team is available by pager for management of pain and symptom crises identified during oncology visits, and can usually see the patient before the patient leaves the medical center.</p> <p>Team huddles after initial consult to determine the most appropriate point person for follow-up. For example, if the patient's needs are mainly management of pain and other physical symptoms, the physician will follow up. For caregiver support, resources, or counseling, the social worker will follow up. For simple symptom re-evaluation, the nurse will follow up, and for patients with complex care needs, the team will follow up.</p> <p>Patients are usually seen two to four weeks after the initial visit; follow-up visits usually last 30 minutes. Patients can have joint visits with oncologists (e.g., if the patient requests clarification about prognosis). Advance care planning discussions take place with the nurse or social worker.</p>
Home-based (multihospital, regional health system)	<p>The nurse typically makes about six visits over a six-week period. The social worker visits within three weeks of the initial CBPC visit, and usually makes two visits. Service protocol requires that care goals are documented at the first visit and are addressed completely by the fourth visit. After the first six weeks, the team provides both case management by phone and in-person visits every four weeks. These program standards are tracked and reported.</p> <p>The team focuses on "anticipatory guidance" — helping patients and family members determine care plans based on expected disease progression. Nurses work with primary care providers or specialists on any symptom issues.</p>
Home-based (hospice)	<p>Team members can follow up with patients in person or by phone.</p> <p>Patients receive an average of four to five visits. Some patients are referred to hospice on the same day as their initial assessment; some remain in the palliative care program for a year. The average length of stay on the palliative care service is 5.5 months.</p>

Source: In-person meetings and webinars of the Palliative Care Action Community, 2013-14.

CASE STUDY

Palliative Care Center of Silicon Valley

Setting and Structure

The Palliative Care Center of Silicon Valley (PCCSV) in San Jose opened in 2013 as the first licensed community clinic in California specifically focused on palliative care. It is a division of Hospice of the Valley, a community-based, independent nonprofit hospice that operates at a separate location. PCCSV provides medical consultation, nursing, counseling, and care management services depending on the patient's needs and desires, and on the capacity and needs of the referring provider. A major amount of PCCSV's funding is provided by Hospice of the Valley, in addition to community philanthropic support

AT-A-GLANCE METRICS

Patients and Staffing

- **Patient population:** any patient with serious illness with unrelieved symptoms or illness progression; to date, 56% oncology; 19% Alzheimer's, dementia, or Parkinson's; 13% heart disease or pulmonary disease; 4% liver disease; 4% renal disease; 3% general decline in health
- **Primary referral sources:** patient/family (31%), physicians (23%), Hospice of the Valley (20%), hospitals (14%), social workers (11%); most physician referrals from oncology practices, followed by primary care providers
- **Unique outpatients per year:** 131
- **Outpatient encounters per year:** 233
- **Staffing (FTE):** 1.2 administration, 0.6 physician, 0.5 nurse practitioner, 0.6 licensed clinical social worker, volunteers (total of 2.9 FTEs)

Measuring Results

Impact Measures

- **Patient- and family-related:** function/acuity scores (Palliative Performance Scale); symptom assessments (Edmonton Symptom Management Scale); ratings of emotional and spiritual distress, unmet care needs, and family/caregiver stress (in-house tool)
- **Provider-related:** physician/referrer satisfaction scores

and reimbursement revenue generated by patient consultations.

The clinic operates five days per week, and the palliative care team provides a full spectrum of services, including assessing and addressing pain and other physical symptoms as well as psychosocial, emotional, and spiritual issues; discussing and documenting goals of care; counseling on and completing advance care planning documents; supporting family members (including support from volunteers); reconciling medications; and educating patients about their disease and prognosis.

Successes, Challenges, and Aspirations

PCCSV's palliative care team leaders include among their successes:

- Gaining community clinic licensure from the California Department of Public Health under strict regulatory requirements and standards
- Creating a full interdisciplinary team with physician, nurse practitioner, social worker, chaplain, administrators, and volunteers
- Increasing the number of self-referrals by patients and families due to extensive community outreach

Challenges, and approaches for managing them, include:

- **Late referrals.** The team is increasing education and outreach to the local medical community and general community to improve understanding of how palliative care can help patients earlier in their disease course.
- **Contracting.** Since the team is working on contracting with commercial insurance plans and independent practice associations (IPAs) with limited understanding of or experience with palliative care, the team is identifying the data and program information these potential partners need to move forward.

PCCSV's long-term goal is to become a replicable model for hospices to provide outpatient palliative care services in their communities.

Teamwork

This section describes how CBPC teams can be staffed. It includes results from surveys of PCAC teams that asked about discipline representation, staffing levels, and volume of patients served. These survey results are provided as examples of staffing and volume at reporting PCAC sites; they are not presented as ideal staffing allocations or volume for CBPC services.

Who Is Part of the Team?

The staff composition of community-based palliative care teams varies widely (see Table 4). Some organizations launch their CBPC services with providers from a single clinical discipline, typically a physician or advanced practice nurse, and then work to incorporate other disciplines as resources allow. Other organizations are able to staff an interdisciplinary team from the launch of their programs. Such teams typically include combinations of the following disciplines: physicians, advanced practice providers (nurse practitioners, clinical nurse specialists, or physician assistants), registered nurses, social workers, and chaplains. Some teams have regular or occasional access to certain specialists, such as psychiatrists or psychologists, nutritionists, and pharmacists, or may seek the services of affiliated (e.g., hospital- or hospice-based) social workers or chaplains, if these disciplines are not represented on the core team. Some teams use volunteers to help support patients and families.

According to surveys of PCAC members, the staff compositions of their CBPC teams varied significantly and have become more interdisciplinary over the course of the one-year project.

From Concept to Practice: PCAC Member Approaches

PROMISING PRACTICE At Olive View–UCLA Medical Center, a psychosomatic fellow from the psychiatry department participates in palliative care clinic sessions to provide counseling, to support conversations on care goals, and to provide mental health interventions as indicated. Team members report that the fellow's participation is "enormously helpful," as it frees the medical provider to attend to physical and symptom issues. Also, some patients who are reluctant to discuss psychosocial issues with their medical provider may feel more comfortable speaking about such issues with the fellow. In these cases, the medical provider and fellow work together to develop a care plan for the patient.

PROMISING PRACTICE The Palliative Care Center of Silicon Valley, a division of Hospice of the Valley, has integrated their hospice volunteer program, Transitions, into their CBPC program to offer support services to palliative care patients at home. The services include practical help around the house, breaks for caregivers, emotional support, and complementary therapies such as massage and music therapy. A screening tool helps identify patient needs.

Table 4. Staff Composition of PCAC CBPC Teams, by Setting

	CLINIC		HOME-BASED		DISTANCE	
	2013 (n=8)	2014 (n=11)	2013 (n=11)	2014 (n=10)	2013 (n=5)	2014 (n=5)
Physician	78%	100%	82%	70%	60%	20%
Advanced practice nurse	44%	55%	55%	50%	40%	20%
Registered nurse	33%	45%	45%	50%	60%	60%
Social worker/case manager/care coordinator	56%	55%	64%	80%	80%	100%
Chaplain	0%	18%	18%	30%	20%	0%
Psychologist/licensed clinical social worker	0%	45%	0%	0%	0%	0%
>1 discipline on team	67%	82%	82%	90%	80%	80%

Source: Surveys of Palliative Care Action Community members, 2013 and 2014.

How Many Staff Make Up the Team?

Just as staff composition varies widely, so does the allocation of full-time equivalents (FTEs) on each team. Staffing allocations and team composition influence the number of clinic sessions, home visits, and phone contacts that the team can make; wait times for those visits; visit length; space needs; and the types of services and support available to patients and their family members. PCAC members reported varying FTEs for each discipline and varying numbers of encounters annually.

Clinic Programs

All 11 reporting PCAC outpatient clinics include a physician, with a median FTE of 0.25 (see Table 5). About half of these clinics have APN/PA providers, with a median allocation of 0.33 FTE. The teams in these clinics have a median of 0.9 FTE clinical providers all together — or just less than 1.0 FTE across a combination of six disciplines. The maximum total FTE allocation reported is 3.5; the minimum is 0.25.

Table 5. CBPC Clinic Staffing Among PCAC Members
*FTE Allocation, by Discipline**

	MIN	MEDIAN	MAX
MD/DO (n=11)	0.10	0.25	1.20
APN/PA (n=6)	0.08	0.33	1.00
SW/CM/CC (n=6)	0.10	0.26	0.50
RN (n=5)	0.10	0.30	1.00
Psychologist/LCSW (n=5)	0.20	0.50	1.00
Chaplain (n=2)	0.10	0.25	0.40
Total FTEs (n=11)	0.25	0.90	3.50

*Of those reporting some FTE for that discipline, excluding those who reported 0% FTE.

Note: See page 4 for abbreviation definitions.

Source: Survey of Palliative Care Action Community members, 2014.

The volume of patients seen in palliative care clinics among reporting PCAC members is relatively small, with an annual median volume of 76 unique patients, who are seen a median of 3.8 times each (see Table 6).

Table 6. CBPC Clinic Volume Among PCAC Members
Annual Metrics

	MIN	MEDIAN	MAX
Visits (n=8)	60	167	1,220
Unique patients (n=8)	24	76	412
Visits per patient (n=7)	1.50	3.80	5.31

Source: Survey of Palliative Care Action Community members, 2014.

Other published literature also shows wide variation in staffing by discipline, patient load, and number of clinic sessions per week in a small number of outpatient palliative care clinic practices.⁴⁻⁶

Home-Based Programs

Ten PCAC members operating home-based palliative care programs reported their staffing allocations. The most commonly staffed position (80% of reporting programs) was SW/CM/CC (see Table 7). Of all disciplines, the RN role, used in five programs, has the greatest FTE count (median of 3.0 FTE). The median total FTEs reported for home-based programs was 2.23 — more than double the median total FTEs reported for the outpatient clinics (0.9 FTE).

Table 7. CBPC Home-Based Program Staffing Among PCAC Members, FTE Allocation, by Discipline*

	MIN	MEDIAN	MAX
SW/CM/CC (n=8)	0.25	0.55	6.00
MD/DO (n=6)	0.05	0.38	1.50
APN/PA (n=5)	0.25	1.00	2.00
RN (n=5)	0.80	3.00	13.10
Chaplain (n=3)	0.20	0.25	0.45
Other (n=1)	2.50	2.50	2.50
Total FTEs (n=10)	0.50	2.23	19.35

*Of those reporting some FTE for that discipline, excluding those who reported 0% FTE.

Note: See page 4 for abbreviation definitions.

Source: Survey of Palliative Care Action Community members, 2014.

The patient volumes reported by home-based programs varied widely. The median number of visits per patient

(7.9) is about twice that of the outpatient clinics (3.8). See Table 8 for details.

Table 8. CBPC Home-Based Volume Among PCAC Members, Annual Metrics

	MIN	MEDIAN	MAX
Visits (n=5)	60	1,479	9,168
Unique patients (n=5)	37	424	520
Visits per patient (n=3)	2.85	7.88	21.62

Source: Survey of Palliative Care Action Community members, 2014.

Distance Programs

Of the eight PCAC members operating phone-based distance palliative care programs, five shared data on staffing and patient volume.⁷

All five programs use SW/CM/CC roles, with a median of 0.2 FTE (see Table 9). Three of the five programs have an RN on staff, one has an MD/DO, and one has an APN/PA. The median total FTEs (0.4) for these programs is about half that of the outpatient clinics (median of 0.9 FTE), and significantly less than the median FTE for home-based programs (2.23 FTE).

Table 9. CBPC Distance Program Staffing Among PCAC Members, FTE Allocation, by Discipline*

	MIN	MEDIAN	MAX
SW/CM/CC (n=5)	0.10	0.20	1.50
RN (n=3)	0.10	0.15	11.00
MD/DO (n=1)	0.10	0.10	0.10
APN/PA (n=1)	0.10	0.10	0.10
Other (n=1)	0.10	0.10	0.10
Total FTEs (n=5)	0.25	0.40	12.50

*Of those reporting some FTE for that discipline, excluding those who reported 0% FTE.

Note: See page 4 for abbreviation definitions.

Source: Survey of Palliative Care Action Community members, 2014.

The patient volumes for distance programs reported by PCAC members also varied widely. The fewest number of unique patients seen was 20, and the most was reported

to be 1,132. The median number of encounters (calls) per patient was just over five (see Table 10).

Table 10. CBPC Distance Program Volume Among PCAC Members, Annual Metrics

	MIN	MEDIAN	MAX
Encounters (n=4)	30	1,288	9,944
Unique patients (n=3)	20	310	1,132
Encounters per patient (n=3)	1.50	5.03	8.78

Source: Survey of Palliative Care Action Community members, 2014.

Can Different Palliative Care Services Share Staff?

Some organizations have dedicated outpatient palliative care teams that only see patients in a clinic or in the patient's residence, while others share staff between their inpatient and outpatient palliative care services. The choice to share staff between services or to develop separate staff for each service can depend on staffing resources, such as funding or the availability of qualified staff, as well as the organization's goals for hours of service in each setting. Having separate staff can increase the availability of services in each setting, but having shared staff can improve care continuity for patients as they transition between settings.

From Concept to Practice: PCAC Member Approaches

One team provides inpatient and outpatient palliative care services using shared resources and staff. The same physicians and nurses provide care in both settings but are assigned to one setting per day. Social workers, meanwhile, tend to work in only one setting or the other. An attending physician is identified each day for each setting. According to this team, the advantage of this model for patients is the continuity of seeing the same providers both as inpatients and as outpatients. This model also enables physicians to easily cover for each other. One challenge is if a patient prefers to see one provider over time, instead of a different provider depending on the day. For these patients, providers communicate with each other, and the patient's preferred provider follows up with the patient, even on off-service days.

What If Patients Need Help Outside of Service Hours?

Teams' availability during non-service hours varies. Some PCAC outpatient services operate one or several half-day clinics per week and are available by phone for issues that need to be addressed outside of clinic hours. Others provide services from 8:00 AM to 5:00 PM, Monday through Friday, and partner with other entities, such as primary care, for night and weekend coverage. Round-the-clock availability is viewed by many PCAC teams as desirable and is aligned with national quality standards for palliative care, but this level of availability is uncommon.

From Concept to Practice: PCAC Member Approaches

PROMISING PRACTICE Palliative Partners' MyDoc^{Anytime} Program is available to patients 24 hours a day, 7 days a week. They believe this availability establishes and reinforces trust between the patient and the care team, helps patients understand that the program is dedicated to them, and lets patients know that there is a reliable, available resource, beyond the emergency department, supporting their medical needs.

How and Where Do Team Members Communicate with Each Other?

One key benefit of interdisciplinary teams is the unique skills and perspectives that each team member brings to the group. In addition to sharing information through electronic medical records, many teams have regular interdisciplinary team meetings to discuss cases, to address operational or interpersonal issues, and to promote team wellness in a field that can be stressful and emotionally taxing. The frequency of these meetings varies from biweekly, to weekly, or to multiple times a week.

Depending on the structure of the service, teams may not have their own dedicated workspace. This can present practical challenges, like where to meet or do documentation, but can also help the team get to know referring and collaborating care providers by sharing their work areas.

From Concept to Practice: PCAC Member Approaches

One team functions as a virtual clinic. Without dedicated clinic space, team members meet with patients where it is most convenient for the patient, and they meet with each other in hallways and in other shared spaces. They share workspace with other specialists, which helps the palliative care team get to know other clinicians and supports the team's goal of being integrated into usual care across their system, rather than functioning as a stand-alone service.

PROMISING PRACTICE At UCSF, weekly palliative care team meetings include a focus on team wellness, including opening each meeting with a poem and closing with members expressing gratitude for something in their personal or professional lives. This team also holds special meetings, including one during which a palliative care patient with a long history of metastatic breast cancer shared some of her personal writings and reflections with the group.

What Kind of Training Is Useful?

Many PCAC members reported difficulty finding experienced staff members. Some invest substantial time and resources into training new staff in palliative care skills or clinical skills specific to their patient population. These trainings focus on techniques for managing pain and other common symptoms such as dyspnea, anxiety, and depression; communication skills; effective documentation in the patient chart; when to connect patients to community resources; working effectively on an interdisciplinary team; and standard treatment approaches for the diseases most commonly seen by the palliative care service. While some of these topics can be addressed with new palliative care staff soon after they are hired, others may be more appropriate as ongoing training for the entire team. Even providers with experience in related settings, such as hospice, may benefit from training.

From Concept to Practice: PCAC Member Approaches

One team that relies on APNs to deliver much of their inpatient and outpatient palliative care has found that several months of intense training, modeling, and communication coaching helps new APNs become highly skilled team members. The site has developed a training program that includes interpersonal communication

scripts and practice drills to help participants build intuitive skills, comfort with helpful language and opening statements (e.g., “I wish” statements, such as “I wish we had more options to offer you”), and exercises to help patients make sense of what they’re going through, such as “naming the emotion.”

PROMISING PRACTICE Partners in Care of El Dorado County emphasizes client-focused approaches by training interdisciplinary team members in the art of trust building and mindful presence with clients. Team members also receive ongoing training to identify and set aside personal preferences and biases that might influence their ability to effectively hear client needs as they are developing and addressing goals of care.

California State University Institute for Palliative Care

One organization working to address the shortage of skilled palliative care staff and improve the palliative care skills of California’s clinical workforce is the California State University Institute for Palliative Care (www.csupalliativecare.org). Through online courses for professionals, classroom and clinical fellowship programs, and certificate programs, the institute is strengthening the pipeline of palliative care professionals in California.

CHCF collaborated with the institute to develop an interdisciplinary online training course, “Excellence in Interprofessional Palliative Care Documentation.” This course teaches participants to:

- ▶ Efficiently and accurately extract and document the most pertinent information about complex cases
- ▶ Communicate information and the perspective of their own discipline in a way that other disciplines can understand and use
- ▶ Implement best practice documentation templates
- ▶ Document in a way that meets standards for reimbursement

To take the online course, visit www.csupalliativecare.org/programs/documentation.

Partnering with Other Care Providers

This section describes the critical role of partnerships between CBPC teams and other care providers. It describes different approaches to building and strengthening relationships with referring providers, how teams work with referring providers to learn about the patient and to provide services that are most useful to the patient and the provider, and ideas for creating productive, collaborative relationships with referring providers who have a range of experiences with and openness to palliative care.

Why Is It Important for CBPC Teams to Partner with Other Providers?

As a specialty service called in to address specific needs of patients with complex illnesses, CBPC teams need to cultivate strong partnerships with referring providers and other clinicians or services involved in the patient’s care. These partnerships help the palliative care team to:

- ▶ Ensure appropriate patient referrals
- ▶ Gain a full clinical picture of the patient and understand what the primary provider has or has not addressed regarding disease trajectory or goals of care
- ▶ Support a positive care experience for the patient

These partnerships can look different depending on whether the palliative care service assumes the primary caregiver role, or is a consult or co-management service, since each of these models places different levels of responsibility on the CBPC team. Whatever the structure, many CBPC services aim to build relationships with referring providers or other referral sources to raise awareness about palliative care services, communicate with providers before and after engaging with the referred patient, and support skill building among referring providers so they can deliver some primary palliative care services themselves.

How Do Teams Build Partnerships with Other Providers?

A variety of approaches have been used by PCAC teams to build and strengthen relationships with providers, including:

- ▶ Providing educational programs within the organization to expand awareness of palliative care and advance care planning
- ▶ Developing evidence-based educational resources to help physicians and other providers, such as case managers, understand the impact of palliative care and when palliative care can be especially helpful
- ▶ Calling or making face-to-face visits to community physicians
- ▶ Conducting outreach and education programs at community entities that may provide referrals, such as nursing homes, community hospitals, or community centers

From Concept to Practice:

PCAC Member Approaches

PROMISING PRACTICE At Optum Palliative and Hospice Care, physicians and nurse practitioners attend five to six monthly patient care conferences in primary care clinics to discuss difficult cases and to offer palliative care home visits for appropriate patients. The team has observed an increase in referrals to palliative care that they attribute to this practice, and believes that the combination of teaching about palliative care, setting up specific criteria for referrals, and providing personal support and encouragement is highly effective.

PROMISING PRACTICE At Hoag Hospital, the outpatient palliative care social worker conducts educational programs for staff at area skilled nursing facilities (SNFs) on primary palliative care techniques and completion and interpretation of Physician Orders for Life-Sustaining Treatment (POLST) forms. Their goal is to empower SNF colleagues to practice primary palliative care and to assist patients with defining their goals of care.

PROMISING PRACTICE To improve staff awareness of the importance of advance care planning (ACP) across their organization, Sharp HealthCare has instituted an education and outreach program called “Lead by Example.”

This program encourages all Sharp employees to begin the advance care planning process and consider completing an advance health care directive. The initiative includes a pre-education survey, an in-person educational presentation on advance care planning and key considerations, a post-education survey, and an offer of one-on-one advance care planning consultation with a trained facilitator.

How Can Teams Support Appropriate Referrals?

Some PCAC members are standardizing and centralizing the referral process by collecting consistent information and establishing common standards for referrals. This consistency helps the palliative care team understand what kind of support is needed by the patient and provider and what conversations have or have not already taken place. It also helps the team assess referral trends, such as which providers are referring most frequently and why patients are being referred. Such information can help teams determine if their referral criteria and processes are identifying the most appropriate patients.

From Concept to Practice:

PCAC Member Approaches

One team maintains a centralized referral process through their electronic medical record that allows any provider, physician or nonphysician, to make a referral to their service. This open process makes it easy for providers to make palliative care referrals. Specific exclusion criteria in the system offer guidance to providers to help minimize inappropriate referrals, such as patients with uncontrolled psychiatric disorders, chronic pain, or active substance abuse.

PROMISING PRACTICE The palliative care clinic in the cancer center at Stanford Health Care updated their referral process to gather information with more consistency. Previously, their electronic medical record’s referral tool was freeform, and the palliative care team found that they often did not have enough information about referred patients and that patients themselves were sometimes unaware of the referral. To address these gaps, the referral form now has several required fields:

- ▶ Reason for referral (with predetermined dropdown options, including “Other”)
- ▶ Is patient aware of referral to Palliative Care?

- Consultation timing preference —
“Joint initial consultation with oncologist?”
- Urgency of appointment

After the Referral, What Are Some First Steps in Working with Other Providers?

Once a referral has been made, the CBPC team can contact the referring provider before the patient’s first visit to learn:

- What the provider sees as the patient’s disease trajectory, prognosis, and appropriate next treatments
- What the provider has already discussed with the patient about the disease trajectory, prognosis, and the patient’s goals of care
- How the patient and family members are coping
- Other relevant family dynamics or psychosocial issues
- Why the provider is referring to palliative care and what outcome they are looking for

These discussions can clarify how the palliative care team can be most helpful in supporting the patient, in concert with the primary provider, and are also an opportunity to educate the primary provider about palliative care principles. PCAC teams have described asking what the primary provider realistically thinks is achievable in terms of disease-modifying goals, and whether that has been conveyed to the patient. As relationships are strengthened, team members can ask referring providers direct questions, such as, “What is your best-case scenario for this patient?” or “Do you think that is a realistic goal for the patient?” or “What do you see as the benefit of that approach?” Ideally, these questions about benefits and best-case scenarios become internalized by primary providers and enable them to have more effective conversations with patients about care plans and goals.

From Concept to Practice: PCAC Member Approaches

One team provides palliative care in a clinic colocated in oncology. When the team receives a referral, they talk with the oncologist about the reason for the referral and how the service can help the provider. For example,

should the CBPC team focus on symptom management, goals of care, or family dynamics? After a consult, the CBPC team goes back to the referring provider to describe the initial meeting and ask if the provider’s expectations have been met. The team emphasizes that they are there to support the providers as well as patients and family members.

Another team always tries to have the primary care provider or oncologist present during a discussion on goals of care to answer the patient’s questions and to ensure that the patient is hearing the same messages from their primary provider and the palliative care team. If the provider can stay only for the first 10 minutes of the meeting, the team will target the discussion and questions to the provider during that time.

PROMISING PRACTICE At Kaiser Permanente’s Santa Clara Medical Center, palliative care services for cancer patients are embedded in the oncology department, allowing patients to have a joint visit with the palliative care physician and their oncologist. This embedded model fosters more seamless, coordinated, comprehensive care than if the palliative care services were brought in from outside the department. Joint visits also help ensure that a patient’s care goals are well understood by all providers, which can be challenging for patients with complex care needs.

How Can Programs Be Responsive to Referring Providers and Not Overwhelm Their Service?

Palliative care services may want to be responsive to referring providers by being available for quick consults or assessments. At the same time, these programs need to keep their referral numbers in line with their team’s capacity and to stay focused on the complex cases that can benefit the most from specialty palliative care. Strategies some PCAC teams have used to address this tension include:

- Ask the primary provider whether they have discussed disease trajectory and goals with the patient, and if not, capitalize on this teaching moment to help build the provider’s skills to do so.
- Address the specific issue that generated the referral, and then ask the primary provider to share

their expectations and to resume ongoing management of the patient's needs.

- ▶ Train referring colleagues on basic primary palliative care skills, such as having discussions about goals of care and basic symptom management, to reserve specialty services for more complex cases.

From Concept to Practice: PCAC Member Approaches

PROMISING PRACTICE When Stanford Health Care's palliative care team realized that they could not support all of the patients who needed palliative care, they focused on developing the primary palliative care skills of the organization's social work staff. All outpatient clinic social workers are being trained in communication techniques to have advance care planning discussions with patients. The team started by training social work leaders, who are then training their direct reports. This training will be required for all Stanford social workers, and similar plans are underway for nurse case managers.

How Can Teams Address Resistance from Potential Referral Sources?

Some reasons providers may be reluctant to refer to palliative care include:

- ▶ The provider fears that the palliative care service will take over the patient's care and that they will lose their patient.
- ▶ They do not have a good understanding about what palliative care is (i.e., equating palliative care with hospice or end-of-life care) and how it can support their patient and themselves.
- ▶ They believe that they already do a good job of providing palliative care.
- ▶ They feel that the patient is not ready for palliative care.

From Concept to Practice: PCAC Member Approaches

When dealing with resistance from potential referral sources, efforts at relationship building and education may be useful. Some strategies used to build interest in and acceptance of palliative care services are shown in Table 11 (page 20).

What Do Teams Do When They Disagree with the Referring Provider's Approach?

There may be challenging cases in which referring providers have not addressed disease severity with the patient and family, or have advocated for aggressive treatment, and are looking to the palliative care team to have the difficult discussions they are unwilling or unable to have themselves.

In these situations, PCAC members offer the following advice: Respect what referring providers have told the patient, even if the palliative care team disagrees with the approach, and work from there. For example, a referring provider may paint a more optimistic picture of the potential effectiveness of a third- or fourth-line chemotherapy treatment than the palliative care team believes is warranted. While the palliative care team may not agree with the information given to the patient by the referring provider, the team can still effectively support the patient in his or her current state of mind and health status.

Table 11. Strategies to Build Interest in Palliative Care Services

EXAMPLES	
Start with a subset of providers and their patients who may be more open to palliative care.	<ul style="list-style-type: none"> ▶ A CBPC program for cancer patients started by working with their organization's Women's Cancer Center, where the typical patient is young and has a family, and therefore is dealing with significant psychosocial issues related to their diagnosis. The palliative care team focused on those social/emotional issues, allowing the oncologists to focus on treating the disease. Once the oncologists saw what the palliative care team could offer them and their patients, they became more apt to provide referrals. Other groups within oncology followed suit. ▶ Another CBPC team started by assisting their gynecology/urology oncologists with their patients' pain. Making the oncologists' work easier was the team's biggest selling point. The team started marketing their service as solving other providers' "biggest headaches." The palliative care service also benefitted from a sibling rivalry effect, where other subspecialists saw the services and resources palliative care patients were getting, and wanted those services for their own patients.
Look for opportunities where palliative care could improve their patients' clinical experience.	<ul style="list-style-type: none"> ▶ Work with providers to examine the average pain scores of a subset of patients to help motivate referrals to palliative care. ▶ Collaboratively identify clinical triggers (e.g., pain scores above a certain threshold) that would generate automatic referrals to palliative care.
Look for opportunities where palliative care could improve patients' overall care experience.	<ul style="list-style-type: none"> ▶ Examine patient satisfaction scores on communication and patient involvement in decisionmaking and identify those provider groups for which scores could be improved. Partner with that group to identify which circumstances might warrant a referral to palliative care for more focused discussion of goals and to ensure that patients feel heard.
Develop core messages describing the value of palliative care and how it is different from hospice.	<ul style="list-style-type: none"> ▶ Emphasize two or three compelling reasons for providers to refer to palliative care (e.g., better symptom control, evidence of patients living longer, relationship to other organizational priorities such as reducing readmissions and creating medical homes) and how palliative care can make the referring provider's life easier (e.g., by assisting with complex social and emotional issues). ▶ Develop a succinct description of palliative care to distinguish it from hospice, such as the Center to Advance Palliative Care definition on page 4, "an extra layer of support for you and your patient," or "medically appropriate goal-setting, best symptom management, and honest and open communication."⁸

Source: In-person meetings and webinars of the Palliative Care Action Community, 2013-14.

Coordination and Transitions

This section describes the importance of CBPC teams coordinating with related programs in their organization to streamline patient care and to ensure that services are complementary and not competitive or duplicative. It also describes strategies that PCAC teams have found useful in partnering with primary providers and hospice programs when palliative care patients are ready for these transitions.

How Do Teams Partner with Related Services?

Many CBPC programs are part of organizations with programs or departments that deliver related or overlapping services, such as complex case management, disease-specific nurse case management, disease-specific or setting-specific social worker support, and home care programs. Thoughtful coordination between palliative care and these services can help prevent confusion or redundancy for patients, and can mitigate potential turf issues or political challenges. CBPC program leaders should have a solid understanding of the complementary programs in their organization, what they do, and how palliative care can fill existing gaps.

From Concept to Practice: PCAC Member Approaches

To help differentiate their services from those of other departments, one team talks to their system's stakeholders about the three core roles of palliative care: (1) ensuring that the actual care received aligns with care goals, (2) controlling pain and symptoms, and (3) coordinating care. In some systems, it may make sense to cede the care coordination role to other providers, such as complex case managers, but the other two roles are where the palliative care team adds value even when other complementary services exist.

A team colocated in the oncology department emphasizes that good communication among all providers caring for a patient is needed to clarify roles and responsibilities

when oncology and palliative care teams are collaborating. This helps prevent confusion for the patient (e.g., "Who do I go to for what?") and resentment between providers. Palliative care team members can explicitly ask their counterparts what they need and how palliative care can help make their lives easier, instead of assuming what their respective roles should be.

What Happens When Patients No Longer Need Palliative Care?

Some patients are referred to palliative care to focus on a specific issue — such as unresolved pain or a challenging family situation — and once that issue is resolved, the patient no longer needs specialty palliative care. In those cases, palliative care teams can work with the patient and primary provider to transition the patient from the palliative care service back to usual care with their primary provider. In these circumstances, good communication is essential to reassure the patient that the palliative care service will be available if other needs arise, and to ensure that the primary provider understands and is supportive of any preferences the patient has expressed about their treatment goals.

How Can Teams Help with Transitions to Hospice?

When patients who are receiving CBPC are clinically and emotionally ready for hospice care, the palliative care team can assist with that transition.

From Concept to Practice: PCAC Member Approaches

Teams have used a variety of approaches to address the challenges that can arise in this phase (see Table 12 on page 22).

Table 12. Addressing Challenges to Transitioning from Palliative Care to Hospice Care

SAMPLE APPROACHES	
Patient feels attached to the CBPC team and resists the idea of transitioning to new caregivers.	<ul style="list-style-type: none"> ➤ Explain that the CBPC program is not equipped to provide all the services that hospice offers. Reassure patients that they will be getting the care they need. ➤ Ensure that in the hand-off to the hospice nurse, the CBPC nurse provides detailed information on the patient and family, and the patient sees the connection and communication between these providers. ➤ To provide continuity of care for the patient, some CBPC team physicians can remain the attending physician for a patient's hospice care. ➤ The CBPC social worker can continue to follow up with patients who had a relationship with the team (i.e., more than one palliative care visit before hospice referral). ➤ Without billing, allow patients to come back to the palliative care clinic, or for a team member to do home or phone visits, to make sure patients' needs are being met. ➤ Let the patient know that the palliative care team is still available. Set a regular time to call the patient to check in.
Team member has a hard time letting go of a patient.	<ul style="list-style-type: none"> ➤ Make sure team members support each other during these transitions. Remind each other of the program's goals and that there are other patients who will benefit from palliative care services.
Team uncertain of the quality of some hospices in their area.	<ul style="list-style-type: none"> ➤ Have the hospice medical director meet with CBPC staff to describe the care philosophy of the agency, standard services that any patient can expect to receive, and special services that are particular to that hospice, such as expertise with particular patient populations. ➤ Before enrollment in hospice, have the team educate the patient about the services they should expect, and tell the patient to call if they are not getting these services. Make sure patients understand their rights under the hospice benefit (e.g., right to pain relief, round-the-clock availability, right to revoke hospice at any time). ➤ Continue communication with the patient after enrollment in hospice to ensure appropriate care is received. If hospice care is substandard, help get the patient discharged and enrolled in another hospice. ➤ Continually evaluate the hospice referral list and remove those that are not performing well. ➤ Ask hospices for monthly reports of the number of patients the palliative care service has referred to them, number admitted, and length of service, along with regular reports of satisfaction scores and other measures of care quality.

Source: In-person meetings and webinars of the Palliative Care Action Community, 2013-14.

CASE STUDY

Hoag Hospital

Setting and Structure

Hoag Hospital is a nonprofit community hospital with two locations, in Newport Beach and Irvine, California. Building on their inpatient palliative care program, in 2012 Hoag launched a symptom management clinic in oncology led by a clinical nurse specialist, as well as a phone-based care management program led by a licensed clinical social worker. In 2013, Hoag launched a physician-led outpatient palliative care clinic. Palliative care is a stand-alone department with oversight from Hoag Family Cancer Institute. The team co-manages patients with the referring provider or other care providers. About 20% of their costs are covered by physician billing and 80% by the hospital.

Palliative care services are available through the physician clinic two half-days per week, the nurse-led oncology symptom management clinic three days per week, and the social worker-led phone case management program five days per week.

AT-A-GLANCE METRICS

Patients and Staffing

- **Patient population:** any patient with an estimated life expectancy of 12 months or less
- **Primary referral sources:** inpatient palliative care program, oncologists, oncology nurses
- **Unique outpatients per year:** 334
- **Outpatient encounters per year:** 1,654
- **Staffing (FTE):** 0.1 physician, 0.4 clinical nurse specialist, 1.0 licensed clinical social worker (total of 1.5 FTEs)

Measuring Results

Impact Measures

- **Patient-related:** results from patients' self-report of pain and symptoms (currently collected and monitored at individual level only)
- **Financial:** PCAC Supportive Care Calculator results (see page 27)

The palliative care team provides a full spectrum of services, including assessing and addressing pain and other physical symptoms as well as psychosocial, emotional, and spiritual issues; discussing and documenting goals of care; counseling on and completing advance care planning documents; supporting family members; reconciling medications; and educating patients about their disease and prognosis.

Successes, Challenges, and Aspirations

Hoag's palliative care team leaders include these among their successes:

- Patients choosing to access their outpatient services and returning for ongoing care
- Expansion of their referral base from the inpatient palliative care program to outpatient oncologists
- Collaboration with a key oncology practice to establish goals to consistently integrate outpatient palliative care for their patients

Challenges, and approaches for managing them, include:

- **Staffing.** The team is working to show the program's financial benefit to secure funding for additional staff.
- **Data capture.** The team is moving from paper-based data entry to an electronic medical record for outpatients, to improve the efficiency of data collection.
- **Tracking.** The team is working with their information technology department to create a notification system that alerts the palliative care team when their patients are hospitalized.

In the future, the team would like to integrate their services throughout the course of illness for patients with cancer, increase staffing to a half-time physician for the clinic, and integrate the palliative care social worker more fully into clinic visits.

Measuring Opportunities and Impact

Why Is It Important to Measure Impact?

Offering palliative care in a variety of settings has been shown to improve outcomes for people with serious illness and for their family members.⁹ Improved outcomes (e.g., better symptom control, more clarity on goals of care) can manifest as avoided health crises, increased capacity to receive care safely in the home, and improved planning of further care. Offering palliative care in different settings has also led to the reduction in use of costly health services such as hospital admissions and emergency department visits, and to the increase in use of other services such as home-based care and hospice care. These changes in type and setting of care result in lower overall health care costs. Quantifying the use and fiscal impacts of CBPC services is the foundation of the business case for CBPC, and also helps programs identify and prioritize opportunities for expansion.

How Can Teams Measure the Impact of Their Programs?

Understanding how patients interact with the health care system in their final months of life offers programs useful information about care quality, drivers of care costs, and the influence of CBPC on both quality and cost of care. A retrospective analysis — starting from the date of death and looking back — is one way to assess these impacts.

The Community-Based Palliative Care Opportunity Analysis was developed with support from the California HealthCare Foundation to help CBPC programs retrospectively assess utilization patterns in the final 6 to 12 months of life for patients with serious illnesses.

Which Measures Are Tracked by the Opportunity Analysis?

The analysis tracks several National Quality Forum (NQF) measures of care quality at the end of life, and other measures of quality and efficiency, such as:

- ▶ Frequency of emergency department visits
- ▶ Frequency, duration, and intensity of hospitalizations
- ▶ Number of 30-day readmissions

- ▶ Number of in-hospital deaths and deaths within 30 days of hospitalization
- ▶ Number of clinic visits (and use of other outpatient and home-based services)
- ▶ Use and timing of specialist palliative care (including inpatient)
- ▶ Use and timing of hospice
- ▶ Fiscal outcomes such as costs, contribution margin, and net margin for inpatient care

The analysis results can be used to compare outcomes for patients who received specialized palliative care with those who did not, or to look at differences in outcomes relative to the timing of initial contact with palliative care services (e.g., early versus late in the disease course).

Which Patient Populations Can Be Examined with the Opportunity Analysis?

The analysis focuses on patients with seven chronic, life-limiting diseases:

- ▶ Cancer
- ▶ Congestive heart failure (CHF)
- ▶ Chronic obstructive pulmonary disease (COPD)
- ▶ Acquired immune deficiency syndrome/human immunodeficiency virus (AIDS/HIV)
- ▶ End stage renal disease (ESRD)
- ▶ Neurological conditions (including dementia)
- ▶ Cirrhosis/liver failure

Outcomes could be developed for all or a subset of these groups, as dictated by the needs and preferences of the CBPC service. Other patient groups could also be identified and analyzed, such as frail elderly patients who do not have one of these diseases.

What Types of Data Are Needed to Conduct the Opportunity Analysis?

The analysis uses three types of data:

- 1. Data that identify a population of decedents.** These data are available from various sources, including the Social Security Administration's Death Master File (DMF), death records maintained by state or county public health offices, the National Death Index, or, for cancer patients only, data from a hospital or health

system cancer registry. Although accessing an external source to identify the population of decedents takes time and effort and, in some cases, costs money, it is the only way to expand the analysis beyond patients who die in the hospital. Because the majority of patients die in settings outside the hospital, these additional data sources are important.

2. **Claims and administrative data.** This includes data describing patients (for example, age, primary payer, and diagnoses), and data describing contacts with the health system, which are needed to assess utilization and fiscal outcomes. The health system encounter data include information describing hospital admissions and emergency department visits, but also might include data describing clinic visits, home health visits, or hospice services, depending on the scope of services offered by a given system. These data are available from hospitals, health systems, or from payers, which have more complete data than the other two sources.
3. **Data on use of specialty palliative care.** If specialty palliative care use data are not included in the health system's administrative database, which is often the case, then they may be obtained from the palliative care program. These data are needed to identify the baseline penetration of existing specialty palliative care services, including the interval between first contact with a specialty care service provider and death.

What Is the Process for This Analysis?

Because the opportunity analysis requires accessing and combining data from multiple sources, CBPC teams will need help from fiscal or data professionals within their organizations to complete the analytic work. In general, the process is as follows:

1. Identify a population of decedents.
2. Focus on disease groups that are progressive and life-limiting, such as cancer, CHF, COPD, HIV, ESRD, neurodegenerative diseases, cirrhosis/liver failure (or a subset of those conditions).
3. Exclude cases that have atypical utilization patterns, such as patients who had admissions for trauma or transplant within six months of death.
4. Analyze the last 6 to 12 months of utilization for these patients, in reference to NQF-endorsed quality metrics and other measures of quality, performance, and costs.

5. Analyze the status quo for palliative care: How much is being done today? What more could be done, or earlier? How do outcomes differ between groups?

How Have Programs Used Results from Opportunity Analysis?

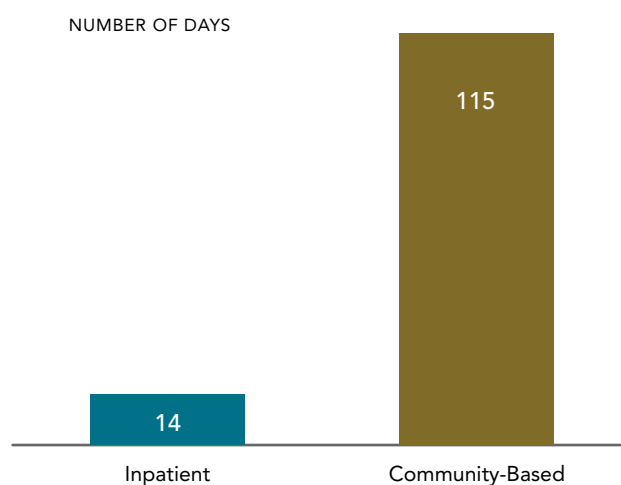
Opportunity analysis results can be used to tell the story of how many patients might benefit from palliative care, and how many (or few) such patients are currently receiving palliative care. PCAC teams have used the data generated from the analysis to inform discussions with their health systems about staffing and funding needs, to quantify the impact of their services, and to support partnership development work, such as negotiations with a medical group for a planned accountable care organization (ACO).

From Concept to Practice: PCAC Member Approaches

One PCAC team used data on utilization patterns among cancer patients cared for at their site to make a case with clinical and administrative leaders about the benefits of early access to palliative care. This site, which has robust inpatient and clinic-based PC services, developed a set of simple graphics to make their case.

First they showed that CBPC is typically offered earlier in the disease course (see Figure 1).

Figure 1. Number of Days Between First Palliative Care Visit and Death, by Type of Program



Source: Results of opportunity analysis conducted by PCAC member.

Next they demonstrated that providing earlier palliative care is associated with better quality outcomes (see Figure 2).

Finally they used the data to highlight the fiscal implications of the reduction in use of inpatient and emergency services that is a predictable result of offering CBPC (see Figure 3). Data describing the impact of CBPC on overall health expenditures can support a planned partnership with a local payer to develop payment mechanisms that will help to make CBPC available to more patients.

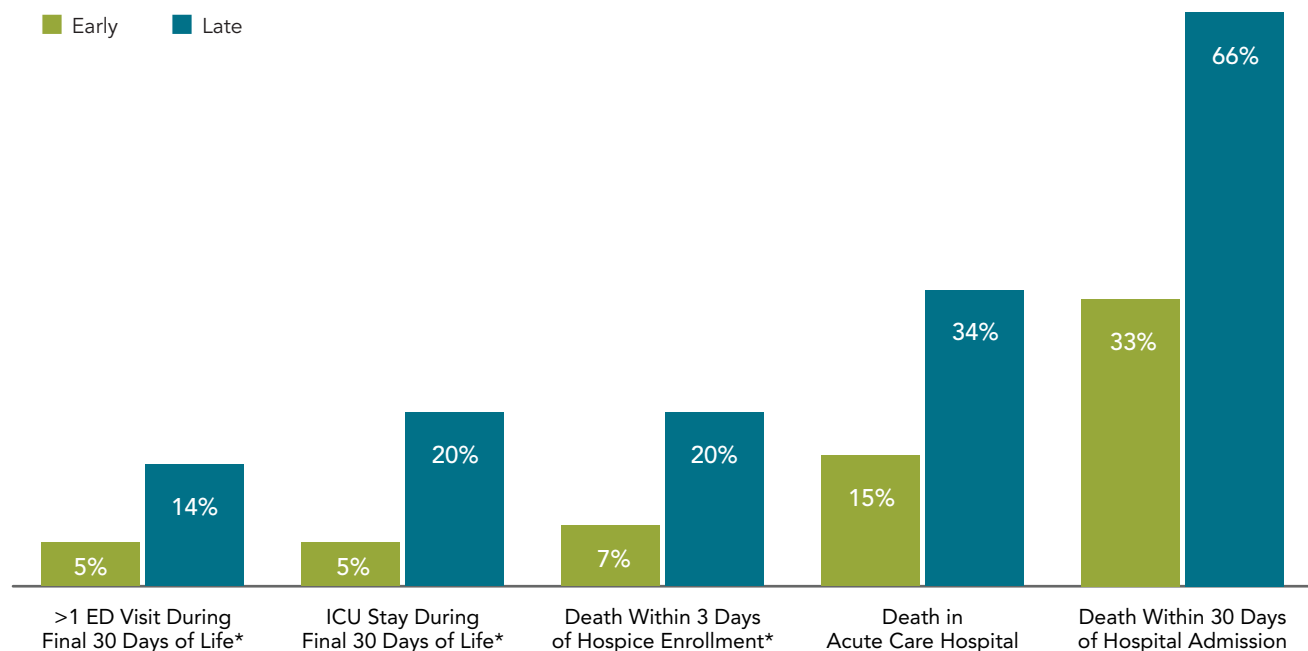
Figure 3. Inpatient Care Cost During the Last Six Months of Life, by Timing of Palliative Care Delivery



Definitions: Initial palliative care contact was greater than 90 days prior to death for Early and within 90 days of death for Late.

Source: Results of opportunity analysis conducted by PCAC member.

Figure 2. Quality Measures, by Timing of Palliative Care Delivery



*National Quality Forum-endorsed metric

Definitions: Initial palliative care contact was greater than 90 days prior to death for Early PC and within 90 days of death for Late PC.

Source: Results of opportunity analysis conducted by PCAC member.

How Can Programs Predict the Return on Investment?

To help PCAC teams estimate the return on investment (ROI) for their programs, CHCF supported the development of Supportive Care Calculators, spreadsheet tools that use the data trends from the opportunity analysis to project impact and ROI for CBPC services.

The calculators help clinical and administrative leaders answer questions about the potential use, costs, and impacts of CBPC services, such as:

- ▶ How many patients could use our services?
- ▶ How many visits per patient should be expected?
- ▶ How many patients per day can be handled by a provider or team?

- ▶ What costs will be generated (e.g., salaries and benefits of clinical and administrative staff)?
- ▶ What revenues will be generated from third party reimbursement?
- ▶ What is the expected gap between costs and revenues, and how will it be filled?
- ▶ How will we demonstrate impact commensurate with investment and effort?

Users input information generated by the opportunity analysis, along with assumptions about referral patterns, length of engagement, staffing model, and billing revenues, into the calculator. The calculator then generates a range of estimates regarding expected program volumes, costs, and impacts, which are summarized in standard reports (see Table 13).

Table 13. Sample Supportive Care Calculator Impact Summary

Estimate of avoided direct costs and service use due to provision of CBPC in one year

Total number of palliative care-appropriate patients (estimated) organization-wide	1,000
Palliative care-appropriate patients referred to CBPC (goal)	25%
Number of expected CBPC patients	250
Fiscal Outcomes	
Total staffing costs (includes administrative staff)	\$502,483
Expected clinical revenues	\$206,250
Profit (cost) per patient (clinical revenues minus staffing costs)	(\$1,185)
Avoided direct costs from avoided hospitalizations at EOL	\$1,830,693
Avoided direct costs per patient from avoided hospitalizations at EOL	\$7,323
Gain (loss) per patient	\$6,138
Gain (loss) for expected population	\$1,534,460
Utilization Outcomes	
Number of avoided emergency department visits	102
Number of avoided inpatient admissions	135
Number of avoided bed-days	1,357
Number of avoided 30-day readmissions	33
Number of avoided hospitalizations for which patients died within 30 days	27

Note: A bed-day is a measure of how many days patients are hospitalized.

Source: Sample impact summary generated by the Supportive Care Calculator, tool available at: www.coalitionccc.org.

How Can We Access These Tools?

Instructions and spreadsheet tools for the opportunity analysis and the Supportive Care Calculators are available through the Coalition for Compassionate Care of California (see Table 14).

Table 14. Business Case Tools

	DATA OUTPUT
Opportunity Analysis (instructions and two spreadsheet files for summarizing data)	<ul style="list-style-type: none">▶ Frequency, intensity, cost, margins, and quality measures for patients with life-limiting diseases▶ Proportion of PC-relevant patients receiving PC▶ Timing of PC prior to death▶ Baseline numbers to plug into calculators to project impact and return on investment
Supportive Care Calculators (versions for clinic-based and home-based programs)	<ul style="list-style-type: none">▶ Information on FTEs, visits, billing revenue▶ Projected impact on quality measures such as 30-day mortality▶ Projected impact on costs and net margin

Source: Coalition for Compassionate Care of California, www.coalitionccc.org.

Quality Improvement

Ongoing quality improvement is core to program development, operation, and growth. As part of their participation in the PCAC, teams outlined specific, achievable aims for the one-year program period and described the related steps needed to achieve each aim. Teams assessed their own progress on these aims throughout the year.

From Concept to Practice: PCAC Member Approaches

A summary of the PCAC members' aims shows how they are developing and improving their programs (see Table 15 on page 29).

Teams reported that they fully achieved 36% of their aims and that they made good progress (halfway there or better) on 31% of their aims. Additional opportunities to strengthen services remain, as teams reported making no or limited progress on 33% of their aims. Many PCAC teams reported that articulating aims, revisiting their appropriateness, and tracking their progress over time helped bring focus and attention to specific issues amid the day-to-day challenges of running a busy clinical service.

Table 15. Sample Aims from PCAC Members, by Category

EXAMPLES	
Service expansion:	
<ul style="list-style-type: none"> ▶ New disease groups/new referral sources 	<ul style="list-style-type: none"> ▶ Increase referrals to palliative care clinic by five new MDs across at least two specialties. ▶ Expand outpatient palliative care to other medical specialties (beyond oncology), starting with liver transplant.
<ul style="list-style-type: none"> ▶ Increasing referrals among existing referral sources 	<ul style="list-style-type: none"> ▶ Identify baseline referral rate of cancer patients to existing palliative care clinic, then increase the rate. ▶ Increase number of patients admitted to at least one home-based palliative care program in their last 18 months of life.
<ul style="list-style-type: none"> ▶ More FTE/new roles on team 	<ul style="list-style-type: none"> ▶ Use metrics to support allocation of additional 0.5 FTE each of SW and NP. ▶ Increase outpatient palliative care provider hours to enable program growth.
<ul style="list-style-type: none"> ▶ New services 	<ul style="list-style-type: none"> ▶ Add phone follow-up of inpatients after discharge and outpatients between visits. ▶ Launch outpatient palliative care clinic in ambulatory care center.
<ul style="list-style-type: none"> ▶ New partners, contracts, or payers 	<ul style="list-style-type: none"> ▶ Expand integrated palliative care services to serve three independent practice associations. ▶ Establish informal partnerships with at least three continuum-of-care agencies/practices that provide palliative care outside the hospital.
Continuity between CBPC and other services	<ul style="list-style-type: none"> ▶ Establish processes to support smooth transitions from inpatient to outpatient palliative care services. ▶ Develop plan to integrate palliative care services across institution and present to leadership.
Improving understanding of CBPC	<ul style="list-style-type: none"> ▶ Enhance knowledge of palliative care and advance care planning among medical community.
Criteria and processes for CBPC referrals and discharge	<ul style="list-style-type: none"> ▶ Develop referral criteria for oncology patients. ▶ Standardize processes to identify congestive heart failure referrals for ACO patients from hospitals.
Patient-level outcomes	<ul style="list-style-type: none"> ▶ Patients with moderate to severe pain will have pain reduced by 50% by second clinic visit.
Improve efficient use of health care resources	<ul style="list-style-type: none"> ▶ 60% of palliative care patients will be discharged to hospice. ▶ Decrease hospital admissions for palliative care patients by more than 50%.
Advance care planning, goals of care, and POLST	<ul style="list-style-type: none"> ▶ Provide advance care planning education for 100% of referrals. ▶ 80% of patients with incurable illness will have goals-of-care discussions and completed POLST forms; 100% of POLST forms will be found in the patient's electronic health record.
Metrics and data analysis	<ul style="list-style-type: none"> ▶ Identify metrics to evaluate and demonstrate efficacy. ▶ Integrate data on patient satisfaction and pain management into hospital quality system.
Financial sustainability	<ul style="list-style-type: none"> ▶ Establish financially sustainable outpatient clinic with 75% of costs met by billing/reimbursement and 10 patient visits per week. ▶ Create cost analysis base to track future cost reduction for program.
Workforce training and competencies	<ul style="list-style-type: none"> ▶ RN and NP to get palliative care certification. ▶ Establish training schedule for core palliative care team.
Operational systems	<ul style="list-style-type: none"> ▶ Complete policy and procedure manual to prepare for expansion of services. ▶ Develop a registry to include 100% of palliative care patients.

Source: In-person meetings of the Palliative Care Action Community, 2013-14.

CASE STUDY

Palo Alto Medical Foundation

Setting and Structure

The Palo Alto Medical Foundation (PAMF) is a large, multispecialty group practice with 1,300 physicians serving approximately 1 million patients in Northern California (Alameda, Santa Clara, Santa Cruz, and San Mateo Counties). PAMF launched its cross-setting outpatient palliative care service in February 2011; it is a stand-alone department that co-manages patients with the referring provider, other care providers, or both. The bulk of their funding comes from institutional support, with supplementation from relative value unit (RVU) billings and philanthropy.

While the service includes one half-day clinic per week in each of their three sites, they primarily see patients in other clinical or community sites, including in the patient's home, in skilled nursing facilities, in hospitals, and during other specialty clinic visits (e.g., oncology visits or chemotherapy appointments). Generally, new consultation appointments last 90 minutes, and follow-up visits last 30 to 60 minutes.

The palliative care team provides a full spectrum of services, including assessing and addressing pain and other physical symptoms as well as psychosocial, emotional, and spiritual issues; discussing and documenting goals of care; counseling on and completing advance care planning documents; supporting family members; reconciling medications; and educating patients about their disease and prognosis.

Successes, Challenges, and Aspirations

PAMF's palliative care team leaders consider among their successes:

- ▶ The satisfaction of patients and referring providers
- ▶ The willingness of organizational leaders to fund the program
- ▶ The dedication and passion of interdisciplinary team members

AT-A-GLANCE METRICS

Patients and Staffing

- ▶ **Patient population:** 40% oncology, 40% debility or dementia, 20% end organ disease
- ▶ **Primary referral sources:** inpatient palliative care program, physicians, case managers
- ▶ **Unique outpatients per year:** 832 (2013); 1,200 projected for 2014
- ▶ **Staffing (FTE):** three geographically based teams — two teams have 1.0 physician, 1.0 advanced practice nurse/physician assistant, 1.0 social worker, 1.0 care coordinator, 1.0 registered nurse (RN) liaison (total of 5.0 FTEs per team); one team has same except no RN liaison (total of 4.0 FTEs). There are 14.0 FTEs total across three teams, with 200 to 300 patients on each team's service per day across settings. Fourth team will begin seeing patients in 2014.

Measuring Results

Impact Measures

- ▶ **Patient-related:** percentage of patients with documented goals of care, percentage of patients with completed POLST/AHCD, patient satisfaction ratings, hospice length of service, percentage of patients who die in hospice care
- ▶ **Provider-related:** percentage of referring providers that would use service again
- ▶ **Financial:** percentage reduction in hospitalizations 30 days after admission into program

Selected Outcomes

- ▶ 96% of patients have documented goals of care
- ▶ 96% of patients have been asked about advance care planning; 75% have completed POLST forms
- ▶ 100% of referring providers reporting that they would use service again
- ▶ 75% reduction in hospitalizations in patients 30 days after admission into the program compared to 90 days prior
- ▶ Median hospice length of service is 40 days.
- ▶ 71% of patients who die are receiving hospice care at time of death

Challenges, and approaches for managing them, include:

- ▶ **Funding.** Through ongoing efforts to engage and educate leadership about the program, the team aims to show the impact of their palliative care service on the use of health care resources (e.g., decrease in hospitalizations). Currently, the program does not show a return on investment for PAMF because in the current fee-for-service environment, lower costs from changes in use of health services benefit the payer, not the physician providers. Nonetheless, the model of cost avoidance will be important when shared savings or other risk-sharing approaches become more widespread.
- ▶ **Finding qualified staff.** The team informally cross-trains staff by pairing new team members with those doing similar work in other geographic regions.
- ▶ **Inability to provide round-the-clock coverage.** The team relies on an on-call service provided by the organization's primary care physicians and specialists.

In the future, the team hopes to increase referrals for end-stage heart, lung, and kidney disease patients; partner with oncology to define standard oncology palliative care work (which will also inform other specialties and primary care); develop a system for routine primary care for a growing population of homebound patients with life expectancies of more than one year; and add a dedicated geriatric psychiatrist and a chaplain to the team.

Appendix A: PCAC Teams and Faculty

Teams

Annadel / St. Joseph Health — Santa Rosa
Community Hospice — Modesto
Community Memorial Hospital — Ventura
Hoag Hospital — Newport Beach
Huntington Hospital — Pasadena
Kaiser Permanente Northern California Region —
Northern California
Kaiser Permanente South Bay Medical Center —
Harbor City
Kaweah Delta Health Care District — Visalia
Marian Cancer Care — Santa Maria
Motion Picture & Television Fund — Los Angeles
Olive View – UCLA Medical Center — Los Angeles
Optum Palliative and Hospice Care — Santa Ana
Palliative Care Center of Silicon Valley — San Jose
Palliative Partners — Riverside
Palo Alto Medical Foundation — Northern California
Partners in Care of El Dorado County — Placerville
Saddleback Coordinated Home Care — Laguna Hills
Sharp HealthCare — San Diego
Stanford Health Care — Stanford
Sutter Health – Sutter Care at Home —
Northern California
University of California, San Francisco (USCF)
Medical Center — San Francisco

Faculty and Staff

J. Brian Cassel, PhD
Virginia Commonwealth University
Kathleen Kerr, consultant
Kate Meyers, MPP, consultant
Kate O'Malley, RN, MS, senior program officer
California HealthCare Foundation
Glenda Pacha, program associate
California HealthCare Foundation
Mike Rabow, MD
UCSF Medical Center

Appendix B: Selected Resources

General Resources for Community-Based Palliative Care

Center to Advance Palliative Care

Improving Outpatient Palliative Care
www.capc.org/ipal/ipal-op

Reference Library
www.capc.org/ipal/ipal-op/reference-library

California HealthCare Foundation

Required Reading: Palliative Care
www.chcf.org/cin/palliative-care

Next Generation of Palliative Care: Community Models Offer Services Outside the Hospital
by Larry Beresford and Kathleen Kerr
www.chcf.org/publications/2012/11/next-generation-palliative-care

National Consensus Project for Quality Palliative Care

Clinical Practice Guidelines for Quality Palliative Care
www.nationalconsensusproject.org/guidelines_download2.aspx

Coalition for Compassionate Care of California

www.coalitionccc.org

Resources for Planning and Assessing Impact of Palliative Care Services

Center to Advance Palliative Care

Improving Outpatient Palliative Care Portfolio (monographs and resources)

www.capc.org/ipal/ipal-op/monographs-and-publications

Includes information on developing a business plan; an overview of outpatient palliative care models; information on starting clinic, home-based, and phone-based palliative care services; tools for conducting needs assessments; and descriptions of some established outpatient programs.

Center to Advance Palliative Care and National Business Group on Health

Improving Care for People with Serious Illness Through Innovative Payer-Provider Partnerships: A Palliative Care Toolkit and Resource Guide
www.chcf.org/publications/2014/06/palliative-care-toolkit

Coalition for Compassionate Care of California

Palliative Care Tools and Resources
www.coalitionccc.org/tools-resources/palliative-care

California State University Institute for Palliative Care

The Business Case for Palliative Care
www.csupalliativecare.org/programs/businesscase

Online Training Resources

California State University Institute for Palliative Care

www.csupalliativecare.org

Appendix C: California's Focus on Palliative Care

Attention to palliative care has grown in recent years not only within health care systems but also within California's broader state health policy community. Four recent efforts are examples of the state-level attention on the role of palliative care in improving population health and health care, and in lowering costs.

The Berkeley Forum

berkeleyhealthcareforum.berkeley.edu

The Berkeley Forum for Improving California's Healthcare Delivery System was a year-long collaboration between policy experts from the University of California, Berkeley; CEOs of major health insurers and health care delivery systems; and leaders from California's public sector. In February 2013, after extensive discussion and analysis, the forum released a roadmap for creating a more affordable and cost-effective health care system to improve the health of Californians. The forum examined the cost-savings potential of seven initiatives:

- ▶ Global budget/integrated care systems
- ▶ Patient-centered medical homes
- ▶ Palliative care
- ▶ Physical activity
- ▶ Nurse practitioners and physician assistants
- ▶ Health care–associated infections
- ▶ Preterm birth

Of these initiatives, the forum highlighted two that they believe have the greatest potential for reducing expenditures while improving health and health care quality: increasing rates of physical activity for all Californians and increasing palliative care access for seriously ill patients.

Let's Get Healthy California

www.chhs.ca.gov/pages/lghctf.aspx

The Let's Get Healthy California Task Force was created through an executive order of Governor Jerry Brown in 2012 to “develop a 10-year plan for improving the health of Californians, controlling health care costs, promoting personal responsibility for individual health, and advancing health equity.” Of the six goals included in the task force's proposed framework to make California the healthiest state in the nation, one specifically focuses

on end-of-life care. A dashboard tracks 39 indicators to assess the state's progress toward these goals:

Health Across the Lifespan

Goal 1. Healthy Beginnings: Laying the Foundation for a Healthy Life

Goal 2. Living Well: Preventing and Managing Chronic Disease

Goal 3. End of Life: Maintaining Dignity and Independence

Pathways to Health

(practice and policy changes needed)

Goal 4. Redesigning the Health System: Efficient, Safe, and Patient-Centered Care

Goal 5. Creating Healthy Communities: Enabling Healthy Living

Goal 6. Lowering the Cost of Care: Making Coverage Affordable and Aligning Financing to Health Outcomes

The California State Innovation Model (CalSIM)

www.chhs.ca.gov/pages/pritab.aspx

CalSIM, an initiative of the federal Centers for Medicare & Medicaid Innovation spearheaded at the local level by California Health and Human Services Agency, is aimed at improving health system performance. Building on the Let's Get Healthy California framework and goals, CalSIM's State Health Care Innovation Plan, released in March 2014, includes palliative care among its four initiatives to help improve health and health care and to lower costs within three years.¹⁰

To identify and provide high-quality care to patients who want and may benefit from palliative care services, the CalSIM palliative care initiative includes two main objectives:

- ▶ Incorporate palliative care capacity within health homes for patients with complex needs.
- ▶ Identify and adopt new benefit and payment approaches to better meet patient preferences for palliative and hospice care.

To meet these objectives, the state team will partner with the California HealthCare Foundation, the Integrated Healthcare Association, and other experts to review and adopt innovative benefit design and payment

mechanisms as they are developed. The state will also support palliative care training of the current workforce. In addition, the state will pursue a Medicare waiver to allow curative and palliative care to be provided simultaneously through Medicare and to extend the hospice benefit to up to 12 months before anticipated death.

Medi-Cal Recommendations from the Coalition for Compassionate Care of California

www.coalitionccc.org

In March 2014, at the request of the California Department of Health Care Services (DHCS), the Coalition for Compassionate Care of California drafted recommendations on actions the state could take to improve access to palliative and end-of-life care for Medi-Cal beneficiaries. These recommendations were based on key informant interviews, literature review of peer-reviewed journals and publications from palliative care initiatives, and other surveys and market research data. In examining the draft recommendations, reviewers considered feasibility, evidence base, affordability, the number of people that would be affected, and alignment with departmental, state, and national initiatives and priorities.

The 23 recommendations described in the final report addressed four focus areas:

- ▶ **Access.** Patients can engage with palliative care providers and services, within and across settings, and over time.
- ▶ **Capacity.** Providers and programs are available and encouraged through incentive alignment to deliver palliative and end-of-life care, that care is aligned with best practices, and systems for supporting advance care planning and medical decisionmaking are in place.
- ▶ **Surveillance.** A system is in place to monitor access, utilization, alignment with best practices, and outcomes.
- ▶ **Implementation.** Activities that would allow key stakeholders to refine, prioritize, endorse, and assist in implementing this report's recommendations are in place.

Endnotes

- 1 Center to Advance Palliative Care, *Growth of Palliative Care in US Hospitals: 2013 Snapshot*, accessed May 7, 2014, www.capc.org.
- 2 Center to Advance Palliative Care, "Defining Palliative Care," accessed May 8, 2014, www.capc.org.
- 3 Larry Beresford and Kathleen Kerr, *Next Generation of Palliative Care: Community Models Offer Services Outside the Hospital*, California HealthCare Foundation, November 2012, accessed May 8, 2014, www.chcf.org.
- 4 Michael Rabow et al., "Outpatient Palliative Care Practices," *Archives of Internal Medicine* 170, no. 7 (2010): 654-5.
- 5 Alexander Smith et al., "The Diverse Landscape of Palliative Care Clinics," *Journal of Palliative Medicine* 16, no. 6 (June 2013): 661-8, doi:10.1089/jpm.2012.0469.
- 6 Michael Rabow, David O'Riordan, and Steven Pantilat, "A Statewide Survey of Outpatient Palliative Care Services," *Journal of Palliative Medicine*. In press.
- 7 Given the small number of survey participants, these data should be used as descriptions only and should be interpreted with caution.
- 8 Webinar presented by Thomas Smith, MD, of Johns Hopkins Medical Institutions, to CHCF Palliative Care Action Community, June 6, 2013.
- 9 Michael Rabow et al., "Moving Upstream: A Review of the Evidence of the Impact of Outpatient Palliative Care," *Journal of Palliative Medicine* 16, no. 12 (2013):1,540-9
- 10 The California State Health Care Innovation Plan's four initiatives are Maternity Care, Health Homes for Complex Patients, Palliative Care, and Accountable Care Communities.