Spotlight on

Home-Based Palliative Care

Insights and Recommendations
from the Center to Advance Palliative Care and
the Palliative Care Quality Collaborative

capc Center to Advance Palliative Care

PCQC Palliative Care Quality Collaborative

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Introduction

Home-based palliative care for frail and seriously ill patients fills a critical gap in the U.S. health care system. It not only enables access to services that can prevent the typical pattern of emergency department visits, hospitalizations, post-acute rehabilitation stays, and early skilled-nursing placement, it also mitigates the unnecessary suffering and spending that accompany these events.

Thanks to a growing evidence base demonstrating better outcomes, higher quality care, and reduced costs, the combination of medical and non-medical services and supports provided by home-based palliative care has attracted the attention of policymakers, population health leaders, and payers.

In 2019, the Center to Advance Palliative Care (CAPC) completed the first-ever national initiative to identify palliative care programs providing services in community settings, including patient homes, and found hundreds of home-based programs serving more than 1,500 U.S. counties. While these numbers indicated greater access to home-based palliative care than had been previously assumed, enormous variability in program design still exists among these programs in terms of capacity, patient eligibility, staffing model, and length of service. To explore this variability further, CAPC and the Palliative Care Quality Collaborative (PCQC) examined data collected through the PCQC national palliative care quality data registry.

As interest in, and prevalence of, home-based palliative care grows, so too does the need to learn more about these programs and their service delivery. We have undertaken this deeper exploration of home-based palliative care program-design variables to support providers and payers alike in understanding the drivers of positive home-based palliative care outcomes. Drawing on the National Consensus Project (NCP) *Clinical Practice Guidelines for Quality Palliative Care*, this report also shares recommendations from the CAPC-led Serious Illness Quality Alignment Hub.

About the Data

Home-based palliative care programs that voluntarily participated in PCQC's annual program survey in 2020 or 2021 were included in the analysis. If a program submitted data in both years, only the most recent responses were included. Data for this report were taken from three sections of the survey:

→ **Section I. Community Program-Level Questions**

→ **Section II. Setting: Patient's Home**

→ **Section V. Staffing**

Most of the questions included in the survey are optional; therefore, not all programs included in this report have answered all questions. The sample size for each topic is included in this report. Additionally, while some palliative care programs may serve people in more than one setting (e.g., in patients' homes and in an office practice), questions pertaining to patient demographics and staffing are specific to the home-based palliative care program.

The final data set includes 83 unique home-based palliative care programs serving more than 38,000 patients annually.

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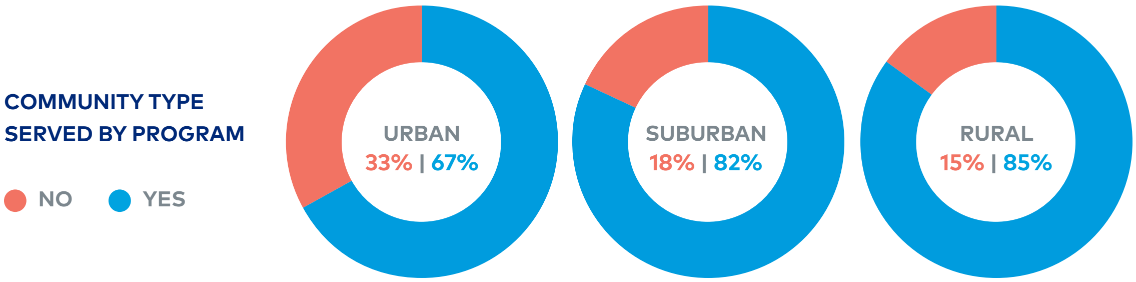
Key Characteristics of Existing Programs

Patients Served

Home-based palliative care programs serve a wide variety of geographies and patients, filling gaps in care for both adults and children.

Community Type: (N=83) Home-based palliative care programs serve three types of communities—urban, suburban, and rural—with a smaller proportion of programs serving urban areas than other community types. More than half of programs (58%) report serving all three types of communities.



Travel Time: (N=57) Some home-based palliative care programs deliver services exclusively via telehealth, while others combine virtual and in-person encounters. For in-person encounters, home-based palliative care professionals spend an average of 41 minutes traveling round-trip to and from their home visits (“windshield time”).

Patient Demographics: (N=83) The vast majority of programs (more than 95%) report serving both adults and older adults (age 65+).

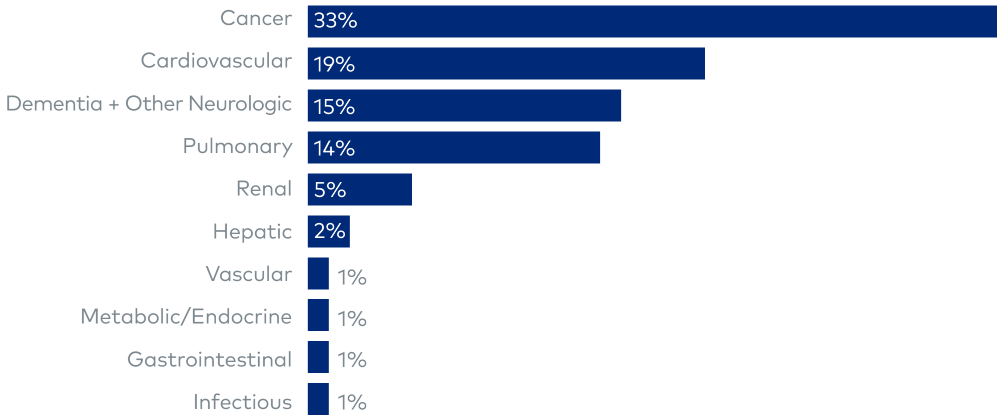
Twenty-one percent (21%) of programs report serving children (age 12 months to 12 years), with 7% providing prenatal palliative care, 13% serving neonates (younger than one month), and 17% serving infants (younger than one year). Five percent (5%) of the programs reporting are exclusively pediatric.

In programs reporting the race of their initial patient encounters (N=28), 80% of home-based palliative care patients were white and 14.5% were Black, consistent with the overall proportion of Black people in the U.S. population. (Other racial groups and ethnic demographics are not reportable from the data.)

Patient Diagnoses: (N=35) The most frequent primary diagnoses reported for initial consultations are cancer and cardiovascular conditions, which is similar to reported diagnoses in inpatient palliative care. The prevalence of these diagnoses in home-based palliative care programs coincides with the body of literature demonstrating palliative care's value.

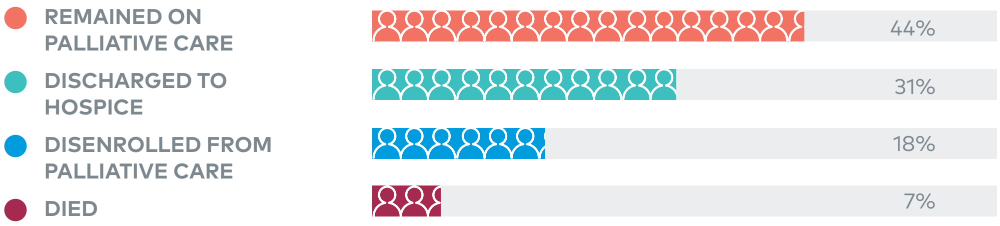
Other frequently seen diagnoses include dementia and other neurological conditions (15%), pulmonary disease (14%), and renal disease (5%).

PRIMARY DIAGNOSIS OF PATIENTS SERVED BY THE PROGRAM



Patient Disposition: (N=31) Nearly one-third of patients (30.9%) were discharged from the home-based palliative care program to hospice, 7% died on the palliative care service, and 44% of patients remained in the program at the time of reporting. This suggests that reporting programs are serving patients well before the end of life.

DISPOSITION OF PATIENTS SERVED BY THE PROGRAM IN THE REPORTING PERIOD

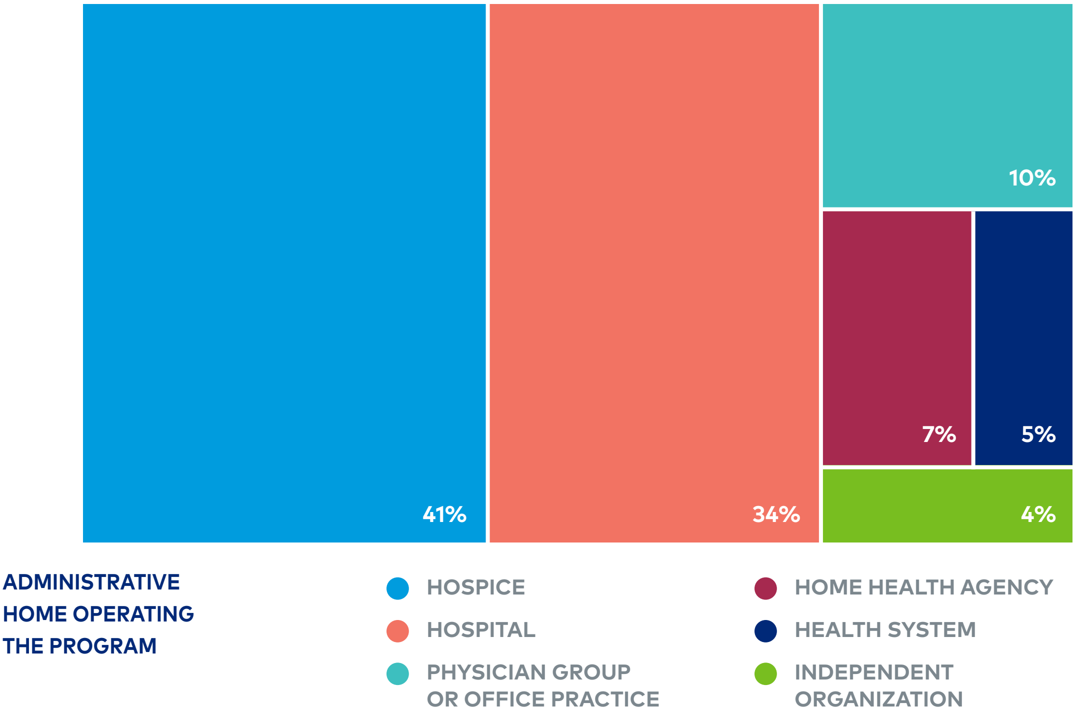


* *Disenrolled patients include those whose service was completed/had consultation sign-off; moved out of the service area; were admitted to long-term care and were no longer served by the program; and were lost to follow-up.*

Program Operations and Funding

Home-based palliative care programs can either provide consultative services, co-manage patients with their treating clinicians, or assume primary care management responsibilities. Consistent with this variety in role, programs report varying lengths of service, and roughly half provide coverage 24/7. Program funding continues to rely primarily on fee-for-service billing.

Administrative Home: (N=83) The largest number of home-based palliative care programs in the data set are operated by a hospice agency (41%). Hospitals operate an additional 34% of these programs.



Patient Volume (N=80) **and Average Daily Census:** (N=74) Patient volumes vary widely, with a median of 205 patients seen annually, and a maximum of more than 2,000 patients. The median average daily census is 51.5, with a range of up to 600 (excluding outliers)[1].

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[1] Because the programs reporting their daily census may be different from those reporting their staff composition, caseloads cannot be calculated from the information in this report.

Length of Service: (N=54) Programs also vary widely in average length of service, ranging from 29 days to more than 1,000 days on the palliative care service, with a median of 123.5 days (four months).

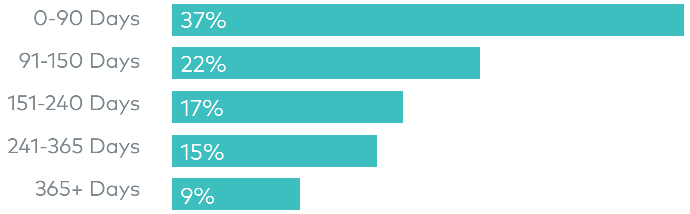
This variation in length of service reflects variation in the goals and models of the home-based palliative care programs themselves, with some concentrating on short-term stabilization and others providing ongoing monitoring or assuming full responsibility for both primary care and palliative care needs.

HOME-BASED PALLIATIVE CARE PROGRAM MODELS

SHORT-TERM	INTERMITTENT	ONGOING
Consults Stabilization	Stabilization with ongoing monitoring	Primary/palliative care at home Mental health care Personal care

Thirty-seven percent (37%) of respondents report that, on average, patients are on their service for fewer than three months. This short length of service is consistent with home-based palliative care bundled payment models, which are used by a small number of payers across the country.

PROPORTION OF PROGRAMS BY AVERAGE LENGTH OF SERVICE

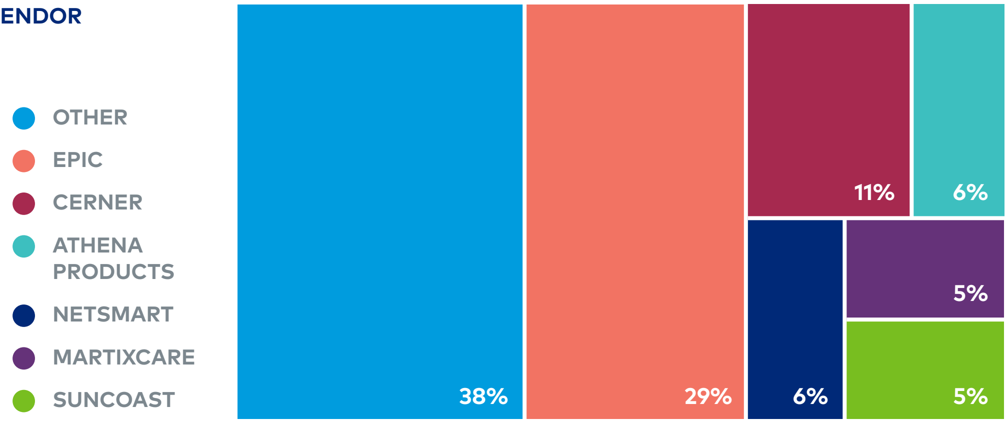


MEDIAN = 123.5 DAYS

24/7 Availability: (N=81) Forty-eight percent (48%) of programs report that they provide coverage across days, evenings, nights, and weekends – 24 hours per day, seven days per week. Another 53% report coverage during evenings and nights, and 51% provide weekend coverage. This coverage spans in-person, telephone, and/or telehealth access.

Electronic Health Record Use: (N=82) Only 2% of reporting programs have no electronic health records (EHR). Among the remaining 98% of programs, a total count of 27 EHR vendors is reported, with Epic being the EHR vendor used by the largest number of respondents.

EHR VENDOR USED

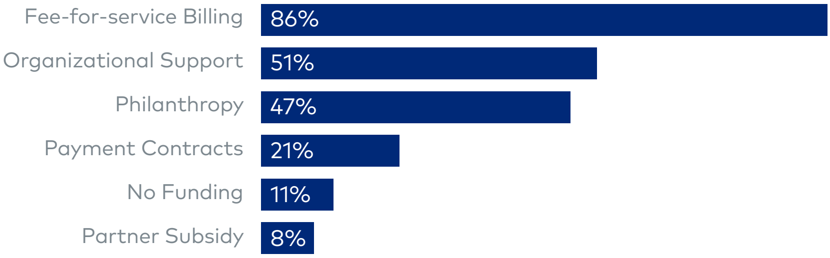


Funding Sources: (N=76) Eighty-six percent (86%) of programs report fee-for-service billing as one of their top three sources of funding. Twenty-one percent (21%) of programs report contracted alternative payment arrangements, such as a fixed monthly payment per patient or a bundled payment covering a fixed number of months or weeks, as one of their top three funding sources. This is a sizable increase from earlier reports collected by CAPC.

Financial subsidy from the parent organization and philanthropy both are still commonly used to support program operations, with half of programs reporting these among their top three funding sources.

FUNDING SOURCES FOR PROGRAM

(SELECTED IN TOP THREE)



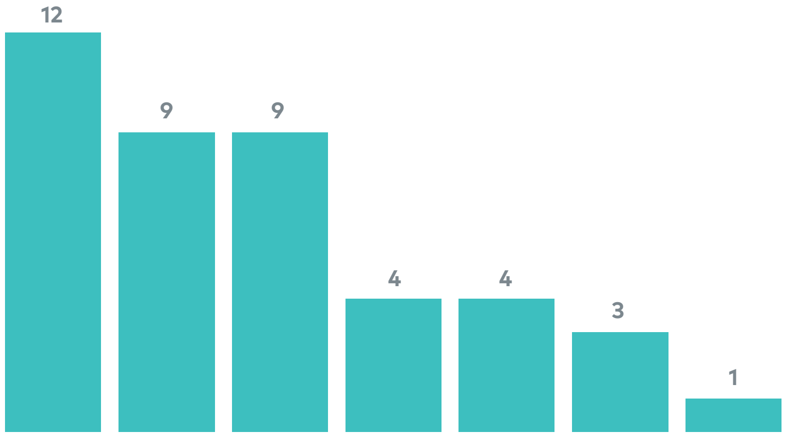
Program Staffing

Effective palliative care relies on an interdisciplinary team to meet the comprehensive needs of patients and family members. Advanced practice providers and physicians are included most often, and most programs include a prescriber with specialty certification in palliative care.

Interdisciplinary Team: (N=72) Across 72 programs, the median number of full-time equivalent (FTE[2]) positions across all disciplines is 5.8. The most commonly reported patient-facing roles are advanced practice providers, including both nurse practitioners and physician associates/assistants (82%); physicians, both as providers and/or medical directors (78%); social workers (75%); registered nurses (64%); chaplains or spiritual care professionals (46%); certified nursing assistants or medical assistants (17%); and licensed practical or vocational nurses (14%).

Other patient-facing disciplines reported by multiple programs include pharmacists (8%); dietitians/nutritionists (8%); massage therapists (4%); physical or occupational therapists (4%); and music/art/recreational therapists (3%).

The vast majority of programs (93%) include a prescribing clinician (physician or advanced practice provider). The typical team is comprised of medical providers, advanced practice providers, social workers, nurses, and spiritual professionals.



NUMBER OF PROGRAMS BY TEAM COMPOSITION

Chaplain	✓	✓					
RN/Care Manager	✓		✓	✓			
Advanced Practice Provider	✓		✓		✓	✓	✓
Social Worker	✓	✓	✓	✓	✓		✓
Physician	✓	✓	✓	✓	✓	✓	

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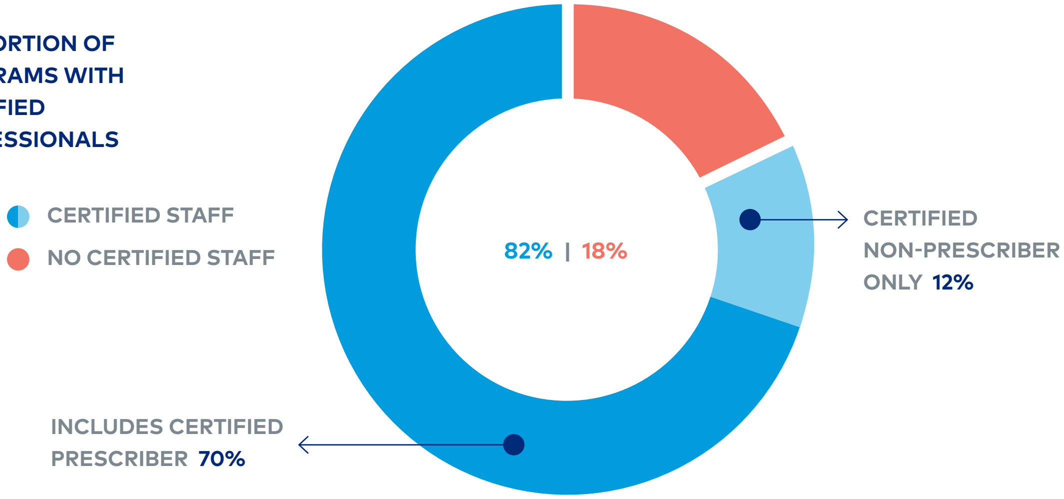
[2] FTE: a full-time equivalent is a unit of worker that calculates their time as a proportion of a standard full-time work week. Thus, if someone works 20 hours per week of a standard 40-hour work week, that individual is a 0.5 FTE.

Team Member Specialty Certification: (N=67) A large majority of programs (82%) report having at least one team member with specialty certification in palliative care. Of those, 86% have at least one certified prescriber on the team.

PROPORTION OF PROGRAMS WITH CERTIFIED PROFESSIONALS



Team Member Well-Being: (N=79) As in the rest of U.S. health care, home-based palliative care clinicians are experiencing high levels of burnout. Fifty-two percent (52%) of programs report being somewhat to extremely concerned about the risk for burnout for staff, given current workloads.

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National Guidelines and Recommendations

High-quality palliative care delivery in any setting should adhere to the field's quality standards, the National Consensus Project *Clinical Practice Guidelines for Quality Palliative Care* (NCP Guidelines), currently in the fourth edition.

The NCP Guidelines cover eight domains of care, including the structure and processes of the palliative care program as well as the physical, psychological/psychiatric, social, spiritual, cultural, end-of-life, ethical, and legal aspects of patient care. The guidance in each domain forms the basis of certification programs for palliative care programs, such as those offered by The Joint Commission and Community Health Accreditation Partner (CHAP).

In 2019, the CAPC-led Serious Illness Quality Alignment Hub convened leaders from across multiple health care sectors. The goal was to coordinate serious illness strategies and standards and to synthesize the NCP Guidelines into a summary that payers and policymakers might use to credential home-based palliative care providers. The list of recommendations includes the following:

- → **An interdisciplinary team should have at least three of the following disciplines, including at least one prescriber:**
    - *Physician (MD or DO)*
    - *Advanced Practice Provider*
    - *Nurse (Registered Nurse or Licensed Practical Nurse)*
    - *Social Worker (Note: Medicaid-serving programs should* ***require*** *a social worker on the team)*
    - *Chaplain or Spiritual Care Professional*

→ **Team members must have either specialty certification in palliative care or documentation of specific competencies in palliative care**, preferably with a goal of working toward certification. At least one prescriber on the team should have specialty certification in palliative care. Specific pain and symptom management competencies gained through education programs such as CAPC Designation may be used while working toward specialty certification.

→ **Reliable access to other health professionals and services should be provided**, such as to pharmacists, community health workers, physical therapists, or personal care services; linkage agreements are acceptable documentation.

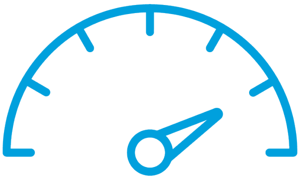
→ **24/7 access to a clinician with proven competencies in pain and symptom management and access to the patient's medical record** must be provided, using telehealth as warranted.

→ **Team members should have demonstrated capability to conduct a comprehensive patient assessment** to include, at a minimum:

  - *Pain and symptom distress*
  - *Functional status*
  - *Cognitive status*
  - *Caregiver burden*
  - *Spiritual needs*
  - *Social needs, including but not limited to financial vulnerability, housing, transportation, nutrition, and safety*

→ **Team members should have demonstrated capability to create a care plan** through shared decision-making and to coordinate that plan across all of the patient's providers and services, including treating providers. Assessment and care-planning capabilities can be demonstrated by the submission of de-identified initial assessment and care plan documents for past patients.

→ **Quality measures, including patient-reported outcomes, must be collected to support continuous quality improvement**. Membership in PCQC with clinical reporting meets this requirement.



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Looking Forward

What does the future hold for home-based palliative care? As the number of patients that could benefit from home-based palliative care in the U.S. grows, and as payers and policymakers explore how they might support such programs, continued scrutiny of home-based palliative care models is all but assured.

Notably, current variation in the design of home-based palliative care programs reflects the diversity of funding sources and payment models. National quality guidelines, however, dictate the core structures a program needs to deliver high-quality palliative care services and improve its capacity to deliver positive patient outcomes. We encourage state and federal policymakers, population health leaders, and public and private payers to use the core structural recommendations in this report to ensure that patients receive care from interdisciplinary and well-skilled teams, to adequately fund care delivery, and to monitor the quality of care delivered.

The Center to Advance Palliative Care and the Palliative Care Quality Collaborative will continue to collect, analyze, and report on program data in the years to come in order to identify trends in home-based palliative care delivery in the U.S.

The Center to Advance Palliative Care (CAPC), established in 1999, is a national organization dedicated to increasing the availability of quality, equitable health care for people living with a serious illness. As the nation's leading resource in its field, CAPC provides health care professionals and organizations with the training, tools, and technical assistance necessary to effectively redesign care systems that meet this need. CAPC is funded through organizational membership and the generous support of foundations and private philanthropy. It is part of the Icahn School of Medicine at Mount Sinai, in New York City.

capc.org

The Palliative Care Quality Collaborative (PCQC) is a non-profit membership organization that supports the only national unified specialty palliative care quality data registry and collaborative. PCQC combines the power of clinical and program data reporting to drive quality and performance improvement in clinical care. The goal of PCQC is to improve the quality of care delivered to people with serious illness and the people that support them. PCQC was incorporated in 2019 and relies on active members within the field to continue to grow its understanding of high-quality palliative care through data.

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