

What's New for the Hospital Survey

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

- 1. Focused Scope:** The new Hospital Survey has strengthened focus on actionable structure and process measures that are feasible for programs to collect.
- 2. Survey Reorganization:** The Hospital Survey has been reorganized into 12 new modules, including 2 specialty modules for pediatric palliative care programs and for hospitals with inpatient palliative care units. All palliative care programs will be able to answer all of the questions in the first four modules which cover “Core Program Information” and should be able to answer a majority of modules 5-10 on “Optional Program Features”.
- 3. Length and Question Changes:** The new Hospital Survey is much shorter than our previous version. Without Specialty Modules 11 and 12, the survey is only 48 questions long. Thirty of these questions have not changed, 15 questions are either new or revised, and 40 have been removed. The largest revision is that for questions where we previously requested a percentage breakdown, we are now requesting a count to make reporting easier for programs. Questions were removed for a series of reasons, including low participation rates, too burdensome for programs to collect, requires chart review/custom reporting from the EMR, non-reliable answers from participants, and/or outside of the process and structure scope of the National Palliative Care Registry™.
- 4. One of Many Data Resources:** While patient reported outcomes and clinical data are extremely important for programs to collect to show program value and impact, the Registry is not the appropriate venue to collect it. Data collection for quality improvement purposes are better met by other systems, such as participating in a palliative care quality improvement collaborative. To help palliative care programs with measurement, CAPC will be releasing a Measurement Toolkit for CAPC Members, including information on which data points are important to collect for different purposes and audiences.

We thank you for your continued participation in the National Palliative Care Registry. Please contact the National Palliative Care Registry™ if you have any questions or concerns about the outlined changes via email at registryhelpdesk@capc.org or call us at 212-201-2689.

Hospital Survey Outline

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Level I: Core Program Information

All questions in the first four Modules are feasible for participating palliative care programs to answer. Palliative care programs should respond to all questions in these sections and use the “I cannot answer this question” option, if needed.

Module 1. Program Basics

1. Is your palliative care program reporting on a full 12 months of data (either calendar year or fiscal year)?
 - a. Yes
 - b. No

Data from palliative care programs that are less than one-year-old can be still submitted. Please report your data accurately for that time period. For example, if your program was operational for only 3 months, then report the data for the actual 3-month period. Do not provide estimates for the entire year based on your 3-month performance.

2. If no, how many months of data are you reporting? _____

If your program has been in operation for less than 10 months, you will still receive comparative reports but your program's data will be excluded from comparisons.

3. In what year was your palliative care program established at this hospital site?

Please select the year that your palliative care program was established at this specific hospital site. If your program was established in 2008, but did not begin providing palliative care at this specific hospital until 2010, then enter 2010. If your program was starting in 2009, but did not start providing palliative care consults until 2010, then enter 2010.

4. How many initial palliative care consults did your inpatient palliative care program provide during the reporting period at this location? _____

Please provide the total number of inpatient palliative care consults based on new orders written during the reporting period. Do not include consults for observation beds or in the emergency department (ED).

Example: If a patient is admitted 3 times during the reporting period and has a consult order for palliative care written each time, this patient would count as 3 initial consults for this question.

5. How many billable follow-up or subsequent visits did your inpatient palliative care program provide during the reporting period? _____

Subsequent visits (or follow-up visits) are visits for a patient after the initial consult, but during the same admission. Only include billable visits provided by a physician (MD/DO), advanced practice registered nurse (APRN), or physician assistant (PA).

6. Is your program at this hospital primarily a pediatric palliative care program?
- Yes
 - No

Please select "yes" if your program identifies as a pediatric palliative care program and primarily sees children and infants. Pediatric programs may also see young adults over the age of 18 or other patient populations, but still consider themselves to be a pediatric palliative care program. By selecting "yes," your survey will display appropriate pediatric questions and answer categories. Additionally, your program will only be compared to other pediatric palliative care programs in the comparative reports on your dashboard.

7. For which inpatient population(s) did your palliative program accept new referrals during the reporting period? (check all that apply)

- Pediatric (less than 18 years)
 - Prenatal (before birth)
 - Neonate (birth to 28 days)
 - Infant (29 days to 11 months)
 - Children (12 months to 12 years)
 - Adolescent (13 to 17 years)
- Young Adult (18 to 25 years)
- Adult (26 years and older)

Please select all ages served by your palliative care program during the reporting period. If selecting "Pediatric", there is an option to provide further details on that population, although this is not required. Young adult is a separate category to represent the unique needs of this population.

Module 2. Hospital Information

8. What is the ownership or tax status of the hospital?
- For-profit
 - Non-profit
 - Public

Indicate the type of organization that is responsible for establishing policy for overall operation of your hospital. Your answer may be pre-populated from the American Hospital Association Annual Survey. If so, please review for accuracy.

- **For-profit (investor-owned):** Individual, Partnership, Corporation
- **Not-for-profit:** Church operated or other not-for-profit
- **Public:** Government/Non Federal (State, County, City-county, Hospital district or authority) or Government/Federal (Air Force, Army, Navy, Veterans Affairs, Public Health Indian Service,

Department of Justice or any other Public Health Service or Federal organization)

9. Is this hospital located in an urban, suburban, or rural area?

- a. Urban
- b. Suburban
- c. Rural

Please select the answer that best represents the location of your hospital. Your answer may be pre-populated from the American Hospital Association. If so, please review for accuracy.

10. Is this hospital a teaching hospital?

- a. Yes
 - b. No
- Major Teaching Hospitals - those with Council of Teaching Hospitals designation (COTH).
 - Minor Teaching Hospitals - those Approved to participate in residency and/or internship training by the Accreditation Council for Graduate Medical Education (ACGME), or American Osteopathic Association (AOA); or those with medical school affiliation reported to the American Medical Association.
 - Non-Teaching Hospitals - those without COTH, ACGME, AOA or Medical School (AMA) affiliation. Your answer may be pre-populated from the American Hospital Association. If so, please review for accuracy.

11. Is this hospital a children's hospital?

- a. Yes - Freestanding children's hospital
- b. Yes - Embedded children's hospital within a general hospital
- c. No - Pediatric ward in a general hospital
- d. No

A children's hospital is a hospital which restricts admissions primarily to children. If a freestanding children's hospital, your answer may be pre-populated from the American Hospital Association. If so, please review for accuracy.

12. Total number of annual hospital admissions during the reporting period?

The number of patients, **excluding newborns**, accepted for inpatient service during the reporting period; the number includes patients who visit the emergency room and are later admitted for inpatient service. Patients seen only while in observation or in the Emergency Department, should be excluded from the total number of hospital admissions.

For Pediatric Programs: Please limit to the total number of pediatric hospital admissions at your facility. Do not include normal newborn admissions (i.e. Level 1 nursery) admissions, if deliveries occur at your hospital.

13. Total number of hospital beds (set up and staffed for use)? _____

The number of beds regularly maintained (set up and staffed for use) for inpatients as of the close of the reporting period. Should exclude newborn bassinets and long-term care beds.

For Pediatric Programs: If your children's hospital is not free-standing, please only include the total number of beds dedicated to pediatric patients. Do not include normal newborn beds (i.e. Level 1 nursery), if deliveries occur at your hospital.

14. If able to obtain, please provide the following metrics about your hospital for the reporting period:

- a. Average daily census for the hospital _____
 I cannot answer this question
 - b. Total hospital inpatient deaths _____
 I cannot answer this question
 - c. Total hospital discharges (including deaths) _____
 I cannot answer this question
- **Average Daily Census:** The average number of people served on an inpatient basis on a single day during the reporting period; the figure is calculated by dividing the number of inpatient days by the number of days in the reporting period. For Pediatric Programs: Please limit to the children's population at your facility.
 - **Total Hospital Deaths:** Provide the total number of hospital deaths during the reporting period. For Pediatric Programs: Please limit to the total number of pediatric deaths at your facility
 - **Total Hospital Discharges:** A person who was formally admitted to a hospital as an inpatient with the expectation of remaining overnight or longer, and who is discharged under one of the following circumstances: (a) is formally discharged from care of the hospital and leaves the hospital, (b) is formally discharged from care of the hospital, but readmitted under another type of care/service (ex. discharge and then re-admission on general inpatient hospice), or (c) has died. For Pediatric Programs: Please limit to the total number of pediatric hospital discharges from your facility.

Module 3. Program Staffing

15. How is your inpatient palliative care program staffed?

- a. Embedded: Program is internal to the hospital (all palliative care team members are employed by the hospital)
- b. Partial: Program is partially internal with additional contracted services
- c. Contracted: Program is administered by an outside, contracted agency

Please select the best option that describes the staffing of your inpatient palliative care service during the reporting period at this site.

16. Which of these disciplines constitute your inpatient palliative care consult team? What is the head count (HC) and full-time equivalent (FTE) for each discipline by funding type (funded, in-kind or volunteer)?

<u>Professional Discipline</u>	<u>Funded</u>	<u>In-kind</u>	<u>Volunteer</u>
	<u>HC, FTE</u>	<u>HC, FTE</u>	<u>HC, FTE</u>
<input type="checkbox"/> Physician	___ ___	___ ___	___ ___
<input type="checkbox"/> Advanced Practice Registered Nurse	___ ___	___ ___	___ ___
<input type="checkbox"/> Physician's Assistant (PA)	___ ___	___ ___	___ ___
<input type="checkbox"/> Registered Nurse (RN)	___ ___	___ ___	___ ___
<input type="checkbox"/> Medical Resident	___ ___	___ ___	___ ___
<input type="checkbox"/> Physician Fellow	___ ___	___ ___	___ ___
<input type="checkbox"/> Licensed Practical Nurse (LPN)	___ ___	___ ___	___ ___
<input type="checkbox"/> Psychologist	___ ___	___ ___	___ ___
<input type="checkbox"/> Psychiatrist	___ ___	___ ___	___ ___
<input type="checkbox"/> Social Worker	___ ___	___ ___	___ ___
<input type="checkbox"/> Chaplain/Spiritual Care	___ ___	___ ___	___ ___
<input type="checkbox"/> Physical/Occupational Therapist	___ ___	___ ___	___ ___
<input type="checkbox"/> Massage Therapist	___ ___	___ ___	___ ___
<input type="checkbox"/> Music/Art Therapist	___ ___	___ ___	___ ___
<input type="checkbox"/> Doula	___ ___	___ ___	___ ___
<input type="checkbox"/> Child life Specialist	___ ___	___ ___	___ ___
<input type="checkbox"/> Dietician/Nutritionist	___ ___	___ ___	___ ___
<input type="checkbox"/> Pharmacist	___ ___	___ ___	___ ___
<input type="checkbox"/> Ethicist	___ ___	___ ___	___ ___
<input type="checkbox"/> Administrator (non-physician)	___ ___	___ ___	___ ___
<input type="checkbox"/> Hospice Liaison	___ ___	___ ___	___ ___
<input type="checkbox"/> Medical Director (non-clinical time)	___ ___	___ ___	___ ___
<input type="checkbox"/> Administrative Support	___ ___	___ ___	___ ___
<input type="checkbox"/> Other, specify _____	___ ___	___ ___	___ ___

For each professional discipline listed, provide the total number of individuals in that role (headcount) and the number of full-time equivalents (FTEs) those individuals represent by type of support - funded, in-kind or volunteer. Staff numbers should represent staffing dedicated to the palliative care program at this specific

site of care and match the time period for which patient volume is being reported.

- **Funded** positions are those that are specifically included in the palliative care program budget at the beginning of year.
- **In-kind** positions are those that are not funded from the palliative care program budget, but rather funded from elsewhere in the hospital's budget.
- **Volunteer** positions are not supported by any palliative care specific source of funding, or any other hospital funding source.

Examples: A full-time staff member represents 1.0 FTE, whereas a halftime team member would be 0.5 FTE. A palliative care team of 6 physicians where each physician works 25%, would be a head count of 6 and 1.5 FTEs. For programs that serve multiple locations: If a palliative care physician spends half her time in the inpatient setting and the other half of her time in the outpatient palliative care clinic, the table above for physician would be 1 Headcount and 0.5 FTE for time spent on the inpatient palliative care program.

17. During the reporting period, were any your palliative care staff certified in palliative medicine or palliative care?

- a. Yes
- b. No

Staff certified in palliative care or palliative medicine can include physicians, advanced practice registered nurses, registered nurses, chaplains, or social workers. Include the following:

- Physicians board-certified in Hospice and Palliative Medicine by the American Board of Medical Specialties (ABMS).
- Advanced Practice Nurses and Registered Nurses board-certified by the National Board for Certification of Hospice and Palliative Nursing (NBCHPN).
- Chaplains certified in hospice and palliative care by the Association of Professional Chaplains/Board of Chaplaincy Certification or the National Association of Professional Chaplains.
- Social Workers who are certified in Hospice and Palliative Social Work (CHP-SW) from the National Association of Social Workers (NASW). Social Workers may hold either a CHP-SW or be Advanced Certified in Hospice and Palliative Social Workers (AHP-SW).

18. If yes, indicate the number (headcount) of staff members with palliative care/medicine certification

- a. Physician _____
- b. Advanced Practice Registered Nurse _____
- c. Registered Nurse _____
- d. Chaplain _____
- e. Social Worker _____

Include the following:

- Physicians board-certified in Hospice and Palliative Medicine by the American Board of Medical

Specialties (ABMS).

- Advanced Practice Nurses and Registered Nurses board-certified by the National Board for Certification of Hospice and Palliative Nursing (NBCHPN).
- Chaplains certified in hospice and palliative care by the Association of Professional Chaplains/Board of Chaplaincy Certification or the National Association of Professional Chaplains.
- Social Workers who are certified in Hospice and Palliative Social Work (CHP-SW) from the National Association of Social Workers (NASW). Social Workers may hold either a CHP-SW or be Advanced Certified in Hospice and Palliative Social Workers (ACHP-SW).

19. Considering the staffing of your palliative care team over the past year, how would you describe your staffing?

- a. Stable - not currently recruiting or requesting additional staff
- b. Reduced staff in the past two years - not currently recruiting or requesting additional staff
- c. Short-staffed and requesting or recruiting additional staff for current work
- d. Requesting staff to manage anticipated future growth

Select the answer that best represents the staffing experiences of your team during the reporting period.

Module 4. Program Features

20. Does your inpatient palliative care program provide 24/7 coverage (definition in guidance) for patients and families?

- a. Yes
- b. No

24/7 coverage is defined as a full-time service, where patients can access palliative care as needed, 24 hours per day. At a minimum 24/7 coverage should include M-F consultation availability and 24/7 telephone support.

21. If no, what times do you have coverage? (check all that apply)

- Weekday, days
- Weekday, evenings
- Weekday, nights
- Weekend, days
- Weekend, evenings
- Weekend, nights

Check all the times where your palliative care program has coverage for palliative care consultations. Coverage can be: on-site, telephone return (your staff responds to care questions as needed; staff will come in at any hour to ensure quick responses to consult requests and to follow-up with existing patients), or telephone-only (your staff responds to care questions by telephone. They do not come in off work hours to provide consults or conduct follow-up visits).

22. Does your palliative care program have Joint Commission Advanced Certification for Palliative Care?

- a. Yes
- b. Yes, and we have been recertified
- c. Yes, but we do not intend to recertify or we have already allowed the certification to lapse
- d. Preparing to apply next year, or have already applied for certification
- e. Not eligible because program does not operate within a Joint Commission accredited hospital
- f. Would like to apply, but my program does not have the required elements to successfully obtain certification (staffing requirements, 24/7 coverage, etc.)
- g. Not planning to apply for other reasons
- h. No. We have pursued alternative certification pathways (i.e. DNV-GL Healthcare Palliative Care Program Certification)

For a full list of Joint Commission eligibility criteria, please visit their website:

http://www.jointcommission.org/certification/eligibility_palliative_care.aspx

23. Does your program use any national palliative care recommendations or guidelines to aid in developing the palliative care service or to guide clinical care? (Check all that apply)

- National Consensus Project (NCP) Clinical Practice Guidelines for Quality Palliative Care
- The Joint Commission Advanced Certification for Palliative Care
- DNV-GL Healthcare Palliative Care Program Certification
- We do not use any national palliative care recommendations or guidelines
- Others, specify _____

National recommendations and guidelines such as those listed here can help guide the development of your palliative care program and clinical care. Through the Registry program dashboard, participating palliative care programs can now receive a comparative report showing how your program is doing meeting national recommendations.

24. Does your palliative care program measure patient and family satisfaction?

- a. Yes
- b. No

Patient and family satisfaction surveys should be specific to palliative care patients, do not include hospital-wide surveys.

25. Does your palliative care program provide team wellness activities?

- a. Yes
- b. No

Common examples of team wellness activities are team retreats, regularly scheduled patient debriefing exercises, relaxation-exercise training, and individual referral for staff counseling.

26. Does your palliative care program utilize standardized screening criteria (triggers) to identify patients with palliative care needs?

- a. Yes
- b. No

Palliative care triggers, screening criteria, or checklists can help identify patients with unmet palliative care needs in the hospital.

27. If yes, is palliative care screening incorporated into your hospital's Electronic Medical/Health Record generating automatic consult requests?

- a. Yes
- b. No
- c. We do not have an EMR

Indicate if your palliative care screening criteria or trigger is incorporated into your hospital's Electronic Medical Record (EMR) and generates automatic palliative care consult requests. If your hospital does not have an EMR, please select c "We do not have an EMR."

28. Does your palliative care program receive custom EMR reports on your palliative care patient population?

- a. Yes
- b. No
- c. We do not have an EMR

Please indicate if your palliative care program is able to receive custom electronic medical record (EMR) reports on your palliative care patient population.

29. Does your palliative care program implement/utilize the following plans?

<u>Plans</u>	<u>Yes</u>	<u>No</u>
a. Marketing Plan	<input type="checkbox"/>	<input type="checkbox"/>
b. Bereavement Plan	<input type="checkbox"/>	<input type="checkbox"/>
c. Education Plan	<input type="checkbox"/>	<input type="checkbox"/>
d. Quality Improvement Plan	<input type="checkbox"/>	<input type="checkbox"/>
e. Strategic Business Plan	<input type="checkbox"/>	<input type="checkbox"/>
f. Multi-year Budget Plan	<input type="checkbox"/>	<input type="checkbox"/>
g. Staff Orientation Plan	<input type="checkbox"/>	<input type="checkbox"/>

None of the Above Plans

- A. Marketing Plan: The marketing plan describes how the palliative care program will promote services to appropriate audiences and position, promote, and communicate effectively over time.
- B. Bereavement Plan: The bereavement plan describes how the palliative care program will assist the patients' family members during the period of transition before and following the death of their loved one.
- C. Educational Plan: Educational activities are offered to palliative care team members or other health professionals to help improve the quality of care provided to patients and their families.
- D. Quality Improvement Plan: The quality improvement plan describes how a palliative care program evaluates its performance in delivering care, and outlines plans for improvements to program service offerings.
- E. Strategic Business Plan: Business planning is necessary for growth and success. Strategic business plans are an organization's process of defining its strategy, or direction, and making decisions on allocating its resources to pursue this strategy.
- F. Multi-year Budget Plan: A multi-year budget plan covers expected expenditures and revenue over the next few years. Multi-year budget plans can help improve financial management, strategic planning, program evaluation, link to operating activities, and identify imbalances between revenues and expenditures.
- G. Staff Orientation Plan: An orientation is provided or facilitated by the palliative care program for the interdisciplinary team members, program staff and volunteers. The orientation plan and specific content are defined by the program leaders. Orientation may be provided over a period of time and in a variety of methods, including live and video presentations; electronic or written materials; clinical experience with a preceptor or mentor; or education at a seminar or other organization.

Level II: Optional Program Information

While we refer to the following five Modules as “optional,” the questions are feasible to answer and all programs should aim to answer Modules 5-10. Some questions may require your palliative care program to track data in a certain way. If you are not able to answer a question in these Modules, please use the “I cannot answer this question” option.

Module 5. Program Integration

30. What is your palliative care program’s relationship to a hospice? (check all that apply)

- No relationship exists
- Our palliative care program and hospice program function under one administrative entity
- The hospital/health system owns its own hospice. It is administratively separate from the palliative care program
- We have contracts with one or more community hospice agencies
- We informally collaborate with community hospice agencies
- Other, specify _____

Please select the options that best represent your palliative care program’s relationship to hospice. If your palliative care program does not fit any of the above options, select “other” and add a short description of your program’s relationship to hospice.

31. Describe the progress of medical ICU and palliative care integration in your hospital (check all that apply)

- We are rarely called to see ICU patients
- We see ICU patients, but there has been minimal work to develop a system of care coordination between ICU and palliative care
- The palliative care and ICU teams have worked collaboratively to develop a system to enhance care in the ICU (e.g., screening criteria, automatic consults)
- The ICU has developed and/or implemented plans to improve delivery of palliative care within the ICU (e.g., palliative care training for ICU staff, patient/family support materials, hired a hospice and palliative medicine (HPM) trained physician, routine family meetings)

Palliative care integration refers to joint activities (between your palliative care program and other hospital sites of care) to promote the use of specialty palliative care services and/or to improve generalist level palliative care within the ICU.

32. Describe the progress of emergency medicine (EM) and palliative care integration in your hospital (check all that apply)

- We are rarely called to see EM patients
- We see EM patients, but there has been minimal work to develop a system of care coordination between EM and palliative care
- The palliative care and EM teams have worked collaboratively to develop a system to enhance care in the EM (e.g., screening criteria, automatic consults)
- The EM team has developed and/or implemented plans to improve delivery of palliative care within the emergency department (e.g., palliative care training for emergency department staff, patient/family support materials, hired a hospice and palliative medicine (HPM) trained physician, routine family meetings)

Palliative care integration refers to joint activities (between your palliative care program and other hospital sites of care) to promote the use of specialty palliative care services and/or to improve generalist level palliative care within Emergency Medicine

33. Did your palliative care team see any patients in the hospital's observation beds?

- a. Yes
- b. No
- c. Not applicable

Observation beds are set up to provide patient care and observation for a short period of time, while determining whether the patient can be safely discharged or if they should be admitted to the hospital as an inpatient. Observation patients are not considered inpatient until they are admitted to the hospital.

34. Provide the number of annual initial palliative care consults by the patients' location at time of referral (secondary categories are optional, should add to the total number of initial consults reported in Module 1)

<u>Referral Location</u>	<u>Number of initial consults</u>
a. Medical/Surgical	_____
i. Medical	_____
ii. Surgical	_____
b. Intensive/Critical Care	_____
i. Medical/Surgical ICU	_____
ii. Neuro ICU	_____
iii. Cardiac ICU	_____
iv. Burn ICU	_____
v. Pediatric ICU	_____
vi. Neonatal ICU	_____
c. Oncology	_____
d. Gastroenterology	_____
e. Maternal-Fetal Medicine	_____
f. Geriatrics ACE unit	_____
g. Emergency Department (ED)	_____
h. Telemetry / step-down	_____
i. MD Office / Home (direct admit)	_____
j. Hospice	_____
k. Other, specify _____	_____

I cannot answer this question

Provide the total number of annual inpatient initial consults referred from the following locations. The sum of all primary categories should equal the total number of initial consults reported during the reporting period. Secondary categories (e.g. for the ICU) are not required but provide a deeper level of information and should sum to the primary category. If you do not track this information or are not able to access it, please check off "I cannot answer this question."

35. Provide the number of annual initial palliative care consults by specialty of referring clinician (should add to the total number of initial consults reported in Module 1)

<u>Referring Specialist</u>	<u>Number of initial consults</u>
a. Hospitalist	_____
b. Oncologist	_____
c. Cardiologist	_____
d. Nephrologist	_____
e. Pulmonary and/or critical care	_____
f. Surgery	_____
g. Neurologist	_____
h. Gastroenterologist	_____
i. Internal Medicine	_____
j. Family Medicine	_____
k. Neonatologist	_____
l. Maternal-Fetal Medicine	_____
m. Other referring clinical specialist	_____
n. Don't Know / Not sure	_____
o. Other, specify _____	_____

I cannot answer this question

Provide the total number of annual inpatient initial consults referred from the outlined physician specialties. The sum of all categories should equal the total number of initial consults reported during the reporting period. If you received referrals from another type of specialist(s), add that information in the “other” option. If you do not track this information or are not able to access it, check off “I cannot answer this question.”

Module 6. Consult Timing and Reasons

36. Select the *top three* reasons given by referring providers for the initial palliative care consult:

- a. Pain
- b. Non-pain symptoms
- c. Establishing goals of care
- d. Advance care planning
- e. Withdrawal of treatment
- f. Family Support and/or Counseling
- g. Coordination of care
- h. End of life or hospice referral
- i. Other, specify _____

Please select the top 3 reasons given by referring clinicians for patient's reason for a palliative care consult.

37. On a scale of 1 to 5, approximately how often are your palliative care consults completed within the first 48 hours of a patient's' admission?

- a. 1- Never
- b. 2 - Rarely
- c. 3 - Sometimes
- d. 4 - Often
- e. 5 - Always

Please use your best judgement to identify how often your palliative care consults are completed within 48 hours from hospital admission.

38. On a scale of 1 to 5, approximately how often are your palliative care consults completed within 24 hours of the patients' referral to palliative care?

- a. 1- Never
- b. 2 - Rarely
- c. 3 - Sometimes
- d. 4 - Often
- e. 5 - Always

Please use your best judgement to identify how often your palliative care consults are completed within 24 hours from the referral date to palliative care.

Module 7. Demographics & Diagnoses

39. Indicate the number of initial palliative care consults by age group seen by your program during the reporting period (secondary categories are optional; should add to the total number of initial consults reported in Module 1)

<u>Age Group</u>	<u>Number of initial consults</u>
a. Pediatric (less than 18 years)	_____
i. Prenatal (before birth)	_____
ii. Neonate (birth to 28 days)	_____
iii. Infant (29 days to 11 months)	_____
iv. Children (12 months to 12 years)	_____
v. Adolescent (13 to 17 years)	_____
b. Young Adult (18 to 25 years)	_____

- c. Adult (26 years and older) _____
- i. 26 to 44 years _____
- ii. 45 to 64 years _____
- iii. 65 to 85 years _____
- iv. 86 years or more _____

I cannot answer this question

Provide the age distribution for inpatient initial palliative care consults during the reporting period. The sum should equal the total number of initial consults reported during the reporting period. Secondary categories (e.g. for Pediatric) are not required but provide a deeper level of information and should sum to the primary category. If you do not track this information or are not able to access it, please check off “I cannot answer this question.”

40. Indicate the number of initial palliative care consults seen by your program in the following ethnicity categories (should add to the total number of initial consults reported in Module 1)

<u>Race/Ethnicity</u>	<u>Number of initial consults</u>
a. Black/African-American non-Hispanic	_____
b. White/Caucasian non-Hispanic	_____
c. Asian non-Hispanic	_____
d. American Indian/Alaska Native non-Hispanic	_____
e. Hawaiian Native/Pacific Islander non-Hispanic	_____
f. Hispanic/Latino	_____
g. Other, specify _____	_____

I cannot answer this question

Provide the ethnicity distribution for inpatient initial palliative care consults during the reporting period. If “unknown” please include in “other.” The sum of all categories should equal the total number of initial consults reported during the reporting period. If you do not track this information or are not able to access it, please check off “I cannot answer this question.” We are unfortunately not able to provide a roadmap of diagnosis codes to each of the categories.

41. For **pediatric palliative care programs**, indicate the number of initial palliative care consults seen in the following primary underlying diagnosis groupings.

<u>Primary Diagnosis</u>	<u>Number of initial consults</u>
a. Cancer/Malignancy	_____
b. Cardiovascular	_____
c. Fetal/Prenatal Consult	_____
d. Genetic/chromosomal syndrome	_____
e. GI/Hepatic	_____
f. Hematologic (non-malignant)	_____
g. Immunologic/Infectious	_____
h. Metabolic	_____
i. Neurologic/Neuromuscular/ Neurodegenerative	_____
j. Other/unknown	_____
k. Prematurity, complications related to	_____
l. Pulmonary	_____
m. Renal	_____
n. Traumatic	_____

I cannot answer this question

This version of the question is available for pediatric palliative care programs to recognize differences in diagnoses categories seen by these programs. If your program is a pediatric palliative care program, please return to Module 1 and select “no” to question 6 to get the non-pediatric version of this question. Please provide the total number of initial consults in the disease/diagnostic groups. These should represent the underlying or primary diagnosis category. The sum of all primary category responses should equal the total number of initial consults reported during the reporting period. If you do not track this information or are not able to access it, please check off “I cannot answer this question.” Fetal/Prenatal consults refer to any consults involving a pregnant mother, regardless of the fetal diagnosis. Use “prematurity, complications related to” if consulted only during birth admission, regardless of complication. Use “Traumatic” for a previously healthy child with sudden serious illness, such as drowning or MVC. We are unfortunately not able to provide a roadmap of diagnosis codes to each of the categories.

41. For **non-pediatric palliative care programs**, indicate the number of initial palliative care consults seen in the following primary underlying diagnosis groupings (secondary categories are optional, should add to the total number of initial consults reported in Module 1)

<u>Primary Diagnosis</u>	<u>Number of initial consults</u>
a. Cancer	_____
i. Hematological	_____
ii. Non-hematological	_____
b. Cardiac	_____
i. CHF	_____
ii. Cardiac Arrest	_____
iii. MI	_____
iv. Other Cardiac	_____
c. Pulmonary	_____
i. COPD	_____
ii. Pneumonia	_____
iii. Other Pulmonary	_____
d. Dementia	_____
e. Complex chronic conditions/failure to thrive/frailty	_____
f. Renal	_____
g. Vascular	_____
h. Congenital/chromosomal	_____
i. Infectious/Immunological	_____
j. Gastrointestinal	_____
k. Hepatic	_____
l. Hematology	_____
m. Endocrine/Metabolic	_____
n. Prematurity	_____
o. In-utero complication/condition	_____
p. Neurologic/stroke/neurodegenerative	_____
q. Trauma	_____
r. Other, specify_____	_____
<input type="checkbox"/> I cannot answer this question	

If your program is a pediatric palliative care program, please return to Module 1 and select “yes” to question 6 to get the pediatric version of this question. Provide the total number of initial consults in the disease/diagnostic groups. These should represent the underlying or primary diagnosis category. The sum of all primary category responses should equal the total number of initial consults reported during the reporting period. Secondary categories are not required, but if available, should add up to the total number in the primary category. If you do not track this information or are not able to access it, please check off “I cannot answer this question.”

Module 8. Documentation

42. Does your palliative care program use a standardized consult note when charting?
- Yes
 - No

Please indicate if your palliative care program used a standardized consult note when charting during the reporting period.

43. If yes, which of the following does your palliative care program document in a patient’s chart and place in the medical record? (check all that apply)
- Goals of care
 - Surrogate decision maker (name and contact information)
 - Life sustaining treatment preferences
 - Advance directive
 - Code Status and/or Do Not Resuscitate order
 - Physician Orders for Life-Sustaining Treatment (POLST)
 - Other, specify _____

If your program used a standardized consult not when charting, please indicate which items were documented in your palliative care patient’s chart and placed in the medical record.

Module 9. Program Funding

44. Select the top three funding sources for your inpatient palliative care program’s budget from the following list:
- Financial support from hospital or other parent organization (including salary stipends, not including philanthropy)
 - Fee for service clinician billing (including Medicare Part B)
 - Bonus payments for quality measures
 - Subsidy from partner organizations
 - Financial contracts/service agreements with other providers or vendors (where

you do not bill the payer directly)

- Philanthropic and foundation support
- Not funded
- Other, specify _____

Please select the top three funding sources for your palliative care program during the reporting period. If a funding source is not listed, please provide a description in the “Other, specify” option.

45. Approximately what percent of your inpatient palliative care program budget comes from the following sources (should add to 100%):

- a. Financial support from hospital or other parent organization (including salary stipends, not including philanthropy) _____
- b. Fee for service clinician billing (including Medicare Part B) _____
- c. Bonus payments for quality measures _____
- d. Subsidy from partner organizations _____
- e. Financial contracts/service agreements with other providers or vendors (where you do not bill the payer directly) _____
- f. Philanthropic and foundation support _____
- g. Not funded _____
- h. Other, specify _____

Provide an approximate breakdown of your total program budget. The sum should equal 100%.

46. Does your organization participate in alternative payments (such as case rates or bundled episode payments)?

- a. Yes
- b. No
- c. Not Sure

Please indicate if during the reporting period your palliative care program or larger hospital participated in alternative payments like shared savings/risk arrangements, bundled payments, or population-based reimbursements.

Module 10. Hospital Discharges

47. Please provide the number of palliative care initial consults by discharge disposition on the day of hospital discharge, during the reporting period (should add to the total number of initial consults reported in Module 1)

<u>Discharge Disposition</u>	<u>Number of Initial Consults</u>
a. Home without Hospice	_____
b. Home with Hospice	_____
c. Hospice - Health Care Facility	_____
d. Acute Care Facility	_____
e. Other Health Care Facility (definition below)	_____
f. Expired	_____
g. Left Against Medical Advice/AMA	_____
h. Not Documented or Unable to Determine (UTD)	_____
i. Not Discharged from the Hospital during Reporting Period	_____

I cannot answer this question

Answers should reflect discharge from the hospital, not discharge from the palliative care service. If a patient was not discharged from the hospital during the reporting period and remained in the hospital, please include them in the last option “Not discharged from the hospital”. The sum of all categories should equal the total number of initial consults reported during the reporting period.

- Home: Assisted living facilities and assisted living care at other health care facilities; Court/Law Enforcement - includes detention facilities, jails, and prison; Home - includes board and care, foster or residential care, group or personal care homes, retirement communities, and homeless shelters; Home with home health services, self-care, or palliative care.
- Hospice - Home: Hospice in the home (or other Home setting as above in “Home”)
- Hospice Health Care Facility: Hospice - General Inpatient and Respite; Hospice - Residential and Skilled Facilities; Hospice - Other Health Care Facilities
- Acute Care Facility: Acute Short Term General and Critical Access Hospitals; Cancer and Children’s Hospitals; Department of Defense and Veterans Administration Hospitals
- Other Health Care Facility: Extended or Intermediate Care Facility (ECF/ICF); Long Term Acute Care Hospital (LTACH); Nursing Home or Facility including Veterans Administration Nursing Facility; Psychiatric Hospital or Psychiatric Unit of a Hospital; Rehabilitation Facility including inpatient Rehabilitation Facility/Hospital or Rehabilitation Unit of a Hospital; Skilled Nursing Facility (SNF), Sub-Acute Care or Swing Bed; Transitional Care Unit (TCU); Veterans Home

If you do not track this information, are not able to access it, or do not follow your palliative care patients to hospital discharge please check off “I cannot answer this question.”

48. For initial consults that were discharged from the hospital during the reporting period, approximately what percent continued to receive palliative care services?

Provide the approximate percent of initial consults that continued palliative care after hospital discharge.

Palliative care services could be provided by your palliative care program or other palliative care programs in the community.

Level III. Specialty Modules (if applicable)

Module 11. Pediatric Palliative Care:

49. Please list the number of beds at this hospital that are dedicated to the following uses:

- a. Dedicated Pediatric Oncology Beds _____
- b. Pediatric Intensive Care Unit Beds _____
- c. Pediatric Cardiac Intensive Care Beds _____
- d. Neonatal Intensive Care Beds _____
- I cannot answer this question

Please list the number of beds associated with each of the above hospital units. If you cannot answer this question, please select "I cannot answer this question." If your hospital does not have beds dedicated to that type, please enter "0."

50. Do you provide coverage to all of the hospital beds reported above? (Check all that apply)

- Yes, we provide coverage to all of the beds reported
- No, we have limited coverage due to insufficient staffing
- No, our program is designed to focus on specific high need areas
- No, we have retracted our coverage area to prevent team burnout
- Other, specify _____

Please select the option(s) that best describes your pediatric palliative care program's operations during the reporting period. This question is specifically about dedicated oncology beds, pediatric intensive care unit beds, pediatric cardiac intensive care beds, and neonatal intensive care beds that were reported in the previous question. If none of the above responses fit your program, use the space provided in "Other."

51. Does your palliative care program provide 24/7 coverage (definition in guidance) for providers caring for patient in the hospital setting?

- a. Yes
- b. No

24/7 coverage is defined as a full-time service, where patients can access palliative care as needed, 24 hours per day. At a minimum 24/7 coverage should include M-F consultation availability and 24/7 telephone support.

52. If no, what times do you have coverage? (Check all that apply)

- Weekday, days
- Weekday, evenings
- Weekday, nights
- Weekend, days
- Weekend, evenings
- Weekend, nights

Check all the times where your palliative care program has coverage for palliative care consultations. Coverage can be: on-site, telephone return (your staff responds to care questions as needed; staff will come in at any hour to ensure quick responses to consult requests and to follow-up with existing patients), or telephone-only (your staff responds to care questions by telephone. They do not come in off work hours to provide consults or conduct follow-up visits).

53. Does your palliative care program provide 24/7 coverage (definition in guidance) for hospice providers in the community?

- a. Yes
- b. No

24/7 coverage is defined as a full-time service, where local hospices can access the palliative care program as needed, 24 hours per day. At a minimum 24/7 coverage should include M-F consultation availability and 24/7 telephone support.

54. If no, what times do you have coverage? (Check all that apply)

- Weekday, days
- Weekday, evenings
- Weekday, nights
- Weekend, days
- Weekend, evenings

Weekend, nights

Check all the times where your palliative care program is available for hospice providers in the community. Coverage can be: on-site, telephone return (your staff responds to care questions as needed; staff will come in at any hour to ensure quick responses to consult requests and to follow-up with existing patients), or telephone-only (your staff responds to care questions by telephone. They do not come in off work hours to provide consults or conduct follow-up visits).

55. When considering your team’s total workload, how concerned are you that your team is at risk for burnout if current workload requirements continue?

1. Not at all concerned
2. Slightly concerned
3. Somewhat concerned
4. Moderately concerned
5. Extremely concerned

Please use your best judgement to select the answer that best represents your pediatric palliative care program’s risk for burnout based on the workload reported during the reporting period.

56. In addition to inpatient palliative care consultation, what other services are offered for pediatric patients as part of the pediatric palliative care program? (Check all that apply)

- Inpatient primary medical management
- Inpatient hospice services
- Ambulatory/outpatient visits
- Home hospice services
- Home palliative care visits
- Complex Care Service
- Consultative Acute Pain Service
- Chronic Pain Management Program
- Complementary Medicine Consult Service
- Telehealth services
- Staff support services
- Bereavement services
- Other, specify: _____

Please select the services that your palliative care program provides. The response can cover your palliative care program’s work across the continuum and does not need to be limited to the inpatient setting.

57. Are hospice services readily and predictably available for your pediatric palliative care patients?

- a. Yes
- b. No

Hospice services are considered readily and predictably available when referrals and assurances about continuity of care occur with equivalent availability and security as when with adults in your community needing those services request them.

58. For your pediatric palliative care patients receiving disease directed treatments yet meeting criteria for hospice admissions, is there resistance to the provision of concurrent care by available hospices?

- a. Yes
- b. No

The Patient Protection and Affordable Care Act (PPACA) allows terminally ill children who are enrolled in a Medicaid or state Children's Health Insurance Plans (CHIP) hospice benefit to concurrently receive curative care related to their terminal health condition. Examples of resistance by available hospices may include refusal of services or enrollment based upon ongoing disease-directed medicines or technology.

59. By formal procedure, does your program share the findings of pediatric palliative care consults with the child's primary care pediatrician?

- a. Yes
- b. No

Does your palliative care program have a formal policy to share findings of pediatric palliative care consults with the child's primary care pediatrician? If your program occasionally shares findings but does not have a formal procedure to do so, please select "no."

60. Does your hospital have a room available for pediatric end-of-life care?

- a. Yes
- b. No

Does your hospital have specific private rooms that allow families to stay with their child at end of life? End-of-life care rooms allow patients and families to spend their last moments together.

61. Do your clinicians participate in the following academic pursuits? (Check all that apply)

- Education and training of other clinicians
- Research

- Submitting publications
- Presenting in national, regional, or local conferences
- Garnering outside funding sources (philanthropy or grants)
- Local, regional, or national leadership involvement in professional organizations
- Other, specify _____

Clinicians on your team refer to physicians, physician assistants and nurses. Please check all that apply to the clinicians on your pediatric palliative care team.

62. Does your palliative care program participate in the structured education of any of the following healthcare professionals? (Check all that apply)

- Fellowship training in HPM for board-certified/board-eligible pediatricians
- Medical Students
- Residents
- Non-HPM Fellows
- Nurse Practitioners
- Nurses
- Social Workers
- Chaplains
- Child Life Specialists
- Expressive Therapists
- Allied Health Professionals (dietitians, rehab personnel, pharmacists)
- Other, specify _____

Structured education refers to focused educational initiatives such as scheduled didactics and options to spend time with the team (clinical rotations or internships). Do not include bedside or “on-the fly” teaching. HPM stands for Hospice and Palliative Medicine.

Module 12. Palliative Care Unit

63. Do you have a dedicated Inpatient Palliative Care Unit?

- a. Yes
- b. No

An inpatient palliative care unit is a physically discrete, inpatient nursing unit where the focus is palliative care. The patient care focus is on symptom relief for complex patients who may be continuing to undergo primary treatment. Care is delivered by palliative medicine specialists.

If no, the following questions are not required.

If yes...

64. How many beds did your inpatient palliative care unit have during the reporting period?

Please provide the number of beds set up and staffed in the palliative care unit for the reporting period.

65. What was the total number of palliative care (non-hospice) admissions to the inpatient palliative care unit during the reporting period? _____

Provide the total number of non-hospice palliative care admissions to the inpatient unit during the reporting period.

66. Are any beds in the inpatient palliative care unit used as swing or dedicated hospice beds?

- a. Yes
- b. No

Some inpatient palliative care units have beds that can be used for swing or hospice. Please indicate if this is the case with your inpatient palliative care unit.

67. For palliative care patients, what is the inpatient mortality rate on the inpatient palliative care unit? _____

Provide the observed mortality rate for the reporting period defined as the number of inpatient palliative care unit admissions who died divided by the total number admitted to the inpatient palliative care unit. This number should be expressed as a percentage.

68. Are the disciplines (e.g., medicine, nursing, social work, and chaplaincy) represented on your inpatient palliative care unit team the same as those represented on your inpatient consultation service team?

- a. Yes
- b. No

Earlier in the survey, you indicated the staffing for your inpatient palliative care consult service. Please indicate if the staffing for your consultation team is the same as the staffing for your inpatient palliative care unit.

69. Are your floor nurses dedicated to the inpatient palliative care unit?

- a. Yes
- b. No

Please indicate if floor nurses are dedicated to the inpatient palliative care unit.

70. In times of low staffing, are your nurses floated to other units due to census variation?

- a. Yes
- b. No

Please indicate if inpatient palliative care unit nurses are floated to other units during times of low staffing due to census variation.

71. Do you have a formal policy guiding admission criteria to your inpatient palliative care unit?

- a. Yes
- b. No

Please indicate if your inpatient palliative care unit has a formal policy guiding admission criteria that determines which patients are admitted to the palliative care unit.

72. If yes, which of the following are included in your palliative care unit admission policy?

Admission Criteria	No	Yes	Yes, with limitations
Require patients to have a DNR order	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Accept patients on ventilators	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Accept patients on dialysis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Accept patients on vasopressors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please indicate if your palliative care unit has any of the following included in the admission policy. If, for example, your palliative care unit accepts patients on vasopressors provided that they are capped and not being titrated, you would select “Yes, with limitations.”

73. If you answered “yes, with limitations” to any of the options in the previous question, please describe those limitations here: _____

If you indicated in the previous question that you have limitations to any of your admission criteria, please outline those limitations here. We’re interested in learning what limitations palliative care units use when admitting patients with DNRs, on ventilators, on dialysis, and on vasopressors.