

Title: Implementing Best Practices in Palliative Care

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Kimberly S. Johnson, MD, MHS (Principal Investigator)  
Duke University School of Medicine

Jean Kutner, MD, MPH  
University of Colorado Health System

Janet Bull, MD  
Four Seasons Compassion for Life

Christine Richie, MD, MPH  
University of California, San Francisco

Laura Hanson, MD, MPH  
University of North Carolina, Chapel Hill

Arif Kamal, MD  
Duke University School of Medicine

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Program Official: **Name:** Burgess, Denise

**Email:** [denise.burgess@ahrq.hhs.gov](mailto:denise.burgess@ahrq.hhs.gov)

## Abstract

**Purpose:** Palliative care focuses on the relief of suffering and achieving the best possible quality of life for patients their caregivers. The growth of palliative care programs in the United States has paralleled the increased realization of the need for a specialized approach to the care of people with life-limiting illness. A relatively new subspecialty, palliative care is building its evidence base supporting clinical practice. Quality monitoring and performance improvement initiatives are an important approach to reinforce evidence implementation. This purpose of this project was to combine the capabilities of the Palliative Care Research Cooperative Group (PCRC) and a collaboratively designed point-of-care quality monitoring program (QDACT) to generate a national network for quality monitoring in palliative care (QDACT-PCRC).

**Scope:** This project is a collaboration of the PCRC led by five sites—Duke University, Four Seasons Compassion for Life, University of North Carolina at Chapel Hill, University of Colorado at Denver, and University of California at San Francisco.

**Methods:** We collaboratively updated and expanded QDACT and demonstrated its use as a tool to assess and benchmark adherence to a common set of quality measures across participating PCRC sites.

**Results:** We successfully developed and deployed the first patient-level quality monitoring and reporting system for specialty palliative care embedded within a research collaborative. This project has provided foundational work to implement and disseminate QDACT-PCRC nationwide, which will result in a larger and more robust quality measurement registry that can be used to improve the care of seriously ill patients.

**Key Words:** palliative care, quality monitoring

## Background/Context

The dramatic rise in the burden of chronic illness and frailty has led to a host of physical and psychological symptoms associated with those conditions. Palliative care and hospice focus on the relief of suffering and achieving the best possible quality of life, including ameliorating symptoms, relieving psychological distress, and promoting spiritual well-being for patients and their caregivers. The growth of palliative care programs and services in the United States has paralleled the increased realization of the need for a rational, specialized approach to the care for people with advanced life-limiting chronic illness. This expansion is broadly evident; for example, today, almost three quarters of all hospitals in the United States (US) provide some palliative care services; the prevalence of hospitals (50 or more beds) with a palliative care team increased from 658 to 1,831—a 178% increase from 2000 to 2016.<sup>1,2</sup> These efforts have been fruitful; studies demonstrate improved patient outcomes and family satisfaction, cost savings, and lower resource utilization.<sup>3-6</sup>

A relatively new subspecialty, palliative care is building its evidence base supporting clinical practice. The National Institute of Nursing Research funded national research network, the Palliative Care Research Cooperative Group (PCRC), is an efficient mechanism for evidence development including comparative effectiveness research.<sup>7,8</sup> The fundamental next step is efficient implementation of new evidence and emerging clinical care guidelines into practice. Quality monitoring and performance improvement initiatives are an important approach to reinforce evidence implementation; there must be a uniform approach to measurement across sites, review of current quality measure conformance, agreement on benchmarks, development of an evidence-derived quality improvement program responsive to findings, and assessment of the impact of proposed change on clinical practice by monitoring data.<sup>9</sup> Prior to the funding of this proposal, a regional electronic point-of-care quality monitoring program called QDACT-PC had been developed and piloted in North Carolina. QDACT-PC was shown to be well liked by clinicians, usable, feasible, and able to generate reliable information that could be used to benchmark conformance with palliative care quality metrics and reinforce best practice. Data elements to define conformance to >80% of currently recognized palliative care measures were included in QDACT-PC, including all of the recently endorsed National Quality Forum (NQF) measures.<sup>10,11</sup>

**The overall goal of this proposal was** to introduce QDACT-PC within the engaged research and clinical care footprint of the PCRC to create a national network for point-of-care palliative care quality monitoring and demonstrate its capabilities for conducting quality improvement projects and reinforcing contemporary standards for clinical best practice. The specific aims, methods, and findings are detailed below.

**AIM 1: To develop and nationally implement a uniform approach to palliative care quality monitoring using a PCRC-specific version of QDACT-PC (QDACT-PCRC).**

**Methods:** We developed a novel point-of-care software as the infrastructure to nationally implement a uniform approach to quality monitoring in specialty palliative care called the Quality Data Collection Tool for the Palliative Care Research Cooperative Group (QDACT-PCRC). Derived from a previously developed and tested software called QDACT-PC, QDACT-PCRC is the second instantiation of QDACT with the addition of new data elements, including a caregiver module and expanded clinical site characteristics. These new data elements were developed from collaboration with the PCRC Measurement Core and Family Caregiver Core. QDACT-PCRC aligns with PCRC core data elements and most nationally recognized palliative care quality measures from The Joint Commission, National Quality Forum, and National Consensus Project for Quality Palliative Care. In addition, we made modifications to the user interface of QDACT-PCRC to assist with system usability at point of care and integration into system workflow of both community and academic palliative care practices.

*Alignment with PCRC:* Since its initial funding, the PCRC has grown to include more than 300 members, representing 130 sites. The PCRC has supported more than 50 research applications and engaged in 27 studies.<sup>12</sup> Given the growth of the PCRC, the QDACT-PCRC Registry will be a more valuable resource if it can be combined with the rest of the PCRC study datasets for secondary data analyses. Using the stakeholder-defined data dictionary as a starting point, programming for the aligned QDACT-PCRC database was initiated (aka the QDACT-PCRC Registry). The software interface was revised to include new content, layout, branching logic, and “look and feel” specific for QDACT-PCRC.

As a first step, we determined the overlap between QDACT-PCRC data elements and the rest of the PCRC databases; the goal was to drive consensus and adoption for one standard when divergent approaches are identified.

Initial assessments demonstrated that approximately 50% of QDACT-PCRC data elements overlap with the planned PCRC core data elements. To increase this, we worked with the PCRC Steering Committee, palliative care leadership at the five participating R18 sites and across the PCRC, as well as at other palliative care organizations, to understand the most important variables to capture, reasons for divergence in data elements, and goals around measures reporting (which will drive adoption and concurrence of data definitions/translation). A dedicated Working Group was formed in partnership with the PCRC to accelerate the process. Two face-to-face meetings were held to facilitate consensus among investigators.

In addition, we systematically mapped the QDACT-PCRC data elements to national data sets (e.g., NCI CancerBIG), caDSR) to ensure maximal interoperability with other national datasets. Because palliative care is a new field, many of our core data elements are missing from these national standards (e.g., data elements related to caregiver distress). Hence, in partnership with the National Cancer Institute (NCI), we are curating data elements into the NCI's caDSR. These critical steps strengthen our ability to create scalable approaches for data collection in myriad source systems that then can link to the QDACT-PCRC Registry. As additional data elements are determined these will also be mapped, curated, piloted, and refined.

*Alignment with Existing Quality Measures:* The team mapped QDACT-PCRC data elements to NQF endorsed measures and five items newly endorsed by the American Academy of Hospice and Palliative Medicine through the American Board of Internal Medicine Choosing Wisely Campaign, ensuring that all measures can be assessed using QDACT-PCRC data and generating a plan to link measures to outcomes.<sup>13,14,15</sup> The team ensured that QDACT-PCRC would facilitate the assessment of these measures in real time and via routine periodic reporting, checking that our methodology for numerators and denominators align with national standards for quality measurement. Because QDACT-PCRC also contains data elements reflective of clinical outcomes, changes in quality measures can be correlated to changes in outcomes. An overall analytic plan for the NQF measures was established as a prototype that can be replicated for other measures as they are added to the QDACT-PCRC portfolio.

*Caregiver Measures:* A unique aspect of palliative care clinical practice and research is our focus on caregivers. In alignment with the goals of the R18, data elements regarding caregivers were added to the QDACT-PCRC data dictionary. In order to define these data elements, we reviewed and evaluated approximately 100 caregiver distress measures; among these, we identified five measures that can be feasibly implemented at point-of-care without causing disruption to the normal clinical interaction between the clinician and the patient. The measures include relationship of the informal caregiver to the patient; role of caregiver (primary, secondary, etc.); type of help provided to the patient; whether caregiver has asked for help from others; and, if yes to the latter, whether caregiver received requested help. These were pressure tested with our community-based investigators and crosschecked with the Caregivers Core in the PCRC. The data elements required to report on these measures were incorporated in the QDACT-PCRC data dictionary; because this work has been done in concert with the PCRC from the outset, they were inherently incorporated into the PCRC core and recommended data dictionaries.

**Results:** In pilot testing, we confirmed usability of current data elements and measures within our QDACT-PCRC system of point-of-care data collection. All five sites participating in this R18---Duke University, Four Seasons Compassion for Life, University of North Carolina-Chapel Hill, University of California-San Francisco, and University of Colorado-Denver---participated in QDACT-PCRC software feasibility testing, which included 256 unique clinical encounters. No major limitations were identified. To date, we have implemented in 32 palliative care sites (Figure 1). Of these, 10 are academic sites, 11 community-based sites, and seven are hospital systems.

At the five PCRC sites included in this R18, we collected data points on 30,963 clinical encounters, representing 14,993 unique patients. The demographics of the sample are included in Table 1. The total number of unique patients currently in the QDACT registry is 29,329, representing 50,000 encounters from all 32 sites.

Sites are actively using these data to inform local quality improvement efforts and collaborative projects, as described below. The registry has also provided data for numerous publications describing the experience of palliative care patients and informing efforts to improve quality.

**Future Directions:** In collaboration with the American Academy of Hospice and Palliative Medicine, the Palliative Care Quality Networks, the Center to Advance Palliative Care, and National Palliative Care Research Center, we have recently received a \$2.4M grant from the Gordon and Betty Moore Foundation to create a nationwide, unified quality measurement infrastructure and registry based on QDACT-PCRC. QDACT-PCRC will serve as the template and framework for expansion efforts, with a 5-year goal that most palliative care organizations participating in the registry.

**Conclusions/Implications:** We have successfully developed and deployed the first patient-level quality monitoring and reporting system for specialty palliative care embedded in a research collaborative. Embedding and testing within the PCRC ensure that specialty palliative care is working toward its goal of achieving rapid learning healthcare, where it learns how to improve the care it delivers simultaneously to delivering the care itself. Achievements during the grant have provided foundational work for the next phase of studies, funded by the Moore Foundation, aiming to implement and disseminate QDACT-PCRC nationwide. Thus, a larger and more robust quality measurement registry to benchmark amongst practices and identify opportunities for improvement will emanate from the aims completed in the R18.

**AIM 2: To define benchmarks for key quality measures in palliative care using network-wide data from the QDACT-PCRC.**

**Methods:** We performed a retrospective review of quality measure adherence across patients evaluated by the specialty palliative care consult service at five sites in the Palliative Care Research Cooperative Group: Duke University, University of California-San Francisco, University of Colorado Health, University of North Carolina-Chapel Hill, and Four Seasons in Hendersonville, NC. Data were collected and stored in the Quality Data Collection Tool (QDACT-PCRC).

**Abstraction:** Experienced research staff alongside one site investigator for each location identified a random or consecutive sample of 50 unique new patients seen at least two times between January 1, 2017, and June 30, 2017. Patients were at least 18 years of age or older and seen in inpatient or outpatient setting. Data abstraction for inpatients included first/new visit and last/discharge visit and for outpatient encounters included the first and second visits. We also included measures based on diagnosis and consultation location in addition. For these, only initial visit was used, as there was no guarantee that diagnosis and consultation location was the same for both visits.

**Quality Measures Assessed:** We chose quality measures based on their importance to palliative care, frequency of data collection among palliative care providers, and alignment with NQF-endorsed or PEACE quality measures.

- Physical Screening Measure: The percentage of seriously ill patients who were screened for numerator for ALL four symptoms: pain, dyspnea, nausea, and constipation. Denominator was all patients.
- Comprehensive Pain Assessment Measure: The percentage of patients who screened positive for pain (ESAS pain severity of 4 or higher) and who received a comprehensive pain assessment (five or more of the following assessed: location, severity, character, duration, frequency, relieving/exacerbating factors/effect on function or quality of life).
- Treatment preference measure: Numerator was patients who had one or more of the following: “discussion had” or “discussion attempted” regarding goals of care OR “yes” or “does not wish to discuss” for “was a discussion had regarding a scope of treatment document or form” OR “yes” or “does not wish to discuss” for “was a discussion had regarding hospice.”

**Results:** Among five sites in the PCRC, we reviewed the consultations of 250 unique patients cared for between January 1, and June 30, 2017. Table 2 includes demographics of total sample and site specific demographics. The median age of all patients was 67. The majority of patients were non-Hispanic Whites, and the most common diagnosis was cancer. Over half of patients were seen in hospital (general ward); outpatient (24%) was the second most common location for patients. There was some notable variation by site with Site D, including patients with older median age and half of patients seen in long-term care. All patients from Site C were seen in the outpatient clinic, and the vast majority (94%) had a cancer diagnosis.

Table 3 includes adherence to quality measures for total sample and by site. For the total sample, adherence ranged from 76.5% for the comprehensive pain assessment measure to 87.2% for the treatment preferences measure. Adherence to all five symptoms in the physical screening measure was 85.6%; however, adherence to each individual symptom exceeded 90%. There was important variation in quality measure adherence across sites. The treatment preferences measure had the highest adherence across sites with a range of 82% to 98%.

Adherence to the physical screening measures (all) ranged from 68% to 100% and to comprehensive pain assessment measure from 50% to 95.2%. Of note, the number of patients eligible for comprehensive pain assessment measure varied widely across sites from 4 to 28.

**Conclusion/Implications:** There was variation in quality measure adherence rates, with the highest rates of adherence for treatment preferences measures. There was also significant variation across sites for all measures. This across site variation may be due to local processes of care or team norms for practice. This suggests that quality improvement efforts are likely to be most effective when guided by local needs, assessments, and practices. Though this is likely to lead to across site variation in targeted quality measures and practices, collaborative projects may provide an opportunity for sites to identify best practices related to adherence to specific quality measures based on the performance of peers.

**AIM 3: To test the use QDACT-PCRC as a mechanism for delivering clinical decision support that reinforces agreed best clinical practice.**

**Revised Focus:** Site investigators in the PCRC who participated in Aim 2 presented the findings to their teams to identify areas for a common quality improvement project that could be implemented across sites. Team members suggested a different direction based on two themes. First, almost all of the five sites were already involved in local quality improvement initiatives based on areas of improvement identified by local monitoring; these areas were not necessarily applicable across sites. Second, in reviewing the variation in quality measure adherence across sites, team members suggested that the findings may represent differences in approaches to palliative care consultation across providers and sites. They were interested in learning more about how other palliative care providers approach comprehensive palliative care assessment and in developing consensus regarding best practices. *Based on this feedback, we developed a collaborative project with the following aims:* (1) Among palliative care clinicians, identify the factors (patient, provider, system, etc.) that determine the content of their clinical assessment during a palliative care consultation. (2) Based on those factors, develop consensus among palliative care providers regarding which elements of a comprehensive palliative care assessment should be included in a palliative care consultation.

**Methods:** We conducted a Delphi survey of the five participating R18 sites in the Palliative Care Research Cooperative Group: Duke University, University of California-San Francisco, University of Colorado Health, University of North Carolina-Chapel Hill, and Four Seasons in Hendersonville, NC. Each of the five sites was asked to identify five palliative care clinicians (physicians, nurse practitioners, or physician assistants) who would like to participate in the survey. To date, we have completed Round 1 of the Delphi survey and have developed Round 2.

**Survey:** The Delphi survey was administered online. Clinicians were sent an email with a link to the survey. Protocol was deemed exempt by Duke Institutional Review Board. The goal of the survey was to determine current practices and opinions regarding the scope of a comprehensive palliative care consultation. For the purposes of the study, we asked about the components of a comprehensive palliative care assessment that the responding clinician or a member of their interdisciplinary team generally addressed during the first three visits of the consultation. We operationalized a comprehensive assessment as including the following domains based on National Consensus Project Guidelines<sup>16</sup>: Physical Symptoms (pain, fatigue, nausea/vomiting, appetite/weight loss, constipation/diarrhea, dyspnea); Psychological, Psychiatric, and Cognitive Aspects of Care (depression, anxiety, cognitive status—orientation, delirium,); Spiritual, Religious, Existential Concerns (spiritual history, existential or spiritual distress, collaborate with patient's primary faith community); Medical Decision Making and Care Planning (goals of care, determination of care preferences, code status, prognostic understanding); Care Transitions and Coordination of Care (determination of place of care, caregiver needs, sources of practical and emotional support, facilitate access to services, assess functional status); and Cultural Aspects of Care and other factors (identify place of residence, determine cultural norms and expectation for communication, roles, and decision making, clarify English proficiency).

Participants were asked to describe their approach to consultation by selecting one of three options: (1) Each consult should aim to address all domains of a comprehensive palliative care assessment within the first three visits. (2) Each consult should be tailored to the particular domains required by the situation, and no domain is a mandatory part of the consult. (3) Each consult should be tailored to the needs of the situation, but certain domains should always be included within the first three visits regardless of the nature of the consult. Participants were asked how often they addressed each of the domains of a comprehensive palliative care assessment above (response: always, usually, sometimes, rarely, never) and to choose any domain (see above) or elements within those domains that they believe should be included in every palliative care consultation.

Finally, participants were asked to select the top five characteristics of a consultation that most influenced the domains that they assess. The list included reason for consult; patient location; consulting service or provider; patient alertness/responsiveness; presence and availability of a caregiver; timing/urgency of consult; institutional culture or team norms, protocols, expectations; and diagnosis, prognosis, acuity of symptoms, other. In response to each of the questions included in the survey, participants were asked to provide the rationale for their response.

**Results:** Twenty-one palliative care clinicians completed the survey—12 physicians, eight nurse practitioners, and one physician assistant. Seven of the clinicians had been practicing fewer than 5 years; four of them, for 6 to 10 years; and 10, for more than 10 years. Most of them practiced across multiple settings. The most common practice site was the hospital (N=13), followed by outpatient clinic (N=8), home-based palliative care (N=6), hospice (N=5), and nursing home/assisted living (N=3).

**Approach to Palliative Care Consultation:** Figure 2 is a graph of participants' descriptions of their approach to palliative care consultation palliative care assessment for the majority of consultations, when considering the domains above. Most (76.2%; responses 2 and 3) stated that a palliative care consult should be **tailored to the needs of the situation**; many (61.9%; Response 3) stated that, **while tailored to consult needs, certain domains should always be included**. Some endorsed the goal of completing all domains of a comprehensive palliative care assessment for each consult (Response 1), but, in qualitative comments, participants cited time constraints, staffing, and institutional expectations as barriers to completing a comprehensive assessment in all situations.

**Qualitative Comments:** Those advocating for the most commonly cited approach (tailored consults with certain mandatory domains) mentioned common themes of (1) the need for flexibility anchored by attainable goals; (2) the need to be efficient and not overwhelm either patients or providers; and (3) the need to adapt while still collecting some baseline information for completeness.

- *“Sometimes other consult services address related issues (e.g., Psych, SW) and I don't feel need to do detailed evaluation. Many of my patients are overwhelmed by consults, so I adjust consult to needs and circumstances. It also depends upon how many consults I have to do - I may have to be less comprehensive in order to see other critical patients.”*
- *“I think it's important to have structure to our work, but that sometimes things have to deviate. We should aim for completeness but sometimes we have to tailor to the situation.”*
- *“Workforce limitations mean we cannot do everything for everyone.”*

Those advocating for tailored assessment with no mandatory domain cited provider autonomy in deciding what to address and the potential relevance of certain domains for an individual's situation.

- *“It provides the consultant an opportunity to decide what fits best for this specific therapeutic relationship.”*
- *“Not all domains are relevant during the first three visits. Often symptoms predominate the first three visits, particularly when addressing pain. Additionally, in the clinic, we are often spending time focusing on symptom management and developing a rapport/trust building with patients as they are pursuing cancer-directed therapy.”*
- *“In the past I used to practice fairly rigidly and felt compelled to address certain domains, but over time I have come to find that consults should be fluid and flexible and certain issues may not be relevant to patient's needs.”*

Those advocating for comprehensive assessment cited overlapping nature of many domains as well as the likelihood that a Palliative Care Consult could be the only opportunity for certain domains to be addressed.

- *“No other specialty will do this type of assessment and if you do not address goals and personal values, you do not have a clear foundation about other elements of the pall care assessment.”*
- *“When assessing a patient and loved ones, a comprehensive, whole person approach is important, as each domain overflows into the next and is linked to the others. For instance, pain in serious illness is entwined with the “non-physical” domains and best managed when the other domains are addressed.”*

**Determinants of Elements of a Palliative Care Consultation:** Participants reported that a variety of factors influenced their approach to **tailoring** an individual consultation. The results are in Figure 3. Acuity of symptoms and reason for consultation were the most commonly cited factors.

*Qualitative Comments:* The primacy of addressing symptom needs and the patient's ability to engage in discussion were frequently mentioned as providers described the factors that influence the scope of their consultations.

- *"The patient's symptom is the most important factor influencing how I initially approach a consult. Their mental state is also a critical factor. In addition, I will engage in advance care planning more consistently initially for patients earlier in their disease trajectory."*
- *"The sicker the patient, the more focused my evaluation will be. So if a patient has uncontrolled symptoms or is in the ICU, I will focus on the domains that are most pertinent to the reason consulted."*
- *"I try to stick to the reason for the consult and honor my referral source. If I identify other things apart from this during my consult, I use tact and diplomacy to address this with the referring provider."*
- *"If a patient is having an acute symptom, I may not be able to address anything else until the symptom is managed or the acute issue addressed."*

Additional themes affecting a consult assessment were "time" available and the need to build rapport prior to addressing more sensitive topics.

- *"It goes without saying that time is also a big influence. The "team" at this community hospital consists of one right now, so the focus is usually streamlined to the reason consulted."*
- *"I always address symptoms as a safe place to start particularly in challenging goals of care discussions. I want to build a relationship and address what most concerns the patient before getting the hard stuff."*

Though few reported that "institutional norms" guided their assessments, many cited such factors in their responses.

- *"We always screen for physical and psychological symptoms because that is our agreed-upon team standard."*
- *"We generally try to discuss Code status because that is our agreed-upon team standard at our institution."*
- *"Oncologists drive what we talk about; we attempt to screen for physical symptoms at each visit."*
- *"We don't assess goals of care on certain services (surgery, GYNONC) unless asked."*

*Frequency of Domain Assessment:* Participants reported frequency of domains assessed based on their approach to majority of palliative care consultations. The results are in Figure 4. Physical, psychological, psychiatric, and cognitive domains were the most frequently reported as "always" assessed followed by medical decision making. Cultural and spiritual domains were less frequently reported as "always" assessed.

*Mandatory Elements of Domains of Care:* Participants were asked which domains they believed should be "mandatory"—included in the majority of consultations (Figure 5). Among the six domains, the domains of Physical Symptoms and Psychiatric, Psychological, and Cognitive Aspects of Care were those that respondents most frequently said should be included with assessment of all elements. For the domain of Medical Decision Making, many respondents felt that all elements should be assessed, but nearly all responded that identification of a surrogate and identification of preferences for care were elements that should be addressed at every consult. With regard to the domain of Care Transitions and Coordination, a patient's functional status and caregiver needs were the most frequently suggested mandatory elements. Participants frequently responded that place of care was a vital element of the domain of Cultural Aspects of Care. For spiritual care, most respondents reported that screening for spiritual distress was mandatory element of this domain. Few thought that all elements of the spiritual domain should be included on a mandatory basis.

**Conclusions/Implications:** A majority of Delphi participants felt that a Palliative Care consult should be tailored to the needs of the situation but should include certain mandatory domains. Physical symptoms, Psychological Factors, and Medical Decision Making were the domains most frequently addressed by participants at every consultation. Within these domains, most respondents felt that a consult should include comprehensive assessment of Symptoms and Psychological factors, but identification of a surrogate and preferences for care were felt to be mandatory aspects of addressing medical decision making, with many responding that all elements should be assessed. Respondents felt that the reason for consultation and the acuity of symptoms were the factors that should most frequently be allowed to drive the scope of the consult.

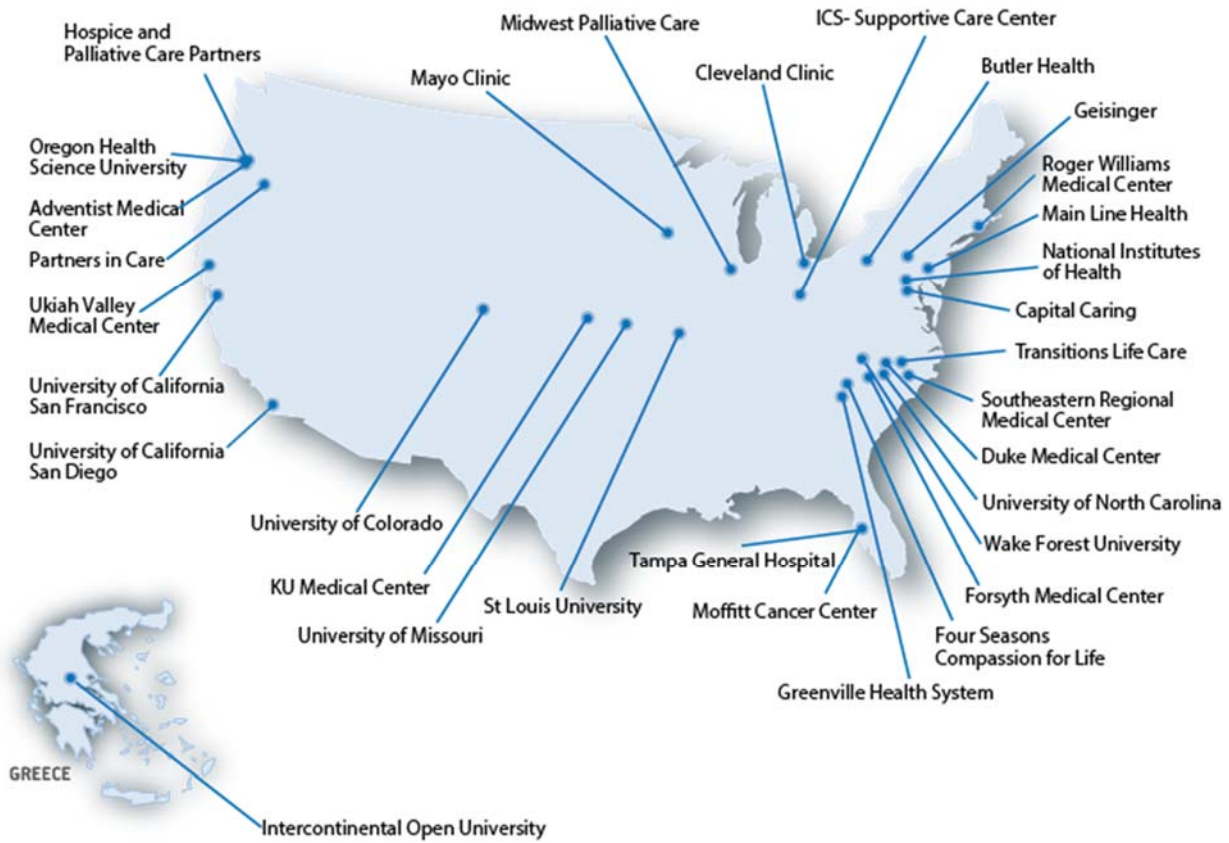
**Follow-up:** Recent National Consensus Project Guidelines<sup>16</sup> recommend comprehensive palliative care assessment. Given the findings of this Delphi with a majority of participants stating that they tailor their assessments, limiting the domains assessed based on the reason for consult and other factors, we will further explore potential barriers to comprehensive assessment in Round 2. Additionally, we will seek consensus on mandatory elements based on most common reasons for consultation (symptom management and medical decision making).



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Figure 1: QDACT-PCRC Implementation Sites



**Table 1: R18 PCRC Sites: Demographics of Patients in QDACT-PCRC**

<b>Variables</b>	<b>N=14,993 Patients (%)</b>
<b>Gender</b> Female	53.6%
<b>Ethnicity</b> NonHispanic Ethnicity	68.3%
<b>Race</b> White Black/African American	70.7% 7.0%
<b>Diagnosis</b> Cancer Cardiovascular Gastrointestinal Infectious Neurologic Pulmonary Renal	18.4% 12.2% 3.6% 6.3% 27.9% 11.4% 3.0%
<b>Location</b> Home Hospital-General Hospital-ICU Long-Term Care Unit Outpatient	11.3% 24.9% 7.5% 36.9% 6.9%

**Table 2: Sample Demographics Aim 2: N=250**

	<i>All</i>	<i>Site A</i>	<i>Site B</i>	<i>Site C</i>	<i>Site D</i>	<i>Site E</i>
<b>Age (median)</b>	67	66	69	61	83	63
<b>Gender N (%)</b>						
Female	128 (51.2)	26 (52)	20 (40)	22 (44)	29 (58)	31 (62)
Male	120 (48)	23 (46)	29 (58)	28 (56)	21 (42)	19 (38)
<b>Ethnicity</b>						
Non Hispanic	215 (86)	45 (90)	48 (96)	43 (86)	38 (76)	41 (82)
Hispanic	20 (8)	2 (4)	2 (4)	7 (14)	0 (0)	9 (18)
<b>Race</b>						
White	159 (63.6)	31 (62)	29 (58)	30 (60)	33 (66)	36 (72)
Black	36 (14.4)	14 (28)	16 (32)	1 (2)	2 (4)	3 (6)
Other	27 (10.8)	0 (0)	5 (10)	13 (26)	0 (0)	9 (18)
<b>Diagnosis</b>						
Cancer	136 (54.5)	30 (60)	20 (40)	47 (94)	6 (12)	33 (66)
Cardiovascular	23 (9.2)	5 (10)	4 (8)	0 (0)	6 (12)	8 (16)
Neurologic	34 (13.6)	4 (8)	8 (16)	0 (0)	21 (42)	1 (2)
Other	57 (39.2)	11 (22)	18 (36)	3 (6)	17 (34)	8 (16)
<b>Location</b>						
Hospital (Ward)	136 (54.5)	47 (94)	34 (68)	0 (0)	8 (16)	31 (62)
Hospital-ICU	32 (12.8)	3 (6)	16 (32)	0 (0)	2 (4)	11 (22)
Outpatient	62 (24.8)	0 (0)	0 (0)	50 (100)	5 (10)	7 (14)
Long-Term Care	25 (10)	0 (0)	0 (0)	0 (0)	25 (50)	0 (0)
Home	10 (4)	0 (0)	0 (0)	0 (0)	10 (20)	0 (0)

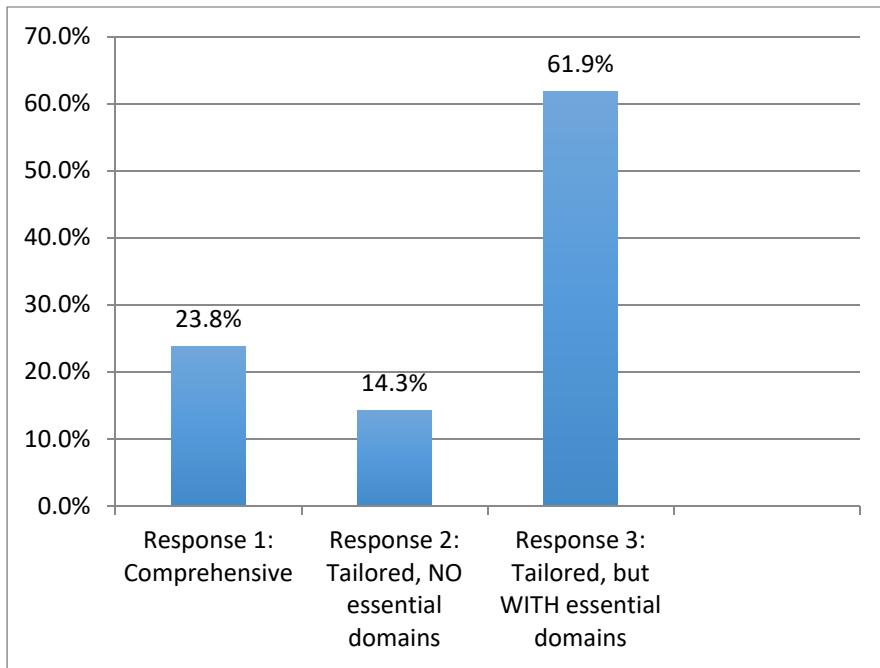
\*N=50 per site; % may not add up to 100 due to missing data.

**Table 3: Adherence to Quality Measures (N=50 per site; total N=250)**

	<i>All</i>	<i>Site A</i>	<i>Site B</i>	<i>Site C</i>	<i>Site D</i>	<i>Site E</i>
<i>N (%)</i>						
<b>Physical Screening Measures (All—pain, dyspnea, nausea, constipation)</b>	214 (85.6)	42 (84)	34 (68)	38 (76)	50 (100)	50 (100)
<b>Physical Screening (Individual Symptoms)</b>						
Pain	237 (94.8)	47 (94)	46 (92)	44 (88)	50 (100)	47 (94)
Dyspnea	236 (94.4)	49 (98)	46 (92)	41 (82)	50 (100)	49 (98)
Nausea	230 (92)	49 (98)	40 (80)	41 (82)	50 (100)	49 (98)
Constipation	229 (91.6)	46 (92)	41 (82)	42(84)	50 (100)	42 (92)
<b>*Comprehensive Pain Assessment</b>	78 (76.5)	26 (96.3)	2 (50)	13 (46.4)	17 (77.3)	20 (95.2)
<b>Treatment Preferences</b>	218 (87.2)	43 (86)	41 (82)	44 (88)	41 (82)	49(98)

\*Five or more of the following assessed: location, severity, duration, character, duration, frequency, relieving/exacerbating factors/effect on function or quality of life. N is the # of patients who screen positive for pain with ESAS of 4 or higher; Site A: N= 27; Site B: N=4; Site C: N=28; Site D: N=17; Site E: N=27; Total N=102.

**Figure 2: Delphi Participants' Views on Approach to Scope of Palliative Care Consultation**



**Figure 3: Factors which Determine Approach to Consultation**

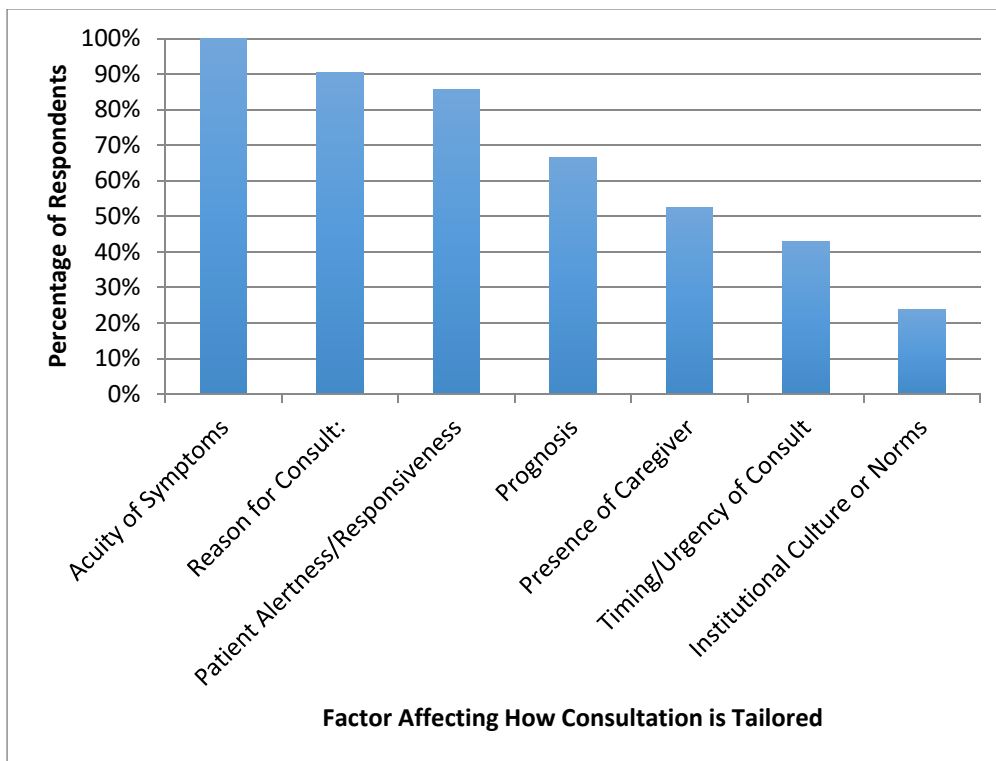
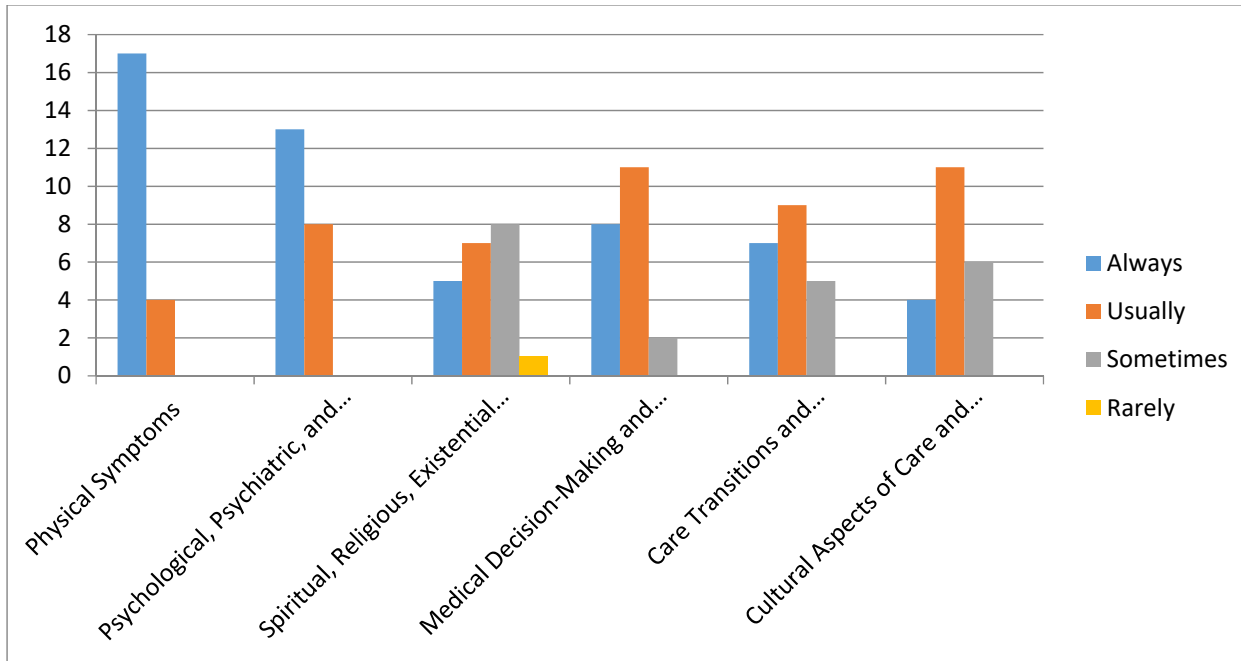
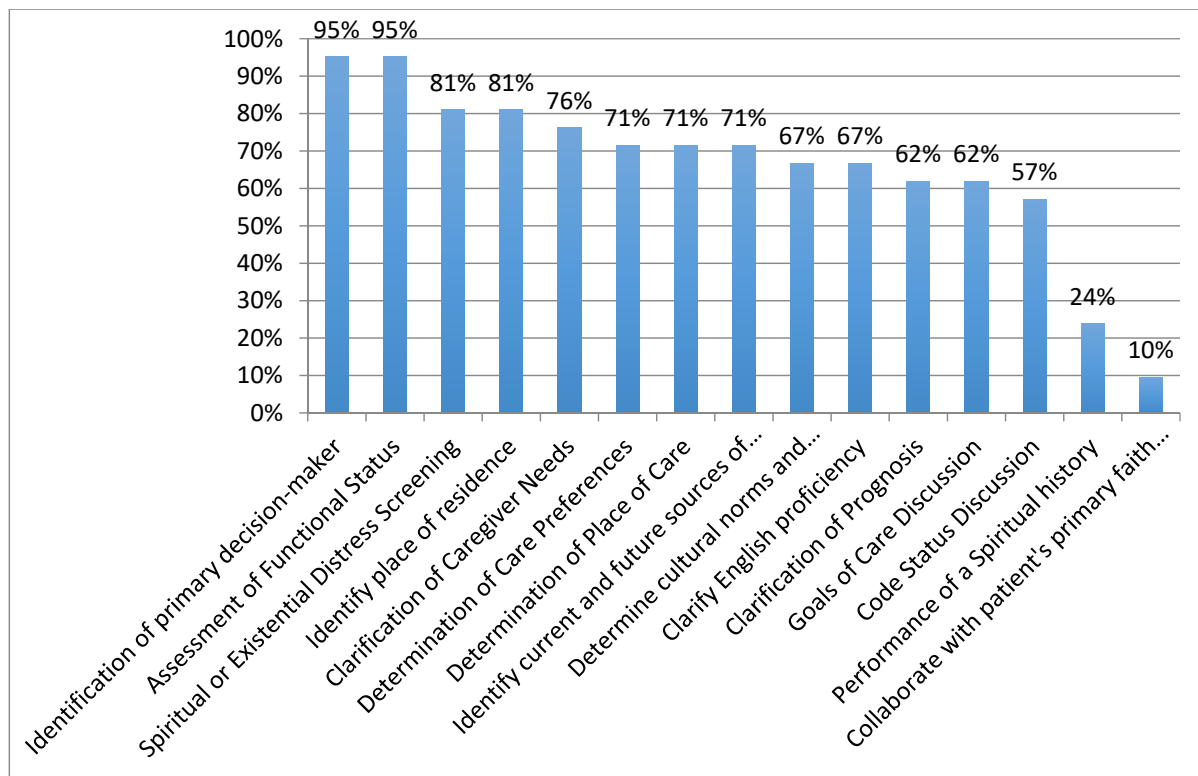


Figure 4: Frequency of Domain Assessment in Majority of Palliative Care Consultations\*



\*See text for full domain names.

Figure 5: Suggested Mandatory Elements for Palliative Care Consultation\*



\*See text for full element names.

## **Publications Related to Award**

1. Kamal AH, Gradison M, Maguire JM, Taylor D, Abernethy AP. Quality measures for palliative care in patients with cancer: a systematic review. *J Oncol Pract* 2014;10(4):281-7.
2. Kamal AH, Bull J, Kavalieratos D, Taylor DH Jr, Downey W, Abernethy AP. Palliative care needs of patients with cancer living in the community. *J Oncol Pract* 2011;7(6):382-8.
3. Kamal AH. Getting to proven: evaluating quality across all of palliative care. *J Pain Symptom Manage* 2014;47(1):e1-2.
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7. Kamal AH, Bull J, Ritchie CS, Kutner JS, Hanson LC, Friedman F, Taylor DH Jr, AAHPM Research Committee Writing Group. Adherence to Measuring What Matters Measures Using Point-of-Care Data Collection Across Diverse Clinical Settings. *J Pain Symptom Manage* 2016;51(3):497-503.
8. LeBlanc et al. Adherence to measuring what matters when caring patients with hematologic malignancies versus solid tumors. *J Pain Symptom Manage* 2016;52:775-82.
9. Kamal et al. Unmet needs of African Americans and Whites at the time of palliative care consultation. *Am J Hosp Palliat Care* 2017;34:461-65.
10. Bostwick D et al. Comparing the palliative care needs of those with cancer to those with common noncancer serious illness. *J Pain Symptom Manage* 2017;1079-1084.
11. Kamal AH, Kirkland KB, Meier DE, Morgan TS, Nelson EC, Pantilat SZ. A Person-Centered, Registry-Based Learning Health System for Palliative Care: A Path to Coproducing Better Outcomes, Experience, Value, and Science. *J Palliat Med*. 2018 Mar;21(S2):S61-S67. doi: 10.1089/jpm.2017.0354. Epub 2017 Nov 1.
12. Hochman MJ, Yu Y, Wolf SP, Samsa GP, Kamal AH, LeBlanc TW. Comparing the Palliative Care Needs of Patients With Hematologic and Solid Malignancies. *J Pain Symptom Manage* 2018 Jan;55(1):82-88.