



Information-Gathering Report – *Focus Groups Addendum*

Hospice Quality Reporting Program—Base Year



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1. BACKGROUND AND PURPOSE

The Centers for Medicare & Medicaid Services (CMS) is committed to the provision of high quality care for Medicare hospice beneficiaries, and has invested substantial resources in the development of a new hospice assessment instrument and related hospice quality measures (QMs) for the Hospice Quality Reporting Program (HQRP).

Abt Associates, under contract with CMS to advance the work of the hospice assessment instrument and QMs, has and continues to conduct multiple activities as part of an overall outreach plan to engage stakeholders and solicit input on this important work. The process is iterative and overlapping, but each activity provides additional information and understanding that is used in the development of subsequent activities. The goal of the patient assessment instrument is to understand the care needs of people through the dying process and to promote the safety and comfort of individuals enrolled in hospice organizations nationwide. The standardized data collected by the Hospice Outcomes & Patient Evaluation (HOPE) assessment tool will support quality measures (QMs) for hospice care throughout the dying process, encourage the delivery of person-centered care, and reflect the CMS Meaningful Measures Framework priorities.

The early project information-gathering and stakeholder-engagement activities are described in more detail in our Information-Gathering Report. These included:

- Listening sessions, presentations and interviews with stakeholders, including provider associations, federal staff, subject matter experts and caregivers
- A debrief with providers who tested a previous draft assessment instruments
- Review of relevant clinical practice guidelines, legislation and regulations
- High-level literature review
- Environmental scan of existing items, instruments, scales and tools

This work led to our focus-group engagement activity with hospice clinicians, which is the subject of this Report Addendum. These focus groups served two important purposes; they helped expand and validate the evidence basis for the draft assessment domains and items and they guided the focus and scope of subsequent cognitive testing. Hospice clinicians conduct assessments, interacting directly and routinely with hospice patients and their families and caregivers. Therefore their input is essential to the patient assessment instrument development process. Abt led virtual focus groups with hospice clinicians to confirm and build on what we had learned up to this point. Focus group results were analyzed and applied to the draft guidance explaining how to complete the HOPE assessment items. These materials were developed and refined with questions for cognitive interviews, which is the next phase of the project: the beginning of testing the draft instrument. Cognitive testing results in turn will inform decisions made about revisions to items and guidance to create the next version of the draft instrument, which we will apply in alpha testing to establish preliminary reliability and validity of the items. Results of alpha testing will be analyzed to determine what items will remain in the final draft of the HOPE assessment instrument, what items require further modification, and what items will be dropped. The final draft of the instrument will be tested in the final phase of testing: the national beta test. Beta testing results will provide CMS with evidence in support of a proposal to be made in hospice rulemaking for implementing the HOPE assessment nationally.

Abt led virtual focus groups with hospice clinicians to solicit their feedback on the following content areas and issues:

1. Key assessment domains
2. Specific assessment elements
3. Frequency of data collection
4. Interoperability.

The eight virtual focus groups were held on:

- Tuesday, August 27th from 3:00 pm – 4:30 pm EST
- Thursday, August 29th from 2:00 pm - 3:30 pm EST
- Thursday, September 5th from 2:00 pm - 3:30 pm EST
- Monday, September 9th from 12:00 pm - 1:30 pm EST
- Tuesday, September 10th from 2:30 pm - 4:00 pm EST
- Thursday, September 12th from 2:00 pm - 3:30 pm EST
- Tuesday, September 17th from 3:00 pm - 4:30 pm EST
- Tuesday, September 24th from 3:00 pm - 4:30 pm EST

About 100 hospice providers were invited to participate in the focus groups, and attendance was strong with over 75% participating in the focus groups.

2. METHODS

2.1. Recruitment

The recruitment period was from July 29, 2019, to August 26, 2019. The focus group application was a survey on the Survey Gizmo platform. The goal of recruitment was to identify a group of hospice clinicians that reflect a broad range of perspectives and experiences:

- Geographic diversity and representation of 4 regions of the country
- Not-for-profit versus for-profit status (defined by 501c3 tax status)
- Urban versus rural (defined by USDA Rural-Urban Commuting Area [RUCA] codes)
- Large versus small (defined as average daily census)
- Department of Veterans Affairs (VA) hospice clinicians
- Hospices providing inpatient care versus routine hospice care in nursing homes or assisted living facilities or in a private residence/home.

The final focus group protocol specified nationally representative target sample sizes for select hospice characteristics (Exhibit 1).

Exhibit 1. Target Sample Size based on National Characteristics

For-profit	Not-for-Profit	Urban	Rural	Large	Medium	Small	Free-Standing	Facility-Based
72%	28%	70%	21%	33%	47%	20%	82%	18%

The solicitation for the recruitment was broadly announced through these channels:

- CMS Hospice QRP Spotlight Announcement (Appendix A)
- CMS Hospice QRP Open Door Forum announcement
- CMS Hospice QRP Listserv announcement
- CMS TEP home page for engagement opportunities
- Direct outreach via email announcement and invitation to participate from CMS to major national, regional, and local hospice stakeholders including:
 - National Hospice and Palliative Care Organization (NHPCO), National Association for Home Care & Hospice (NAHC), Visiting Nurse Associations of America (VNAA), National partnership for Hospice Innovation (NPHI)
 - All of the U.S. State Hospice/Palliative Care Organizations/Associations

The initial announcement was distributed on July 19, 2019. A follow-up announcement was emailed directly to existing applicants on August 13, 2019, to notify them of additional September focus group dates that were added after they had submitted their applications and to request their updated availability. In total, almost 400 focus group applications were received.

2.2. Selecting Focus Group Participants

2.2.1 Eligibility to Participate in a Focus Group

Hospice clinicians were eligible to participate in a focus group if they were currently employed by a hospice (so that we could get perspectives based on current practice), and if they had experience in the hospice setting, and had experience conducting patient assessments such as admissions and discharges. We wanted to hear from clinicians who worked in a variety of different environments, so we collected information on the location of services they provided (home, nursing home, assisted living, etc.), the ownership (profit, nonprofit), and the type of geographic area served (urban, rural).

In order to include representation from as many hospices as possible, only one hospice participant was selected per individual CMS Certification Number (CCN). This meant that when an applicant was selected for a focus group, all other applicants with the same CCN could not be considered for the remaining focus groups. Seventeen applicants were eliminated for focus group selection because their CCNs had already been selected.¹

2.2.2 Tracking Participant Characteristics

Participant selection was primarily guided by the targets defined in the focus group protocol. A secondary selection consideration was the request by CMS to prioritize the inclusion of small and/or rural hospices. We expected that convening a group for small and rural hospices would provide these participants with an opportunity to share and discuss their unique experiences and perspectives. An exclusively rural focus group was held on August 27, 2019. Small hospices were prioritized for selection during the September 5, 2019, focus group. Although much of the feedback was consistent, rural hospices noted that getting needed clinical information was dependent on the referral source and was sometimes a struggle to obtain.

Exhibit 2 presents the characteristics of the hospices represented by 96 applicants who were selected for focus group participation compared with both the characteristic targets from the national data and the characteristics of all eligible applicants (n=306). Note that the 96 selected applicants includes the subset who ultimately did not attend the focus group (n=23).

Exhibit 2. Hospice characteristics of the Selected Applicants for Focus Group Participation Compared with Targets and Applicants

	For-profit	Not-for-Profit	Urban	Urban and Rural ^A	Rural	Large	Medium	Small	Free-Standing	Facility-Based
Target Characteristic Percentages based on National Data	72%	28%	70%	<i>n/a</i>	21%	33%	47%	20%	82%	18%
Eligible Applicants' Characteristics Percentages (n=306)	26%	74%	14%	65%	21%	64%	31%	5%	25%	75%
Selected Focus Group	56%	44%	21%	47%	32%	46%	44%	10%	79%	21%

¹ One CCN was selected for two focus groups because the applicants had used different CCN formats therefore the search function did not identify them as duplicates. The duplication was discovered after the focus group assignments were complete.

	For-profit	Not-for-Profit	Urban	Urban and Rural ^A	Rural	Large	Medium	Small	Free-Standing	Facility-Based
Participants' Characteristics Percentages (n=96)										
Focus Group Participants' Characteristics Percentages (n=73)	58%	42%	17%	49%	34%	48%	42%	10%	80%	20%

Notes:

^AThe focus group application included this category but the target characteristics did not.

The challenges for matching the national characteristic percentages were:

1. There were very few applicants from small hospices (n=15); three that applied selected the focus group dates that were cancelled or the rural-only focus group date.
2. The rate of for-profit hospice applicants (26%) was much lower than the national target (72%).
3. Only one applicant per CCN could participate in a focus group; therefore, once a CCN was associated with a focus group applicant, anyone else who had that CCN would not be eligible for subsequent focus group assignment.
4. Selecting for small and rural focus groups led to a greater percentage of not-for-profit and rurality characteristics.

2.3. Format of the Focus Groups

The virtual focus groups were held as WebEx events with a facilitator. Apart from the groups constructed specifically for rural hospices and small hospices, participants were assigned to a group based on their availability and represented an array of provider types. The structure was a combination of viewing a slide deck and digital polling via WebEx, followed by open discussion of the polling results (see Appendix D for the focus group slide deck). The slide deck was created by the Abt HOPE instrument team with input from CMS in an iterative process of reviewing, discussing, and refining. The slides focused on content under consideration for the draft assessment tool, such as the general domains to be assessed, a checklist with clinical signs of actively dying, and a symptom severity assessment scale. Participants contributed feedback by answering a series of electronic polling questions, rating some of the content, and elaborating during facilitated discussions. Participants also answered some general queries about their current nursing assessment practices, performance scales used at their hospices, and their electronic health record (EHR) systems.

In addition to the invited hospice clinicians, the focus groups were attended by CMS staff and project support staff from the Abt Team.

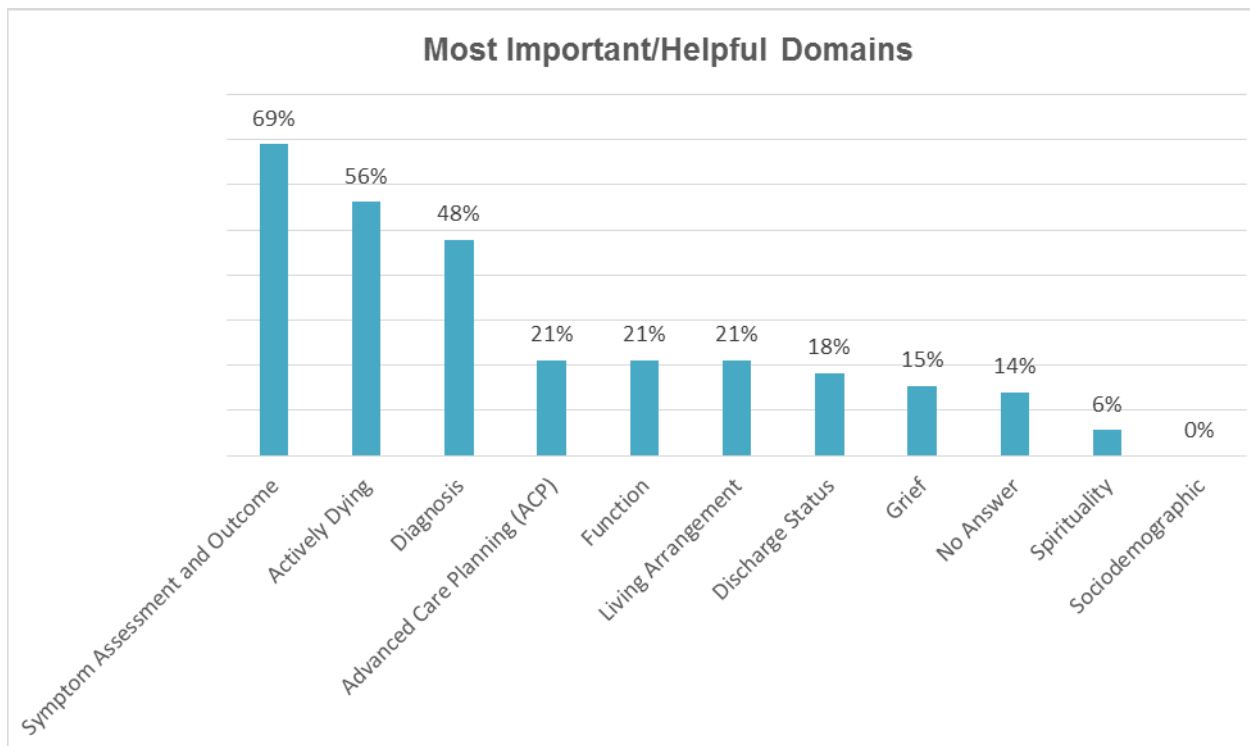
3. RESULTS

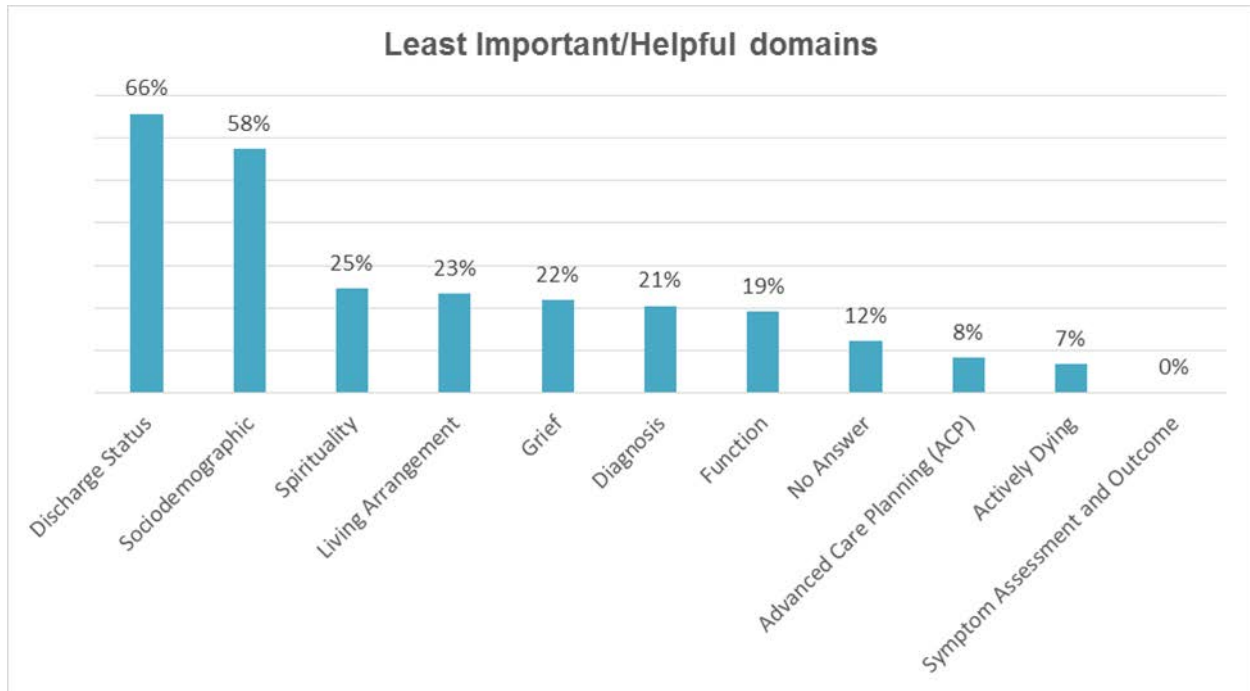
3.1. Draft Domains for Inclusion in the HOPE Assessment

The first poll question was, “Please choose what you think are the three most important/helpful domains to be included in this assessment” followed by 11 draft domain options. Exhibit 3 presents the results. “Symptom Assessment and Outcome” (69%), “Actively Dying” (56%), and “Diagnosis” (48%) were the top three choices.

Participants were also asked to select the three least important domains; these results are also shown in Exhibit 3. “Discharge Status” (66%), “Sociodemographic” (58%), and “Spirituality” (25%) were voted the three least important domains.

Exhibit 3. Polling Results on the Most and Least Important Domains to Include in HOPE





These results show more consensus on the value of some domains, such as Symptom Assessment, relative to others, such as diagnosis, which was rated as most important by 48% of participants and least important by another 21%. Following each poll, participants discussed the reasons for their selections and offered suggestions to improve the domains. Participants reported that in routine nursing practice, they collected information related to all of these domains. Exhibit 4 summarizes these discussions.

Exhibit 4. Discussion of Domain Polling Results

Domain	Value	Considerations	Recommendations
Actively Dying	If a patient is actively dying, the hospice clinician must act quickly to identify the necessary resources.	N/A	Group with Symptom Assessment and Outcome. A skip pattern related to this domain would be helpful.
Advanced Care Planning (ACP)	The patient or family may not have accepted the reality of the situation. ACP allows for the patient and family to articulate what is important to them, and may include elements of spirituality and grief.	N/A	N/A
Diagnosis	N/A	CMS needs this but it's "just a label." Caring for the patient should be the focus.	Group with Symptom Assessment
Discharge Status	Hospices need to know about any live discharges because revocations may negatively impact the hospice and could indicate quality of care issues.	It's "unpredictable" so it is difficult to control for. It's a process measure more than a treatment measure. This information is likely captured when the patient is no longer receiving services.	Discharge status should clarify if a patient was discharged with a life-limiting diagnosis.

Domain	Value	Considerations	Recommendations
Function	Impacts all aspects of hospice care, including caregiver needs and burden as well as what equipment the patient needs.	Functional decline is an expected part of hospice care. Likely already captured elsewhere.	N/A
Grief	Families and patients struggle with grief, and that can impact symptom management and the patient's "ability to let go." It is important throughout hospice care, not just during actively dying stage.	Doesn't impact how the hospice will provide physical symptom relief.	N/A
Living arrangement	Helps the hospice clinician to better understand the needs and constraints of the patient and family, especially if the patient is living alone. If the patient is living with family, the hospice clinician may need to do caregiver education.	Likely already captured elsewhere.	Group with Sociodemographic
Sociodemographic	Helps the hospice clinician to better understand the needs of the patient and family (e.g., a potential language barrier).	All patients are treated the same; this information doesn't affect patient outcomes. This information is already available elsewhere.	Group with Living Arrangements
Spirituality	For some patients and families, this can be the most important factor driving their decision making.	Should be explored with patient throughout hospice care, not the initial visit. Doesn't impact how the hospice will provide physical symptom relief.	Group with ACP
Symptom Assessment and Outcome	N/A	N/A	Group with Diagnosis and Function

Several participants declined to select any of the domains as most important or least important because, they explained, all of the domains are important to understanding the “whole picture” and develop an appropriate care plan. When asked what other domains were important to assess for hospice patients participants suggested those below. The instrument team will take these into consideration in future HOPE refinements and testing.

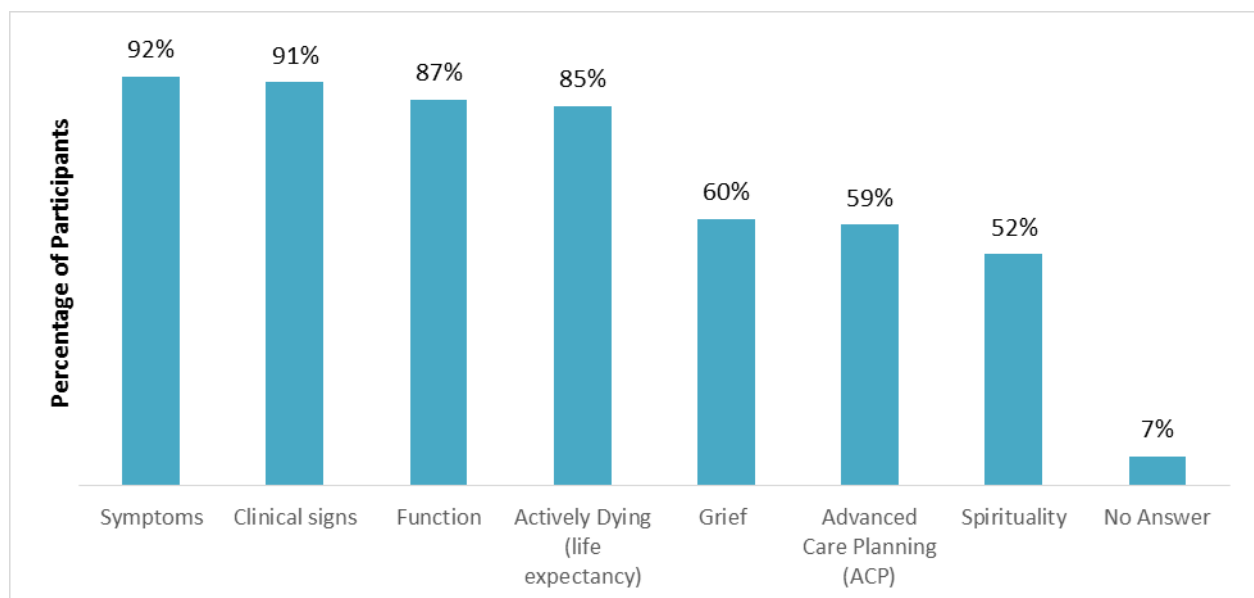
- **Education:** educate both the patient and family about what hospice is, which could be explicit under ACP rather than its own domain. Participants noted it's important to understand what a patient already knows, so that patient education can be tailored.
- **Veteran status:** this may affect a patient's psychosocial status and thoughts on grief; participants identified that veterans, because their experiences differ from non-veterans, have unique needs in hospice, and knowing that a person is a veteran can help the clinician provide appropriate care.
- **Psycho-social determinants:** any emotional, behavioral and/or mental status issues impacting the patient and family situation at home. Participants shared that when a patient has behavioral health issues, this can strongly impact the situation at home, and whether the patient can remain at home.

- **Access to care:** this would include insurance status and any transportation issues. This helps nurses understand what resources patients have, what their insurance benefit will cover or exclude, for example. Patients may still be getting out to appointments, to the oncologist, for example, or to receive radiation for pain; thus, any issues with transportation may be a barrier to receiving care.
- **Physical assessment:** height and weight; participants noted that assessment includes physical findings, such as height and weight, which may be important in calculation of medication doses.

3.2. Current Assessments on Routine Nursing Visits

In another polling question, participants were asked to “Please choose any of these categories that you currently assess on routine nursing visits.” Exhibit 5 presents the percentage of participants that currently assess each item.

Exhibit 5. Polling Results for Categories that Participants Currently Assess on Routine Nursing Visits



The most frequently identified domains for routine assessment were symptoms, clinical signs, function and actively dying, or life expectancy. This feedback confirms that these clinicians routinely assess domains identified as important to include in the draft instrument. In addition to the domains already listed (Exhibit 5), we asked participants to identify other areas they routinely assess.

- Anxiety or Depression: neurological/cognitive/emotional considerations
- Pain
- Movement toward goal(s)
- Medications: reconciliation, side effects, and frequency of use of comfort medications
- Support/Caregiver status: ability and education needs

- Response to interventions
- Suicide risk assessment
- Airway secretions
- Home Safety: oxygen risk, general home safety, fall risk, and disaster planning
- Supplies Needed
- Burden: any factors that may affect the patient, such as a caretaker having to quit a job to take care of a patient

The routine assessment of these domains supports the current structure of the draft HOPE assessment instrument. One of our goals is that the patient assessment instrument captures information hospice clinicians are already collecting, which will be less burdensome than collecting different information. The assessment areas participants identified align with our findings of important domains to represent in the instrument. More detail is provided below, beginning with the most often assessed domain of symptoms.

3.3. Symptom Severity (SOS) Scale and Pain

The focus group facilitator presented participants with a severity scale to assess pain, shortness of breath, nausea, vomiting, hallucination, agitation, anxiety, and constipation and diarrhea. Participants were then polled to identify if any of the severity scale definitions were unclear (Exhibit 6). The most unclear definitions were for “Moderate” and “Overwhelming.” An overarching comment was to quantify the distinctions between “Mild,” “Moderate,” and “Severe” by using a scale out of 10. Ideally the patient would be the one to choose their severity; whoever the source of the severity score is (patient, caregiver, hospice clinician) should be clearly documented. Another way to quantify a definition would be to specify the duration in terms of number of hours in a day or consecutive days. Forty-five% of participants thought that all of the definitions were clear as written. One participant noted that the patient’s stress level may fluctuate from admission in home health to admission in hospice, which could impact their assessment. This feedback and the comments of individual participants about what was unclear and why was leveraged to identify items for further cognitive testing and to develop draft item guidance.

Exhibit 6. Poll Results on the Clarity of the Severity Scale Definitions

Severity Scale Definitions	% Who Found Unclear	Participant Comments
None: patient does not have the symptom.	7%	N/A
Mild: symptom has little impact on any of the following: sleep, day to day activities, and/or ability to interact with others.	5%	Quantify what this means. On a scale of 1-10, this could be 1-3. Change “has little impact” to “has some impact.”
Moderate: symptom impacts on any of the following: sleep, day to day activities, and/or ability to interact with others for <u>some of time</u> .	22%	Quantify what this means. On a scale of 1-10, this could be 3-7.

Severity Scale Definitions	% Who Found Unclear	Participant Comments
Severe: symptom significantly impacts on any of the following: sleep, day to day activities, and/or ability to interact with others for <u>majority of time</u> .	19%	Quantify what this means. On a scale of 1-10, this could be 8-9. There were conflicting responses about combining this with "Overwhelming."
Overwhelming: symptom is at a level such that the patient is unable to think of anything else and/or do any other activities.	22%	Quantify what this means. On a scale of 1-10, this could be 10. There were conflicting responses about combining this with "Severe."
Cannot assess: patient is comatose or unconscious.	11%	There are many reasons why you cannot assess a patient: comatose, unconscious, have dementia, caregiver is unreliable, in a facility setting where it is difficult to measure the extent of the symptoms. There are tools to assess patients during some of those scenarios. The definition should include "Patient is nonverbal" or "Unable to respond." If there was a language barrier, participants would seek an interpreter and would not select this option.
<i>None selected, all definitions are clear</i>	45%	

3.4. Actively Dying Signs

Participants were presented with a list of signs that could indicate if a patient was actively dying, and to select any items that could be interpreted in multiple ways. As shown in Exhibit 6, the items most subject to potential misinterpretation were "Decrease response to verbal stimuli" (50%), "Decrease in blood pressure" (41%), "Decreased urine output" (39%), and "Low oxygen saturation" (38%). Participants also noted that many of these items could occur due to general patient decline or a pre-existing condition rather than being in a state of actively dying. These findings, for example, led to drafting guidance clarifying these items, which we plan to share in cognitive interviews, to determine if we are able to successfully clarify the intent of these items. If cognitive testing results further reinforce that these particular items are confusing or may be too often related to something other than actively dying, we would consider dropping these parts of the item.

Exhibit 7 also presents poll results for which items participants suggested removing from the actively dying checklist. The most popular items were "Drooping of nasolabial fold" (54%), "New dysphagia of liquids" (45%), and "Respiration with mandibular movement" (41%). Comments included suggestions for combining items, such as creating a "Change/decline in respiratory status" category that could include Cheyne-stokes respirations, death rattle, and respiration with mandibular movement. Participants reiterated that many of these items in isolation could indicate something other than actively dying.

Exhibit 8 synthesizes the item-specific discussions for both of the Actively Dying polling questions. Participants suggested the following additional actively dying signs:

- Temperature
- Mottling/skin turgor
- Agitation
- Responsiveness: decreased responsiveness to tactile stimuli; general unresponsiveness

- Decreased level of consciousness/ increased sleeping pattern
- Cognitive function

Feedback on item ambiguity and recommended item removals was used to help guide priorities for cognitive testing, as well as associated testing materials. Knowing items can be interpreted in multiple ways is valuable creating guidance and informing testing probes. Focus group participant comments help elucidate the sources of ambiguity.

Exhibit 7. Polling Results for Actively Dying Items that Could Be Interpreted in Multiple Ways and Actively Dying Items That Could Be Removed from the List

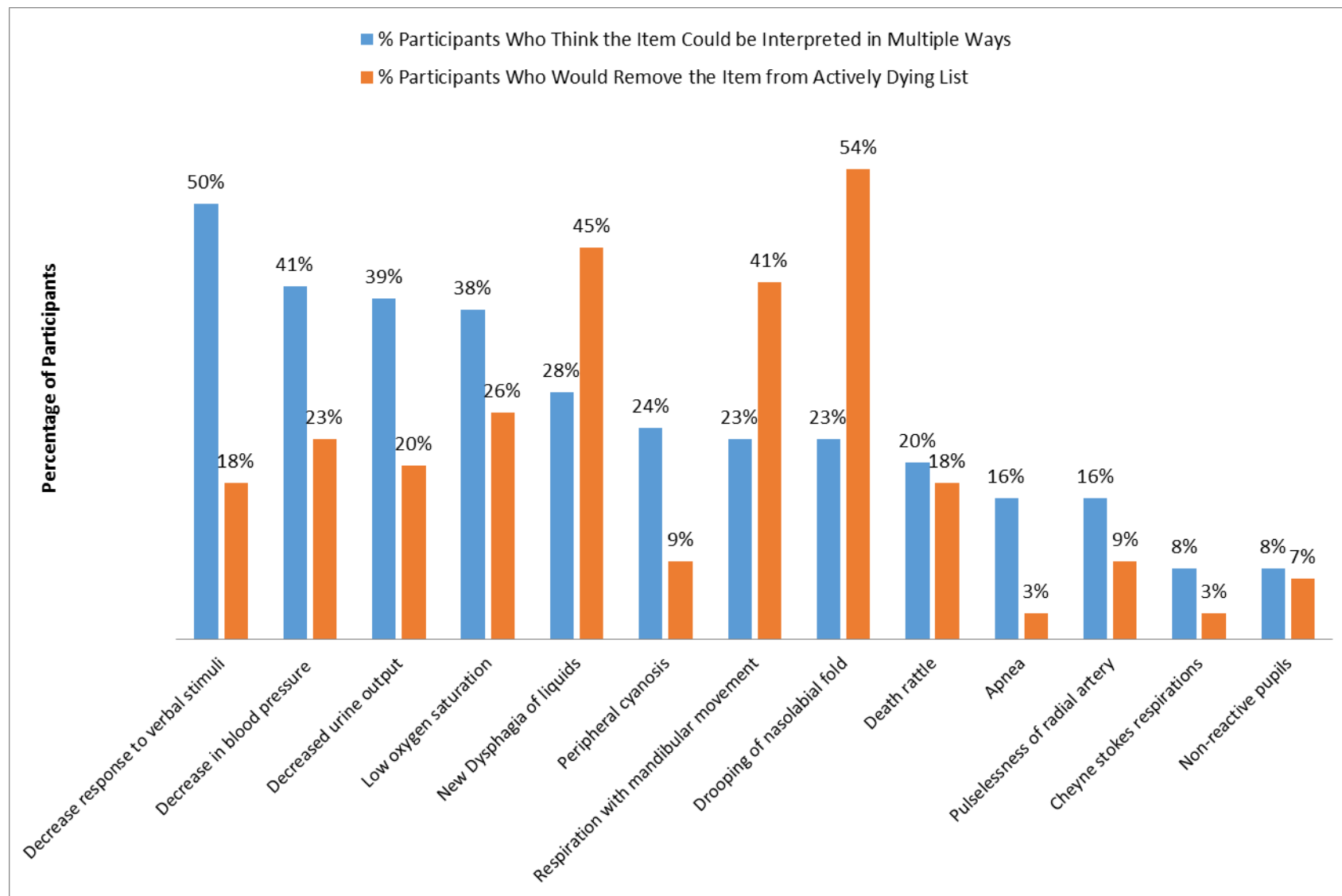


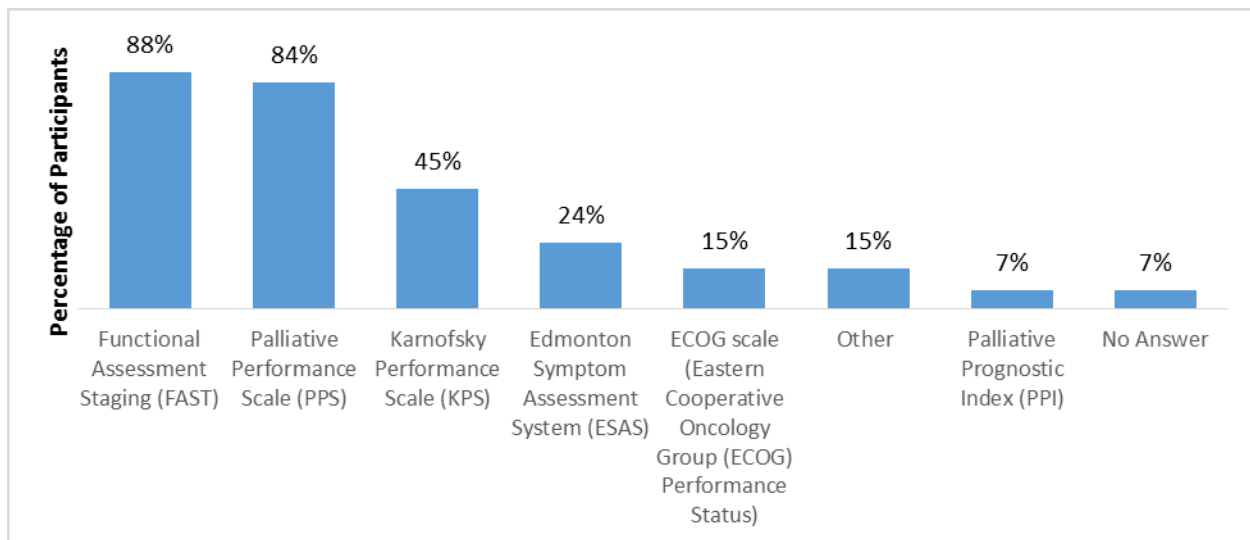
Exhibit 8. Summary Table of Actively Dying Signs Discussions

Actively Dying Signs	% Who Think Sign Could be Misinterpreted	% Who Suggest Removing Sign	Participant Comments
Decrease response to verbal stimuli	50%	18%	Requires clear definition of “decreased.” This could be due to dementia. Alternative term: “Level of Consciousness.”
Decrease in blood pressure	41%	23%	Requires clear definition of “decrease.”
Decreased urine output	39%	20%	Requires clear definition of “decreased.” This could be due to a urinary tract infection, heart disease, dehydration, or something else other than actively dying.
Low oxygen saturation	38%	26%	Requires clear definition of “low.” It can be difficult to get an accurate reading and hospices may not normally monitor this. Specify if the patient is ambulatory or bed-bound.
New Dysphagia of liquids	28%	45%	Specify if this is thickened or regular liquids. Also consider change to food intake, which could be grouped with functional status. Requires clear definition for duration of dysphagia. May have implications for what form of medication the patient can take.
Peripheral cyanosis	24%	9%	Needs to specify the level and severity of cyanosis [fingers, whole hands, and/or feet.] This is common for patients with chronic obstructive pulmonary disorder (COPD), and is indicative of worsening cardio status but not necessarily actively dying. The ubiquity of pulse oximeters can lead to over-diagnosis of cyanosis. “Mottling” would be a better sign.
Respiration with mandibular movement	23%	41%	Requires measurable components. This type of breathing can occur after strenuous exercise.
Drooping of nasolabial fold	23%	54%	Requires clear definition. Many participants did not understand what this meant and/or do not document it.
Death rattle	20%	18%	This is an “old fashioned term” that is subjective, rarely used by the clinicians interviewed, and could be confused with Cheyne-Stokes. Alternative term: “terminal secretions” or “excessive secretions with respirations.”
Apnea	16%	3%	Quantify what qualifies as apnea. Periods of apnea can present before a patient is actively dying. Many patients may have periods of apnea during sleep, but refuse continuous positive airway pressure (CPAP) therapy.
Pulselessness of radial artery	16%	9%	This could be interpreted to mean a possible blood clot.
Cheyne-Stokes respirations	8%	3%	N/A
Non-reactive pupils	8%	7%	Opioid overdoses can cause this also and may be conflated with actively dying.
No Answer	15%	16%	N/A

3.5. Performance Status Scales

Participants were polled on the performance status scales that they use on a regular basis (Exhibit 9). The most commonly used scales are the Functional Assessment Staging (FAST; 88%), the Palliative Performance Scale (PPS; 84%), and the Karnofsky Performance Scale (KPS; 45%). Other commonly used scales reported by participants include the New York Heart Association Functional Classification, the Dyspnea Scale, and the MAC 10.

Exhibit 9. Poll Results on Participants' Use of Performance Status Scales



Given the number of disparate scales, the facilitator then asked participants their opinion if hospices were limited to one or two performance scales. Participants were concerned that this may create challenges for electronic health record (EHR) systems that use a scale that is no longer supported. Another concern was that some scales are specific to certain populations or diagnoses that may not be accurately assessed otherwise. Several participants were supportive of this idea if KPS or PPS were the selected scales.

3.6. Complete Assessment Frequency

Participants were polled on how often it is feasible to complete a full/comprehensive hospice assessment. Forty-seven percent said that it was “feasible at the time of recertification (90 days, 90 days, 60 days, etc.),” 28% said “Every 30 days,” 12% said “Every 60 days,” and 16% did not answer. Participants discussed the potential difficulty of completing a comprehensive assessment every 30 days with all disciplines, but generally agreed that it is feasible. Several participants said that their hospices do comprehensive assessments every 14 or 15 days, noting that Medicare Interdisciplinary Group (IDG) requirements are for a re-assessment every 15 days. A participant stated that tracking assessments that must be completed at different frequencies would be difficult. Most participants said that it would be feasible to complete a subset (i.e., skip pattern based) of the comprehensive hospice assessment every two weeks (36%) because it aligns with the IDG timing, or prior to an IDG meeting (35%). Nine% of participants said every week was feasible, 18% declined to answer, and 7% answered “Other,” explaining that it depends on the initial interval (i.e., if you chose to do a monthly comprehensive assessment, then that would affect when you did the subset) and the patient’s needs. Using skip patterns increases the feasibility of doing more regular subset assessments.

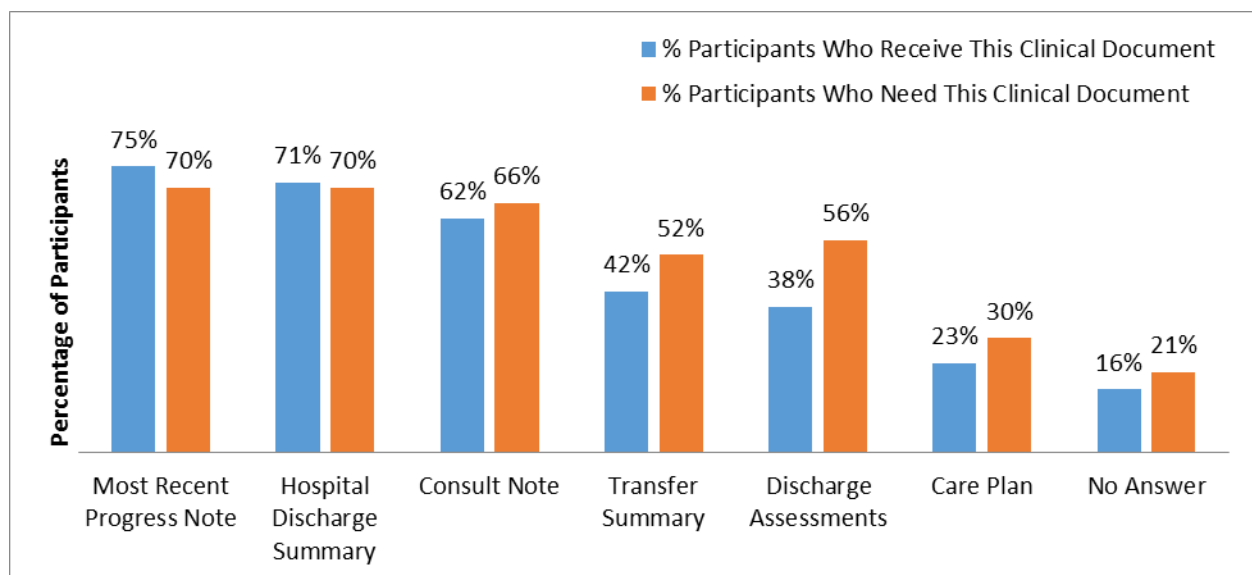
Participants reported that they currently capture the following domains before the IDG meeting:

- Symptom Management; Status of Active Symptoms
- Functional Status
- Patient Family Coping/Anxiety
- Changes to the Care System

3.7. Information Exchange

Participants were polled about which clinical documents they currently receive at admission, as well as which documents they require for patient care (Exhibit 9). The most important clinical documents to receive are the “Most Recent Progress Note” (70%), the “Hospital Discharge Summary” (70%), and the “Consult Note” (66%); these clinical documents are all currently received by the majority of participants.

Exhibit 10. Poll Results on Clinical Documents that Participants Currently Receive and Their Perceived Value



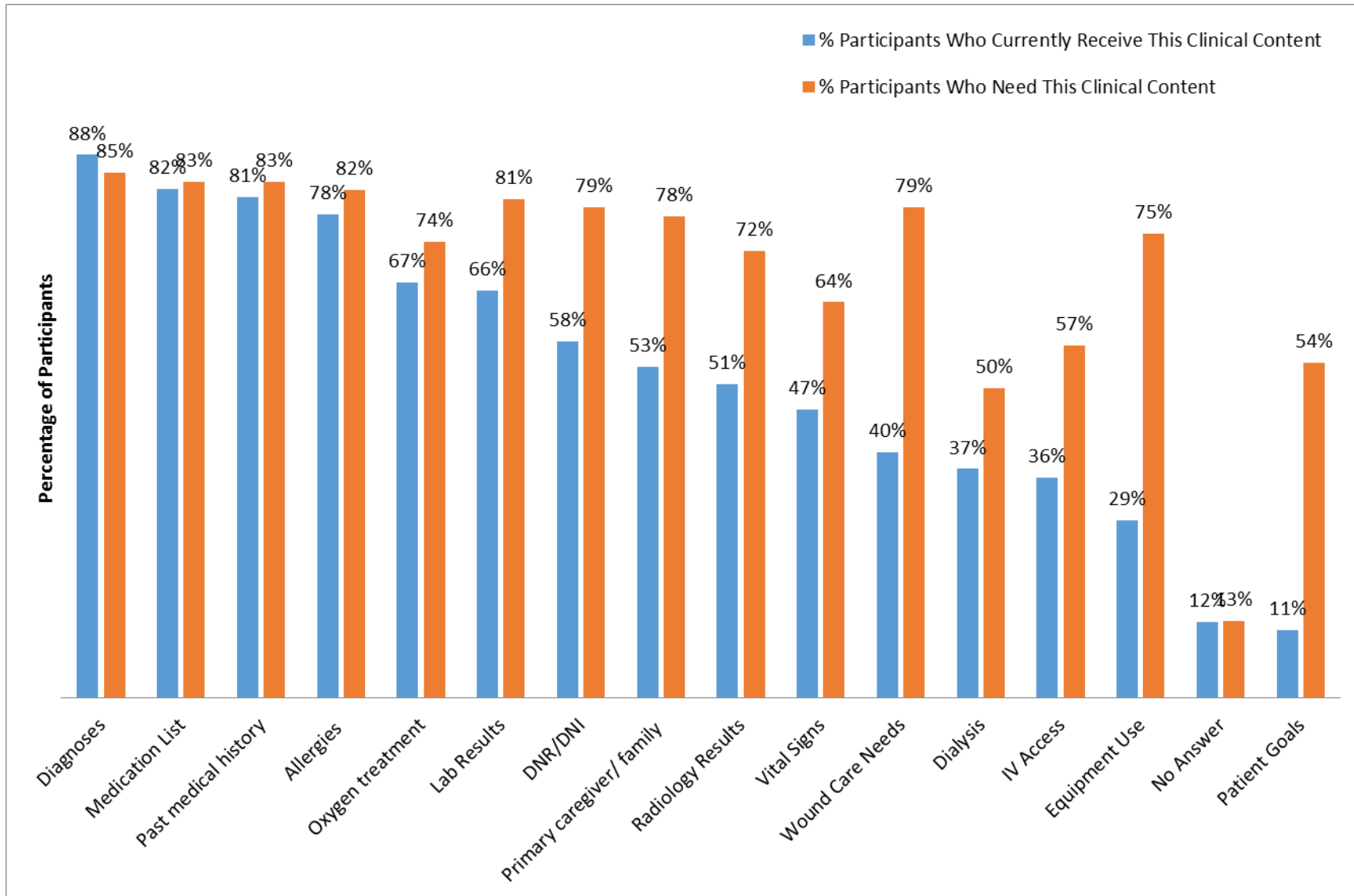
Participants stated that the clinical documents that they receive vary based on the referral source (i.e., if the patient is coming from a hospital or from home), and occasionally this is challenging in rural areas. Overall, many participants are able to access this information via an EHR. Additional clinical documents that participants would like to consistently are listed below. This type of information about gaps in information received can inform HOPE item development in this domain.

- Current Physician’s Orders for Life-Sustaining Treatment (POLST)
- H&P (history and physical examination)
- *If the patient is coming from another hospice facility:* “Face to Face (F2F)” documentation, Certificate of Terminal Illness, and Discharge Summary
- Documentation of disease progression

- Living arrangements information
- Insurance Information

Participants were then polled on the specific clinical content that they currently receive, and which clinical content they need to care for patients (Exhibit 11). “Wound Care Needs” and “Equipment Needs” had the largest discrepancy between the percentage of participants who currently receive that information (40% and 29%, respectively) and the percentage of participants who need that information (79% and 75%). Participants reiterated the variation that they see in the type and completeness of information based on the source. Additional helpful clinical content would include insurance information, any history of violence, any history of chemotherapy or transfusions, referral source, and if the attending physician wants to continue to follow the patient.

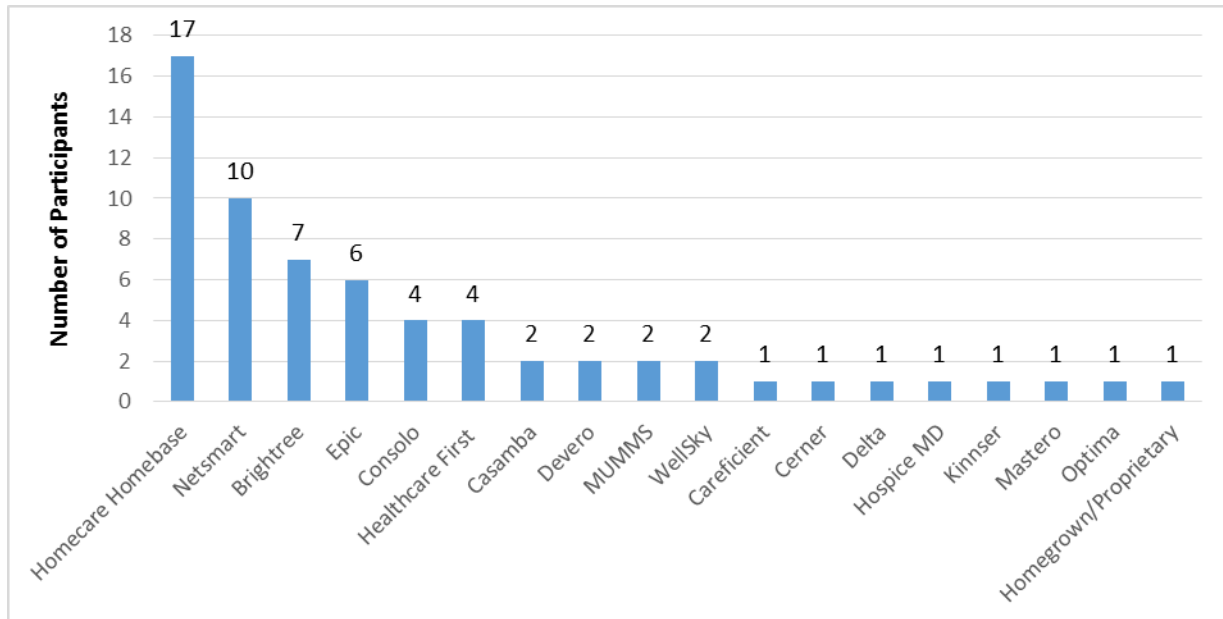
Exhibit 11. Poll Results on Clinical Content that Participants Currently Receive and Their Perceived Value



3.8. Electronic Health Record (EHR) Use

The focus group closed with a poll about EHR use at participants’ hospices (Exhibit 12), to help inform engagement with EHR vendors. Sixty-four participants provided the name of the EHR vendors used by their hospices. Eighteen EHR vendors were identified; however, it should be noted that some of these vendors may be owned by the same parent company. Homecare Homebase was the most commonly used EHR in the focus group cohort, used by 27% of participants. No participants said that their hospices do not use an EHR, although nine participants did not provide information on their hospices’ EHR.

Exhibit 12. EHRs Used by Participants’ Hospices (n=64)



4. FOCUS GROUP DATA AND NEXT STEPS: COGNITIVE TESTING

The hospice patient assessment instrument, the Hospice Outcome Patient Evaluation (HOPE), currently under development asks hospice clinicians to report on many aspects of hospice care for the first time since CMS implemented the hospice benefit in 1983. Our focus groups have provided the Abt team with important feedback about how hospice clinicians perceive elements of the draft instrument and their utility for reporting on quality of care. We have used focus group data to inform the next phase of instrument development, which is cognitive testing. In cognitive testing, hospice clinicians will provide feedback about their understanding of the instructions for HOPE instrument items. Specifically, focus group data was critical in deciding which areas of the instrument to focus on in the cognitive-testing phase. Focus group participants listed the three most helpful/important domains of the draft instrument as a) symptoms, b) actively dying, and c) diagnosis. Additionally, focus group participants reported that areas of assessment they routinely include in clinical practice are a) symptoms (92%), b) clinical signs (91%), c) function (87%), and d) actively dying (85%). Therefore, HOPE instrument items that focus on these areas will comprise the majority of questions posed during cognitive testing.

5. APPENDICES

APPENDIX A – RECRUITMENT ANNOUNCEMENT

Hospice Assessment Instrument Focus Group Overview

The Centers for Medicare & Medicaid Services (CMS) has recently contracted with Abt Associates, Inc. to develop a hospice assessment instrument that expands on the current Hospice Item Set (HIS) to include a more comprehensive patient assessment for hospice providers. The instrument development work is a part of the larger contract for Home Health and Hospice Quality Reporting Program, Quality measures and Assessment Instrument Development, Modification and Maintenance, & Quality Reporting Program Oversight Support. The contract number is 75FCMC18D0014, and the task order number is 75FCMC19F0001.

The long term vision and goal for this assessment instrument is to ensure consistency in assessing hospice patients so that the same quality of hospice care is delivered no matter where patients are receiving care regardless of the location, or type of hospice provider they receive care from. In addition, a standardized assessment instrument will provide hospices with important information to help them understand and address patient and family needs, and ensure delivery of high quality care throughout the patient stay.

A key goal and requirement for this assessment instrument is that it places minimal burden on actively dying patients and their families, and hospice providers. For example, the important areas of focus include how to minimize burden, and integrate EHRs. This work will build on all of the previous development conducted on the HEART assessment instrument, and will build on the foundation CMS and HQRP learned from this prior work in regards to developing an assessment instrument for the HQRP. An integral part of the hospice assessment instrument development is stakeholder input. To expand this comprehensive understanding of stakeholder and patient needs, Abt is soliciting input via virtual focus groups on four primary themes:

1. Key assessment concepts for hospice;
2. Definition and how the assessment instrument should be adapted for the actively dying;
3. Symptom severity assessment approaches;
4. What patient and family circumstances results in need for more intense services (such as GIP or continuous care); and
5. Key measures to capture the quality of hospice for public reporting.

Projected Timeline

- June 2019: Recruit hospice participants with varying characteristics (size, location, organizational features)
- August - September 2019: Data collection - Focus Groups
- September 2019: Abt data analysis
- October 2019: Prepare Environmental Scan report
- November 2019: Present findings to Technical Expert Panel (TEP)

Hospice Provider Roles and Responsibilities

- June – July 2019: Express interest in participating in virtual focus group by responding to Interest Form
- August & September 2019: Participate in a 90 minute, one-time, not-in-person, voluntary participation, online focus group (via webinar)

If you are interested in participating, please complete the focus group interest form located in the download section of the HQRP Requirements and Best Practices tab on the HQRP website and email it to hospiceQRP@abtassoc.com by July 29, 2019. The project team will contact you to further discuss the focus group logistics. If you have questions about the focus groups, please email hospiceQRP@abtassoc.com.

APPENDIX B – INTEREST FORM FOR FOCUS GROUP PARTICIPANTS

Thank you for your interest in participating in the Hospice Assessment Instrument Focus Group. The focus groups will be conducted via webinar in an online format. They will be 90 minutes, and will be scheduled in late August, and early September. Participation is voluntary.

Please fill out the form below to express your interest in participating in the Focus Group. We ask for this information to ensure that we are getting as broad a representation of hospice types, sizes and geography.

1. Personal Contact information
 - Name:
 - Job title:
 - Phone:
 - Email:
2. Hospice Information
 - CCN
 - Name of Hospice:
 - Address:
 - City:
 - State:
 - Zip:
 - Number of CCNs associated with your organization?
 - Number of offices associated with that CCN?

APPENDIX C – INFORMATION SHEET FOR FOCUS GROUP PARTICIPANTS

Information Sheet for Focus Group Participants

Welcome. You or your hospice agency has agreed to participate in a Focus Group for the development of a new hospice assessment instrument. The goal of the Focus Group is to gather perspective and input on current CMS hospice assessments and quality measures, and potential future assessment and measurement. The focus groups will solicit input on four primary themes:

1. Key assessment concepts for hospice;
2. Definition and how the assessment instrument should be adapted for the actively dying;
3. What patient and family circumstances results in need for more intense services (such as GIP or continuous care); and
4. Key measures to capture the quality of hospice for public reporting.

What to expect. The Focus Group discussion will last about 90 minutes, and will include open-ended questions on the themes outlined above. Additional probing questions to clarify and expand the discussion will be asked if necessary.

Participation is voluntary. You do not have to take part in this discussion. Declining to take part will not affect your relationship with your employer, and will not affect your employer's relationship with CMS. You may choose not to answer a question, or to leave at any point for any reason.

Your privacy. Protecting your privacy is very important to us. We will not use names (of hospice agency, patients, or staff) in the discussion, and we will not record your name on our paperwork or in our notes. There is minimal risk of breach of confidentiality. We will not share information that identifies you to anyone outside the project team, except as required by law.

Thank you for your participation. Taking part in this group discussion allows you to actively contribute to the development of a hospice assessment instrument and associated quality metrics. Sharing your hands-on experience provides the development team with unique and valuable information that is not captured anywhere else in our information gathering activities.

Your feedback about hospice assessment instruments is important to us, and we appreciate your time.

Questions. If you have questions about the Focus Group or your rights as a participant, please feel free to contact the Focus Group project manager, Kyle Cobb of Abt Associates Inc. at 301-347-5820 or by email at kyle_cobb@abtassoc.com If you have questions about your rights as a research participant, you may contact Katie Speanburg, the Abt Institutional Review Board Chairperson at (877)-520-6835.

APPENDIX D. FOCUS GROUP SLIDE DECK



Focus Group Session

**Hospice Assessment
Instrument
Development**

**August-September
2019**



Alt Associates (pg 1)



Agenda

- Housekeeping and Guidelines
- Introductions
- Objectives
- Background
- Discussion
- Next Steps



Alt Associates (pg 2)

Housekeeping



- We will be recording our conversation
- Please mute your line when you are not speaking
- This discussion is scheduled to last for 90 minutes
- If you encounter any technical issues, you can use the Q&A function to connect with our team



Alt Associates (pg 3)

Guidelines for Our Virtual Discussion



- We anticipate a collegial discussion! There will be both oral discussion and polling.
- Please be honest with your feedback. There are no right or wrong answers.
- Please introduce yourself (first name only) when you speak.
- We want to hear from you! We may call on you if we haven't heard from you in a while.
 - You can use the webinar Q&A function to indicate that you would like to speak if you are having difficulty entering the conversation.

Alt Associates (pg 4)

Objectives for This Focus Group



- We will be reviewing and seeking your feedback on:
 - Key assessment domains
 - Specific assessment elements
 - Frequency of data collection
 - Interoperability

Alt Associates (pg 5)

Commonly Used Acronyms



ACP	Advanced Care Planning	HQRP	Hospice Quality Reporting Program
CAHPS	Hospice Consumer Assessment of Healthcare Providers and Systems CAHPS® Survey	HIS	Hospice Item Set
CMS	Centers for Medicare & Medicaid Services	QAPI	Quality assurance/performance improvement
COP	Conditions of Participation		

Alt Associates (pg 5)

Why is CMS Developing a New Patient Assessment Instrument?



- CMS is committed to ensuring quality of care for hospice beneficiaries through the Hospice Quality Reporting Program (HQRP)
- The Hospice Item Set (HIS) provides basic information about the patient and his or her hospice stay, and is not a patient assessment tool that can support outcome quality measures
- The new Patient Assessment Instrument is intended to:
 - Collect data that can help hospices understand and address patient and family needs
 - Consider existing items that hospices already collect in their current EHR systems
 - Provide value to patients and families by helping guide consumer choice of hospice programs, and also engage them in critical decision making about their care
 - Help CMS provide stewardship for meaningful quality measurement, with measures focused on the outcomes of care

Alt Associates (pg 7)

Information Gathering Process To Date



Alt Associates (pg 8)

Draft Assessment Domains for Hospice Care



- A. **Actively Dying:** life expectancy of less than 3 days
- B. **Advanced Care Planning (ACP)**
- C. **Symptom Assessment and Outcome:** Pain, nausea and vomiting, dyspnea, agitation, anxiety, delirium
- D. **Sociodemographic:** ethnicity, race, language, gender, age
- E. **Diagnosis:** related/ unrelated to the terminal illness
- F. **Living arrangement:** live alone, with someone else, or congregate housing
- G. **Function:** bed mobility, toileting, transfers, eating
- H. **Grief**
- I. **Spirituality**
- J. **Discharge Status:** live discharge or death, revocation

ABT Associates | pg 9

Poll: Assessment Domains



- Please choose what you think are the **3 most** important/helpful domains to be included in this assessment.
 - A. **Actively Dying:** life expectancy of less than 3 days
 - B. **Advanced Care Planning (ACP)**
 - C. **Symptom Assessment and Outcome:** Pain, nausea and vomiting, dyspnea, agitation, anxiety, delirium
 - D. **Sociodemographic:** ethnicity, race, language, gender, age
 - E. **Diagnosis:** related/unrelated to the terminal illness
 - F. **Living arrangement:** live alone, with someone else, or congregate housing
 - G. **Function:** bed mobility, toileting, transfers, eating
 - H. **Grief**
 - I. **Spirituality**
 - J. **Discharge Status:** live discharge or death, revocation

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Poll Results



- [review poll results and discuss]
- Are there any domains that you would add?

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Poll: Assessment Domains



- Please choose what you think are the 3 **least** important/helpful domains to be included in this assessment.
 - Actively Dying:** life expectancy of less than 3 days
 - Advanced Care Planning (ACP)**
 - Symptom Assessment and Outcome:** Pain, nausea and vomiting, dyspnea, agitation, anxiety, delirium
 - Sociodemographic:** ethnicity, race, language, gender, age
 - Diagnosis:** related/unrelated to the terminal illness
 - Living arrangement:** live alone, with someone else, or congregate housing
 - Function:** bed mobility, toileting, transfers, eating
 - Grief**
 - Spirituality**
 - Discharge Status:** live discharge or death, revocation

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Poll Results



- [review poll results and discuss]

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Routine Nursing Assessment



- Please choose any of these categories that you currently assess on routine nursing visits. Check all that apply.
 - A. Actively Dying: (life expectancy)
 - B. Advanced Care Planning (ACP)
 - C. Symptoms
 - D. Function
 - E. Clinical signs
 - F. Grief
 - G. Spirituality

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Poll Results



- [review poll results and discuss]

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Domain: Actively Dying Signs



- | | |
|-----------------------------------|---|
| A. Cheyne stokes respirations | G. Respiration with mandibular movement |
| B. Apnea | H. Non-reactive pupils |
| C. Pulselessness of radial artery | I. Decrease response to verbal stimuli |
| D. Peripheral cyanosis | J. Drooping of nasolabial fold |
| E. Decreased urine output | K. Low oxygen saturation |
| F. Death rattle | L. New Dysphagia of liquids |
| | M. Decrease in blood pressure |

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Poll: Actively Dying Signs



- Please select any items that you think could be interpreted in multiple ways.
 - A. Cheyne stokes respirations
 - B. Apnea
 - C. Pulselessness of radial artery
 - D. Peripheral cyanosis
 - E. Decreased urine output
 - F. Death rattle
 - G. Respiration with mandibular movement
 - H. Non-reactive pupils
 - I. Decrease response to verbal stimuli
 - J. Drooping of nasolabial fold
 - K. Low oxygen saturation
 - L. New Dysphagia of liquids
 - M. Decrease in blood pressure

ADT Associates | pg 17

Discussion: Actively Dying



- [discuss poll results]
- Are there better terms that would be more likely to be interpreted consistently?
- Are there any signs that you think should be added? Why?

ADT Associates | pg 18

Poll: Actively Dying



- Are there any signs that could be removed from this checklist?
 - A. Cheyne stokes respirations
 - B. Apnea
 - C. Pulselessness of radial artery
 - D. Peripheral cyanosis
 - E. Decreased urine output
 - F. Death rattle
 - G. Respiration with mandibular movement
 - H. Non-reactive pupils
 - I. Decrease response to verbal stimuli
 - J. Drooping of nasolabial fold
 - K. Low oxygen saturation
 - L. New Dysphagia of liquids
 - M. Decrease in blood pressure

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Discussion: Actively Dying



- [discuss poll results]

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Symptom Severity SOS Scale & Pain



- **Items to be assessed:** pain, shortness of breath, nausea, vomiting, hallucination, agitation, anxiety, constipation & diarrhea
- **Severity Scale:**
 - A. **None:** patient does not have the symptom.
 - B. **Mild:** symptom has little impact on any of the following: sleep, day to day activities, and/or ability to interact with others.
 - C. **Moderate:** symptom impacts on any of the following: sleep, day to day activities, and/or ability to interact with others for some of time.
 - D. **Severe:** symptom significantly impacts on any of the following: sleep, day to day activities, and/or ability to interact with others for majority of time.
 - E. **Overwhelming:** symptom is at a level such that the patient is unable to think of anything else and/or do any other activities.
 - F. **Cannot assess:** patient is comatose or unconscious.

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Poll: Severity Scale



- Are any of these definitions unclear?
 - A. **None:** patient does not have the symptom.
 - B. **Mild:** symptom has little impact on any of the following: sleep, day to day activities, and/or ability to interact with others.
 - C. **Moderate:** symptom impacts on any of the following: sleep, day to day activities, and/or ability to interact with others for some of time.
 - D. **Severe:** symptom significantly impacts on any of the following: sleep, day to day activities, and/or ability to interact with others for majority of time.
 - E. **Overwhelming:** symptom is at a level such that the patient is unable to think of anything else and/or do any other activities.
 - F. **Cannot assess:** patient is comatose or unconscious.

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Discussion: Severity Scale



- [discuss poll results]
- Should any of these categories be collapsed/merged?

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Poll: Performance Status Scales



- Which Performance Status Scale(s) do you use on a regular basis?
 - A. Karnofsky Performance Scale (KPS)
 - B. Palliative Performance Scale (PPS)
 - C. Palliative Prognostic Index (PPI)
 - D. Edmonton Symptom Assessment System (ESAS)
 - E. ECOG scale (Eastern Cooperative Oncology Group (ECOG) Performance Status)
 - F. Functional Assessment Staging (FAST)
 - G. Other

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Results: Performance Status Scales



- [display poll results]



Poll: Complete Assessment Frequency



- How often is it feasible to complete the full/ comprehensive hospice assessment?
 - A. Every 30 days
 - B. Every 60 days
 - C. At time of recertification (90 days, 90 days, 60 days, etc.)



Discussion: Complete Assessment Frequency



- [discuss poll results]

ADT Associates | p. 27

Poll: Re-Assessment Frequency



- How often is it feasible to complete a subset (skip patterns) of the comprehensive hospice assessment (i.e., 5-10 questions)?
 - A. Prior to an interdisciplinary group meeting
 - B. Every week
 - C. Every 2 weeks
 - D. Other

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Discussion: Re-Assessment Frequency



- [discuss poll results]

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Information Exchange



Documents

- Recent progress notes
- Transfer Summaries
- Hospital Discharge Summary
- Consult Note
- Care Plans
- Discharge Assessments

Clinical Content

- Past medical history
- Current/ recent medical history
 - Diagnoses
 - Allergies
 - Lab results
 - Radiology results
 - Medication list
 - Vital signs
 - Wound care needs
 - Equipment Use
- Advanced care planning information
 - Primary caregiver/ family
 - DNR/ DNI
 - Patient Goals
- Treatments
 - Oxygen
 - Dialysis
 - IV Access

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Poll: Documents Received



- What clinical documents do you receive?
 - A. Most Recent Progress Note
 - B. Transfer Summary
 - C. Hospital Discharge Summary
 - D. Consult Note
 - E. Care Plan
 - F. Discharge Assessments

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Poll: Documents of Least Value



- What clinical documents are of least value to you to receive from a referral source?
 - A. Most Recent Progress Note
 - B. Transfer Summary
 - C. Hospital Discharge Summary
 - D. Consult Note
 - E. Care Plan
 - F. Discharge Assessments

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Poll: Documents you need



- What clinical documents do you need?
 - A. Most Recent Progress Note
 - B. Transfer Summary
 - C. Hospital Discharge Summary
 - D. Consult Note
 - E. Care Plan
 - F. Discharge Assessments

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Poll: Clinical Content Received



- What clinical content do you receive?

<ol style="list-style-type: none"> A. Past medical history B. Diagnoses C. Allergies D. Lab Results E. Radiology Results F. Medication List G. Vital Signs 	<ol style="list-style-type: none"> H. Wound Care Needs I. Equipment Use J. Primary caregiver/family K. DNR/DNI L. Patient Goals M. Oxygen treatment N. Dialysis O. IV Access
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Poll: Clinical Content of Least Value



- What clinical content is of least value to you to receive from a referral source?
 - A. Past medical history
 - B. Diagnoses
 - C. Allergies
 - D. Lab Results
 - E. Radiology Results
 - F. Medication List
 - G. Vital Signs
 - H. Wound Care Needs
 - I. Equipment Use
 - J. Primary caregiver/family
 - K. DNR/DNI
 - L. Patient Goals
 - M. Oxygen treatment
 - N. Dialysis
 - O. IV Access

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Poll: Clinical Content Needed



- What clinical content do you need?
 - A. Past medical history
 - B. Diagnoses
 - C. Allergies
 - D. Lab Results
 - E. Radiology Results
 - F. Medication List
 - G. Vital Signs
 - H. Wound Care Needs
 - I. Equipment Use
 - J. Primary caregiver/family
 - K. DNR/DNI
 - L. Patient Goals
 - M. Oxygen treatment
 - N. Dialysis
 - O. IV Access

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Poll: EHR Use

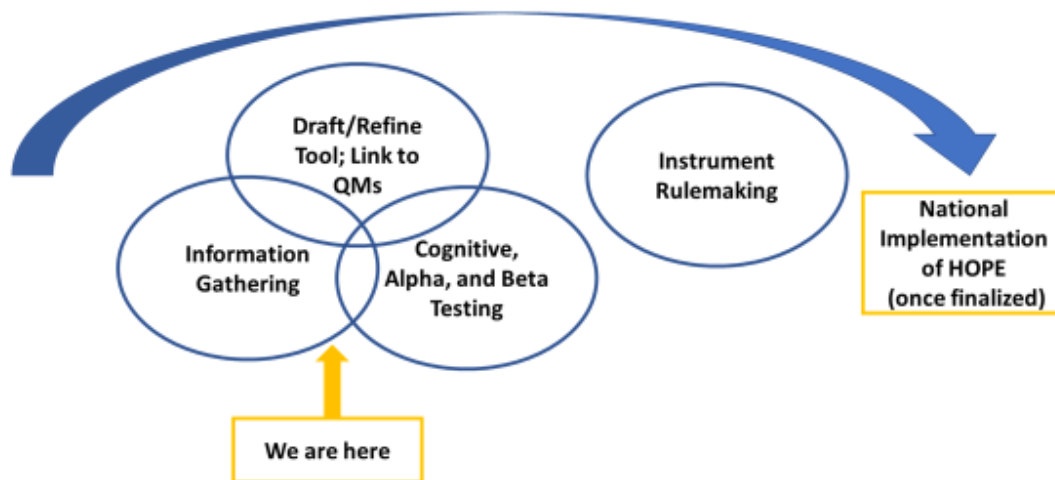


- Does your hospice agency use an electronic health record?
- A. Yes
- B. No
- C. Unsure

Using the Q&A feature, please message “the Panelists” with the name of your EHR system.

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Next Steps



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Your Feedback is Appreciated!



If you think of anything else, contact us:

HospiceAssessment@cms.hhs.gov

This mailbox is actively monitored

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Thank You