Hospice Quality Reporting Program

Hospice Outcomes and Patient Evaluation (HOPE)
Development and Testing

December 18, 2023

Submitted to:
Centers for Medicare & Medicaid Services
7500 Security Blvd
Baltimore, MD 21244

Submitted by:
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Rockville, MD 20852

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About This Report

The analyses upon which this publication is based were performed under Contract 75FCMC18D0014 and task order number 75FCMC19F0001 funded by the Centers for Medicare & Medicaid Services, Department of Health, and Human Services. The content of this publication does not necessarily reflect the views or policies of the Department of Health and Human Services, nor does the mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government. Abt Associates assumes full responsibility for the accuracy and completeness of the information presented.

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Background

Hospice care is a comprehensive, holistic approach to care for end-of-life patients that recognizes death as a natural process. Hospice care uses a patient-and family-centered approach to deliver compassionate medical, nursing, psychosocial, and spiritual care for patients with an expected prognosis of six months or less. High-quality hospice services are important and beneficial to terminally ill patients and their families. In their commitment to providing high-quality care to Medicare beneficiaries enrolled in hospice, CMS established the Hospice Quality Reporting Program (HQRP) under section 1814(i)(5) of the Social Security Act to help them better understand and inform the public about the quality of hospice care.

Currently the HQRP includes quality measures that reflect care processes and patient and caregiver experience of care, but not care outcomes, which are a priority of CMS' Meaningful Measures Framework (MMF). This lack of data on patient outcomes is in part because existing HQRP data sources, the Hospice Item Set (HIS) and Medicare claims, do not provide information on the care a patient receives over the course of their hospice stay nor the results of any care provided.

In recognition of this gap, CMS contracted with Abt Associates (Abt) to develop, test, and prepare to implement Hospice Outcomes and Patient Evaluation (HOPE), a novel hospice data collection tool intended to comprehensively capture information on patient outcomes and on patient, family, and caregiver needs at multiple timepoints throughout the hospice stay. Beta HOPE test results, which are the focus of this report, will inform development of HOPE version 1.0. CMS expects to propose national implementation of HOPE version 1.0 in future rulemaking.

HOPE Development and Testing Overview

Abt initiated HOPE development in 2019 with extensive information gathering activities such as expert interviews, listening sessions, focus groups, and environmental scans. The information gathering phase culminated in the first draft of HOPE, which included existing, modified, and *de novo* data elements, to be collected by hospice staff including registered nurses (RNs), social workers (SWs), and chaplains. Abt also engaged a technical expert panel throughout HOPE development and testing to provide input on hospice quality measurement concepts.

After developing the first draft of HOPE, Abt tested the tool over several sequential phases:

- Initial cognitive testing evaluated hospice staff's understanding of selected draft data elements and response options.
- Pilot testing evaluated the testing procedures and materials, including the draft HOPE tool and guidance manual.
- Alpha testing evaluated the feasibility of completing HOPE at multiple timepoints throughout the hospice stay and determined preliminary reliability and validity of the data elements.
- Beta testing assessed the validity, feasibility, and reliability of data elements included in the revised draft of the HOPE tool (i.e., Beta HOPE).

Methods

Beta HOPE included forms to be completed by the RN, SW, and chaplain. A demographic form completed at patient enrollment collected administrative information and basic patient demographics

(gender, age). Each discipline (i.e., RN, SW, and chaplain) was then to complete one form per patient at admission and discharge timepoints. Included data elements across the forms reflected patient health status, functional ability, symptom experience and preferences for symptom management, advance care planning, and patient and family/caregiver needs for nursing, psychosocial and spiritual care needs. RNs also completed a symptom reassessment form two days after admission for patients experiencing moderate or severe symptom impacts.

Abt recruited 60 hospices to implement Beta HOPE in a national field test. Although the sample was not designed to be nationally representative, participating hospice providers represented a mix of sizes, geographic regions, ownership types, and urbanicity. At 38 of the participating hospices, hospice staff including RNs, SWs, and chaplains completed at least one HOPE form.

In all, 381 hospice patients enrolled in HOPE beta testing (i.e, initated the demograpic form) , and hospice staff ultimately initiated at least one Beta HOPE form (i.e., the form had at least one data element completed by the applicable hospice discipline) for 371 of these patients. In total, hospice staff initiated a total of 901 forms across disciplines and timepoints (i.e., admission, symptom reassessment, discharge). Abt analyzed these data to assess the validity, feasibility, and reliability of Beta HOPE data elements.

Abt additionally collected qualitative data to inform the validity and feasibility of Beta HOPE data elements through several different mechanisms. Hospice staff were able to enter comments directly in the data collection form, and provide informal feedback using a dedicated study emailbox and during regularly scheduled office hours. They also completed a survey early in the data collection period. Hospice staff also participated in fifteen 60- to 90-minute focus groups.

Ultimately, Abt tested 64 unique Beta HOPE data elements, several of which had multiple components (e.g., a single data element required both a patient response and a caregiver response) to assess their validity, feasibility, and reliablity. Data elements and their components collectively represent 171 unique data points, some of which data were collected at multiple timepoints (e.g., at admission and discharge).

Beta Test Results

RNs reported that the scope and content of the RN Admission and RN Symptom Reassessment forms aligned well with their current assessment practices, but they were concerned about the forms' length. Some RNs noted that HOPE more heavily involved caregivers and added structure to the information they were already collecting at admission. However, other RNs found the length of the RN Admission form difficult for them and for patients, particularly for complex patients. Few RNs completed an RN Discharge form, as these were completed only for live discharges which can be infrequent.

SWs and chaplains both conveyed that while the HOPE domains aligned with their current assesments, their HOPE forms did not support relationship building in the same way. SWs noted patients feeling overwhelmed with the SW Admission form. Chaplains noted challenges for patients who identify as neither religious nor spiritual. Both SWs and chaplains found their respective admission forms difficult to complete in a single visit, as patients may not be ready to answer the more personal questions involved in determining social work or spiritual care needs until a more solid rapport has been established.

Beta test results demonstrate the HOPE data elements' strong psychometric properties. Descriptive statistics supported face validity for almost all data elements, and overall, data elements had good content validity. Few data elements or components had missingness rates above 10 percent (< 2 percent). Twenty percent of data elements had missingness rates of between 5 percent and 10 percent, suggesting some data elements may need more training and instruction to collect than others. Nearly all data elements and their components (96 percent; n=163) had at least moderate rater agreement (i.e., a Kappa statistic greater than

0.40). Eighty-two percent of RN data elements had good to very good rater agreement, with lower percentages among SW data elements (42 percent) and chaplain data elements (62 percent).

Hospice staff initially found HOPE burdensome, were unclear on how to administer HOPE, and needed guidance on who was considered a caregiver for HOPE purposes. Hospice staff were initially completing HOPE in addition to their regular assessments, which they perceived as duplicating their efforts. However, over time and with additional guidance, they found it easier to integrate HOPE into their usual assessment. Hospice staff were uncertain whether HOPE should be treated as an interview with questions to be asked as written and were advised that any questions that were required to be asked verbatim would include explicit instructions to do so. Hospice staff were also unclear who was considered a caregiver, particularly for patients in a facility providing hospice care.

Discussion and Conclusion

Although CMS has considered several different hospice quality measurement concepts for HQRP inclusion, CMS's initial priorities have been to develop symptom management quality measures that assess whether symptoms that are moderately or severely impacting the patient are reassessed in a timely manner. The beta test indicated that 40 percent of patients experience moderate or severe impacts from pain, and six to 36 percent of patients experience moderate or severe impacts from other symptoms.

Throughout HOPE development, federal stakeholders, the technical expert panel, and hospice staff have stated that acknowledging and considering patient preferences is important for symptom management. Beta test results for patient preference data elements indicated that patients continued to highly prioritize pain reduction on reassessment, and underscore that preferences are meaningful to patients.

In addition to a variety of other physical assessment items, the RNs tested new data elements that included *J0915. Neuropathic Pain*, which is a specific pain type that develops when the nervous system is damaged due to disease or injury. Collecting a data element like *J0915* could both inform prevalence estimates in the hospice setting and allow the creation of quality measure concepts that explicitly consider neuropathic pain as distinct from other types of pain. RNs also tested *J1410. Death Is Imminent* and *J1420. Signs of Imminent Death* to identify those who may be actively dying. While the main purpose of these data elements was to allow nurses to complete only a subset of HOPE for actively dying (rather than completing the entire form) including data elements that consider whether a patient is actively dying can inform future potential measure concepts that account for such limited life expectancy.

Beta test findings will inform CMS about the data elements that are appropriate for hospice patients and the HQRP as they consider implementation of HOPE version 1.0. HOPE data that is valid, feasible to collect, and reliable can support CMS in differentiating hospices while improving the overall quality of hospice services. While some data elements outperformed others, the results of the beta test provide a firm basis for future HOPE enhancements and refinements.

1. Background

Hospice care is a comprehensive, holistic approach to end-of-life care for patients that recognizes death as a natural process. The focus of hospice care is palliation of pain and other symptoms, rather than a continuation of curative treatments. Hospice care uses a patient- and family-centered approach to deliver compassionate medical, nursing, psychosocial, and spiritual care for patients with an expected prognosis of six months or less. Among all Medicare patients who died in 2021, 1.7 million patients (47 percent) received hospice services, from 5,358 unique hospice providers, with total Medicare expenditures for hospice services of $23.1 billion in 2021.[i]

High-quality hospice services are important and beneficial to terminally ill patients and their families. In their commitment to providing high-quality care to Medicare beneficiaries enrolled in hospice care, CMS established the Hospice Quality Reporting Program (HQRP) under section 1814(i)(5) of the Social Security Act. The HQRP currently requires hospice providers to submit certain data:

- The Hospice Item Set (HIS), a standardized set of patient-level items required to be submitted by all Medicare-certified hospice providers for each hospice admission since 2014.
- Medicare hospice claims, which are administrative data hospice providers routinely submit to Medicare to receive payment for services. HQRP does not require hospices to provide data in addition to what they would otherwise submit for payment.
- The Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Hospice Survey, a national survey of informal caregivers (family or friends) about patient and family experiences of care for patients who died while under hospice care.

CMS uses these data sources to calculate the hospice provider's performance on four quality measures (see Exhibit 1-1).

Exhibit 1-1. HQRP Quality Measures

Measure	Description	Data Source
HQRP Process Measures		
Hospice and Palliative Care Composite Process Measure – HIS Comprehensive Assessment at Admission (CBE #3235)	Percentage of patient stays for which the hospice performed all seven care processes on admission: Beliefs/Values Addressed if desired by the patient, Treatment Preferences, Pain Screening, Pain Assessment, Dyspnea Screening, Dyspnea Treatment, and Patients Treated with an Opioid Who Are Given a Bowel Regimen, as applicable.	HIS
Hospice Visits in Last Days of Life (CBE #3645)	The proportion of hospice patients who have received in-person visits from a Registered Nurse or Medical Social Worker on at least two out of the final three days of the patient's life.	Medicare Claims
Hospice Care Index	Hospice Care Index captures care processes occurring throughout the hospice stay, between admission and discharge. It is a single measure comprising 10 indicators calculated from Medicare claims data. The indicators included in the Hospice Care Index are: Continuous Home Care (CHC) or General Inpatient Provided, Gaps in Skilled Nursing Visits, Early Live Discharges, Late Live Discharges, Burdensome Transitions (Type 1) – Live Discharges from Hospice Followed by Hospitalization and Subsequent Hospice Readmission, Burdensome Transitions (Type 2) – Live Discharges from Hospice Followed by Hospitalization with the Patient Dying in the Hospital, Per-beneficiary Medicare Spending, Skilled Nursing Care Minutes per Routine Home Care Day, Skilled Nursing Minutes on Weekend Routine Home Care Days, and Visits Near Death.	Medicare Claims

Measure	Description	Data Source
Patient/Caregiver Experience of Care Measures		
CAHPS® Hospice Survey measures (CBE #2651)	All eight of the survey measures are endorsed under Consensus Based Entity (CBE) #2651: Communication with Family; Getting Timely Help; Treating Patient with Respect; Emotional and Spiritual Support; Help for Pain and Symptoms; Training Family to Care for Patient; Rating of This Hospice; Willingness to Recommend This Hospice.	CAHPS® Hospice Survey

HQRP is currently a "pay-for-reporting" program, which means that timely submission and acceptance of complete data (HIS, Medicare claims, and the CAHPS® Hospice Survey), not quality measure performance, determine compliance with HQRP requirements.[ii] HQRP quality measures are publicly reported on Care Compare to help inform patients, families, and caregivers when selecting a hospice. The failure of hospices to comply with quality data reporting requirements results in a percentage-point reduction to the Annual Payment Update (APU), or the annual percentage increase that CMS applies to Medicare reimbursement for eligible hospices, for the corresponding fiscal year. Beginning with the fiscal year 2024 APU the APU penalty for noncompliance is 4 percentage points, an increase over the previous penalty of 2 percentage points.

HQRP does not currently have outcome measures, which are a priority of the CMS Meaningful Measures Framework. This is in part because existing HQRP data sources do not provide the types of information needed to develop meaningful outcome measures in the hospice setting. The HIS is primarily completed by hospice staff based on record review, without direct observation of patients, and captures status only at admission and discharge, not the entire course of a hospice stay. Hospice claims contain limited information about the care provided, and the CAHPS® Hospice Survey is focused exclusively on patient and caregiver experiences and is administered after death.

In recognition of this gap, CMS contracted with Abt Associates (Abt) to develop, test, and implement the Hospice Outcomes & Patient Evaluation (HOPE), a novel hospice data collection tool intended to comprehensively capture information on patient outcomes and on patient, family, and caregiver needs at multiple timepoints throughout the hospice stay. The primary objectives of HOPE are:

- Provide quality data for HQRP requirements through standardized data collection.
- Support survey and certification processes.
- Provide additional clinical data that could inform future payment and quality improvement refinements.

Abt developed and tested HOPE in an overlapping and iterative process, during which stakeholder input and testing results were integrated into successive drafts for the following testing phase. Abt completed four phases of HOPE development and testing from late 2019 through 2022, culminating in development and testing of Beta HOPE.

Beta HOPE test results, which are the focus of this report, will inform development of HOPE version 1.0. The remainder of this report describes HOPE beta testing results, including:

- An overview of the HOPE development and testing phases prior to beta testing.
- A brief overview of beta test methods.
- Beta testing validity, feasibility, and reliability findings for each data element.
- A discussion of the implications of beta test findings for national implementation.

CMS expects to propose national implementation of HOPE version 1.0 in future rulemaking.

2. HOPE Development and Testing Overview

Abt initiated HOPE development in 2019 with extensive information gathering activities such as expert interviews, listening sessions, focus groups, and environmental scans.[iii,iv,v,vi] Abt also convened a technical expert panel to provide input on hospice quality measurement concepts, with their engagement continuing throughout HOPE development and testing.[vii,viii,ix] The information gathering phase culminated in the first draft of HOPE, which included existing, modified, and *de novo* data elements, to be collected by hospice staff including registered nurses (RNs), social workers (SWs), and chaplains, across targeted care domains:

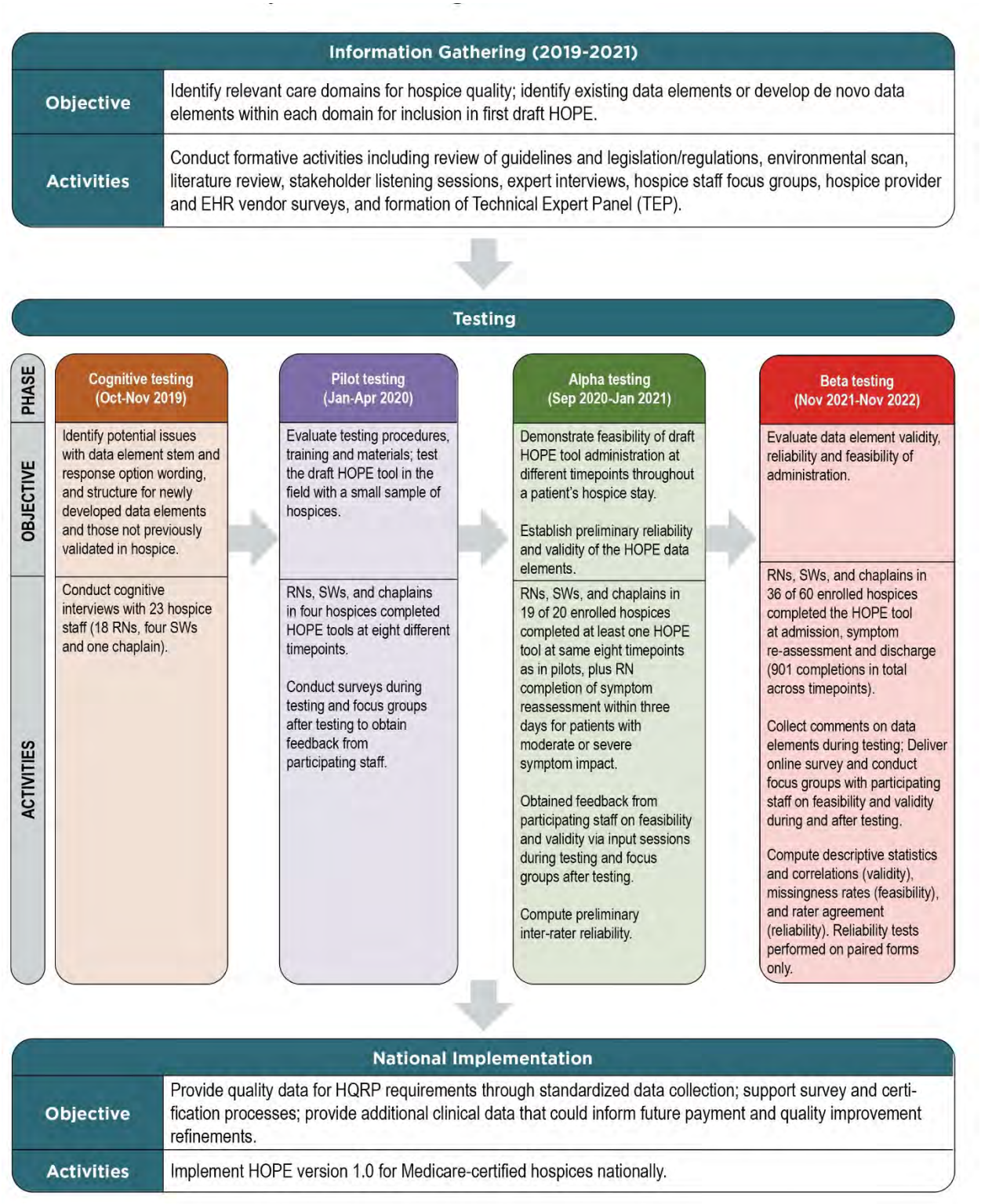
- Advance care planning
- Diagnosis
- Discharge status
- Function (e.g., patient ability to eat, toilet, move into and out of bed)
- Living arrangements
- Risk factors for complicated grief
- Sociodemographic information
- Spirituality
- Symptom assessment and outcome (e.g., pain, dyspnea, anxiety)

After developing the first draft, Abt conducted testing of HOPE over several sequential phases, each building on the last to inform subsequent content and design:

- Initial cognitive testing evaluated hospice staff's understanding of selected draft data elements and response options.
- Pilot testing evaluated the testing procedures and materials, including the draft HOPE tool and guidance manual.
- Alpha testing evaluated the feasibility of completing HOPE at multiple timepoints throughout the hospice stay and determined preliminary reliability and validity of the data elements.
- Beta testing assessed the validity, feasibility, and reliability of data elements included in the revised draft of the HOPE tool (i.e., Beta HOPE).

Exhibit 2-1 provides an overview of objectives and key activities for each phase of HOPE development, testing, and anticipated future implementation.

Exhibit 2-1. HOPE Development and Testing Phases



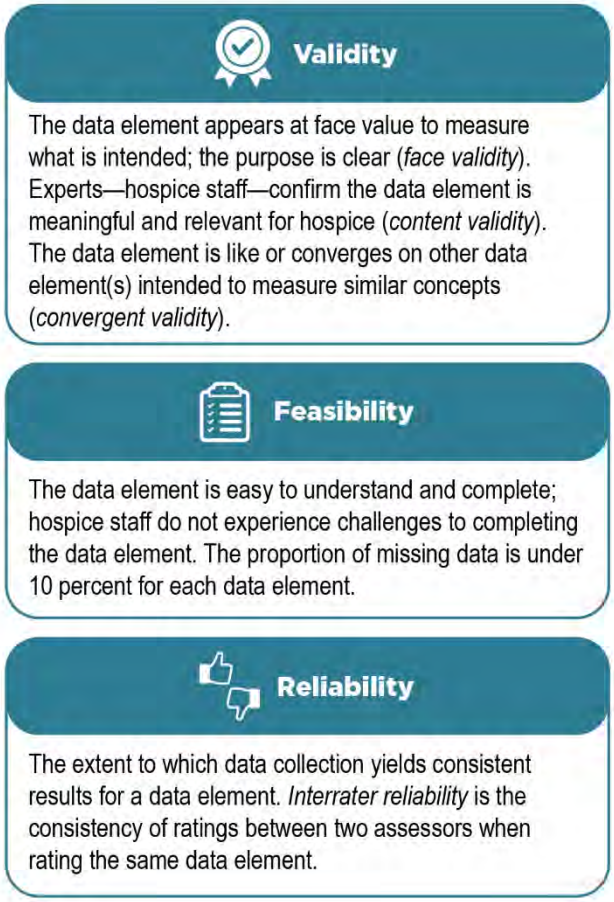
Additional details on methods and findings from previous development and testing phases are provided in Appendix A.

3. Methods Overview

HOPE is intended to comprehensively capture information on patient outcomes and patient, family, and caregiver needs and multiple timepoints through the hospice stay. HOPE data are ultimately intended to support care planning, inform quality measurement, and support providers' quality improvement efforts.

High-quality data are essential to the success of these initiatives. High-quality data elements must be *valid*, *feasible*, and *reliable*; see call-out box to right for definitions. Collectively, these attributes support usability.[x] When data elements exhibiting all three of these attributes are completed as directed, CMS and other intersted parties can be confident in the accuracy and quality of data produced.

To support assessment of included data elements across these three attributes, Abt recruited 60 hospices to implement Beta HOPE in a national field test. While the sample was not designed to be nationally representative, a mix of hospice care providers based on size, geographic region, ownership, and urbanicity participated. Beta HOPE included forms to be completed by the RN, SW, and chaplain. At 38 of the participating hospices, hospice staff including RNs, SWs, and chaplains completed at least one HOPE form.



Administrative information and basic patient demographics (gender, age) were collected on a demographic form completed at patient enrollment. Staff from each discipline were then to complete one form per patient at admission and discharge timepoints.[1] Discharge forms were intended only for live discharges. RNs were to additionally complete an RN Symptom Reassessment form within two calendar days for any patient where the RN Admission form indicated a symptom impact of *moderate* or *severe*. See Exhibit 3-1 for an illustration of which disciplines completed which forms.

[1] To minimize burden, beta testing did not include an interdisciplinary group timepoint as the feasibility of data collection at this point was established during both pilot and alpha testing. Refer to Appendix A for additional information.

Exhibit 3-1. HOPE Forms by Discipline

Relatively early in Beta HOPE testing data collection, because of reported hospice staffing challenges, Abt directed SWs and chaplains to complete only the admission form instead of both admission and discharge forms Beta HOPE data elements collected by SWs and chaplains are the same at admission and discharge, except for needs identified and plan of care established, which are collected at admission only. This shift helped to alleviate challenges participating hospices experienced completing SW and chaplain forms at both timepoints. Though the number of completed SW and Chaplain Discharge forms was limited, these data are included in the results.

Beta HOPE tested 64 unique data elements, several of which had multiple components (e.g., a single data element requiring both a patient response and a caregiver response). Data elements and their components collectively represent 171 unique data points, some of which were collected at multiple timepoints (e.g., at admission and discharge). Included data elements across the forms reflected patient health status, functional ability, symptom experience and preferences for symptom management, advance care planning, and patient and family/caregiver nursing, psychosocial, and spiritual care needs (Exhibit 3-2). Refer to Appendix B for a PDF version of the Beta HOPE forms, excepting the SW Discharge and Chaplain Discharge forms, which, as previously described, were not substantively different from the SW Admission and Chaplain Admission forms.

Exhibit 3-2. Beta HOPE Data Elements

HOPE Form(s)	Data Elements
Demographic Forms (n=2)	
Demographic (n=2)	• Gender and Age
RN Forms (n=41)	
RN Admission (n=17)	• A0205. Site of Service • A1005. Ethnicity • A1010. Race • A1110. Language • F0900. Living Arrangements • F0915. Availability of Assistance • F1000. Advance Care Planning Preferences • I0030. Primary Medical Condition Category • I0050. Comorbidities and Co-existing Conditions • J0905. Pain Active Problem • J0915. Neuropathic Pain

HOPE Form(s)	Data Elements
	• J1410. Death Is Imminent • J1420. Signs of Imminent Death • JJ0010. Chaplain/Spiritual Care Offered • JJ0015. Social Work Offered • Q1000. Patient and Caregiver Education and Training Needs • Q1100. Patient and Caregiver Resource Needs
RN Admission and RN Discharge (n = 8)	• GG0130. Self-Care • GG0170. Mobility • M0210. Unhealed Pressure Ulcers/Injuries • M0300. Current Number of Unhealed Pressure Ulcers/Injuries at Each Stage • M1085. Other Skin Conditions • M1090. Characteristics of Pressure Ulcers/Injuries and Other Skin Conditions • M1095. Interventions for Pressure Ulcers/Injuries and Other Skin Conditions • N0470/N0471/N0472. Medication Management (patient and caregiver)
RN Admission and RN Symptom Reassessment (n=3)	• J0900. Pain Screening • J2060. Patient Desired Tolerance Level for Symptoms • J2070. Patient Preferences for Symptom Management
RN Admission, RN Symptom Reassessment, and RN Discharge (n=1)	• J2050. Symptom Impact (e.g., pain, shortness of breath, anxiety, nausea)
RN Symptom Reassessment Only (n=1)	• J2080. Follow-up Symptom Control
RN Discharge Only (n=11)	• A1850. Emergency Room Use • A1855. Date of Emergency Room Use • A2105. Discharge Location • A2115. Reason for Discharge • A2121.Provision of Current Reconciled Medication List to Subsequent Provider, • A2122. Route of Current Reconciled Medication List Transmission to Subsequent Provider • A2123. Provision of Current Reconciled Medication List to Subsequent Patient at Discharge • A2124. Route of Current Reconciled Medication List Transmission to Subsequent Patient • F1010. Advance Care Planning Preferences Follow-up • J1800. Any Falls Since Admission or Recertification • J1900. Number of Falls
SW Forms (n=16)	
SW Admission (n=7)	• D0150. Patient Mood Interview • D0160. Total Severity Score • D0180. Patient Feeling Anxious or Worried • D0190. Family Feeling Anxious or Worried • JJ0180. Identification of Psychosocial Needs • JJ0200. Establish Psychosocial Plan of Care • Q1200. Patient and Caregiver Resource Needs
SW Admission and SW Discharge (n=9)	• JJ0050. Psychosocial Assessment Complete • JJ0100. Patient Care Needs • JJ0110. Patient Safety • JJ0120. Financial Resources • JJ0130. Social Support

HOPE Form(s)	Data Elements
	• JJ0150. Awareness of Prognosis • JJ0160. Coping Related to Anticipatory Grief • JJ1040. Cultural Values
Chaplain Forms (n = 8)	
Chaplain Admission (n=2)	• AA0150. Identification of Spiritual or Religious Needs • AA0200. Establish Plan of Care
Chaplain Admission and Chaplain Discharge (n=6)	• AA0050. Patient Response (ability and willingness) • AA0100. Patient at Peace • AA0110. Meaning and Joy • AA0120. Spiritual or Religious Struggles • AA0130. Comfort and Strength • AA0140. Visits or Support from Faith Community

In all, 381 hospice patients enrolled in HOPE beta testing, and hospice staff ultimately initiated at least one Beta HOPE form (i.e., the form had at least one data element completed by the applicable hospice discipline) for 371 of those patients.[2] In total, hospice staff initiated 901 forms across disciplines (i.e., RN, SW, chaplain) and timepoints (i.e., admission, symptom reassessment, discharge).[3] To support the computation of inter-rater reliability, whenever feasible each form was completed separately by two hospice staff members, an assessor and an observer; we refer to forms completed for the same patient at the same timepoint by two different hospice staff as "paired forms", where a single paired form includes information recorded by both the assessor and the observer. 778 such paired forms were successfully completed by both staff. Paired forms were used for inter-rater reliability analyses only. Other analyses conducted to assess feasibility and validity as described below used only data from assessor-completed forms. Exhibit 3-3 shows the number of completed forms for each discipline and timepoint.

Exhibit 3-3. Number of Initiated Beta HOPE Forms by Discipline

Initiated Forms	Admission			Symptom Reassessment	Discharge			Total
	RN	SW	Chaplain	RN	RN	SW	Chaplain	
Total	289	253	233	55	30	24	17	901
Paired	250	218	205	40	28	21	16	778

Notes: RN – registered nurse; SW – social worker. Multiple Beta HOPE forms were initiated per patient; therefore the number of forms in this table does not reflect the number of patients. A form is initiated if the applicable hospice discipline completes at least one data element.
Discharge forms were expected for live discharges only.
Paired forms are forms completed separately by two staff, an observer and an assessor.

Hospice staff completing Beta HOPE forms were asked to provide informal feedback throughout the field test via a dedicated study mailbox and regularly scheduled virtual office hours. Hospice staff were also able to enter comments on individual data elements directly into the data collection form in real time.

In addition, 52 staff completed an online survey early in the data collection period (May 2022) to provide feedback on:

- Clinical usefulness of the data elements

[2] Participating hospices initiated a beta HOPE form for, on average, ten patients (minimum = 1; maximum = 40).

[3] The RN Reassessment form and the SW Admission form each had a small number of patients for whom the forms were started but not completed (two and one, respectively). Note that a completed form reflects a form for which the final administrative data elements on the form were completed, not necessarily that all applicable fields within the form were completed.

- Ease and burden of data collection for both assessors and patients/families
- Factors that affected hospice staff ability to collect information for Beta HOPE
- Time to complete Beta HOPE
- Additional questions or comments related to Beta HOPE

Finally, hospice staff (57 RNs, 44 SWs, and 30 chaplains) participated in fifteen 60- to 90-minute focus groups. The initial five focus groups included all disciplines but later groups had RNs meet separately from the SWs and chaplains so each could focus on the data elements most salient to their discipline.

Abt conducted five RN-only focus groups and and an additional five focus groups with SWs and chaplains. The RN focus groups covered challenges in completing data elements, alignment of the HOPE RN Symptom Reassessment form with usual practice for symptom reassessment, and which data elements RNs felt were most important to be included in the RN Admission, RN Symptom Reassessment, and RN Discharge forms.

The SW and chaplain focus groups covered the the HOPE psychosocial and spiritual data elements, challenges in completing data elements, and which data elements SWs and chaplains felt where most important to be included in the SW and Chaplain Admission and Discharge forms.

Using data from the completed Beta HOPE forms, informal hospice staff feedback, and structured feedback from the online survey and focus groups, Abt performed a series of quantitative and qualitative analyses to assess validity, feasibility, and reliability of Beta HOPE data elements. Exhibit 3-4 provides an overview of the mixed methods analytic approach, with additional methodological details described in Appendix C.

Exhibit 3-4. Mixed Methods Analytic Approach to Assessing Validity, Feasibility, and Reliability for Beta HOPE Data Elements

Data Source	Analytic Approach		
	Validity	Feasibility	Reliability
Completed Beta HOPE forms	**Face validity:** Descriptive statistics **Convergent validity:** Cross-tabulations/chi-square statistics for conceptually related data elements	**Missingness rate** for each data element: >10% considered evidence of feasibility challenges	**Inter-rater reliability** (Kappa) estimates: <0.2 = Poor reliability 0.2 - <0.4 = Fair reliability 0.4 - <0.6 = Moderate reliability 0.6 - <0.8 = Good reliability 0.8+ = Very good reliability
• Informal hospice staff feedback • Online survey • Focus groups	**Content validity:** Qualitative analysis to assess: • whether data element was relevant and meaningful for hospice • whether data element supports care planning and patient care	Qualitative analysis to assess: • whether purpose and intent of data elements were **easy to understand** • whether data elements were **easy or challenging to complete** • whether data elements were **similar to current assessments** and fit with current workflow	*Not Applicable*

4. Beta Test Results: Overview

This chapter provides an overview of HOPE beta test results, including a summary of hospice staff feedback on overall HOPE validity and feasibility and a brief summary of information collected on the demographic form for enrolled patients (age and gender).

4.1 General Hospice Staff Feedback on HOPE Validity and Feasibility

Hospice staff initially found HOPE burdensome, but experienced some improvement as they integrated the forms into their usual assessment process. Some hospice staff initially viewed the HOPE tools as a standalone activity hospice staff would complete in addition to their usual comprehensive assessment. Despite the training and guidance provided, some hospice staff began the beta test by completing their usual assessment, then completing their applicable HOPE tool, which resulted in repetition of some content already assessed.

Abt engaged with hospice staff and provided reinforcement through training, emphasizing that the intent was for integration of the HOPE tool with their comprehensive assessment. As hospice staff became accustomed to their respective HOPE tools, most found it easier to integrate the task with their comprehensive assessment. However, despite this improvement over time, hospice staff expressed mixed opinions on the added burden of HOPE data collection to assessors and patients/families. Some comments about burden referred to the difficulty of scheduling and completing joint visits (i.e., a visit with an assessor and observer for reliability calculations). Some respondents noted that the HOPE tools took longer to complete than expected.

Hospice staff were initially unclear as to how to administer HOPE. Some hospice staff asked whether the HOPE data elements would be completed by interviewing the patient or family/caregiver(s) and relaying the questions exactly as written. The Abt team responded to questions and provided follow-up training to clarify that the hospice staff should not treat completing the HOPE data elements as an interview. Further clarification noted that only data elements requiring hospice staff to use the exact wording with patients or family/caregiver(s) would include explicit instructions to do so.

Hospice staff needed guidance on who was considered a caregiver for HOPE purposes. For data elements that included caregivers (family and facility staff), many hospice staff questioned who should be considered the caregiver(s) and whether hospice staff providing care in an inpatient hospice (e.g., hospice house), long-term care nursing home, or assisted living facilities were included. For example, RNs asked whether facility staff could be asked for input about the patient. Other staff sought clarification about which family member to assess when multiple family members participated in the patient's care.

RNs reported that their HOPE forms aligned with their current assessments but expressed concern at its length. RNs stated that the scope and content of HOPE aligned with their current assessment practices, and some RNs added that HOPE more heavily involved caregivers and added structure to the information they were already collecting. However, some RNs found the length of the RN Admission form difficult for them and for patients, particularly for complex patients. On average RN Admission forms took an average of 52 minutes to complete, while RN Symptom Reassessments and Discharge forms took 39 minutes and 31 minutes, on average, respectively.[4] RNs indicated the RN Symptom Reassessment form aligned with their usual practice of evaluating the initial effect of interventions provided during the visit. Few RNs completed an RN Discharge form, as they were completed only for live discharges. While RNs viewed the discharge form as straightforward and working well with their current processes, they noted it could be difficult to track down family caregivers at discharge.

[4]Calculations exclude extreme outliers.

Social workers reported that the SW HOPE domains aligned with their current assessments, but the HOPE SW Admission forms did not support relationship building in the same way. SWs found their usual assessments, which vary across hospices, more specific and organic. SWs noted patients feeling overwhelmed with the SW Admission form and reluctatant to discuss more personal topics, such as their prognosis or finances. SWs also found some data elements difficult to collect at without a caregiver present; SWs are less likely to see the patient on the first day of addmission when family members are present. The SW Admission took an average for 41 minutes to complete.[5]

Like social workers, chaplains indicated that while the domains of the Chaplain HOPE forms aligned with their current assessments, they did not facilitate relationship building as well and presented challenges for patients who identify as neither religious nor spiritual. Chaplains also expressed challenges completing their Admission form at the first visit, as patients may not be ready to answer the more personal questions involved in determining spiritual care needs. The Chaplain Admission form took an average of 39 minutes to complete.[6]

4.2 Summary of Validity, Feasibility, and Reliability

4.2.1 Validity

Overall, data elements had good content validity, though each discipline noted content validity challenges for some data elements. For the RN forms, *F1000. Advance Care Planning Preferences*, and three of the symptom-related data elements – *J2050. Symptom Impact*, *J2060. Patient Desired Tolerance Level for Symptoms*, and *J2070. Patient Preferences for Symptom Management* – had identified content validity challenges. *F1000* included some "double negative" response options (e.g., a yes response indicating the patient does not want chest compressions) that may affect whether the patients' wishes are accurately captured. Hospice staff also noted that advance care planning often happens prior to hospice enrollment.

For *J2050*, hospice staff indicated the data element was applicable at admission, but questioned its usefulness at discharge and noted that the data element did not align well with their current workflow. For *J2060* and *J2070*, hospice staff found the questions difficult to explain and difficult for patients to understand. There was confusion over why a patient would prefer to tolerate a high level of a symptom and concerns that patients might misinterpret the question and answer with the level of symptom they were willing to tolerate, even if they preferred not to experience the symptom at all. Some RNs noted that *JJ0010. Chaplain/Spiritual Care Offered* and *JJ0015. Social Work Offered* were not useful data elements, as social work and chaplain or spiritual services are already standard parts of the hospice care team. As noted previously, *N0470. Medication Management* had significant content validity issues and was changed partway through beta testing. Initially this data element captured information on both the patient and the caregiver together, but it was converted into two distinct data elements to capture patient and caregiver responses separately (*N0471* and *N0472*).

For almost all items, descriptive statistics supported face validity. The only exception was data element *N0470. Medication Management*, which was updated partway through beta testing because of both face and content validity challenges.

For related data elements correlations suggest good convergent validity. The pain screening component of J0900. Pain Screening correlated with the pain component of J2050. Symptom Impact, with almost 70 percent of patients indicated as having *Severe* pain severity as also having pain impact indicated as *Severe. J2050* was correlated with *J2060. Patient Desired Tolerance Level for Symptoms* and *J0270. Patient Preferences for Symptom Management*. Similarly, the ability of a patient to independently

[5]Calculations exclude extreme outliers.

[6]Calculations exclude extreme outliers.

manage their medications (*N0471. Patient Medication Management – Patient*) correlated with both *F0900. Living Arrangements* and *F0915. Availability of Assistance*. Additionally, for data elements collected at both admission and symptom reassessment (*J0090*, *J2050*, *J2060*, and *J2090*) responses across time periods were correlated. The discharge sample size was too small to determine correlations across timepoints.

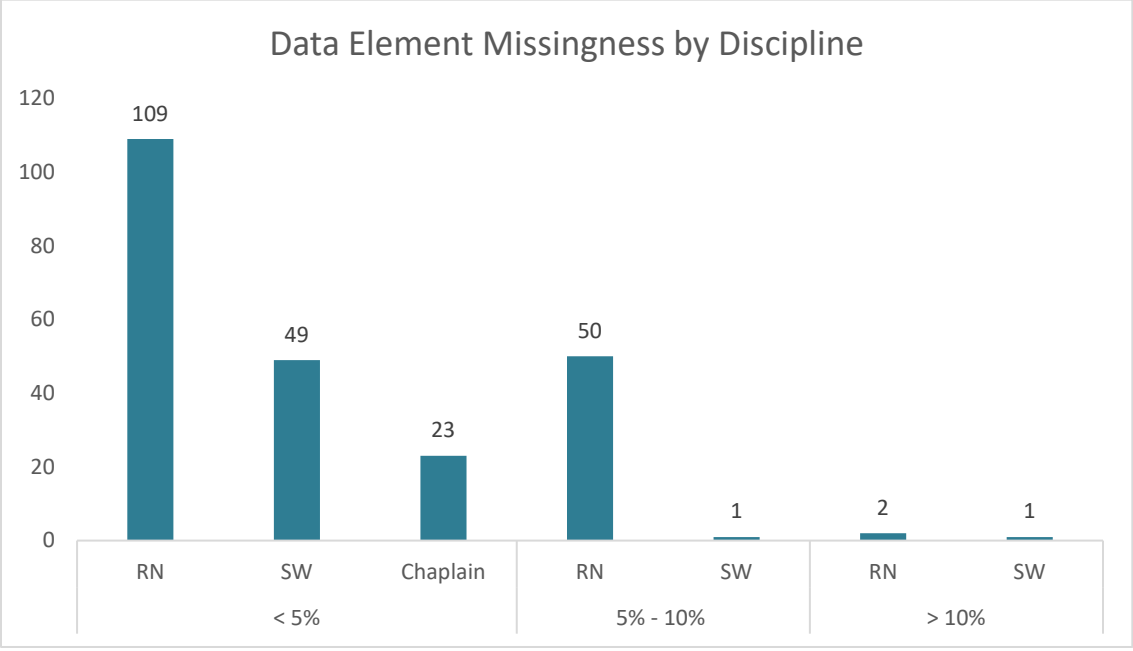
SWs and chaplains described some data elements as feeling "forced" or not well integrated into existing workflows for the hospice population. For *D0150. Patient Mood Interview (Patient Health Questionnaire [PHQ]-2),* Some SWs disliked the standardized response questions and found it did not integrate well into their existing assessments. Similarly, one SW reported *JJ0120. Financial Needs* was not something they typically assessed with hospice patients and their caregivers. Among chaplains, *AA0100. Meaning and Joy* was not typically something they reported assessing, and some reported that the term "joy" might be difficult for patients who are very ill.

Regarding *AA0120 Spiritual or Religious Struggles*, chaplains indicated this data element should focus solely on the patient, rather than both the patient and the caregiver. Chaplains further indicated terms like "spiritual" and "religious" might not be well received, and preferred the open-ended questions they typically ask, which allow for more tailoring to patients' preferences.

4.2.2 Feasibility

Abt calculated a missingness rate for each data element, with the assumption that items are not complete because the needed data are difficult for the assessor to collect. Some evidence suggests that more than 10 percent missing data is likely to cause bias in analyses.[xi] **While most data elements had missingness rates of less than 10 percent, several data elements had missingness rates between 5 percent and 10 percent**. See Exhibit 4-1.

Exhibit 4-1. Data Element Missingness Results by Discipline



Notes: Missingness was calculated for data elements and their components for each discipline at each timepoint (n=235). Several of the 171 unique data elements are collected by more than one discipline or more than one timepoint. Missingness was not calculated for D0160 because it is a calculated field rather than a social worker entered field. Missingness rates were not calculated for data elements that required a drop-down or free-text entry (*A1100.A Language* and *M0300. Number of Unhealed Pressure Ulcers/Injuries at Each Stage*). These data elements are neither binary nor check all that apply; missingness rates cannot determine whether the entry was meaningful making it a poor indicator of feasibility.

Source: Abt analysis based on assessor-initiated Beta HOPE forms.

While the higher rate of missingness for some data elements does not suggest feasibility challenges per se, it does suggest more training or instruction is needed for some data elements compared to others. For the RN discipline, the missingness rates between 5 percent and 10 percent align with the data elements that were indicated to have feasibility challenges based on the qualitative data, including items that are otherwise collected on the HIS (*A0205. Site of Service at Admission* and *J0090. Pain Screening*), and the symptom-related questions about which they had also expressed content validity concerns (*J2050. Symptom Impact*, *J2060. Patient Desired Tolerance Level for Symptoms*, and *J2070. Patient Preferences for Symptom Management)*. *J2050* measures pain impact, rather than pain severity, which some nurses were not accustomed to, while *J2060* and *J2070* were described as complex to understand and explain.

Some data elements raised unique feasibility challenges. For *M0300. Current Number of Unhealed Pressure Ulcers/Injuries at Each Stage,* RNs were to enter the number of pressure ulcers or injuries that corresponded with each stage (Stage 1 to Stage 4 or unstageable). RNs were also supposed to enter a zero for any stages that did not reflect the patient's current wound status. This was intended to allow each part of the data element to have a response, however, despite training and reinforcement, many RNs did not enter a zero when needed. For *J1800. Any Falls Since Admission of Recertification*, RNs noted this information was rarely in a pre-defined electronic health record field making it difficult to collect.

Lastly, for the medication management items (*N0471. Medication Management – Patient*, and *N0472. Medication Management – Caregiver*.), RNs reported specific feasibility challenges for patients in facilities, as the hospice may not have access to the facility's medical record and therefore must engage family members, as well as facility staff who may be monitoring medications, to understand a patient's medication management needs.

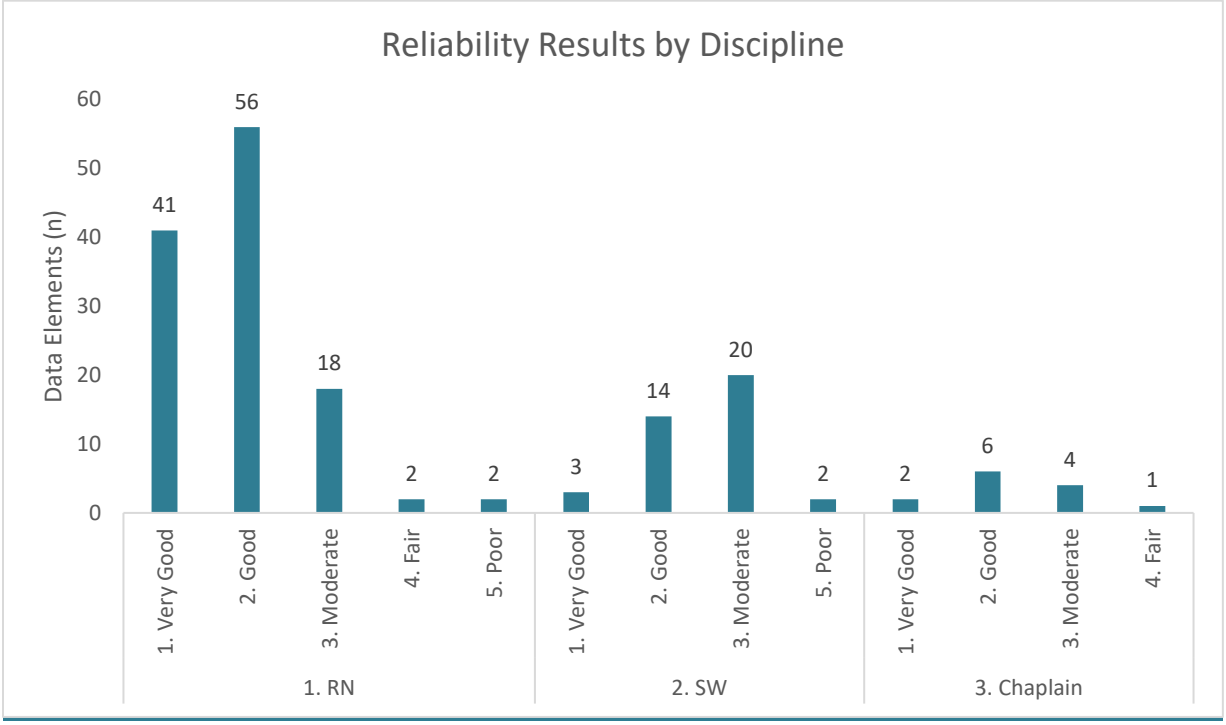
A set of related data elements had missingness rates above 10 percent associated with their *Other* component: *Q1000. Patient and Caregiver Education and Training*, *Q1100. Patient and Caregiver Resource Needs (RN)*, and *Q1200. Patient and Caregiver Resource Needs (SW)*. RNs and SWs reported that they tended to skip over (i.e., not complete) the *Other* data element component because they thought it did not apply one or more of the more specific data element components were selected.

4.2.3 Reliability

Most data elements had good or very good rater agreement, particularly the RN forms.[xii] The RN forms had the highest proportion of data elements with very good or good rater agreement. The SW and chaplain forms had few data elements with very good rater agreement, and higher proportions of data elements with moderate rater agreement. See Exhibit 4-2. This is consistent with the overall validity and feasibility challenges noted for these forms.

Data elements with poor or fair rater agreement reflect data elements that also suggested validity or feasibility challenges. Consistent with the feasibility challenges described for *Q1200*, the two *Other* component associated with this question each had a Kappa statistic of -0.01 – indicating consistent disagreement among assessors. Similarly, the data elements with fair rater agreement also had identified feasibility or reliability challenges (*J0090. Pain Screening*, *AA0120. Spiritual or Religious Struggles*, and *Q1000. Patient and Caregiver Education and Training*).

Exhibit 4-2. Data Element Reliability Results by Discipline



Notes: Results reflect kappa statistics where Very Good = > 0.8; Good = 0.6 < 0.8; Moderate = 0.4 < 0.8; Fair= 0.2 < 0.4; Poor =<0.2. For data elements with multiple components, reliability was determined for each component.
Source: Abt analysis based on paired Beta HOPE forms.

5. Beta Test Results: Demographic Form

Hospice staff completed demographic information for each patient enrolled in the beta test, regardless of which form was initiated. A total of 381 unique patients were enrolled (agreed to participate) in the beta test. Hospice staff completed more than one HOPE form for some patients (e.g., a HOPE RN Admission plus a HOPE Symptom Reassessment, or a HOPE SW Admission plus a HOPE SW Discharge). Therefore, the number of patients in the sample does not match the total number of HOPE tools completed.

Alpha HOPE, which was a single form representing all disciplines, included sex (also known as sex assigned at birth), sexual orientation, and two versions of gender (self-reported gender identity) in the SW section as part of its larger psychosocial assessment. These data elements were identified in collaboration with the Office of Minority Health.

Alpha testing suggested challenges with collecting these data elements. Hospice staff participating in the alpha test expressed many challenges with the sexual orientation and gender identity items. Some hospice staff reported that the sex assigned at birth, sexual orientation, and self-reported gender identity data elements were relevant to patient care but challenging to discuss with patients. Other participants reported that these data elements were not relevant to their patients or to hospice care. Many hospice staff expressed the sense that these items were "intrusive," especially when they were trying to build rapport upon first meeting the patient and family for the admission assessment. Several clinicians noted that these data elements were not well received or were confusing to patients and family. Based on this feedback, CMS elected not to include data elements for sex assigned at birth, sexual orientation, and self-reported gender identity in Beta HOPE.

Beta HOPE collects gender and date of birth in the initial Demographic form before a HOPE form is initiated, first confirming the patient is over 18 years old to verify age eligibility, then collecting patient date of birth and patient gender (male or female). The Demographic form concludes by documenting verbal agreement to participate by either the patient or caregiver.

These well-established administrative data elements, already collected in the hospice setting, were included in Beta HOPE only to describe the patient sample, so Abt did not assess validity, feasibility, or reliability for these data elements. Age was reported for all 381 total patients enrolled, and gender was reported for all but one. Patients were 60.1 percent female and 39.6 percent male. The average age was 81.1, with few patients under 65 (7.9 percent). See Exhibit 5-1 and Exhibit 5-2.

As noted in the Methods section, only 371 of those patients who enrolled in the beta test ultimately had a HOPE form initiated. There were no statistically significant differences between those who enrolled in the beta test and had a HOPE form initiated compared to those who enrolled but did not have a HOPE form initiated.

Exhibit 5-1. Age of Beta Test Enrollees

	All Patients		Patients Any Form Initiated	
Age Group	Number	Percent	Number	Percent
Less than 65 years old	30	7.9%	28	7.5%
65–74 years old	77	20.2%	77	20.8%
75–84 years old	110	28.9%	107	28.8%
85 and older	164	43%	159	42.9%
Missing	0	0%	0	0%
Total	381	100%	371	100%

Source: Assessor-initiated Beta HOPE Demographic forms.

Exhibit 5-2. Gender of Beta Test Enrollees

	All Patients		Patients with Any Form Initiated	
Gender	Number	Percent	Number	Percent
Male	151	39.6%	145	39.1%
Female	229	60.1%	225	60.6%
Missing	1	0.3%	1	0.3%
Total	381	100%	371	100%

Source: Assessor-initiated Beta HOPE Demographic forms.

6. Beta Test Results: RN Forms

Beta HOPE includes three RN forms: RN Admission, RN Symptom Reassessment, and RN Discharge. The RN data elements captured administrative data and information in domains such as symptom assessment, medications, and patient and family/caregiver needs that are relevant for hospice care and quality. Here we discuss qualitative findings for the RN forms overall, followed by results for each data element.

6.1 Overall RN Form Feasibility and Validity

Overall, RNs reported that the scope and content of HOPE aligned with their current assessment practices and the symptoms they typically assess. Assessor comments included that the HOPE tool was slightly more "in-depth" than their current assessments, and more heavily involved caregivers compared to their typical assessment, and added structure to the information they were already collecting. HOPE was generally well received; one assessor commented that it was "excellent information to collect and use in providing care to patients."

Some assessors, however, found the length of the HOPE tool burdensome for patients and families and thought the timeframe for the completion (i.e., at the patient's first visit) might not be feasible or realistic for complex patients or those with unstable family dynamics—particularly when considering other all of the activities RNs undertake to establish a patient during their first visit (e.g., setting up medical equipment, reviewing medications). Some RNs reported patients being frustrated with the questions, with one RN reporting a patient specifically commented that the assessment process was stressful. RN assessors commented that following the questions did not allow the conversation to flow and made the assessment unnatural, some data elements were confusing and difficult for patients and families to understand, caregivers were sometimes unavailable, and some patients were dealing with high symptom burden, which made it hard for them to respond to the questions.

One RN noted that during the admissions process families wanted hospice staff to focus on answering their questions about hospice care and what to expect, and the HOPE questions seemed "excessive."

Hospice RNs provided feedback that the timing of RN Symptom Reassessment in the beta test aligned with their usual practice of reassessing symptoms within 24 to 48 hours. During the beta test, RNs were instructed to conduct the RN Symptom Reassessments in person, and as a joint visit. Hospice staff completed only about half of the RN Symptom Reassessments within two days when so required based on the data collected on the RN Admission tool. However, the beta test was conducted during the COVID-19 public health emergency, which created atypical logistical issues for in-person meetings, joint visit requirements, and completion of the RN Symptom Reassessment within two days.

RNs noted that in their usual practice they might reassess troubling patient symptoms before the end of their visit, to evaluate the initial effect of interventions provided during the visit. They asked whether they could complete the RN Symptom Reassessment this way. For beta test purposes, RNs were instructed to complete the RN Symptom Reassessment tool after the RN Admission as part of a separate patient visit.

Many assessors did not complete a live discharge assessment, and among those who did, feedback varied. Several spoke positively about the HOPE discharge assessment, reporting that it generally worked well with their current processes and was straightforward to complete. One RN commented that live discharges were easier to complete than admission assessments as the team already knew the patient. Challenges with the HOPE discharge assessment included family caregiver availability and staff scheduling, live discharges that can be unexpected and happen quickly, and difficulty tracking down family caregivers to obtain their input for the live discharge assessment.

6.2 Administrative Information

The RN Admission and the RN Discharge forms collects admission date (*A0220*; RN Admission only) or discharge date (*A0270*; RN Discharge only). The RN Admission form also collects site of service at admission (*A0205*), ethnicity (*A1005*), race (*A1010*), language (preferred language [*A1110.A*]) and need for interpreter [*A1110.B]*), concluding with data elements on whether death is imminent (*J1410*), and (if yes) signs of imminent death (*J1420*). The RN Discharge form administrative information section concludes with the reason for discharge (*A2215*).

6.2.1 Admission Date (A0220) and Discharge Date (A0270)

Admission and discharge dates are standard administrative items already collected in the HIS. Abt did not test these data elements; the information was used to match records for analysis and determine the intervals between HOPE tools (e.g., admission and symptom reassessment).

6.2.2 Site of Service at Admission (A0205)

A current HIS data element, *A0205. Site of Service at Admission*, identified the location of care for the patient at the time of hospice admission. For Beta HOPE testing, this data element was collected as part of the RN Admission form only. Results are reported for the 289 initiated RN Admission forms. Abt included this data element for Beta HOPE to describe the patient sample in terms of service location (e.g., to distinguish patients receiving home-based care from those receiving care in facilities).

Validity

Descriptive statistics support face validity. RNs identified home/residence as the site of service at admission for 53.6 percent of patients, assisted living facility for 13.1 percent, and long-term care for 13.5 percent – consistent with where patients typically receive hospice services. See Exhibit 6-1.

Exhibit 6-1. *A0205. Site of Service at Admission*

	Number	Percent
Hospice provided in patient's home/residence	155	53.6%
Hospice provided in assisted living facility	38	13.1%
Hospice provided in nursing long term care or non-skilled nursing facility	39	13.5%
Hospice provided in skilled nursing facility	19	6.6%
Hospice provided in inpatient hospital	0	0%
Hospice provided in inpatient hospice facility	6	2.1%
Hospice provided in long-term care hospital	0	0%
Hospice provided in inpatient psychiatric facility	0	0%
Hospice provided in place not otherwise specified (NOS)	2	0.7%
Hospice home care provided in a hospice facility	9	3.1%
Missing	21	7.3%
Total	289	100%

Source: Assessor-initiated Beta Test HOPE RN Admission forms.

Feasibility

The proportion of missing data for this data element was 7.3 percent, suggesting **no feasibility challenges**. Refer to Appendix D for additional feasibility data.

Qualitative data suggests some feasibility challenges. Beta test training and guidance directed the RNs to collect *A0205. Site of Service at Admission* and other HIS data elements included as part of Beta HOPE. However, some RNs reported that they automatically skipped these included HIS data elements,

noting that the other hospice staff typically completed them. Some RNs noted that they assumed that a different staff member would complete the included HIS data elements later.

During the course of the beta test, Abt clarified the response options in the data collection tool. Although most RNs became accustomed to completing these data elements as data collection progressed, the early challenges they experienced highlighted a need to carefully distinguish who is responsible for completing HIS data elements included in HOPE.

Reliability

Kappa statistics indicate **very good rater agreement** for *A0205. Site of Service at Admission* (0.91). See Appendix E for additional reliability data.

6.2.3 Ethnicity (A1005), Race (A1010), and Language (A1110)

The data elements *A1005. Ethnicity*, *A1010. Race*, and *A1110. Language* are considered SDOH items and are standard post-acute care data elements used in CMS's post-acute care quality reporting programs. Alpha HOPE included ethnicity, race, and language (preferred language and need for interpreter) in the SW section as part of its large psychosocial assessment. These data elements are in the administrative section of the Beta HOPE RN Admission form.

Validity

Descriptive statistics support face validity. Most patients identified as white (91.0 percent) and not of Hispanic/Latino/a or Spanish origin (94.1 percent). None of the patients in this sample identified as more than one race category. Nearly all patients identified English as their preferred language (*A1110A*) and only two needed an interpreter (*A1110B*). See Exhibit 6-2 through Exhibit 6-4 for additional details.

Exhibit 6-2. *A1005. Ethnicity*

Are you of Hispanic, Latino/a, or Spanish origin?								
	Yes		No		Not asked		Total	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent
No, not of Hispanic, Latino/a, or Spanish origin	272	94.1%	12	4.2%	5	1.7%	289	100%
Yes, Mexican, Mexican American, Chicano/a	10	3.5%	274	94.8%	5	1.7%	289	100%
Yes, another Hispanic, Latino, or Spanish origin	2	0.7%	282	97.6%	5	1.7%	289	100%
Yes, Puerto Rican	0	0%	284	98.3%	5	1.7%	289	100%
Yes, Cuban	0	0%	284	98.3%	5	1.7%	289	100%
Patient unable to respond	3	1%	281	97.2%	5	1.7%	289	100%

Source: Assessor-initiated Beta Test HOPE RN Admission forms.

Exhibit 6-3. *A1010. Race*

What is your race? Check all that apply.								
	Yes		No		Not asked		Total	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent
A. White	263	91%	21	7.3%	5	1.7%	289	100%
B. Black or African American	18	6.2%	266	92%	5	1.7%	289	100%
C. American Indian or Alaska Native	1	0.3%	283	97.9%	5	1.7%	289	100%

What is your race? Check all that apply.								
	Yes		No		Not asked		Total	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent
D. Asian Indian	0	0%	284	98.3%	5	1.7%	289	100%
E. Chinese	0	0%	284	98.3%	5	1.7%	289	100%
F. Filipino	1	0.3%	283	97.9%	5	1.7%	289	100%
G. Japanese	0	0%	284	98.3%	5	1.7%	289	100%
H. Korean	0	0%	284	98.3%	5	1.7%	289	100%
I. Vietnamese	1	0.3%	283	97.9%	5	1.7%	289	100%
J. Other Asian	0	0%	284	98.3%	5	1.7%	289	100%
K. Native Hawaiian	0	0%	284	98.3%	5	1.7%	289	100%
L. Guamanian or Chamorro	0	0%	284	98.3%	5	1.7%	289	100%
M. Samoan	0	0%	284	98.3%	5	1.7%	289	100%
N. Other Pacific Islander	0	0%	284	98.3%	5	1.7%	289	100%
X. Patient Unable to Respond	4	1.4%	280	96.9%	5	1.7%	289	100%

Source: Assessor-initiated Beta Test HOPE RN Admission forms.

Exhibit 6-4. *A1110. Language*

	Number	Percent
A1110.A. What is your preferred language?		
English	282	97.6%
French	1	0.3%
Spanish	4	1.4%
Vietnamese	1	0.3%
Missing	1	0.3%
Total	289	100%
A1110.B. Do you need or want an interpreter to communicate with a doctor or health care staff?		
No	284	98.3%
Yes	2	0.7%
Unable to determine	2	0.7%
Missing	1	0.3%
Total	289	100%

Source: Assessor-initiated Beta Test HOPE RN Admission forms.

Feasibility

All of these data elements suggested **no feasibility challenges**, with the proportion of missing data at less than 5 percent (1.7 percent for *A1005. Ethnicity*; 1.7 percent for *A1010. Race*; and 0.3 percent for *A1110. Language*.) See Appendix D for additional feasibility data.

Hospice staff did not identify any challenges in completing these data elements.

Reliability

Kappa statistics indicate **very good rater agreement** for ethnicity (.99), race (.99), and preferred language (.99), and **good rater agreement** for need for interpreter (.66). See Appendix E for additional reliability data.

6.2.4 Death is Imminent (J1410) and Signs of Imminent Death (J1420)

The intent of *J1410. Death is Imminent* was to identify patients who were not expected to live longer than three days, based on the RN's comprehensive assessment and clinical judgment. Abt developed this data element for potential use as a gateway question that, when answered yes, would trigger a skip pattern for the RN to complete only a subset of subsequent data elements. This skip pattern reduces the incidence of providers asking patients unnecessary questions, reducing burden for these patients. If RNs selected "yes" for *J1410*, the data element *J1420. Signs of Imminent Death* provided information on the signs and symptoms the patient exhibited that led the RN to conclude that death may be imminent. These data elements were collected on the RN Admission form only.

Validity

Qualitative data mostly supports content validity. In preparation for testing, the list of signs and symptoms (J1420) was developed from literature reviews and expert interviews. Hospice staff in cognitive interviews identified signs they believed were most relevant markers of imminent death. In pilot testing each sign/symptom was selected at least once and the full list was retained for alpha testing, with the addition of an option for none of the above. Hospice staff in Alpha HOPE focus groups confirmed their preference for "terminal respiratory secretions (death rattle)" to replace the term "death rattle." Alpha focus groups also found the questions relevant, as they let the RN know how quickly all disciplines need to get involved in the care of the patient. Additionally, for Beta HOPE, instructions in the item text were clarified to indicate signs/symptoms should be selected that were present "at the time of this assessment." During the initial beta test focus groups, RNs had mixed opinions regarding the most important signs of imminent death to assess for patients who are imminently dying and noted that some of these signs can appear earlier, a few weeks before death.

Although the data elements were rearranged following cognitive interviews, so that death is imminent (J1410) appeared first on the HOPE form, some hospice RNs still asked in the other phases of testing whether the signs of imminent death were intended to inform their determination of whether death was imminent. Abt clarified at each stage that the signs listed in J1420 did not determine the response to J1410.

Descriptive statistics support face validity. Most patients were not identified as imminently dying (93.8 percent). The most frequently noted signs and symptoms of imminent death included decreased urine output (80 percent) and decreased response to verbal stimuli (66.7 percent). See Exhibit 6-5 and Exhibit 6-6.

Exhibit 6-5. *J1410. Death Is Imminent*

Does the patient appear to have a life expectancy of 3 days or less?		
	Number	Percent
No	271	93.8%
Yes	15	5.2%
Missing	3	1%
Total	289	100%

Source: Assessor-initiated Beta Test HOPE RN Admission forms.

Exhibit 6-6. *J1420. Signs of Imminent Death*

Check all that apply at the time of this assessment.								
	Yes		No		Not Assessed		Total	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent
A. Cheyne-Stokes respirations	2	13.3%	12	80%	1	6.7%	15	100%

Check all that apply at the time of this assessment.								
	Yes		No		Not Assessed		Total	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent
B. Apnea	6	40%	8	53.3%	1	6.7%	15	100%
C. Pulselessness of radial artery	0	0%	14	93.3%	1	6.7%	15	100%
D. Peripheral cyanosis	4	26.7%	10	66.7%	1	6.7%	15	100%
E. Decreased urine output	12	80%	2	13.3%	1	6.7%	15	100%
F. Terminal respiratory secretions (death rattle)	3	20%	11	73.3%	1	6.7%	15	100%
G. Respiration with mandibular movement	1	6.7%	13	86.7%	1	6.7%	15	100%
H. Non-reactive pupils	1	6.7%	13	86.7%	1	6.7%	15	100%
I. Decreased response to verbal stimuli	10	66.7%	4	26.7%	1	6.7%	15	100%
J. Drooping of nasolabial fold	3	20%	11	73.3%	1	6.7%	15	100%
K. Low oxygen saturation	6	40%	8	53.3%	1	6.7%	15	100%
L. New dysphagia of liquids	6	40%	8	53.3%	1	6.7%	15	100%
M. Decrease in blood pressure	4	26.7%	10	66.7%	1	6.7%	15	100%
N. None of the above	0	0%	14	93.3%	1	6.7%	15	100%

RN completed this data element only for patients who were actively dying (n=15: see data element J1410).
Source: Assessor-initiated Beta Test HOPE RN Admission forms.

Feasibility

All these data elements exhibited **no feasibility challenges.** The proportion of missing data was 1 percent for death is imminent, and 6.7 percent for signs and symptoms of imminent death. See Appendix D for additional feasibility data.

Reliability

Kappa statistics indicated **very good** rater agreement for death is imminent (.88) and signs of imminent death (.89). See Appendix E for additional reliability data.

6.2.5 Reason for Discharge (A2115)

Both Pilot HOPE and Alpha HOPE included this HIS data element, which confirms the reason for discharge. Beta HOPE retained these elements to better identify the disposition of patients discharged alive from hospice. Abt instructed RNs to complete the RN Discharge form only for patients discharged alive from hospice.

Validity

Descriptive statistics support face validity. Among the 30 RN Discharges completed, most reflected patients who were no longer terminally ill (66.7 percent). One record was marked expired, in error. See Exhibit 6-7.

Exhibit 6-7. *A2115. Reason for Discharge*

	Number	Percent
Expired	1	3.3%
Revoked	7	23.3%
No longer terminally ill	20	66.7%
Moved out of hospice service area	0	0%

	Number	Percent
Transferred to another hospice	1	3.3%
Discharged for cause	0	0%
Missing	1	3.3%
Total	30	100%

Abt instructed assessors to complete discharge forms for live discharges only.
Source: Assessor-initiated Beta Test HOPE RN Discharge forms.

Feasibility

A2115. Reason for Discharge exhibited **no feasibility challenges,** with only one record (3.3 percent) missing a response. Hospice RNs identified no feasibility issues with this data element. See Appendix D for additional feasibility data.

Reliability

Kappa statistics indicate **very good rater agreement** for *A2115. Reason for Discharge* (0.92). See Appendix E for additional reliability data.

6.3 Preferences for Customary Routine and Activities

Living Arrangements (F0900), Availability of Assistance (F0915), Advance Care Planning Preferences (F1000)

F0900. Living Arrangements identified whether the patient lived alone, with other(s), in a congregate or inpatient setting, or lacked a permanent home. *F0915. Availability of Assistance* identified the level of in-person assistance from available and willing caregiver(s) including family and facility staff but excluding hospice staff, at the time of data collection. *F1000. Advance Care Planning Preferences* is a new data element developed for HOPE testing to capture information more fully about patient needs, wishes, and goals related to end-of-life care.

Hospice RNs asked during alpha testing whether to complete the *F1000* data element based on patient self-report only, and Abt clarified the instruction in the data element stem to read "Identify the patient's preferences for the following based upon the discussion with the patient and/or caregiver."

Validity

Qualitative data suggests good content validity for *F0900* and *F0195*, but also suggests challenges for *F1000*.

Hospice RNs identified no validity challenges for living arrangements or availability of assistance, with alpha testing focus groups indicating living arrangements and availability of assistance are important to assess to ensure patients have the resources they need.

For advance care planning preferences, some RNs reported confusion with the response categories. They reported the phrasing *None of the Above* seemed like a "double negative" when they considered the interventions, which were also phrased as negative statements (e.g., Do not attempt chest compressions). Alpha test focus groups acknowledged that advance care planning preferences were relevant for patient care and completion of physicians' order for life-saving treatment, but also noted that an advance care plan is often completed before the patient officially enrolls in hospice care, to ensure they understand the care that will be provided.

Descriptive statistics support face validity. RNs indicated that most patients lived at home with others (48.8 percent), followed by those in an inpatient facility (26.6 percent). This is consistent with most patients indicated as having around-the-clock assistance (83.0 percent). Advance care planning preferences (F1000), a *Check All That Apply* data element, reflects most patients rejecting life-saving interventions such as chest compressions (84.4 percent) and intubation (69.2 percent) – consistent with patients receiving hospice care. See Exhibit 6-8 through Exhibit 6-10.

Exhibit 6-8. *F0900. Living Arrangements*

Identify the patient's living arrangement at the time of this assessment.		
	Number	Percent
Person lives alone – no other residents in the home.	20	6.9%
Person lives with others in the home (e.g., family, friends, or paid caregiver).	141	48.8%
Person lives in congregate home (e.g., assisted living or residential care home).	50	17.3%
Person is in an inpatient facility (e.g., skilled nursing facility, nursing home, inpatient hospice, hospital).	77	26.6%
Person does not have a permanent home or is homeless.	0	0%
Missing	1	0.3%
Total	289	100%

Source: Assessor-initiated Beta Test HOPE RN Admission forms.

Exhibit 6-9. *F0915. Availability of Assistance*

Code the level of in-person assistance from available and willing caregiver(s), excluding hospice staff, at the time of the assessment.		
	Number	Percent
No assistance available	5	1.7%
Occasional short-term assistance (with infrequent exceptions)	28	9.7%
Regular nighttime (all night every night with infrequent exceptions)	6	2.1%
Regular daytime (all day every day with infrequent exceptions)	9	3.1%
Around-the-clock (24 hours a day with infrequent exceptions)	240	83%
Missing	1	0.3%
Total	289	100%

Source: Assessor-initiated Beta Test HOPE RN Admission forms.

Exhibit 6-10. *F1000. Advance Care Planning Preferences*

Check all that apply at the time of this assessment.								
	Yes		No		Not Assessed		Total	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent
A. Do not attempt chest compressions.	244	84.4%	41	14.2%	4	1.4%	289	100%
B. Do not intubate.	200	69.2%	85	29.4%	4	1.4%	289	100%
C. Do not hospitalize unless for the patient's comfort.	221	76.5%	64	22.1%	4	1.4%	289	100%
D. None of the above	24	8.3%	261	90.3%	4	1.4%	289	100%
X. Not discussed	2	0.7%	283	97.9%	4	1.4%	289	100%

Forty-six patients selected three interventions option, 20 selected two interventions, and 193 selected all three interventions
Source: Assessor-initiated Beta Test HOPE RN Admission forms.

Feasibility

All these data elements exhibited **no feasibility challenges**. The proportion of missing data for living arrangements and availability of assistance was 0.3 percent for each data element, and 1.4 percent for advance care planning preferences. See Appendix D for additional feasibility data.

Reliability

Kappa statistics indicated **very good rater agreement** for living arrangements (.88) and advance care planning preferences (.99), and **good rater agreement** for availability of assistance (.77). See Appendix E for additional reliability data.

6.4 Functional Abilities

HOPE testing included the standard post-acute care data elements for functional abilities, self-care (*GG0130*), and mobility (*GG0170*), to assess the level of assistance the patient requires to complete self-care and mobility activities. Each of these data elements comprise multiple activities. RNs used a coding scale to identify the amount of assistance a patient needed from another person (or two people) to perform each self-care and mobility activity. These data elements were collected at admission and discharge.

The standard post-acute care guidance for these data elements required minimal alteration for application to the hospice setting. However, for HOPE testing, when training participants Abt heavily emphasized the purpose of these assessment data elements in hospice care. Unlike in other post-acute care settings, where improvement is expected, in the hospice setting these data elements ensure patients are safe and have the assistance they need to accomplish daily activities for as long as their condition permits.

6.4.1 Self-Care (*GG0130*) and Mobility (*GG0170*)

Abt included most of the available self-care (*GG0130*) activities in cognitive, pilot, and alpha testing. Analysis following the alpha test identified several activities were often coded as not attempted, or not applicable (upper and lower body dressing, and putting on/taking off footwear), and did not retain these in Beta HOPE. Similarly, for mobility (*GG0170*) certain activities included in cognitive, pilot, and alpha testing (sit to lying, lying to sitting on side of the bed, picking up an object, and patient use of a wheelchair or scooter) were not included in Beta HOPE because of how often RNs coded them as not attempted or not applicable.

Validity

There were **no content validity challenges** identified for these data elements. Hospice RNs asked how to complete the patient assessment for these data elements, such as whether direct observation was required for all activities (it was not).

Descriptive statistics support face validity. In general, on admission some patients remained independent, with self-care activities ranging from 9.7 percent for showering/bathing to 25.3 percent for oral hygiene. RNs indicated that fewer than 20 percent of patients could independently toilet and fewer than 10 percent could independently bathe. See Exhibit 6-11.

For mobility activities, patients indicated as independent on admission ranged from 21.1 percent for walking 10 feet to 39.1 percent for rolling left and right in bed. More than 20 percent of patients were documented as being independent in each mobility component. See Exhibit 6-12.

Because RNs completed the RN Discharge form only for patients discharged alive, the percentage of patients identified as being able to engage in self-care activities and move independently is higher relative to the percentage for patients assessed at admission. See Exhibit 6-11 and Exhibit 6-12.

Exhibit 6-11. *GG0130. Self-Care*

	Admission		Discharge	
	Number	Percent	Number	Percent
A. Eating: The ability to use suitable utensils to bring food and/or liquid to the mouth and swallow food and/or liquid once the meal is placed before the patient				
Independent	72	24.9%	12	42.9%
Setup or clean-up assistance	92	31.8%	7	25%
Supervision or touching assistance	13	4.5%	1	3.6%
Partial/moderate assistance	18	6.2%	1	3.6%
Substantial/maximal assistance	18	6.2%	0	0%
Dependent	53	18.3%	2	7.1%

	Admission		Discharge	
	Number	Percent	Number	Percent
Patient refused	3	1%	0	0%
Not applicable – Not attempted and the patient did not perform this activity prior to the current illness, exacerbation, or injury	10	3.5%	3	10.7%
Not attempted due to environmental limitations	0	0%	0	0%
Not attempted due to medical conditions or safety concerns	10	3.5%	1	3.6%
Missing	0	0%	1	3.6%
Total	289	100%	28	100%
B. Oral hygiene: The ability to use suitable items to clean teeth				
Independent	73	25.3%	9	32.1%
Setup or clean-up assistance	52	18%	8	28.6%
Supervision or touching assistance	17	5.9%	0	0%
Partial/moderate assistance	19	6.6%	3	10.7%
Substantial/maximal assistance	23	8%	1	3.6%
Dependent	89	30.8%	2	7.1%
Patient refused	1	0.3%	0	0%
Not applicable – Not attempted and the patient did not perform this activity prior to the current illness, exacerbation, or injury	12	4.2%	3	10.7%
Not attempted due to environmental limitations	0	0%	0	0%
Not attempted due to medical conditions or safety concerns	3	1%	1	3.6%
Missing	0	0%	1	3.6%
Total	289	100%	28	100%
C. Toileting hygiene: The ability to maintain perineal hygiene, adjust clothes before and after voiding or having a bowel movement				
Independent	54	18.7%	6	21.4%
Setup or clean-up assistance	15	5.2%	4	14.3%
Supervision or touching assistance	21	7.3%	4	14.3%
Partial/moderate assistance	35	12.1%	5	17.9%
Substantial/maximal assistance	35	12.1%	3	10.7%
Dependent	111	38.4%	2	7.1%
Patient refused	2	0.7%	0	0%
Not applicable – Not attempted and the patient did not perform this activity prior to the current illness, exacerbation, or injury	10	3.5%	2	7.1%
Not attempted due to environmental limitations	0	0%	0	0%
Not attempted due to medical conditions or safety concerns	6	2.1%	1	3.6%
Missing	0	0%	1	3.6%
Total	289	100%	28	100%
E. Shower/bathe self: The ability to bathe self, including washing, rinsing, and drying self (excludes washing of back and hair); does not include transferring in/out of tub/shower				
Independent	28	9.7%	5	17.9%
Setup or clean-up assistance	13	4.5%	1	3.6%
Supervision or touching assistance	20	6.9%	3	10.7%
Partial/moderate assistance	37	12.8%	8	28.6%
Substantial/maximal assistance	48	16.6%	4	14.3%
Dependent	124	42.9%	3	10.7%
Patient refused	2	0.7%	0	0%

	Admission		Discharge	
	Number	Percent	Number	Percent
Not applicable – Not attempted and the patient did not perform this activity prior to the current illness, exacerbation, or injury	9	3.1%	2	7.1%
Not attempted due to environmental limitations	0	0%	0	0%
Not attempted due to medical conditions or safety concerns	7	2.4%	1	3.6%
Missing	1	0.3%	1	3.6%
Total	289	100%	28	100%

At discharge, the RN did not complete this data element for patients with a discharge reason of Expired (n=1; see data element A2115).
Patients for whom the discharge reason was missing are not included (n=1; see data element A2115).
Source: Beta test HOPE RN Admission and Discharge forms.

Exhibit 6-12. *GG0170. Mobility*

	Admission		Discharge	
	Number	Percent	Number	Percent
A. Roll left and right: The ability to roll from lying on back to left and right side and return to lying on back on the bed				
Independent	113	39.1%	15	53.6%
Setup or clean-up assistance	4	1.4%	1	3.6%
Supervision or touching assistance	19	6.6%	2	7.1%
Partial/moderate assistance	31	10.7%	1	3.6%
Substantial/maximal assistance	35	12.1%	3	10.7%
Dependent	70	24.2%	2	7.1%
Patient refused	1	0.3%	0	0%
Not applicable – Not attempted and the patient did not perform this activity prior to the current illness, exacerbation, or injury	11	3.8%	2	7.1%
Not attempted due to environmental limitations.	0	0%	0	0%
Not attempted due to medical conditions or safety concerns	5	1.7%	1	3.6%
Missing	0	0%	1	3.6%
Total	289	100%	28	100%
D. Sit to stand: The ability to come to a standing position from sitting in a chair, wheelchair, or on the side of the bed				
Independent	67	23.2%	12	42.9%
Setup or clean-up assistance	6	2.1%	1	3.6%
Supervision or touching assistance	22	7.6%	5	17.9%
Partial/moderate assistance	40	13.8%	2	7.1%
Substantial/maximal assistance	38	13.1%	3	10.7%
Dependent	53	18.3%	1	3.6%
Patient refused	1	0.3%	0	0%
Not applicable – Not attempted and the patient did not perform this activity prior to the current illness, exacerbation, or injury	27	9.3%	2	7.1%
Not attempted due to environmental limitations	0	0%	0	0%
Not attempted due to medical conditions or safety concerns	35	12.1%	1	3.6%
Missing	0	0%	1	3.6%
Total	289	100%	28	100%
E. Chair/bed-to-chair transfer: The ability to transfer to and from a bed to a chair (or wheelchair)				
Independent	63	21.8%	10	35.7%
Setup or clean-up assistance	7	2.4%	0	0%
Supervision or touching assistance	18	6.2%	3	10.7%

	Admission		Discharge	
	Number	Percent	Number	Percent
Partial/moderate assistance	41	14.2%	4	14.3%
Substantial/maximal assistance	41	14.2%	3	10.7%
Dependent	55	19%	1	3.6%
Patient refused	1	0.3%	0	0%
Not applicable – Not attempted and the patient did not perform this activity prior to the current illness, exacerbation, or injury	27	9.3%	5	17.9%
Not attempted due to environmental limitations.	1	0.3%	0	0%
Not attempted due to medical conditions or safety concerns.	35	12.1%	1	3.6%
Missing	0	0%	1	3.6%
Total	289	100%	28	100%
F. Toilet transfer: The ability to get on and off a toilet or a commode				
Independent	66	22.8%	9	32.1%
Setup or clean-up assistance	9	3.1%	1	3.6%
Supervision or touching assistance	19	6.6%	5	17.9%
Partial/moderate assistance	39	13.5%	3	10.7%
Substantial/maximal assistance	37	12.8%	2	7.1%
Dependent	44	15.2%	2	7.1%
Patient refused	1	0.3%	0	0%
Not applicable – Not attempted and the patient did not perform this activity prior to the current illness, exacerbation, or injury	29	10%	4	14.3%
Not attempted due to environmental limitations	0	0%	0	0%
Not attempted due to medical conditions or safety concerns	44	15.2%	1	3.6%
Missing	1	0.3%	1	3.6%
Total	289	100%	28	100%
I. Walk 10 feet: Once standing, the ability to walk at least 10 feet in a room, corridor, or similar space				
Independent	61	21.1%	9	32.1%
Setup or clean-up assistance	7	2.4%	2	7.1%
Supervision or touching assistance	26	9%	5	17.9%
Partial/moderate assistance	23	8%	2	7.1%
Substantial/maximal assistance	17	5.9%	3	10.7%
Dependent	28	9.7%	0	0%
Patient refused	1	0.3%	0	0%
Not applicable – Not attempted and the patient did not perform this activity prior to the current illness, exacerbation, or injury	47	16.3%	3	10.7%
Not attempted due to environmental limitations	0	0%	2	7.1%
Not attempted due to medical conditions or safety concerns	79	27.3%	1	3.6%
Missing	0	0%	1	3.6%
Total	289	100%	28	100%

At discharge, the RN did not complete this data element for patients with a discharge reason of Expired (n=1; see data element A2115).
Patients for whom the discharge reason was missing are not included (n=1; see data element A2115).
Source: Assessor-initiated Beta Test HOPE RN Admission and Discharge forms.

Feasibility

All these data elements exhibited **no feasibility challenges**. There was no missing data at RN Admission for most activities including eating, oral hygiene, and toileting hygiene (self-care) and rolling left and

right, sitting to stand, chair transfer, and walking 10 feet (mobility). Missingness was very low at admission for the remaining activities, 0.3 percent for showering/bathing (self-care) and 0.3 percent for toilet transfer (mobility). The proportion of missing data at RN Discharge was higher than at admission – 3.6 percent for all self-care and mobility activities. See Appendix D for additional feasibility data.

Reliability

Kappa statistics indicated **good rater agreement** for all activities except for one (Kappa statistics ranged from 0.64 to 0.75). Kappa statistics indicated **moderate rater agreement** (0.55) for rolling left and right in bed (*GG0170A*). See Appendix E for additional reliability data.

6.5 Active Diagnoses

This section includes standard post-acute care cross-setting data elements for the patient's primary medical condition category (*I0030*) and comorbidities and co-occurring conditions (*I0050*). Hospice RNs completed these data elements only on the RN Admission form.

6.5.1 Primary Medical Condition Category (*I0030*)

The patient's primary medical condition category reflects the chief reason the patient is eligible for hospice care, also known as the terminal diagnosis. The data element *I0030. Primary Medical Condition Category* is a list of nine condition categories plus an "Other Medical Condition" option for RNs to select if the patient's primary medical condition category was not among the nine. This data element is an expansion of the current HIS item (*I0010. Principal Diagnosis*) and intended to accurately capture the patient's primary hospice medical condition category.

During alpha testing for this data element, RNs selected "Other" as the primary medical condition category for 18 patients (22 percent). RNs were able to write in the specific condition for which they had selected "Other." The most common conditions entered fell into the category "cardiovascular conditions (excluding heart failure)." The Abt team therefore added the "cardiovascular conditions (excluding heart failure)" category to the beta test version of data element *I0030* to reduce the prevalence of "Other" medical condition category.

Validity

Descriptive statistics support face validity. Cancer was the most common primary medical condition category (28 percent), followed by dementia (22.8 percent), and heart failure (10.4 percent). RNs selected *Other Medical Condition* for 12.1 percent, a reduction relative to the alpha test, as intended. See Exhibit 6-13.

Exhibit 6-13. *I0030. Primary Medical Condition Category*

Indicate the patient's primary medical condition category.		
	Number	Percent
Cancer	81	28%
Dementia (including Alzheimer's disease)	66	22.8%
Other medical condition	35	12.1%
Heart failure	30	10.4%
Neurological condition (e.g., Parkinson's disease, multiple sclerosis, amyotrophic lateral sclerosis)	21	7.3%
Chronic obstructive pulmonary disease	18	6.2%
Cardiovascular (excluding heart failure)	10	3.5%
Renal disease	8	2.8%
Stroke	6	2.1%
Liver disease	4	1.4%
Missing	10	3.5%

Indicate the patient's primary medical condition category.		
	Number	Percent
Total	289	100%

Source: Assessor-initiated Beta Test HOPE RN Admission forms.

Feasibility

All these data elements exhibited **no feasibility challenges**, with 3.5 percent of expected responses missing. See Appendix D for additional data.

Reliability

Kappa statistics indicated **very good rater agreement** for primary medical condition category (.90). See Appendix E for additional data.

6.5.2 Comorbidities and Co-existing Conditions (*I0050*)

I0050 aims to identify all comorbidities and co-existing conditions that were addressed in, or had the potential to impact, the patient's plan of care.

Validity

Descriptive statistics support face validity. Hospice RNs most frequently identified cardiovascular conditions (excluding heart failure) (39.4 percent), dementia (25.3 percent), diabetes (21.1 percent), and renal disease (20.1 percent) as comorbidities or co-occurring conditions at admission.[7] See Exhibit 6-14.

Exhibit 6-14. *I0050. Comorbidities and Co-existing Conditions*

Check all that apply.		
	Number	Percent
Cancer		
I0100. Cancer		
No	217	75.1%
Yes	55	19.0%
Not assessed	17	5.9%
Total	289	100%
Heart/circulation		
I0600. Heart failure (e.g., congestive heart failure and pulmonary edema)		
No	223	77.2%
Yes	49	17.0%
Not assessed	17	5.9%
Total	289	100%
I0900. Peripheral vascular disease or peripheral arterial disease		
No	245	84.8%
Yes	27	9.3%
Not assessed	17	5.9%
Total	289	100%
I0950. Cardiovascular (excluding heart failure)		
No	158	54.7%
Yes	114	39.4%
Not assessed	17	5.9%

[7] Entries for *I0050. Comorbidities and Co-existing Conditions* sometimes overlapped with the *I0030. Primary Medical Condition Category.*

Check all that apply.		
	Number	Percent
Total	289	100%
Gastrointestinal		
I1101. Liver disease (e.g., cirrhosis)		
No	261	90.3%
Yes	11	3.8%
Not assessed	17	5.9%
Total	289	100%
Genitourinary		
I1510. Renal disease		
No	214	74.0%
Yes	58	20.1%
Not assessed	17	5.9%
Total	289	100%
Infections		
I2102. Sepsis		
No	264	91.3%
Yes	8	2.8%
Not assessed	17	5.9%
Total	289	100%
Metabolic		
I2900. Diabetes mellitus		
No	211	73.0%
Yes	61	21.1%
Not assessed	17	5.9%
Total	289	100%
I2910. Neuropathy		
No	242	83.7%
Yes	30	10.4%
Not assessed	17	5.9%
Total	289	100%
Neurological		
I4501. Stroke		
No	236	81.7%
Yes	36	12.5%
Not assessed	17	5.9%
Total	289	100%
I4801. Dementia (including Alzheimer's disease)		
No	199	68.9%
Yes	73	25.3%
Not assessed	17	5.9%
Total	289	100%
I5150. Neurological conditions (e.g., Parkinson's disease, multiple sclerosis, ALS)		
No	255	88.2%
Yes	17	5.9%

Check all that apply.		
	Number	Percent
Not assessed	17	5.9%
Total	289	100%
I5401. Seizure disorder		
No	263	91.0%
Yes	9	3.1%
Not assessed	17	5.9%
Total	289	100%
Pulmonary		
I6202. Chronic obstructive pulmonary disease		
No	228	78.9%
Yes	44	15.2%
Not assessed	17	5.9%
Total	289	100%
Other		
I8005. Other medical condition		
No	153	52.9%
Yes	119	41.2%
Not assessed	17	5.9%
Total	289	100%

Source: Assessor-initiated Beta Test HOPE RN Admission forms.

Feasibility

The comorbidities and co-existing conditions data element exhibited **no feasibility challenges**, with 5.9 percent of expected data elements missing. Some hospice RNs in the beta test indicated that their physician colleagues identified and documented the patient's primary and other diagnoses, while others reported that RNs at their hospice typically collected this information.

Reliability

Kappa statistics indicated **very good rater agreement** for comorbidities and co-existing conditions (.99).

6.6 Health Conditions

This section presents results for data elements collected for the RN Admission and RN Symptom Reassessment forms. They describe patients' symptom experience and preferences.

6.6.1 Pain Screening (J0900), Pain Active Problem (J0905), and Neuropathic Pain (J0915)

Beta testing included several pain assessment data elements, because of their potential for use in hospice quality measures under development. Among these, Abt evaluated two components of one HIS data element (*J0900. Pain Screening*): 1) whether the patient was screened for pain (*J0900A*), and 2) the severity of pain (*J0900C*). Another HIS data element, *J0900.* was collected as part of the RN Admission and RN Symptom Reassessment forms.

The intent of *J0915. Neuropathic Pain*, a new data element, was to identify whether the patient had pain that was neuropathic in nature, which could be described in terms such as burning, tingling, pins and needles, and/or hypersensitivity to touch, among others. Abt developed this data element in case distinguishing this type of pain from others might be necessary to calculate part of a potential pain or symptom management quality measure in the future. RNs asked about neuropathic pain only at admission.

Pain Active Problem identified whether pain was an active problem for the patient and was collected only for the RN Admission form.

Validity

No content validity challenges were identified for pain screening, pain severity, or pain is an active problem. These data elements are currently part of the HIS, are included in every hospice admission assessment, and contribute to a current hospice quality measure (Comprehensive Assessment at Admission CBE# 3235). No content validity challenges were identified for neuropathic pain.

Descriptive statistics support face validity. RNs screened nearly all patients for pain (96.2 percent). Among those screened for pain, 17.3 percent had moderate pain and 8.3 percent had severe pain (*J0900C*). See Exhibit 6-15. Beta testing required that patients identified as having moderate or severe pain at admission have an RN Symptom Reassessment form completed within two days of the admission assessment.

Pain was an active problem for 71.6 percent of patients. See Exhibit 6-16. Among patients screened for pain, RNs indicated 18 percent as having neuropathic pain. See Exhibit 6-17.

Correlations support good convergent validity. At admission, *J0900*'s pain severity component was significantly correlated with the pain component of *J2050. Symptom Impact.* Almost 70 percent of patients for whom pain severity was indicated as *Severe* also had the impact of pain indicated as *Severe* (p-value < 0.001). *J0090* responses at admission and symptom reassessment were also correlated (p-value < 0.001). The discharge sample size is too small to determine whether its data element responses correlated with responses at other timepoints. See Appendix F.

Exhibit 6-15. *J0900. Pain Screening*

Was the patient screened for pain?				
	Admission		Reassessment	
	Number	Percent	Number	Percent
No	11	3.8%	4	7.3%
Yes	278	96.2%	48	87.3%
Missing	0	0%	3	5.5%
Total	289	100%	55	100%
The patient's severity was:				
	Admission		Reassessment	
	Number	Percent	Number	Percent
None	156	56.1%	17	35.4%
Mild	50	18%	18	37.5%
Moderate	48	17.3%	5	10.4%
Severe	23	8.3%	7	14.6%
Not assessed	0	0%	0	0%
Missing	1	0.4%	1	2.1%
Total	278	100%	48	100%

RN entered a pain severity value only for patients who were screened for pain (n=278 for admission and n=48 for reassessment).
Source: Assessor-initiated Beta Test HOPE RN Admission and Reassessment forms.

Exhibit 6-16. *J0905. Pain Active Problem*

Is pain an active problem for the patient?		
	Number	Percent

No	79	27.3%
Yes	207	71.6%
Missing	3	1%
Total	289	100%

Source: Assessor-initiated Beta Test HOPE RN Admission forms.

Exhibit 6-17. *J0915. Neuropathic Pain*

Does the patient have neuropathic pain?		
	Number	Percent
No	234	81%
Yes	52	18%
Missing	3	1%
Total	289	100%

Source: Assessor-initiated Beta Test HOPE RN Admission forms.

Feasibility

The pain screening data elements exhibited **no feasibility challenges**, with all data elements having missingness rates of 1 percent or less at admission. At symptom reassessment, *J0900.A Patient Screened for Pain* had a missingness rate of 5.5 percent and *J0900.C Pain Severity* had a missingness rate of 2.1 percent. See Appendix D for additional data.

However, **qualitative data suggest some feasibility challenges** for *J0900.A Patient Screened for Pain,* and *J0900.C Pain Severity.* These items are also HIS items, and many RNs automatically skipped the included HIS data elements. They noted that other hospice staff typically completed the HIS, and some RNs assumed that a different staff member would complete the included HIS data elements later. Training and guidance highlighted that the RNs should also collect this information as part of HOPE.

Reliability

Kappa statistics indicated **good rater agreement** for pain severity (.75), pain is an active problem (.78) and neuropathic pain (.78), but only **fair rater agreement** for patient screened for pain (.27). See Appendix E for additional data.

Abt concluded the kappa was low for this *J0900.A* because almost all responses were "yes," making the distribution unbalanced. When the response distribution is unbalanced, and when the data element has only two response options ("yes" and "no" in this case), the kappa calculation is sensitive to any disagreement.

6.6.2 Symptom Impact (J2050)

Data element *J2050* identified the impact of symptoms on the patient. The Abt team adapted this data element from an Integrated Palliative Outcome Scale (IPOS) data element that asked about the effect of symptoms on the patient[xiii] This HOPE data element initially included response options that indicate the severity of the symptom's impact (i.e., none, mild, moderate, severe, overwhelming) for pain, shortness of breath, and anxiety. Prior to pilot testing, the list of assessed symptoms was expanded to include the following eight symptoms common in hospice patients: pain, shortness of breath, anxiety, nausea, vomiting, diarrhea, constipation, and agitation.

The term "severity" was removed from the draft data element following the pilot test because the term did not match the data element's intent –to capture the impact of symptoms on activities and not their severity. During pilot testing hospice staff were able to indicate a patient's symptom as having an "overwhelming" impact. However, RNs never selected this option, so it was removed from the alpha test version of the data element. Other notable changes after the pilot test include revising the coding scale to

include "not applicable" to capture that a patient was not experiencing the symptom, and "not at all" to indicate that the symptom did not affect the patient.

The RNs completed *J2050. Symptom Impact* for the RN Admission and RN Discharge forms, considering how each symptom had affected the patient over the past two days. If symptom impact at admission was "moderate" or "severe" the RN Symptom Reassessment was required within two days of the admission assessment. When completing the RN Symptom Reassessment, the RN considered the impact of symptoms on the patient since the admission assessment, instead of the past two days, so there would be no overlap in the time frame assessed at these two timepoints.

Abt structured the data elements *J2050, J2060* and *J2070* in Beta HOPE by concept, so that RNs assessed symptom impact for all symptoms, followed by desired tolerance level for all symptoms (*J2060*), and then the patient's symptom management preferences for all symptoms (*J2070*).

Validity

Most feedback on the symptom impact was positive, suggesting **good content validity at admission**. RNs from several focus groups reported this data element aligned with their current assessment practices and was helpful for their assessment. RNs noted that it was useful to have one data element that covers all the symptoms they assess. One nurse noted that the list provided a teachable moment on admission to let patients and families know the symptoms that hospice care can help to address. However, many RNs questioned the usefulness of completing this data element at discharge, noting that a comprehensive assessment of symptom status at discharge was not common in their practice. This suggests **limited content validity at discharge**.

Descriptive statistics support face validity. At admission, across all symptoms except pain, an impact of *Not at all* had the highest proportion of patients. RNs indicated that most patients were moderately impacted by pain (28.0 percent). Note that not experiencing symptom impacts does not suggest a patient is not experiencing that symptom – the data element provides unique response options for no symptom impact and not experiencing the symptom. At reassessment, most patients were indicated as experiencing slight impacts from pain (34.5 percent); slight impacts from shortness of breath (29.1 percent), anxiety (40.0 percent), and not experiencing nausea, vomiting, diarrhea, or constipation as symptoms at all. At discharge, for most symptoms, RNs indicated the patient was not experiencing the symptom or was not impacted by it at all. See Exhibit 6-18.

Correlations support good convergent validity. At admission, responses for *J2050* were significantly correlated with response for both *J2060.Patient Desired Tolerance Level for Symptoms* and *J2070. Patient Preferences for Symptom Management* (p-value < 0.001 for all symptoms). Additionally, *J2050* responses at admission and symptom reassessment were significantly correlated for all symptoms except anxiety (p-value = 0.02 for shortness of breath and < 0.001 for remaining symptoms). The discharge sample size is too small to determine whether its data element responses correlated with responses at other timepoints. See Appendix F.

Exhibit 6-18. *J2050. Symptom Impact*

Over the past 2 days, how has the patient been affected by each of the following symptoms?						
	Admission		Reassessment		Discharge	
	Number	Percent	Number	Percent	Number	Percent
A. Pain						
Not at all – symptom does not affect the patient, including symptoms well-controlled with current treatment	76	26.3%	7	12.7%	16	53.3%
Slight	68	23.5%	19	34.5%	5	16.7%

Over the past 2 days, how has the patient been affected by each of the following symptoms?						
	Admission		Reassessment		Discharge	
	Number	Percent	Number	Percent	Number	Percent
Moderate	81	28%	12	21.8%	4	13.3%
Severe	33	11.4%	7	12.7%	1	3.3%
Not applicable (patient is not experiencing the symptom)	29	10%	6	10.9%	2	6.7%
Missing	2	0.7%	4	7.3%	2	6.7%
Total	289	100%	55	100%	30	100%
B. Shortness of breath						
Not at all – symptom does not affect the patient, including symptoms well-controlled with current treatment	95	32.9%	10	18.2%	15	50%
Slight	51	17.6%	16	29.1%	6	20%
Moderate	69	23.9%	9	16.4%	1	3.3%
Severe	14	4.8%	2	3.6%	1	3.3%
Not applicable (patient is not experiencing the symptom)	58	20.1%	14	25.5%	5	16.7%
Missing	2	0.7%	4	7.3%	2	6.7%
Total	289	100%	55	100%	30	100%
C. Anxiety						
Not at all – symptom does not affect the patient, including symptoms well-controlled with current treatment	77	26.6%	10	18.2%	10	33.3%
Slight	73	25.3%	22	40%	8	26.7%
Moderate	57	19.7%	6	10.9%	4	13.3%
Severe	23	8%	2	3.6%	2	6.7%
Not applicable (patient is not experiencing the symptom)	57	19.7%	11	20%	4	13.3%
Missing	2	0.7%	4	7.3%	2	6.7%
Total	289	100%	55	100%	30	100%
D. Nausea						
Not at all – symptom does not affect the patient, including symptoms well-controlled with current treatment	131	45.3%	18	32.7%	18	60%
Slight	30	10.4%	6	10.9%	2	6.7%
Moderate	27	9.3%	2	3.6%	0	0%
Severe	6	2.1%	1	1.8%	0	0%
Not applicable (patient is not experiencing the symptom)	93	32.2%	24	43.6%	8	26.7%
Missing	2	0.7%	4	7.3%	2	6.7%
Total	289	100%	55	100%	30	100%
E. Vomiting						
Not at all – symptom does not affect the patient, including symptoms well-controlled with current treatment	152	52.6%	20	36.4%	19	63.3%

Over the past 2 days, how has the patient been affected by each of the following symptoms?						
	Admission		Reassessment		Discharge	
	Number	Percent	Number	Percent	Number	Percent
Slight	15	5.2%	1	1.8%	0	0%
Moderate	6	2.1%	0	0%	0	0%
Severe	4	1.4%	0	0%	0	0%
Not applicable (patient is not experiencing the symptom)	110	38.1%	30	54.5%	9	30%
Missing	2	0.7%	4	7.3%	2	6.7%
Total	289	100%	55	100%	30	100%
F. Diarrhea						
Not at all – symptom does not affect the patient, including symptoms well-controlled with current treatment	140	48.4%	21	38.2%	19	63.3%
Slight	19	6.6%	2	3.6%	0	0%
Moderate	13	4.5%	0	0%	0	0%
Severe	9	3.1%	0	0%	0	0%
Not applicable (patient is not experiencing the symptom)	106	36.7%	28	50.9%	9	30%
Missing	2	0.7%	4	7.3%	2	6.7%
Total	289	100%	55	100%	30	100%
G. Constipation						
Not at all – symptom does not affect the patient, including symptoms well-controlled with current treatment	119	41.2%	15	27.3%	14	46.7%
Slight	43	14.9%	7	12.7%	3	10%
Moderate	22	7.6%	6	10.9%	2	6.7%
Severe	11	3.8%	1	1.8%	1	3.3%
Not applicable (patient is not experiencing the symptom)	92	31.8%	22	40%	8	26.7%
Missing	2	0.7%	4	7.3%	2	6.7%
Total	289	100%	55	100%	30	100%
H. Agitation						
Not at all – symptom does not affect the patient, including symptoms well-controlled with current treatment	111	38.4%	15	27.3%	15	50%
Slight	43	14.9%	11	20%	4	13.3%
Moderate	45	15.6%	5	9.1%	4	13.3%
Severe	10	3.5%	1	1.8%	0	0%
Not applicable (patient is not experiencing the symptom)	78	27%	19	34.5%	5	16.7%
Missing	2	0.7%	4	7.3%	2	6.7%
Total	289	100%	55	100%	30	100%

Source: Assessor-initiated Beta Test HOPE RN Admission, Reassessment, and Discharge forms.

Feasibility

Across all timepoints (admission, reassessment, and discharge) the data element exhibited **no feasibility challenges**. At admission less than 1 percent of RN Admission forms were missing this data element (0.7 percent), and the RN Symptom Reassessment and RN Discharge forms had missingness rates of less than 10 percent (7.3 percent and 6.7 percent, respectively). See Appendix D for additional data.

Qualitative data suggests **some confusion about the rating scale**. RNs reported that *J2050* was generally easy to understand, although some RNs initially confused data elements related to pain impact and those related to pain severity. Some reported challenges selecting the appropriate response options for symptom impact (not at all, slight, moderate, severe, not applicable) as they were more accustomed to the 1 through 10 numeric scale they typically use in pain severity.

Some RNs suggested that grouping data elements *J2050* and the subsequent data elements *J2060* and *J2070* by symptom rather than by concept would improve usability, potentially better highlighting the intent of *J2060* and *J2070* and their relationship to *J2050*. The Abt team also noted that a skip pattern allowing users to skip these data elements if the patient was not experiencing the symptom would improve usability.

Reliability

Kappa statistics indicated **good rater agreement** for pain (0.71), shortness of breath (0.65), anxiety (0.60), and nausea (0.61), and **moderate rater agreement** for vomiting (0.59), diarrhea (0.59), constipation (0.51), and agitation (0.45). See Appendix E for additional data.

6.6.3 Patient Desired Tolerance Level for Symptoms (J2060)

Throughout HOPE development, federal stakeholders, technical experts, and hospice staff have expressed the idea that acknowledging and considering patient preferences is important for symptom management. This input drove the development of new data elements *J2060. Patient Desired Tolerance Level* and *J2070. Patient Preferences for Symptom Management*, and analyses of how these data elements interact with *J2050. Symptom Impact*.

J2060. Patient Desired Tolerance Level for Symptoms aimed to identify the patient's desired tolerance level for their symptoms and to understand what the patient hopes symptom management can achieve. An understanding of what a patient feels to be acceptable for the symptoms they experience informs individualized symptom management. *J2060* was collected as part of the RN Admission form and the RN Symptom Reassessment form but was not repeated at discharge on the RN Discharge form.

In the pilot test, hospice staff indicated they interpreted this data element as patient self-report only, and that the question and response options should be read verbatim to the patient and/or family. In response to this feedback, the instructions for this data element were revised to clarify that *J2060* is not patient self-report only and should be completed based on the RN's clinical assessment including input from the patient and/or caregiver. In response to feedback from alpha testing, Abt changed the data element formatting to improve readability.

For the beta test, RN training included guidance on potential questions to ask the patient as part of completing this data element, such as, "At what level are you willing to tolerate this symptom?" and "Do you prefer not to experience this symptom at all?" The HOPE guidance manual included approaches RNs could use to explain this concept to patients, such as describing tolerance as the level of each symptom the patient feels they can tolerate, or "live with." The response scale for this data element included *None*, which was selected if the patient preferred not to experience the symptom at all, as well as *Slight*, *Moderate* and *High*. *Not applicable* was selected for patients not experiencing the symptom.

Validity

Assessors reported mixed feedback about *J2060. Patient Desired Tolerance Level for Symptoms*, suggesting **content validity challenges**. They had difficulty conveying the data element's intent for this item and found it confusing and difficult for patients and families to understand and often required rephrasing. RNs also questioned its usefulness, as they indicated that few patients would be likely to state their desired tolerance as high. However, RNs' assessments demonstrated that while most patients may prefer not to experience symptoms at all, some may express different preferences about the level of a symptom they believe they are willing to tolerate. The differing tolerance preferences may reflect differing patient preferences for overall goals for care and quality of life.

Descriptive statistics support good face validity. Most patients preferred not to experience these symptoms at all. Desired tolerance level for symptoms was different at symptom reassessment relative to admission. See Exhibit 6-19. A lower proportion of patients preferred not to experience the symptom at all; preferences shifted toward a slight tolerance, perhaps reflecting a better understanding on the part of patients about the effect(s) of symptom management. RNs' assessments indicated that some patients had desired tolerance levels of slight or moderate for symptoms, and a few had high desired tolerance levels. For example, RNs indicated that desired tolerance level for pain was slight for 23.2 percent of patients, was moderate for 9.3 percent, and high for eight 2.8 percent. See Exhibit 6-19.

Desired tolerance level for symptoms was different at symptom reassessment relative to admission. See Exhibit 6-18. A lower proportion of patients preferred not to experience the symptom at all; preferences shifted toward the slight tolerance level, perhaps reflecting a better understanding on the part of patients about the effect(s) of symptom management.

Correlations support good convergent validity. At admission, responses for *J2060.Patient Desired Tolerance Level for Symptoms* were significantly correlated with *J2050. Symptom Impact* (p-value < 0.001 for all symptoms). Additionally, *J2060* responses at admission and symptom reassessment were significantly correlated for all symptoms (p-value < 0.001). The discharge sample size is too small to determine whether its data element responses correlated with responses at other timepoints. See Appendix F.

Exhibit 6-19. J2060. Patient Desired Tolerance Level for Symptoms

What is the patient's desired tolerance level for each of the following symptoms?				
	Admission		Reassessment	
	Number	Percent	Number	Percent
A. Pain				
None – patient prefers not to experience the symptom at all	137	47.4%	14	25.5%
Slight	67	23.2%	22	40%
Moderate	27	9.3%	2	3.6%
High	8	2.8%	3	5.5%
Not applicable (patient is not experiencing the symptom)	45	15.6%	11	20%
Missing	5	1.7%	3	5.5%
Total	289	100%	55	100%
B. Shortness of breath				
None – patient prefers not to experience the symptom at all	125	43.3%	21	38.2%
Slight	57	19.7%	10	18.2%
Moderate	9	3.1%	1	1.8%
High	4	1.4%	2	3.6%

What is the patient's desired tolerance level for each of the following symptoms?				
	Admission		Reassessment	
	Number	Percent	Number	Percent
Not applicable (patient is not experiencing the symptom)	89	30.8%	18	32.7%
Missing	5	1.7%	3	5.5%
Total	289	100%	55	100%
C. Anxiety				
None – patient prefers not to experience the symptom at all	137	47.4%	21	38.2%
Slight	54	18.7%	11	20%
Moderate	12	4.2%	2	3.6%
High	2	0.7%	2	3.6%
Not applicable (patient is not experiencing the symptom)	79	27.3%	16	29.1%
Missing	5	1.7%	3	5.5%
Total	289	100%	55	100%
D. Nausea				
None – patient prefers not to experience the symptom at all	114	39.4%	15	27.3%
Slight	28	9.7%	3	5.5%
Moderate	6	2.1%	0	0%
High	1	0.3%	0	0%
Not applicable (patient is not experiencing the symptom)	135	46.7%	34	61.8%
Missing	5	1.7%	3	5.5%
Total	289	100%	55	100%
E. Vomiting				
None – patient prefers not to experience the symptom at all	102	35.3%	12	21.8%
Slight	16	5.5%	1	1.8%
Moderate	1	0.3%	0	0%
High	1	0.3%	0	0%
Not applicable (patient is not experiencing the symptom)	164	56.7%	39	70.9%
Missing	5	1.7%	3	5.5%
Total	289	100%	55	100%
F. Diarrhea				
None – patient prefers not to experience the symptom at all	95	32.9%	8	14.5%
Slight	22	7.6%	2	3.6%
Moderate	8	2.8%	0	0%
High	1	0.3%	0	0%
Not applicable (patient is not experiencing the symptom)	158	54.7%	42	76.4%
Missing	5	1.7%	3	5.5%
Total	289	100%	55	100%
G. Constipation				
None – patient prefers not to experience the symptom at all	97	33.6%	9	16.4%
Slight	33	11.4%	10	18.2%
Moderate	9	3.1%	1	1.8%
High	8	2.8%	2	3.6%

What is the patient's desired tolerance level for each of the following symptoms?				
	Admission		Reassessment	
	Number	Percent	Number	Percent
Not applicable (patient is not experiencing the symptom)	137	47.4%	30	54.5%
Missing	5	1.7%	3	5.5%
Total	289	100%	55	100%
H. Agitation				
None – patient prefers not to experience the symptom at all	122	42.2%	14	25.5%
Slight	36	12.5%	9	16.4%
Moderate	8	2.8%	0	0%
High	3	1%	2	3.6%
Not applicable (patient is not experiencing the symptom)	114	39.4%	27	49.1%
Missing	6	2.1%	3	5.5%
Total	289	100%	55	100%

Source: Assessor-initiated Beta Test HOPE RN Admission and Reassessment forms.

Feasibility

Across all timepoints (admission, reassessment, and discharge) the data element **missingness rates exhibited no feasibility challenges**. Missingness rates were low at admission (2.1 percent for agitation and 1.7 percent for all other symptoms) and increased somewhat at symptom reassessment (5.5 percent for all symptoms). See Appendix D for additional data.

However, **qualitative data suggest potential feasibility challenges**. RNs reported *J2060* was difficult to understand or explain to patients and families. While positive about the multidimensional symptom data elements, they did not find the *J2060* language to be user-friendly. RNs found it easier to complete *J2060* when assessing for pain, compared with some other assessed symptoms such as nausea, vomiting, diarrhea, constipation, and agitation.

As with *J2050. Symptom Impact*, RNs suggested that usability might be improved by grouping J2050, J2060, and J2070 by symptom rather than by content, and potentially adding a skip pattern for the latter two data elements for patients not experiencing the symptom.

Reliability

Kappa statistics indicated **good rater agreement** for shortness of breath (0.70), nausea (0.60), vomiting (0.71), constipation (0.70) and agitation (0.60), and **moderate rater agreement** for pain (0.55), anxiety (0.57), and diarrhea (0.59). See Appendix E for additional data.

6.6.4 Patient Preferences for Symptom Management (J2070)

Patient preferences for symptom management (J2070) identified whether patients who have specific symptoms prioritize treatment for those symptoms, even with potential side effects or inconveniences. For example, common side effects of pharmacologic pain management include drowsiness or sedation. Some patients might prioritize reducing the pain they experience, regardless of whether that makes them drowsy or less alert. Others might prioritize staying awake and alert to visit with family and friends. The response options for this data element include *No*, *Yes*, and *Not applicable*. *Not applicable* is selected when the patient is not experiencing the symptom. RNs completed the patient's preference for symptom management section of the RN Admission and RN Symptom Reassessment forms.

Parallel to changes made for *J2060. Patient Desired Tolerance Level for Symptoms and* the *J2070*, and consistent with pilot testing feedback, the Abt team revised the instructions to clarify that the data element

should be based on the RN's clinical assessment, including input from the patient and/or caregiver. In response to feedback from alpha testing, Abt revised the data element formatting to improve readability.

Validity

As with *J2060. Patient Desired Tolerance Level for Symptoms,* assessors reported mixed feedback about *J2070. Patient Preferences for Symptom Management,* suggesting **content validity challenges**. Assessor survey feedback indicated that patients had difficulty understanding these data elements and nurses had difficulty conveying the intent of the item. While some agreed that preferences were important to understand, others found this item confusing, and it often required rephrasing. Some nurses questioned its usefulness, noting that for some of the symptoms, preferences will change over time as symptoms worsen.

Descriptive statistics suggest face validity. RNs' assessments of patient symptom management preferences indicated that while more patients prioritized symptom reduction than did not, some patients did not prioritize symptom reduction. At admission, more than 80 percent of patients who experienced pain (i.e., pain management preferences were not indicated as *Not Applicable* or missing) prioritized pain reduction. The remaining patients did not prioritize it – preferring instead to avoid or minimize pain treatment side effects or inconveniences. At symptom reassessment, the proportions were nearly the same at admission for pain, and nausea, but smaller for other symptoms. See Exhibit 6-20.

Correlations support good convergent validity. At admission, responses for *J2070.Patient Preferences for Symptom Management* were significantly correlated with *J2050. Symptom Impact* (p-value < 0.001 for all symptoms). Additionally, *J2070* responses at admission and symptom reassessment were significantly correlated for all symptoms except anxiety (p-value = 0.45 for anxiety; < 0.001 for remaining symptoms). The discharge sample size is too small to determine whether its data element responses correlated with responses at other timepoints. See Appendix F.

Exhibit 6-20. *J2070. Patient Preferences for Symptom Management*

Does the patient prioritize reduction in their symptoms, even with potential treatment side effects or inconvenience?				
	Admission		Reassessment	
	Number	Percent	Number	Percent
A. Pain				
No	38	13.1%	6	10.9%
Yes	177	61.2%	35	63.6%
Not applicable (the patient is not experiencing the symptom)	70	24.2%	10	18.2%
Missing	4	1.4%	4	7.3%
Total	289	100%	55	100%
B. Shortness of breath				
No	36	12.5%	8	14.5%
Yes	133	46%	21	38.2%
Not applicable (the patient is not experiencing the symptom)	117	40.5%	22	40%
Missing	3	1%	4	7.3%
Total	289	100%	55	100%
C. Anxiety				
No	40	13.8%	12	21.8%
Yes	138	47.8%	21	38.2%
Not applicable (the patient is not experiencing the symptom)	108	37.4%	18	32.7%
Missing	3	1%	4	7.3%

Does the patient prioritize reduction in their symptoms, even with potential treatment side effects or inconvenience?				
	Admission		Reassessment	
	Number	Percent	Number	Percent
Total	289	100%	55	100%
D. Nausea				
No	34	11.8%	3	5.5%
Yes	73	25.3%	10	18.2%
Not applicable (the patient is not experiencing the symptom)	179	61.9%	38	69.1%
Missing	3	1%	4	7.3%
Total	289	100%	55	100%
E. Vomiting				
No	31	10.7%	2	3.6%
Yes	48	16.6%	4	7.3%
Not applicable (the patient is not experiencing the symptom)	207	71.6%	45	81.8%
Missing	3	1%	4	7.3%
Total	289	100%	55	100%
F. Diarrhea				
No	31	10.7%	3	5.5%
Yes	51	17.6%	3	5.5%
Not applicable (the patient is not experiencing the symptom)	204	70.6%	45	81.8%
Missing	3	1%	4	7.3%
Total	289	100%	55	100%
G. Constipation				
No	35	12.1%	8	14.5%
Yes	78	27%	9	16.4%
Not applicable (the patient is not experiencing the symptom)	173	59.9%	34	61.8%
Missing	3	1%	4	7.3%
Total	289	100%	55	100%
H. Agitation				
No	23	8%	9	16.4%
Yes	106	36.7%	12	21.8%
Not applicable (the patient is not experiencing the symptom)	157	54.3%	30	54.5%
Missing	3	1%	4	7.3%
Total	289	100%	55	100%

Source: Assessor-initiated Beta Test HOPE RN Admission and Reassessment forms.

Feasibility

Missingness rates were low at admission for patient preferences for symptom management – with moderately higher rates at symptom reassessment, but those rates were still below 10 percent, indicating **no feasibility challenges**. The proportion of missing data was 1 percent for all symptoms except pain, which was 1.4 percent. The proportion of missing data for all symptoms at symptom reassessment was 7.3 percent.

However, as with *J2060. Patient Desired Tolerance Level for Symptoms,* **qualitative data suggest potential feasibility challenges**. As with *J2060*, RNs found *J2070* hard to understand or explain to

patients and families, and that it would improve usability to group the three symptom data elements *J2050, J2060,* and *J2070* by symptom rather than by concept, and to add a skip pattern for the latter two data elements for patients not experiencing the symptom.

Reliability

Kappa statistics indicated **good rater agreement** across all symptoms, ranging from 0.73 for nausea and constipation to 0.64 for agitation. See Appendix E for additional data.

6.6.5 Follow-Up Symptom Control (J2080)

Abt developed follow-up symptom control (*J2080*) for the RN Symptom Reassessment form. For patients whom the RN identified as having moderate or severe pain (*J0900C*) or moderate or severe symptom impact (*J2050*) upon admission, the RN was instructed to complete an RN Symptom Reassessment form within two days of the admission. This reassessment helped identify whether the hospice had controlled a patient's symptoms during their first few days in hospice.

Abt evaluated differing time periods to reassessment during pilot and alpha testing. These prior testing phases informed the beta testing requirement of reassessment within two days of admission.

In response to questions about whether follow-up symptom control should be assessed only for the symptoms that triggered a symptom reassessment (i.e., moderate, or severe pain, or a symptom with moderate to severe impact), beta test guidance directed RNs to complete the data element for all symptoms to facilitate analysis of symptom changes between time points that could support separate quality measurement development efforts.

Validity

Descriptive statistics suggest face validity. RNs indicated that for most patients, the symptom(s) the patient was experiencing had been controlled. However, for almost all symptoms, some number of patients were indicated as not having achieved symptom control and therefore required ongoing symptom management. Diarrhea was the only symptom for which RNs indicated all patients experiencing the symptom (i.e., diarrhea control was not indicated as *Not Applicable* or missing) had it controlled (four of four patients). See Exhibit 6-21.

Exhibit 6-21. *J2080. Follow-Up Symptom Control*

At the time of this assessment, has the patient achieved symptom control?		
	Number	Percent
A. Pain		
No	10	18.2%
Yes	31	56.4%
Not applicable (the patient is not experiencing the symptom)	11	20%
Missing	3	5.5%
Total	55	100%
B. Shortness of breath		
No	2	3.6%
Yes	27	49.1%
Not applicable (the patient is not experiencing the symptom)	23	41.8%
Missing	3	5.5%
Total	55	100%
C. Anxiety		
No	5	9.1%
Yes	28	50.9%

At the time of this assessment, has the patient achieved symptom control?		
	Number	Percent
Not applicable (the patient is not experiencing the symptom)	19	34.5%
Missing	3	5.5%
Total	55	100%
D. Nausea		
No	3	5.5%
Yes	8	14.5%
Not applicable (the patient is not experiencing the symptom)	41	74.5%
Missing	3	5.5%
Total	55	100%
E. Vomiting		
No	1	1.8%
Yes	3	5.5%
Not applicable (the patient is not experiencing the symptom)	48	87.3%
Missing	3	5.5%
Total	55	100%
F. Diarrhea		
No	0	0%
Yes	4	7.3%
Not applicable (the patient is not experiencing the symptom)	48	87.3%
Missing	3	5.5%
Total	55	100%
G. Constipation		
No	5	9.1%
Yes	11	20%
Not applicable (the patient is not experiencing the symptom)	36	65.5%
Missing	3	5.5%
Total	55	100%
H. Agitation		
No	5	9.1%
Yes	13	23.6%
Not applicable (the patient is not experiencing the symptom)	33	60%
Missing	4	7.3%
Total	55	100%

Source: Assessor-initiated Beta Test HOPE RN Admission forms.

Feasibility

Missingness rates across all symptoms were below 10 percent, suggesting **no feasibility challenges**. The proportion missing for all symptoms was 5.5 percent, except for agitation, for which it was 7.3 percent. See Appendix D for additional data.

Reliability

Kappa statistics indicated **moderate rater agreement for diarrhea** (0.53); **good rater agreement for pain and vomiting** (0.79 and 0.72, respectively); and **very good rater agreement for remaining symptoms**, ranging from 0.95 for shortness of breath to 0.81 for agitation. See Appendix E for additional data.

6.7 Patient and Family Needs

This section presents results for data elements capturing education and training and resource needs of the patient and family/caregiver (*Q1000* and *Q1100*, respectively), and *JJ0010. Chaplain/Spiritual Care Offered* and *JJ0015. Social Work Offered.* The latter two captured whether patients were offered and accepted these services. RNs collected these data elements only at admission.

6.7.1 Patient and Caregiver Education and Training (Q1000) and Patient and Caregiver Resource Needs (Nurse Assessment) (Q1100)

Q1000. Patient and Caregiver Education and Training identified whether the patient, the caregiver, or both had an education or training need in any of the following areas: communication, basic caregiving, wound care, mouth and/or oral care, infection control, equipment use and management, medication management, symptom management, signs, and symptoms of patient decline, and other. The second component of this data element identified whether education/training was initiated, at the current visit or at a prior visit, for any need identified.

Q1100. Patient and Caregiver Resource Needs captured distinct information about patient and caregiver resource needs for any of the following areas: volunteer support, aide support, durable medical equipment (DME) and/or medical equipment, inpatient respite care, general inpatient or continuous home care, or other. As with Q1000, the second component of this data element identified whether a referral was provided for any resource need identified.

Abt developed and modified *Q1000* and *Q1100* from data elements developed from the prior Hospice Evaluation and Assessment Reporting Tool development effort.[8] Based on cognitive testing feedback, Abt added to both data elements the ability to specify whether needs were the patient's or a caregiver's. Abt also added a section for RNs to indicate whether education and training was initiated for areas where a need was identified for *Q1000* and whether a referral was made or declined for a needed resource for *Q1100*.

After pilot testing, medication management, symptom management, and the *Other* component were added to *Q1000* as additional options for which RNs could indicate an education or training need. Abt also moved the option for *No Education or Training Needs* to the end of the options list to ensure each need was considered before this option was selected. Prior to beta testing, Abt also reformatted *Q1000* to create a skip pattern; if the patient or caregiver did not have a particular need, the RN skipped the second component (whether education was initiated or ongoing).

For *Q1100. Patient and Caregiver Resource Needs*, pilot testing feedback led Abt to restructure the list of resources needed into two lists: one for the RN Admission form and one for the SW Admission form.[9] This change aligned the needs assessed with the most appropriate discipline. In alignment with the formatting changes Abt made to *Q1000*, for *Q1100* Abt presented the *No Resources Needed* option last and implemented a skip pattern.

Validity

Descriptive statistics suggest face validity. Education and training needs (*Q1000*) were identified for patients, caregivers, and both patients and caregivers across all needs. More than half of patients and/or caregivers needed education and training in the following areas: communication, infection control, medication management, symptom management, and signs and symptoms of patient decline. When needs

[8] CMS started development of the Hospice Evaluation and & Assessment Reporting Tool. After pilot testing CMS ceased efforts to develop the tool and began HOPE development.

[9] See *Q1200. Patient and Caregiver Resource Needs* discussion in the SW Forms Section.

were identified, RNs indicated that more than 90 percent of patients and/or caregivers received education and training. See Exhibit 6-22.

For *Q1000*, more than 60 percent of patients and/or caregivers were indicated as having a resource need for aide support and DME. More than 90 percent of patients were identified as being referred for aide support or medical equipment. Nearly half of patients who were offered inpatient respite or general inpatient care declined such support. See Exhibit 6-23.

Exhibit 6-23. *Q1000. Patient and Caregiver Education and Training*

At the time of this assessment, does the patient and/or caregiver(s) (family and non-family) need education or training to meet the needs of the patient?		
A. Communication (e.g., hospice contact information, when to contact hospice)		
Patient	9	3.1%
Caregiver	99	34.3%
Both	107	37%
No education or training needs	68	23.5%
Not applicable (e.g., patient unconscious or caregiver not available)	4	1.4%
Missing	2	0.7%
Total	289	100%
B. Basic caregiving skills (e.g., feeding, bathing, repositioning, change in occupied bed)		
Patient	8	2.8%
Caregiver	82	28.4%
Both	49	17%
No education or training needs	142	49.1%
Not applicable (e.g., patient unconscious or caregiver not available)	6	2.1%
Missing	2	0.7%
Total	289	100%
C. Wound care		
Patient	4	1.4%
Caregiver	25	8.7%
Both	14	4.8%
No education or training needs	166	57.4%
Not applicable (e.g., patient unconscious or caregiver not available)	78	27%
Missing	2	0.7%
Total	289	100%
D. Mouth and/or oral care		
Patient	5	1.7%
Caregiver	52	18%
Both	34	11.8%
No education or training needs	183	63.3%
Not applicable (e.g., patient unconscious or caregiver not available)	13	4.5%
Missing	2	0.7%
Total	289	100%
E. Infection control (e.g., wound care, handwashing, universal precautions)		
Patient	13	4.5%
Caregiver	63	21.8%
Both	74	25.6%
No education or training needs	126	43.6%
Not applicable (e.g., patient unconscious or caregiver not available)	11	3.8%
Missing	2	0.7%

At the time of this assessment, does the patient and/or caregiver(s) (family and non-family) need education or training to meet the needs of the patient?		
Total	289	100%
F. Equipment use and management (e.g., oxygen tanks, nebulizer, feeding pump, mechanical lift, patient-controlled analgesia pumps)		
Patient	15	5.2%
Caregiver	60	20.8%
Both	58	20.1%
No education or training needs	132	45.7%
Not applicable (e.g., patient unconscious or caregiver not available)	22	7.6%
Missing	2	0.7%
Total	289	100%
G. Medication management		
Patient	10	3.5%
Caregiver	102	35.3%
Both	77	26.6%
No education or training needs	93	32.2%
Not applicable (e.g., patient unconscious or caregiver not available)	5	1.7%
Missing	2	0.7%
Total	289	100%
H. Symptom management (current and anticipated)		
Patient	16	5.5%
Caregiver	110	38.1%
Both	111	38.4%
No education or training needs	46	15.9%
Not applicable (e.g., patient unconscious or caregiver not available)	4	1.4%
Missing	2	0.7%
Total	289	100%
I. Signs and symptoms of patient decline		
Patient	11	3.8%
Caregiver	116	40.1%
Both	110	38.1%
No education or training needs	45	15.6%
Not applicable (e.g., patient unconscious or caregiver not available)	5	1.7%
Missing	2	0.7%
Total	289	100%
J. Other		
Patient	0	0%
Caregiver	5	1.7%
Both	5	1.7%
No education or training needs	123	42.6%
Not applicable (e.g., patient unconscious or caregiver not available)	64	22.1%
Missing	92	31.8%
Total	289	100%
2. Code if education and training was initiated at this visit or ongoing from a prior visit.[1]	Number	Percent
A. Communication (e.g., hospice contact information, when to contact hospice)		
Yes	208	96.7%
No	1	0.5%
Missing	6	2.8%
Total	215	100%
B. Basic caregiving skills (e.g., feeding, bathing, repositioning, changing an occupied bed)		
Yes	130	93.5%

At the time of this assessment, does the patient and/or caregiver(s) (family and non-family) need education or training to meet the needs of the patient?		
No	7	5%
Missing	2	1.4%
Total	139	100%
C. Wound care		
Yes	39	90.7%
No	3	7%
Missing	1	2.3%
Total	43	100%
D. Mouth and/or oral care		
Yes	85	93.4%
No	5	5.5%
Missing	1	1.1%
Total	91	100%
E. Infection control (e.g., wound care, handwashing, universal precautions)		
Yes	138	92%
No	5	3.3%
Missing	7	4.7%
Total	150	100%
F. Equipment use and management (e.g., oxygen tanks, nebulizer, feeding pump, mechanical lift, patient-controlled analgesia pumps)		
Yes	122	91.7%
No	7	5.3%
Missing	4	3%
Total	133	100%
G. Medication management		
Yes	182	96.3%
No	2	1.1%
Missing	5	2.6%
Total	189	100%
H. Symptom management (current and anticipated)		
Yes	231	97.5%
No	3	1.3%
Missing	3	1.3%
Total	237	100%
I. Signs and symptoms of patient decline		
Yes	222	93.7%
No	8	3.4%
Missing	7	3%
Total	237	100%
J. Other		
Yes	10	100%
No	0	0%
Missing	0	0%
Total	10	100%

[1] Total reflects the respondents (the patient, the caregiver, or both) the RNs indicated as having the education and training need. That could be addressed with the resource.
Source: Assessor-initiated Beta Test HOPE RN Admission forms.

Exhibit 6-24. ***Q1100. Patient and Caregiver Resource Needs***

At the time of this assessment, does the patient and/or caregiver (including family and non-family) have any of the following resource needs?		
A. Volunteer support		

At the time of this assessment, does the patient and/or caregiver (including family and non-family) have any of the following resource needs?		
Patient	25	8.7%
Caregiver	21	7.3%
Both	28	9.7%
No resource needs	195	67.5%
Not applicable (e.g., patient unconscious or caregiver not available)	16	5.5%
Missing	4	1.4%
Total	289	100%
B. Aide support		
Patient	141	48.8%
Caregiver	25	8.7%
Both	50	17.3%
No resource needs	64	22.1%
Not applicable (e.g., patient unconscious or caregiver not available)	6	2.1%
Missing	3	1%
Total	289	100%
C. DME and/or medical equipment		
Patient	119	41.2%
Caregiver	24	8.3%
Both	48	16.6%
No resource needs	88	30.4%
Not applicable (e.g., patient unconscious or caregiver not available)	7	2.4%
Missing	3	1%
Total	289	100%
D. Inpatient respite care		
Patient	3	1%
Caregiver	14	4.8%
Both	5	1.7%
No resource needs	238	82.4%
Not applicable (e.g., patient unconscious or caregiver not available)	25	8.7%
Missing	4	1.4%
Total	289	100%
E. General inpatient care or continuous home care		
Patient	6	2.1%
Caregiver	6	2.1%
Both	8	2.8%
No resource needs	240	83%
Not applicable (e.g., patient unconscious or caregiver not available)	25	8.7%
Missing	4	1.4%
Total	289	100%
F. Other		
Patient	0	0%
Caregiver	0	0%
Both	1	0.3%
No resource needs	147	50.9%
Not applicable (e.g., patient unconscious or caregiver not available)	50	17.3%
Missing	91	31.5%
Total	289	100%
1. Code if a referral was made or declined[1]	Number	Percent
A. Volunteer support		
Yes, request made	59	79.7%
No, service declined	12	16.2%
Missing	3	4.1%

At the time of this assessment, does the patient and/or caregiver (including family and non-family) have any of the following resource needs?		
Total	74	100%
B. Aide support		
Yes, request made	196	90.7%
No, service declined	9	4.2%
Missing	11	5.1%
Total	216	100%
C. DME and/or medical equipment		
Yes, request made	175	91.6%
No, service declined	7	3.7%
Missing	9	4.7%
Total	191	100%
D. Inpatient respite care		
Yes, request made	11	50%
No, service declined	10	45.5%
Missing	1	4.5%
Total	22	100%
E. General inpatient care or continuous home care		
Yes, request made	9	45%
No, service declined	9	45%
Missing	2	10%
Total	20	100%
F. Other		
Yes, request made	0	0%
No, service declined	1	100%
Missing	0	0%
Total	1	100%

[1] Total reflects the respondents (the patient, the caregiver, or both) the RNs indicated as having a resource need that could be addressed with the resource.
Source: Assessor-initiated Beta Test HOPE RN Admission forms.

Feasibility

Most components of these data elements do not suggest feasibility challenges, but use of an *Other* component in each does. Almost all components of both *Q1000. Patient and Caregiver Education and Training Needs* and *Q1100. Patient and Caregiver Resource Needs* had missingness rates of less than 10 percent. Referrals made to general inpatient or continuous home care (*Q1100*) had a missingness rate of exactly 10 percent. The *Other* categories for both *Q1000* and *Q1100* had notably higher missingness rates: 31.8 percent and 31.5 percent, respectively. See Appendix D for additional data.

RNs reported they tended to skip over (i.e., not complete) the response option *Other* in both *Q1000* And *Q1100* because they thought it did not apply if other response options were selected. RNs also asked several questions about the resource needs data element, such as whether to identify something as a need if the resource was already present, and how to answer the second component, "Referral Given" if the resource had already been ordered.

Reliability[10]

For *Q1000. Patient and Caregiver Education and Training Needs* Kappa statistics indicated **very good rater agreement for one component** (identification of wound care training and education needs; 0.83),

[10] For analysis, Abt collapsed the categories for patient need identified, caregiver need identified, and patient and caregiver need identified because of relatively small numbers when these were evaluated separately.

moderate rater agreement for five components (identification of symptom management, signs and symptoms of patient decline, other education and training needs and initiation of education, training for symptom management, and signs and symptoms of patient decline; 0.46 to 0.53); and **fair rater agreement for one component** (other initiated education and training; 0.24). Kappa statistics for the **remaining components indicated good rater agreement** (0.63 to 0.72).

For *Q1100. Patient and Caregiver Resource Needs,* kappa statistics indicated **very good rater agreement for one component** (need for aide support; 0.82); **good rater agreement for five components** (need for volunteer support and medical equipment, and referral given for aide support, volunteer support, and medical equipment; 0.67–0.80), **moderate rater agreement for four components** (the general inpatient or continuous homecare and inpatient respite care categories in both resource needs and referral given; 0.44–0.59), and **poor rater agreement for two components** (the *Other* component in both identification of need for and initiation of training and education; 0.00).

6.7.2 Chaplain/Spiritual Care Offered (JJ0010) and *Social Work Offered (JJ0015)*

JJ0010. Chaplain/Spiritual Care Offered and *JJ0015. Social Work Offered* captured whether patients were offered and accepted these services. RNs collected these data elements only at admission.

Validity

A few RNs expressed **content validity challenges**. They remarked that because social work and chaplain or spiritual services are expected to be offered and such staff are core members of the hospice care team, these items were not useful**.**

Descriptive statistics suggest face validity. Most RNs indicated patients as being offered and accepting chaplain or spiritual care services (79.9 percent) social work services (90 percent). See Exhibit 6-24 and Exhibit 6-25.

Exhibit 6-25. *JJ0010. Chaplain/Spiritual Care Offered*

Were hospice chaplain/spiritual care services offered to the patient and/or caregiver (family caregiver and non-family caregiver)?		
	Number	Percent
Yes, offered and accepted – hospice chaplain/spiritual care services were offered and accepted	231	79.9%
Yes, offered but declined as active with non-hospice spiritual care services – chaplain/spiritual care services were offered from the hospice, but declined due to receiving non-hospice services	16	5.5%
Yes, offered and declined – hospice chaplain/spiritual care services were offered but declined	28	9.7%
No, not offered – hospice chaplain/spiritual care services were not offered	0	0%
Currently active with hospice chaplain/spiritual care – chaplain/spiritual care is currently an active service with the hospice	11	3.8%
Not assessed	1	0.3%
Missing	2	0.7%
Total	289	100%

Source: Assessor-initiated Beta Test HOPE RN Admission forms.

Exhibit 6-26. *JJ0015. Social Work Offered*

Were hospice social work services offered to the patient and/or caregiver (family caregiver and non-family caregiver)?		
	Number	Percent
Yes, offered and accepted – hospice social work services were offered and accepted	260	90%
Yes, offered but declined as active with non-hospice social services – social work services were offered from the hospice, but declined due to receiving non-hospice services	6	2.1%
Yes, offered and declined – hospice social work services were offered but declined	10	3.5%

Were hospice social work services offered to the patient and/or caregiver (family caregiver and non-family caregiver)?		
	Number	Percent
No, not offered – hospice social work services were not offered	0	0%
Currently active with hospice social services – social work is currently an active service with the hospice	11	3.8%
Not assessed	0	0%
Missing	2	0.7%
Total	289	100%

Source: Assessor-initiated Beta Test HOPE RN Admission forms.

Feasibility

Both data elements had missingness rates of 0.7 percent, suggesting **no feasibility challenges**. See Appendix D for additional details.

Reliability

Kappa statistics indicated **good rater agreement** for both *JJ010. Chaplain/Spiritual Care Offered* and *JJ0015. Social Work Offered* (0.70 and 0.66, respectively). See Appendix E for additional details.

6.8 Skin Conditions

This section presents results for the skin integrity data elements. Initially Abt developed a data element that captured whether the patient had any pressure ulcers (by stage) or other skin conditions, which we included in cognitive interviews. The data element's pressure ulcer portion was tested against a standard cross-setting post-acute care data element that identified the current number of unhealed pressure ulcers/injuries (*M0300*). Hospice staff feedback indicated a preference for the standard item, and *M0300* was retained for Beta HOPE. Other data elements included in this section indicate whether the patient has other skin conditions (*M1085*), and characteristics (*M1090*) and interventions (*M1095*) provided for the pressure ulcers/injuries and other skin conditions. These data elements were collected on the RN Admission and RN Discharge forms.

6.8.1 *Unhealed Pressure Ulcers/Injuries (M0210), Current Number of Unhealed Pressure Ulcers/Injuries at Each Stage (M0300)*

M0210. Unhealed Pressure Ulcers/Injuries identified whether the patient had one or more unhealed pressure ulcers/injuries at any stage and served as a gateway question. If the RN answered *Yes*, they completed the *M0300. Current Number of Unhealed Pressure Ulcers/Injuries at Each Stage*. If the RN answered *No*, they skipped *M0300*. *M0300* identified the number of unhealed pressure ulcers/injuries at Stages 1, 2, 3 and 4, and the number of unstageable pressure ulcers/injuries due to a non-removable dressing or device, slough or eschar, or deep tissue injury.

RNs completed these data elements at admission and discharge. At admission RNs were instructed not to complete these data elements for patients who were actively dying (*J1410*).

Validity

Descriptive statistics suggest face validity. At admission, RNs indicated that 11.7 percent of patients had any unhealed pressure ulcer/injury. For those patients, all had a stage indicated, with Stage 2 pressure ulcers being the most common (46.9 percent). At discharge RNs indicated that only one patient had unhealed pressure ulcers/injuries; this was indicated as Stage 1. See Exhibit 6-26 and Exhibit 6-27.

Exhibit 6-27. *M0210. Unhealed Pressure Ulcers/Injuries*

Does this patient have one or more unhealed pressure ulcers/injuries?				
	Admission		Discharge	
	Number	Percent	Number	Percent
No	240	87.6%	27	96.4%
Yes	32	11.7%	1	3.6%
Missing	2	0.7%	0	0%
Total	274	100%	28	100%

At admission, RN did not complete this data element for patients who were actively dying (n=15; see data element J1410). At discharge, the RN did not complete this data element for patients with a discharge reason of Expired (n=1; see data element A2115). Patients for whom the discharge reason was missing are not included (n=1; see data element A2115).
Source: Assessor-initiated Beta Test HOPE RN Admission and Discharge forms.

Exhibit 6-28. ***M0300. Current Number of Unhealed Pressure Ulcers/Injuries at Each Stage***

	Admission		Discharge	
	Number	Percent	Number	Percent
A. Stage 1 1. Number of Stage 1 pressure injuries				
0	14	43.8%	0	0%
1	5	15.6%	1	100%
Missing	13	40.6%	0	0%
Total	32	100%	1	100%
B. Stage 2 1. Number of Stage 2 pressure ulcers				
0	7	21.9%	1	100%
1	15	46.9%	0	0%
2	2	6.3%	0	0%
5	1	3.1%	0	0%
Missing	7	21.9	0	0%
Total	32	100%	1	100%
C. Stage 3 1. Number of Stage 3 pressure ulcers				
0	12	37.5%	1	100%
1	3	9.4%	0	0%
Missing	17	53.1%	0	0%
Total	32	100%	1	100%
D. Stage 4 1. Number of Stage 4 pressure ulcers				
0	13	40.6%	1	100%
1	3	9.4%	0	0%
Missing	16	50%	0	0%
Total	32	100%	1	100%
E. Unstageable 1. Number of unstageable pressure ulcers/injuries due to non-removable dressing device				
0	15	46.9%	1	100%
1	2	6.3%	0	0%
Missing	15	46.9	0	0%
Total	32	100%	1	100%
F. Unstageable: Slough and/or eschar 1. Number of unstageable pressure ulcers due to coverage of wound bed by slough and/or eschar				
0	14	43.8%	1	100%
1	2	6.3%	0	0%

	Admission		Discharge	
	Number	Percent	Number	Percent
2	1	3.1%	0	0%
Missing	15	46.9%	0	0%
Total	32	100%	1	100%
G. Unstageable: Deep tissue injury *1.* Number of unstageable pressure injuries presenting as deep tissue injury				
0	14	43.8%	1	100%
1	4	12.5%	0	0%
2	1	3.1%	0	0%
Missing	13	40.6%	0	0%
Total	32	100%	1	100%

At admission, RN did not complete this data element for patients who were actively dying (n=15; see data element J1410). At discharge, the RN did not complete this data element for patients with a discharge reason of Expired (n=1; see data element A2115). Patients for whom the discharge reason was missing are not included (n=1; see data element A2115).
Source: Assessor-initiated Beta Test HOPE RN Admission and Discharge forms.

Feasibility

M0210. Unhealed Pressure Ulcers/Injuries suggested **no feasibility challenges,** with a missingness rate of 0.7 percent at admission and no missing data at discharge. See Appendix D for additional data.

At admission, *M0300. Current Number of Unhealed Pressure Ulcers/Injuries at Each Stage* descriptively had a high proportion of missing data for each stage, suggesting **potential feasibility challenges**. RNs were to manually enter number of ulcers/injuries at stage (or *Unstageable*) reflecting the patient's identified pressure ulcer(s) and enter a zero for the remaining stages (or *Unstageable*). This was intended to allow each data element component to have a response. Although the Abt team provided training and reinforcement of this requirement, results indicate that many RNs did not enter a zero when needed. If this data element is implemented, most point of care data in practice are collected with electronic devices that warn users if any question is left blank and therefore will reduce the number of missing responses. Also, if this data element is implemented, technical specifications for data submission may be written to prevent submission of an incomplete record, minimizing the chance for missing data. At discharge, the number was recorded for the single patient that had an unhealed pressure ulcer/injury, so there was no missing data at that time point. Appendix D does not include additional details for *M0300*, as it is neither a binary nor a check-all-that-apply response option.

Reliability

For *M0210. Unhealed Pressure Ulcers/Injuries* kappa statistics indicated **very good rater agreement** for whether the patient had any unhealed pressure ulcers/injuries (0.88).

For *M0300. Current Number of Unhealed Pressure Ulcers/Injuries at Each Stage* kappa statistics indicated **very good rater agreement for Stage 1, 3, 4, and unstageable** (0.84–0.99) and **good rater agreement for Stage 2** (0.68).

6.8.2 Other Skin Conditions (M1085), Characteristics of Pressure Ulcers/Injuries and Other Skin Conditions (M1090), and *Interventions for Pressure Ulcers/Injuries and Other Skin Conditions (M1095)*

Abt developed *M1085. Other Skin Conditions*, *M1090. Characteristics of Pressure Ulcers/Injuries and Other Skin Conditions*, and *M1095. Interventions for Pressure Ulcers/Injuries and Other Skin Conditions* as new data elements for HOPE. Pilot testing results and feedback informed expansion of the list of wound characteristics to capture those most frequently reported.

Based on pilot testing feedback, Abt revised *M1095* instructions to change "check all that apply" to "check all interventions that are on the plan of care at the time of the assessment." Ensuring instructions were explicit

about what the item captured (not just interventions, but interventions on the plan of care), and timing (at the time of the assessment, specifically) addressed questions RNs asked about how to complete the item.

Results and feedback from alpha testing informed further revisions, including clarification that *M0190* and *M1095* were to be identified for both ulcers/injuries (*M0300*) and other skin conditions (*M0185*). Abt also added more interventions to *M1095* related to pressure ulcer prevention and management.

M1090 and *M1095* were intended as summary data elements for both ulcers/injuries and other skin conditions. Because whether the patient had pressure ulcers/injuries and other skin conditions (*M0210* and *M1085*, respectively) are collected as their own separate data elements, no skip pattern was engaged for *M0190* and *M1095*, and Abt added a response option of *Not Applicable* for the beta test version.

M1085, *M1090*, and *M1095* were collected for the RN Admission and RN Discharge. At admission RNs were instructed not to complete these data elements for patients who were actively dying (*J1410*).

Validity

Descriptive statistics suggest face validity. For *M1085. Other Skin Conditions*, at admission, RNs indicated that a little more than 70 percent of patients had no skin condition (n = 196). Of those with a skin condition, other skin conditions (e.g., a rash or skin tear) were indicated most often (n=52). Similarly, at discharge RNs indicated that 75 percent of patients had no skin condition, and of those with a skin condition, other skin conditions were indicated most often (n=4).

For *M1090. Characteristics of Pressure Ulcers/Injuries and Other Skin Conditions*, at admission only 30 total wound characteristics were indicated, with wound discharge being most common (n=14). Similarly, at discharge 11 total wound characteristics were indicated, each with one patient identified as having that wound characteristic. The results are consistent with those for *M1085*, indicating few patients having surgical wounds or ulcers.

For *M1095. Interventions for Pressure Ulcers/Injuries and Other Skin Conditions*, at admission, the most indicated interventions included: dressing change (n=35), incontinence management (n=25), and topical medication (n=25). At discharge, RNs indicated few patients as receiving interventions, consistent with few patients being indicated as having skin conditions.

Exhibit 6-29. *M1085. Other Skin Conditions*

At the time of this assessment the patient has which of the following other skin conditions? Check all that apply.				
	Admission		Discharge	
	Number	Percent	Number	Percent
A. Surgical Wound				
No	250	91.2%	25	89.3%
Yes	13	4.7%	1	3.6%
Not assessed	11	4%	2	7.1%
Total	274	100%	28	100%
B. Ulcers other than pressure ulcers/injuries (e.g., Kennedy ulcer, venous stasis ulcer, arterial ulcer, diabetic ulcer)				
No	259	94.5%	26	92.9%
Yes	4	1.5%	0	0%
Not assessed	11	4%	2	7.1%
Total	274	100%	28	100%
C. Other skin conditions (e.g., rash, skin tear)				
No	211	77%	22	78.6%
Yes	52	19%	4	14.3%
Not assessed	11	4%	2	7.1%
Total	274	100%	28	100%

At the time of this assessment the patient has which of the following other skin conditions? Check all that apply.				
	Admission		Discharge	
	Number	Percent	Number	Percent
D. None of the above				
No	67	24.5%	5	17.9%
Yes	196	71.5%	21	75%
Not assessed	11	4%	2	7.1%
Total	274	100%	28	100%

At admission, RN did not complete this data element for patients who were actively dying (n=15; see data element J1410). At discharge, the RN did not complete this data element for patients with a discharge reason of Expired (n=1; see data element A2115). Patients for whom the discharge reason was missing are not included (n=1; see data element *A2115*).
Source: Assessor-initiated Beta Test HOPE RN Admission and Discharge forms.

Exhibit 6-30. ***M1090. Characteristics of Pressure Ulcers/Injuries and Other Skin Conditions***

	Admission		Discharge	
	Number	Percent	Number	Percent
A. Wound discharge				
No	244	89.1%	25	89.3%
Yes[1]	14	5.1%	1	3.6%
Not assessed	16	5.8%	2	7.1%
Total	274	100%	28	100%
B. Signs and symptoms of infection				
No	252	92%	25	89.3%
Yes	6	2.2%	1	3.6%
Not assessed	16	5.8%	2	7.1%
Total	274	100%	28	100%
C. Pain including with wound assessment and/or treatment				
No	251	91.6%	25	89.3%
Yes	7	2.6%	1	3.6%
Not assessed	16	5.8%	2	7.1%
Total	274	100%	28	100%
D. Odor				
No	255	93.1%	25	89.3%
Yes	3	1.1%	1	3.6%
Not assessed	16	5.8%	2	7.1%
Total	274	100%	28	100%
E. None of the above				
No	181	66.1%	19	67.9%
Yes	77	28.1%	7	25%
Not assessed	16	5.8%	2	7.1%
Total	274	100%	28	100%
F. Not applicable (no pressure ulcers/injuries or other skin conditions)				
No	98	35.8%	8	28.6%
Yes	160	58.4%	18	64.3%
Not assessed	16	5.8%	2	7.1%
Total	274	100%	28	100%

At admission, RN did not complete this data element for patients who were actively dying (n=15; see data element *J1410*). Patients for whom the discharge reason was missing are not included (n=1; see data element *A2115*).

	Admission		Discharge	
	Number	Percent	Number	Percent

No responses include both patients who did not have the wound characteristic and patients indicated as not having a pressure ulcer/injury (n=240 at admission and n=27 at discharge; see *M0210*) or other skin condition (n=67 at admission and n=5 at discharge; see *M1085*).
[1] Eight forms indicated "Yes" for Wound Discharge without have previously indicated the patient had a pressure ulcer/injury (*M0210*) or other skin condition (*M1085*).
Source: Assessor-initiated Beta Test HOPE RN Admission and Discharge forms.

Exhibit 6-31. *M1095. Interventions for Pressure Ulcers/Injuries and Other Skin Conditions*

Indicate the interventions that are on the plan of care at the time of this assessment, for identified pressure ulcers/injuries and other skin conditions. Check all that apply.				
	Admission		Discharge	
	Number	Percent	Number	Percent
A. Debridement				
No	259	94/5%	26	92.9%
Yes	0	0%	0	0%
Not assessed	15	5.5%	2	7.1%
Total	274	100%	28	100%
B. Dressing change				
No	224	81.8%	24	85.7%
Yes	35	12.8%	2	7.1%
Not assessed	15	5.5%	2	7.1%
Total	274	100%	28	100%
C. Incontinence management				
No	234	85.4%	25	89.3%
Yes	25	9.1%	1	3.6%
Not assessed	15	5.5%	2	7.1%
Total	274	100%	28	100%
D. Medicate prior to wound care				
No	252	92%	26	92.9%
Yes	7	2.6%	0	0%
Not assessed	15	5.5%	2	7.1%
Total	274	100%	28	100%
E. Negative pressure wound therapy				
No	258	94.2%	26	92.9%
Yes	1	0.4%	0	0%
Not assessed	15	5.5%	2	7.1%
Total	274	100%	28	100%
F. Pressure relief items				
No	239	87.2%	26	92.9%
Yes	20	7.3%	0	0%
Not assessed	15	5.5%	2	7.1%
Total	274	100%	28	100%
G. Repositioning				
No	218	79.6%	25	89.3%
Yes	41	15%	1	3.6%
Not assessed	15	5.5%	2	7.1%

Indicate the interventions that are on the plan of care at the time of this assessment, for identified pressure ulcers/injuries and other skin conditions. Check all that apply.				
	Admission		Discharge	
	Number	Percent	Number	Percent
Total	274	100%	28	100%
H. Topical medication				
No	234	85.4%	25	89.3%
Yes	25	9.1%	1	3.6%
Not assessed	15	5.5%	2	7.1%
Total	274	100%	28	100%
I. Other				
No	252	92%	26	92.9%
Yes	7	2.6%	0	0%
Not assessed	15	5.5%	2	7.1%
Total	274	100%	28	100%
J. None of the above				
No	223	81.4%	21	75%
Yes	36	13.1%	5	17.9%
Not assessed	15	5.5%	2	7.1%
Total	274	100%	28	100%
K. Not applicable (no pressure ulcers/injuries or other skin conditions)				
No	102	37.2%	8	28.6%
Yes	157	57.3%	18	64.3%
Not assessed	15	5.5%	2	7.1%
Total	274	100%	28	100%

At admission, RN did not complete this data element for patients who were actively dying (n=15; see data element *J1410*). At discharge, the RN did not complete this data element for patients with a discharge reason of *Expired* (n=1; see data element *A2115*). Patients for whom the discharge reason was missing are not included (n=1; see data element *A2115*). *No* responses include both patients who did not have the wound characteristic and patients indicated as not having a pressure ulcer/injury (n=240 at admission and n=27 at discharge; see *M0210*) or other skin condition (n=67 at admission and n=5 at discharge; see *M1085*).
Source: Assessor-initiated Beta Test HOPE RN Admission and Discharge forms.

Feasibility

All three data elements had missingness rates under 10 percent, suggesting **no feasibility challenges**. At admission, missingness rates ranged from 4 percent (other skin conditions) to 5.8 percent (characteristics), and at discharge the missingness rate was 7.1 percent for all three data elements. See Appendix D for additional details.

Reliability

Kappa statistics indicated **very good rater agreement** for all three data elements (0.99 for each). See Appendix E for additional details.

6.9 Medications

This section presents results for the medication related data elements: *N0470. Medication Management*, *N0471. Medication Management – Patient*, and *N0472. Medication Management – Caregiver*.

For pilot testing, Abt modified a standard cross-setting post-acute care data element to identify when the patient was prescribed any medications that fell into one of four drug classes (analgesic, antiemetic, laxative, anxiolytic) and whether the Medicare Hospice Benefit paid for the identified prescription.

Because hospice staff found this data element confusing and difficult to complete, Abt clarified the question and its instructions and responses for the alpha test. Alpha testing feedback indicated that all of these medications appeared routinely as part of the comfort kit provided to patients at admission, so Abt did not include the data element in beta testing.

6.9.1 Medication Management (N0470)

N0470. Medication Management was added during alpha testing and was intended to capture information that CMS could potentially use in support of a quality measure. Abt modified an existing home health Outcome and Assessment Information Set item to develop *N0470*. Alpha testing feedback informed revisions to the question and its instructions and response options. The revisions clarified the data element's intent to capture whether the patient, family, and/or caregivers can manage a patient's medication: independently, with assistance from another person, or with complete dependence on another person.

Validity

N0470. Medication Management had **significant content validity challenges** and proved problematic in beta testing. RNs reported confusion over when to document the patient's ability and when to document the family/caregiver's ability. About halfway through beta test data collection Abt separated the medication management data element into two elements: one that identified the patient's ability with medication management (N0471) and another that identified the family or caregiver's ability. Two hundred sixteen RN Admission forms and 28 RN Discharge forms used this data element before the beta test RN Admission and Discharge forms form were revised to separate patient and caregiver responses.

Descriptive statistics cannot determine face validity. RNs indicated that most patients/caregivers were able to take medications independently (44 percent at admission and 36 percent at discharge) or with assistance from another person (22 percent at admission and 21 percent at admission). See Exhibit 6-31. Face validity expectations meaningfully differ depending on whether the patient or caregiver is expected to manage their medications. Because this data element combines patients and caregivers, our data cannot assess face validity.

Exhibit 6-32. *N0470. Medication Management*

At the time of this assessment, indicate the patient and/or caregiver's (including family and facility staff) ability to prepare and take medications safely and reliably, including administration of the correct dosage at the appropriate times. Instructions: If level of assistance varies between medications, select the response based on the medication that requires the most assistance.				
	Admission		Discharge	
	Number	Percent	Number	Percent
Independent: Independently and safely takes correct medication and proper dosage(s) at the correct times	95	44.0%	10	35.7%
Needs assistance: Takes medication(s) safely and accurately at the correct times if individual dosages are prepared in advance by the hospice nurse	48	22.2%	6	21.4%
Dependent: Unable to take medication safely and accurately	70	32.4%	12	42.9%
Not applicable (e.g., patient is not taking any medications)	1	0.5%	0	0%
Missing	2	0.9%	0	0%
Total	216	100%	28	100%

At admission, RN did not complete this data element for patients who were actively dying (n=15; see data element *J1410*). At discharge, the RN did not complete this data element for patients with a discharge reason of *Expired* (n=1; see data element *A2115*). Patients for whom the discharge reason was missing are not included (n=1; see data element *A2115*). This data element was discontinued partway through beta testing and was therefore not included in 73 RN Admission forms.

At the time of this assessment, indicate the patient and/or caregiver's (including family and facility staff) ability to prepare and take medications safely and reliably, including administration of the correct dosage at the appropriate times. Instructions: If level of assistance varies between medications, select the response based on the medication that requires the most assistance.				
	Admission		Discharge	
	Number	Percent	Number	Percent

Source: Assessor-initiated Beta Test HOPE RN Admission and Discharge forms.

Feasibility

The missingness rate for *N0470. Medication Management* was 0.9 percent, reflecting missing data for only two of 216 RN admission forms that included the data element. No forms were missing the data element at discharge, suggesting **no feasibility challenges**. See Appendix D for additional details.

Reliability

Kappa statistics indicated **very good rater agreement** for *N0470. Medication Management* (0.84). See Appendix E for additional details.

6.9.2 Medication Management – Patient (N0471) and *Medication Management – Caregiver (N0472)*

N0471. Medication Management – Patient identified the level of assistance the patient required from another person to prepare and take their medication(s) safely and accurately. The instructions for this data element directed RNs to include all prescribed and over-the-counter medications currently taken by any route on the plan of care.

N0472. Medication Management – Caregiver captured the level of assistance the caregiver (including facility staff for those living in a facility) required from another person to prepare and administer that patient's medication(s) safely and accurately.

Both data elements included instructions to include all prescribed and over-the-counter medications.

Because Abt implemented these data elements partway through beta testing, they were only included on 73 RN Admission forms and were not included on any RN Discharge forms.

Validity

Descriptive statistics suggest face validity. RNs indicated most patients were dependent on others for medication management (80 percent). In contrast, most family or caregivers were independent with medication management at admission (84 percent). See Exhibit 6-32 and Exhibit 6-33.

Correlations support good convergent validity. At admission, responses for *N0471. Medication Management - Patient* were significantly correlated with *F0900. Living Arrangements* (p-value < 0.001) and *F0915. Availability of Assistance* (p-value < 0.001). See Appendix F.

Exhibit 6-33. *N0471.* Medication Management – Patient

At the time of this assessment, indicate the level of assistance from another person required by the patient to prepare and take medication(s) and proper dosage(s) at the correct times safely and accurately. Instructions: If level of assistance varies between medications, select the response based on the medication that requires the most assistance.		
	Admission	
	Number	Percent
Independent: Patient does not require assistance from another person.	9	12.3%

At the time of this assessment, indicate the level of assistance from another person required by the patient to prepare and take medication(s) and proper dosage(s) at the correct times safely and accurately. Instructions: If level of assistance varies between medications, select the response based on the medication that requires the most assistance.	Admission	
	Number	Percent
Needs some assistance: Patient requires some assistance from another person (e.g., if individual dosages are prepared in advance by another person, if another person sets up a reminder system allowing the patient to take medications correctly).	6	8.2%
Dependent: Patient is unable to complete task(s) related to preparation and administration of their medications and relies completely on another person.	58	79.5%
Not applicable: Patient is not taking any medications.	0	0%
Missing	0	0%
Total	73	100%

At admission, RN did not complete this data element for patients who were actively dying (n=15; see data element J1410).
This data element was not included in any RN Discharge forms. This data element was implemented partway through beta testing and was therefore not included in 216 RN Admission forms.
Source: Assessor-initiated Beta Test HOPE RN Admission forms.

Exhibit 6-34. *N0472. Medication Management – Caregiver*

At the time of this assessment, indicate the level of assistance required by the caregiver to prepare and administer the patient's medication(s) safely and accurately. The caregiver includes family caregivers, non-family caregivers, or, for patients residing in any facility setting, such as assisted living or long-term care, caregivers include the facility staff. Instructions: If level of assistance varies between medications, select the response based on the medication that requires the most assistance.	Admission	
	Number	Percent
Independent: Caregiver does not require assistance from another person.	61	83.6%
Needs some assistance: Caregiver requires some assistance from another person (e.g., if individual dosages are prepared in advance by another person, if another person sets up a reminder system allowing the caregiver to administer the medications correctly).	7	9.6%
Dependent: Caregiver is unable to complete task(s) related to preparation and administration of the patient's medications and relies completely on another person.	3	4.1%
Not applicable: Patient is not taking any medications, or patient does not require assistance from another person to prepare and take medication(s) and proper dosage(s) at the correct times.	1	1.4%
Missing	1	1.4%
Total	73	100%

At admission, RN did not complete this data element for patients who were actively dying (n=15; see data element J1410).
This data element was not included in any RN Discharge forms. This data element was implemented partway through beta testing and was therefore not included in 216 RN Admission forms.
Source: Assessor-initiated Beta Test HOPE RN Admission forms.

Feasibility

No data was missing for *N0471. Medication Management – Patient,* and the prevalence of missing data was low for *N0472. Medication Management – Caregiver* (1.4 percent). This suggests **no feasibility challenges.** See Appendix D for more details.

Qualitative data suggest limited feasibility challenges for patients who reside in facility settings such as nursing homes or assisted living facilities. RNs reported that they must engage family members as well as facility staff who may be monitoring medications, and one RN noted challenges because the

hospice team does not have access to the facility's electronic medical record. For patients living in a private home, RNs reported no challenges with these items and stated that assessing medication management is already part of their routine assessment.

Reliability

Kappa statistics indicated **very good rater agreement** for both data elements (0.96 for each).

6.10 Other RN Discharge Data Elements

This section presents results on data elements collected only as part of the RN Discharge form. One reflects discharge location (*A2015. Discharge Location*). Four reflect transmission of medication lists (*A2121. Provision of Current Reconciled Medication List to Subsequent Provider at Discharge*, *A2122. Route of Current Reconciled Medication List Transmission to Subsequent Provider*, *A2123. Provision of Current Reconciled Medication List to Patient at Discharge*, and *A2124. Route of Current Reconciled Medication List Transmission to Patient*). Two reflect falls status (*J1800. Any Falls Since Admission of Recertification* and *J1900. Number of Falls*), and two reflect emergency room use (*A1850. Emergency Room Use* and *A1855. Date of Emergency Room Use*). One reflects advance care planning (F1010. Advance Care Planning Preferences Follow-up).

Thirty RN Discharge forms were completed. While RNs were instructed to complete an RN Discharge form only for live discharges, one RN completed a discharge form for an expired patient.

6.10.1 Discharge Location (*A2105*)

Discharge location is a cross-setting standard post-acute care data element from the Long-Term Care Data Set. HOPE includes this item because it identifies the discharge location for the purposes of the transfer of health information items. RNs completed this data element at discharge.

Validity

Descriptive statistics suggest face validity. More than half of patient discharges were to home or to the community (57.1 percent), followed by discharge to a nursing home (25 percent). See Exhibit 6-34.

Exhibit 6-35. *A2105. Discharge Location*

	Number	Percent
Home/community (e.g., private home/apt., board/care, assisted living, group home, transitional living, other residential care arrangements)	16	57.1%
Nursing home (long-term care facility)	7	25%
Skilled nursing facility (SNF, swing beds)	0	0%
Short-term general hospital (acute hospital, IPPS)	1	3.6%
Long-term care hospital (LTCH)	1	3.6%
Inpatient rehabilitation facility (IRF, free standing facility or unit)	0	0%
Inpatient psychiatric facility (psychiatric hospital or unit)	0	0%
Intermediate care facility (ID/DD facility)	0	0%
Hospice (home/non-institutional)	0	0%
Hospice (institutional facility)	0	0%
Critical access hospital (CAH)	1	3.6%
Home under care of organized home health service organization	0	0%
Not listed	1	3.6%
Missing	1	3.6%
Total	28	100%

	Number	Percent

At discharge, the RN did not complete this data element for patients with a discharge reason of *Expired* (n=1; see data element *A2115*). Patients for whom the discharge reason was missing are not included (n=1; see data element *A2115*).

Source: Assessor-initiated Beta Test HOPE RN Discharge forms.

Feasibility

Missingness rates were low for this data element (3.6 percent), indicating **no feasibility challenges**. See Appendix D for more information.

Reliability

Kappa statistics indicated **very good rater agreement** for discharge location (0.88).

6.10.2 Provision of Current Reconciled Medication List to Subsequent Provider at Discharge (A2121), Route of Current Reconciled Medication List Transmission to Subsequent Provider (A2122), Provision of Current Reconciled Medication List to Patient at Discharge (A2123), and *Route of Current Reconciled Medication List Transmission to Patient (A2124)*

These are standard cross-setting post-acute care data elements associated with a cross-setting Transfer of Health Information quality measure. In Beta HOPE, these data elements identify if a reconciled medication list was provided to the subsequent provider, or to the patient, family and/or caregiver when the patient is discharged. Because these are standard data elements, they were not modified following pilot or alpha testing. Abt used hospice staff feedback to inform revisions to the training for these data elements, when necessary.

Validity

Descriptive statistics suggest face validity. For patients discharged to another provider, most RNs indicated that the reconciled medication list was provided to the subsequent provider (72.7 percent). For patients with a transferred medication list, RNs indicated almost half were sent using paper-based methods, such as via fax or paper print-out (50.0 percent), with three of the eight transmitted via electronic health record. For patients discharged to home or the community, RNs indicated that 81.2 percent had a reconciled medication list provided to the patient, a family member, or a caregiver. Of the 13 patients who received the list, 9 received the list verbally and 8 received a paper-based list; a single patient may have had their list transmitted using more than one route. See Exhibit 6-35 through Exhibit 6-38.

Exhibit 6-36. *A2121. Provision of Current Reconciled Medication List to Subsequent Provider at Discharge*

At the time of discharge to another provider, did your agency provide the patient's current reconciled medication list to the subsequent provider?		
	Number	Percent
No – Current reconciled medication list not provided to the subsequent provider	3	27.3%
Yes – Current reconciled medication list provided to the subsequent provider	8	72.7%
Missing	0	0%
Total	11	100%

RNs completed this data element only for patients with a discharge location that was not *Home/Community* (n=11; see data element *A2105*).
Source: Assessor-initiated Beta Test HOPE RN Discharge forms.

Exhibit 6-37. *A2122. Route of Current Reconciled Medication List Transmission to Subsequent Provider*

Indicate the route(s) of transmission of the current reconciled medication list to the subsequent provider. Check all that apply.		
Route of Transmission	Number	Percent
A. Electronic health record		
No	5	62.5%
Yes	3	37.5%
Not assessed	0	0%
Total	8	100%
B. Health information exchange organization		
No	8	100%
Yes	0	0%
Not assessed	0	0%
Total	8	100%
C. Verbal (e.g., in-person, telephone, video conferencing)		
No	7	87.5%
Yes	1	12.5%
Not assessed	0	0%
Total	8	100%
D. Paper-based (e.g., fax, copies, printouts)		
No	4	50%
Yes	4	50%
Not assessed	0	0%
Total	8	100%
E. Other methods (e.g., texting, email, CDs)		
No	7	87.5%
Yes	1	12.5%
Not assessed	0	0%
Total	8	100%

RNs completed this data element only for patients with *Yes – Current reconciled medication list provided to the subsequent provider* (n=8; see data element *A2121*).
Source: Assessor-initiated Beta Test HOPE RN Admission forms.

Exhibit 6-38. *A2123. Provision of Current Reconciled Medication List to Patient at Discharge*

At the time of discharge, did your agency provide the patient's current reconciled medication list to the patient, family and/or caregiver?		
	Number	Percent
No – Current reconciled medication list not provided to the patient, family and/or caregiver	3	18.8%
Yes – Current reconciled medication list provided to the patient, family and/or caregiver	13	81.2%
Missing	0	0%
Total	16	100%

RNs completed this data element only for patients with a discharge location that was not *Home/Community* (n=16; see data element *A2105*).
Source: Assessor-initiated Beta Test HOPE RN Discharge forms.

Exhibit 6-39. *A2124. Route of Current Reconciled Medication List Transmission to Patient*

Indicate the route(s) of transmission of the current reconciled medication list to the patient/family/caregiver. Check all that apply.		
Route of Transmission	Number	Percent
A. Electronic health record		
No	10	76.9%
Yes	3	23.1%
Not assessed	0	0%
Total	13	100%
B. Health information exchange organization		
No	12	92.3%
Yes	1	7.7%
Not assessed	0	0%
Total	13	100%
C. Verbal (e.g., in-person, telephone, video conferencing)		
No	4	30.8%
Yes	9	69.2%
Not assessed	0	0%
Total	13	100%
D. Paper-based (e.g., fax, copies, printouts)		
No	5	38.5%
Yes	8	61.5%
Not assessed	0	0%
Total	13	100%
E. Other methods (e.g., texting, email, CDs)		
No	13	100%
Yes	0	0%
Not assessed	0	0%
Total	13	100%

RNs completed this data element only for patients with Yes – Current reconciled medication list provided to the patient, family and/or caregiver (n=13; see data element *A2123*).
Source: Assessor-initiated Beta Test HOPE RN Discharge forms.

Feasibility

There was no missing data for these data elements, indicating **no feasibility challenges**. See Appendix D for more information. Though a few RNs completed an RN Discharge Assessment form, some described their typical process, which included preparing a discharge packet with information about the medication list for the provider.

Reliability

Kappa statistics indicated **good rater agreement** for *A2123. Provision of Current Reconciled Medication List to Patient at Discharge* (0.68) and **very good rater agreement** for the remaining data elements (0.84 to 0.89).

6.10.3 Any Falls Since Admission or Recertification (J1800), Number of Falls (J1900)

J1800. Any Falls Since Admission or Recertification indicated whether a patient has had any falls since the hospice admission or recertification, whichever was most recent. For patients who had a fall, *J1900. Number of Falls* identified the number of falls associated with no injury, with non-major injury, and with major injury.

Validity

Descriptive statistics suggest face validity. RNs indicated that 16.7 percent of patients had had one or more falls since admission or recertification. Patients with one fall were reflected in each of the injury categories. Patients with two or more falls experienced no injury, or non-major injury. See Exhibit 6-39 and Exhibit 6-40.

Exhibit 6-40. *J1800. Any Falls Since Admission or Recertification*

	Number	Percent
No	23	76.7%
Yes	5	16.7%
Missing	2	6.7%
Total	30	100%

Source: Assessor-initiated Beta Test HOPE RN Discharge forms.

Exhibit 6-41. *J1900. Number of Falls*

Number of falls since admission of recertification, whichever is more recent.		
	Number	Percent
A. No injury: No evidence of any injury is noted on physical assessment by the nurse or primary care clinician; no complaints of pain or injury by the patient; no change in the patient's behavior is noted after the fall.		
None	0	0%
One	2	40%
Two or more	3	60%
Missing	0	0%
Total	5	100%
B. Injury (except major): Skin tears, abrasions, lacerations, superficial bruises, hematomas, and sprains; or any fall-related injury that causes the patient to complain of pain		
None	2	40%
One	2	40%
Two or more	1	20%
Missing	0	0%
Total	5	100%
C. Major injury: Bone fractures, joint dislocations, closed head injuries with altered consciousness, subdural hematoma		
None	3	60%
One	2	40%
Two or more	0	0%
Missing	0	0%
Total	5	100%

RNs completed this data element only for patients with a fall since readmission or recertification (n=5; see data element J1800).

Source: Assessor-initiated Beta Test HOPE RN Discharge forms.

Feasibility

J1800. Any Falls Since Admission or Recertification had a missingness rate of 6.7 percent, and *J1900. Number of Falls* had no missing data, suggesting **no feasibility challenges**. See Appendix D for more information.

Qualitative data suggests some feasibility challenges. To complete these data elements, RNs had to review the patient's clinical record to identify the number of times the patient fell, and the extent of injury associated with each fall. Several RNs noted that completing this record review was challenging because

their electronic health records did not include a specific field to capture or tracking feature for documenting falls.

Reliability

Kappa statistics indicated **very good rater agreement** for any falls (0.86) and number of falls with *No injury* (0.88) and *Major Injury* (0.88), and **good rater agreement** for number of falls with *Injury (except major)* (0.66). See Appendix E for more information.

6.10.4 *Emergency Room Use (A1850)* and *Date of Emergency Room Use (A1855)*[11]

Abt added *A1850. Emergency Room Use* as new data element for beta testing to identify if patient had used the emergency room, including for holding or an observation stay, at any time during the hospice stay. The intent was to capture information about whether and when hospice patients accessed emergency room care. A companion data element identified dates of emergency room use, if any occurred.

Validity

Descriptive sstatistics suggest face validity. RNs indicated that only three patients used the emergency room during their hospice stay. See Exhibit 6-41. RNs entered a date for all three patients, with one of those patients having three dates entered to reflect three emergency room visits during the patient's hospice stay (data not presented).

Exhibit 6-42. *A1850. Emergency Room Use*

At any time during this admission has the patient utilized an emergency room (including holding/observation status)?		
	Number	Percent
No	26	86.7%
Yes, used emergency room but not admitted to hospital	0	0%
Yes, used emergency room and admitted to hospital	3	10%
Missing	1	3.3%
Total	30	100%

Source: Assessor-initiated Beta Test HOPE RN Discharge forms.

Feasibility

For *A1850. Emergency Room Use*, the proportion of missing data was low (3.3 percent), suggesting **no feasibility challenges**. See Appendix D for additional information.

Missing rates were not calculated for *A1855. Date of Emergency Room Use*, though all three patients RNs indicated as having used the emergency room had corresponding dates reported.

Reliability

For *A1850. Emergency Room Use*, kappa statistics indicated **very good rater agreement** (.99). Kappa was not calculated for *A1855. Date of Emergency Room Use.*

6.10.5 *Advance Care Planning Preferences Follow-Up (F1010)*

Abt developed *F1010. Advance Care Planning Preferences Follow-up* as a follow-up data element to *F1000. Advanced Care Planning Preferences.* RNs collected *F1000* at admission and *F1010* at discharge. *F1010. Advance Care Planning Preferences Follow-up* indicated whether the hospice had followed the patient's preferences for advance care planning (chest compressions, intubation, hospitalization) throughout the patient's hospice stay. Pilot and alpha testing feedback informed revisions for readability but no major changes were made across the different phases of testing.

[11] Items *A1850 and A1855* may also be referred to as *A10001* and *A0002*, respectively.

Validity

Descriptive statistics suggest face validity. RNs did not identify any patients whose preferences for advance care planning were not followed during the patient's stay, even if those preferences changed over the course of the stay. See Exhibit 6-42.

Exhibit 6-43. ***F1010. Advance Care Planning Preferences Follow-Up***

Were patient preferences followed throughout this hospice stay?		
	Number	Percent
A. Chest compression		
Yes, preferences did not change throughout the hospice stay and were followed.	27	90%
Yes, preferences changed during the hospice stay and were followed.	2	6.7%
No, preferences were not followed throughout the hospice stay.	0	0%
Not applicable: Not discussed at any time during the hospice stay.	0	0%
Missing	1	3.3%
Total	30	100%
B. Intubation		
Yes, preferences did not change throughout the hospice stay and were followed.	27	90%
Yes, preferences changed during the hospice stay and were followed.	2	6.7%
No, preferences were not followed throughout the hospice stay.	0	0%
Not applicable: Not discussed at any time during the hospice stay.	0	0%
Missing	1	3.3%
Total	30	100%
C. Hospitalization		
Yes, preferences did not change throughout the hospice stay and were followed.	27	90%
Yes, preferences changed during the hospice stay and were followed.	2	6.7%
No, preferences were not followed throughout the hospice stay.	0	0%
Not applicable: Not discussed at any time during the hospice stay.	0	0%
Missing	1	3.3%
Total	30	100%

Source: Assessor-initiated Beta Test HOPE RN Discharge forms.

Feasibility

F1010. Advance Care Planning Preferences Follow-up had missingness rates of 3.3 percent for chest compression, intubation, and hospitalization, suggesting **no feasibility challenges**. See Appendix D for additional information.

Reliability

Kappa statistics indicated **good rater agreement** for whether advance care planning preferences were followed for chest compressions (0.65), and **very good rater agreement** for intubation (0.99) and hospitalization (0.99). See Appendix E for additional information.

7. Beta Test Results: SW Forms

Based on results from pilot and alpha testing, the Abt team substantially revised the SW Admission and Discharge forms for Beta HOPE. Abt developed all but three of the SW Admission and SW Discharge form elements as new elements in response to hospice staff feedback that the SW tools did not appropriately reflect the SW scope of practice. The three exceptions were *D0150. Patient Mood Interview*, *D0180. Patient Feeling Anxious or Worried*, and *D0190. Family Feeling Anxious or Worried*, which Abt introduced in earlier phases of testing.

The Abt team conducted an accelerated data element development process, consistent with the CMS Blueprint, to develop the new psychosocial data elements for beta testing. The beta test data elements aligned with concepts central to patient-centered hospice care provided by SWs, including mood, anxiety, safety, and patient and caregiver psychosocial needs. These data elements are completed by the SW based on their comprehensive assessment, using multiple assessment strategies such as observation and clinical judgment, and with input from the patient, family, and/or caregiver(s) as applicable. The beta test guidance manual included instructions and strategies for completing each data element.

7.1 Overall SW Form Validity and Feasibility

SW feedback suggested **some content validity but several feasibility challenges** for the SW Admission and Discharge forms. SWs generally indicated that the psychosocial assessment aligned with the domains of their current assessment, though some noted that the questions in their own assessments were more specific. SWs viewed the array of HOPE data elements as thorough but not necessarily appropriate for all patients and families.

SWs reported typically using time during the first visit to have a conversation, build rapport, and develop trust with patients and families before they addressed potentially sensitive topics. SWs noted that current assessments are more organic, allowing SWs to "meet patients where they are at." Some SWs found addressing all the HOPE form topics during their first encounter uncomfortable. They noted that some patients and families are overwhelmed at admission and reluctant to discuss topics such as prognosis and finances.

Several SWs commented on the length of the psychosocial assessment and noted that patients and family caregivers seemed "exhausted" after completing it.

SWs found HOPE data elements difficult to collect when a caregiver was absent, particularly for hospice patients living in facilities. This presented challenges, as the SW is less likely to visit on the first day of admission when many family members are present. This was also noted as an issue for the SW discharge form.

7.2 Administrative Information

As with the RN forms, immediately following the Demographic form, the SW Admission and the SW Discharge forms collect the admission date (*A0220*) or discharge date (*A0270*).

Admission Date (A0220) and Discharge Date (A0270)

Admission and discharge dates are standard administrative items already collected in the HIS. Abt did not test these data elements.

7.3 Mood

This section presents results for the *D0150. Patient Mood Interview (PHQ-2)*, *D0160. Total Severity Score*, *D0180. Patient Feeling Anxious or Worried*, and *D0190. Family Feeling Anxious or Worried*.

CMS's post-acute care quality reporting programs include *D0150. Patient Mood Interview (PHQ-2)* and *D0160. Total Severity Score*. Abt included these data elements in beta testing to evaluate their performance in the hospice setting.

D0180. Patient Feeling Anxious or Worried, and *D0190. Family Feeling Anxious or Worried* identified whether the patient was feeling anxious or worried about their illness or treatment and if the family/caregivers were feeling anxious or worried about the patient. These data elements asked the SW to consider patient and family feelings over the past three days, rather than on the day of the assessment.

All of the mood data elements were collected at admission only.

7.3.1 Patient Mood Interview (PHQ-2) (D0150) and *Total Severity Score (D0160)*

This section presents results for the *D0150. Patient Mood Interview (PHQ-2)* and *D0160. Total Severity Score*. *D0150* reflects Patient Health Questionnaire-2 (PHQ-2), which is an established screening tool to identify the signs and symptoms of mood distress. Pfizer, Inc. holds the copyright for all PHQ screeners and has granted CMS permission to use and slightly modify this instrument for cross-setting use in the post-acute data collection instruments.

D0150 identifies the presence of signs and symptoms of mood distress, while *D0160* provides a depression severity score using response information from *D0150*.

Two versions of a depression screener were evaluated in HOPE pilot and alpha testing. Hospice staff preferred the PHQ-2 because it includes questions about frequency of symptoms, so it was retained, unmodified, for Beta HOPE.

These data elements were collected only at admission.

Validity

Qualitative data suggested some **content validity challenges**. SWs questioned the validity of this item for the hospice population, noting that standardized responses felt forced and interrupted the flow of the assessment. One SW commented that this data element was the only aspect of the HOPE that did not feel "seamless" with their typical assessment, as it was the only item requiring patient self-report.

Descriptive statistics suggest face validity. SWs indicated that more than a quarter of patients experienced little interest or pleasure in doing things (34 percent), or reported feeling down, depressed, or hopeless (29.2 percent). Of patients who experienced these symptoms, SWs most frequently indicated patients experiencing them nearly every day. See Exhibit 7-1.

D0150 symptom frequency responses were coded as a number to facilitate calculation of the *D0160. Total Severity Score*. The numbers ranged from 0 to 3, with symptoms experienced with less frequency receiving a lower number. Total severity scores of 3 or higher are considered indicative of major depression, and further assessment and diagnosis are required.[xiv] Among the 98 unique patients experiencing at least one of the symptoms, 60 (61.3 percent) scored three or higher. See Exhibit 7-2.

Exhibit 7-1. *D0150. Patient Mood Interview (PHQ-2)*

Say to patient: "Over the last 2 weeks, have you been bothered by any of the following problems?" If yes, then ask the patient: "About how often have you been bothered by this?" Read and show the patient a card with the symptom frequency choices.		
A. Little interest or pleasure in doing things 1. Symptom Presence	Number	Percent
No	106	41.9%
Yes	86	34%
No response	54	21.3%
Missing	7	2.8%

Total	253	100%
2. Symptom frequency – about how often have you been bothered by this?		
Never or 1 day	5	5.8%
2–6 days (several days)	21	24.4%
7–11 days (half or more of days)	14	16.3%
12–14 days (nearly every day)	45	52.3%
Missing	1	1.2%
Total	86	100%
B. Feeling down, depressed, or hopeless 1. Symptom presence	Number	Percent
No	116	45.8%
Yes	74	29.2%
No response	56	22.1%
Missing	7	2.8%
Total	253	100%
2. Symptom frequency – About how often have you been bothered by this?[1]		
Never or 1 day	4	5.4%
2–6 days (several days)	24	32.4%
7–11 days (half or more of days)	19	25.7%
12–14 days (nearly every day)	26	35.1%
Missing	1	1.4%
Total	74	100%

Only patients indicated as *Yes* to symptom present were asked about symptom frequency.
Source: Assessor-initiated Beta Test HOPE SW Admission forms.

Exhibit 7-2. *D0160. Total Severity Score*

Add scores for all frequency responses, Symptom Frequency. Total score must be between 0 and 6.		
	Number	Percent
0	6	6.1%
1	15	15.3%
2	17	17.3%
3	20	20.4%
4	8	8.2%
5	9	9.2%
6	23	23.5%
Total	98	100%

A total severity score was calculated only for patients who reported at least one of the two symptoms asked about in the PHQ-2 (see data element D0150).
Source: Assessor-initiated Beta Test HOPE SW Admission forms.

Feasibility

D0150. Patient Mood Interview (PHQ-2) had low rates of missing data, suggesting **no feasibility challenges**. Both symptom presence questions had missingness rates of 2.8 percent, and the frequency questions have missingness rates of 1.2 percent (little interest or pleasure in doing things) and 1.4 percent (feeling down, depressed, or hopeless). See Appendix D for additional information.

Missingness data was not calculated for *D0160. Total Severity Score* as it is a calculated field.

Reliability

For *D0150. Patient Mood Interview (PHQ-2)*, kappa statistics indicated **very good rater agreement** for the feeling down, depressed or hopeless questions (0.83 for symptom presence and 0.82 for symptom frequency). Kappa statistics indicated **good rater agreement** for the little interest or pleasure in doing things question (0.76 for symptom presence and 0.78 for symptom frequency). See Appendix E for additional information.

A Kappa statistic is not presented for *D0160. Total Severity Score*, as it is a calculated field.

7.3.2 Patient Feeling Anxious or Worried (*D0180*) and Family Feeling Anxious or Worried (*D0190*)

Abt adapted the anxiety-related data elements (*D0180, D0190*), with permission, from the IPOS, a valid and reliable clinical assessment tool.[xv] These data elements aim to measure patient anxiety and family/caregiver anxiety about the patient. Based on alpha testing feedback, Abt added additional response categories for both data elements: *Patient Unable to Respond* to the patient feeling anxious data element (*D0180*), and *Not Applicable* to the family feeling anxious data element (*D0190*).

Validity

Descriptive statistics suggest face validity. SWs indicated that 34 percent of patients were not feeling anxious or worried at all, with 11.5 percent of patients feeling anxious or worried most of the time. For family, RNs indicated that 24.5 percent of caregivers were not feeling anxious or worried about the patient at all, while 16.6 percent were indicated as feeling anxious or worried about the patient most of the time. See Exhibit 7-3 and Exhibit 7-4.

Exhibit 7-3. *D0180. Patient Feeling Anxious or Worried*

Over the past three days, and based on your assessment, has the patient been feeling anxious or worried about his/her illness or treatment?		
	Number	Percent
Not at all	86	34%
Occasionally	44	17.4%
Sometimes	44	17.4%
Most of the time	29	11.5%
Always	3	1.2%
Not applicable (cannot assess, e.g., unconscious)	40	15.8%
Missing	7	2.8%
Total	253	100%

Source: Assessor-initiated Beta Test HOPE SW Admission forms.

Exhibit 7-4. *D0190. Family Feeling Anxious or Worried*

Over the past three days, and based on your assessment, how often has the family felt anxious or worried about the patient?		
	Number	Percent
Not at all	62	24.5%
Occasionally	50	19.8%
Sometimes	48	19.%
Most of the time	42	16.6%
Always	21	8.3%
Not applicable	24	9.5%
Missing	6	2.4%
Total	253	100%

Source: Assessor-initiated Beta Test HOPE SW Admission forms.

Feasibility

Both data elements had missingness rates of less than 3 percent, suggesting **no feasibility challenges.** Missingness rates were 2.8 percent for the patient-focused data element and 2.4 percent for the family/caregiver focused data element.

Hospice staff asked how to identify which family member/caregiver to assess for the data element family/caregiver anxious or worried, or, whether to consider the family as a group. Abt clarified the intent of the data element (i.e., to identify the family's anxiety or worry for all family engaged with the patient), which helped to reduce hospice staff confusion around this data element.

Reliability

Kappa statistics indicated **good rater agreement** for patient feeling anxious or worried (0.67), and **moderate rater agreement** for the family/caregivers data element (0.52).

7.4 Patient and Family Needs

This section presents results for *Q1200. Patient and Caregiver Resource Needs*, *JJ0100. Patient Care Needs*, and *JJ0110. Patient Safety*. This also presents results for identified psychosocial needs: *JJ0120. Financial Resources*, *JJ0130. Social Support*, *JJ0140. Cultural Values*, *JJ01050. Awareness of Prognosis*, and *JJ0160. Coping Related to Anticipatory Grief*.

7.4.1 Patient and Caregiver Resource Needs (Q1200)

Q1200 is the SW version of the Patient and Caregiver Resource Needs data element collected as part of the RN Admission form (*Q1100*). The intent of the data element was to identify patient and family/caregiver needs to inform care planning and it is collected at admission only.

As with *Q1100*, the data element identified both resource needs and, if a need was identified, whether a referral to meet those needs was made or declined. Resource needs identified at prior assessments, for which referrals were already completed, were not included in this data element.

This data element was introduced in alpha testing, and no major changes were made for the beta test.

Validity

Descriptive statistics suggest face validity. RNs most commonly identified needs for SW support (70 percent), chaplain and/or spiritual counselor support (57.7 percent), and connect to community resources (29 percent). For patients and caregivers for whom those needs were identified, referrals were typically made (91.5 percent for SW support, 90.4 percent for chaplain and/or spiritual counselor support, and 86.5 percent for connection to community resources). Overall, patients and caregivers received referrals for identified needs. See Exhibit 7-5.

Exhibit 7-5. *Q1200. Patient and Caregiver Resource Needs (Social Worker Assessment)*

At the time of this assessment, does the patient and/or caregiver (including family and non-family) have any of the following resource needs?		
1. Code who needs resources	Number	Percent
A. Mental health counseling		
Patient	9	3.6%
Caregiver	8	3.2%
Both	3	1.2%
No resource needs	217	85.8%
Not applicable (e.g., patient unconscious or caregiver not available)	9	3.6%
Missing	7	2.8%
Total	253	100%
B. Social worker support		
Patient	33	13%
Caregiver	31	12.3%
Both	113	44.7%
No resource needs	67	26.5%
Not applicable (e.g., patient unconscious or caregiver not available)	3	1.2%
Missing	6	2.4%

At the time of this assessment, does the patient and/or caregiver (including family and non-family) have any of the following resource needs?		
Total	253	100%
C. Chaplain and/or spiritual counselor support		
Patient	45	17.8%
Caregiver	12	4.7%
Both	89	35.2%
No resource needs	95	37.5%
Not applicable (e.g., patient unconscious or caregiver not available)	4	1.6%
Missing	8	3.2%
Total	253	100%
D. Cultural support		
Patient	1	0.4%
Caregiver	1	0.4%
Both	3	1.2%
No resource needs	236	93.3%
Not applicable (e.g., patient unconscious or caregiver not available)	5	2%
Missing	7	2.8%
Total	253	100%
E. Financial		
Patient	7	2.8%
Caregiver	7	2.8%
Both	7	2.8%
No resource needs	219	86.6%
Not applicable (e.g., patient unconscious or caregiver not available)	6	2.4%
Missing	7	2.8%
Total	253	100%
F. Connection to community resources		
Patient	21	8.3%
Caregiver	9	3.6%
Both	22	8.7%
No resource needs	190	75.1%
Not applicable (e.g., patient unconscious or caregiver not available)	4	1.6%
Missing	7	2.8%
Total	253	100%
G. Transportation		
Patient	5	2%
Caregiver	1	0.4%
Both	3	1.2%
No resource needs	230	90.9%
Not applicable (e.g., patient unconscious or caregiver not available)	7	2.8%
Missing	7	2.8%
Total	253	100%
H. Other		
Patient	3	1.2%
Caregiver	1	0.4%
Both	3	1.2%
No resource needs	198	78.3%
Not applicable (e.g., patient unconscious or caregiver not available)	11	4.3%
Missing	37	14.6%
Total	253	100%
2. Code if a referral was made or declined (if resources needed)	Number	Percent
A. Mental health counseling		

At the time of this assessment, does the patient and/or caregiver (including family and non-family) have any of the following resource needs?		
Yes, a referral was made	10	50%
No, a referral was declined	8	40%
Missing	2	10%
Total	20	100%
B. Social worker support		
Yes, a referral was made	162	91.5%
No, a referral was declined	7	4%
Missing	8	4.5%
Total	177	100%
C. Chaplain and/or spiritual counselor support		
Yes, a referral was made	132	90.4%
No, a referral was declined	8	5.5%
Missing	6	4.1%
Total	146	100%
D. Cultural support		
Yes, a referral was made	3	60%
No, a referral was declined	2	40%
Missing	0	0%
Total	5	100%
E. Financial		
Yes, a referral was made	19	90.5%
No, a referral was declined	2	9.5%
Missing	0	0%
Total	21	100%
F. Connected to community resources		
Yes, a referral was made	45	86.5%
No, a referral was declined	7	13.5%
Missing	0	0%
Total	52	100%
G. Transportation		
Yes, a referral was made	6	66.7%
No, a referral was declined	3	33.3%
Missing	0	0%
Total	9	100%
H. Other		
Yes, a referral was made	7	100%
No, a referral was declined	0	0%
Missing	0	0%
Total	7	100%

Source: Assessor-initiated Beta Test HOPE SW Admission forms.

Feasibility

Most components of these data elements do not suggest feasibility challenges, but use of an *Other* component does. Almost all components in *Q1200. Patient and Caregiver Resource Needs* had missingness rates of less than 5 percent. Referral for mental health counseling had a missingness rate of exactly 10 percent. The *Other* component in the identification of need section had a notably higher missingness rate of 14.6 percent. See Appendix D for additional data.

Qualitative data suggests feasibility challenges. SWs expressed confusion over the need for social work support, and need for chaplain/spiritual care support, stating these are already part of core hospice services. Abt clarified that the SW should indicate these needs if the service would continue with the patient past the initial visit and should indicate a referral was made if the service was added to the plan of care. These data elements require instructions, and guidance modification (or elimination of these needs from the data element) is required to ensure they measure what is intended for social work and chaplain/spiritual care support needs. Additionally, some SWs indicated thinking they should skip the data element if no resource needs were identified.

Reliability[12]

Kappa statistics indicated that **eight components had moderate rater agreement**: mental health counseling, transportation, cultural support, and financial resource needs (0.48 to 0.57) and transportation, financial, mental health counseling, and cultural support referrals (0.44 to 0.56).

Kappa statistics indicated that **six components had good rater agreement:** SW support, chaplain and/or spiritual counselor, and connection to community resources for both identification of the resource need and whether the referral was provided (0.68 to 0.75).

Kappa statistics indicated that **poor rater agreement for the *Other* component** for both resource need and whether a referral was provided (-0.01 for both). A negative kappa value indicates consistent disagreement among assessors compared to consistent agreement in a positive kappa value.

See Appendix E for additional information.

7.4.2 Patient Care Needs (JJ0100) and *Patient Safety (JJ0110)*

JJ0100. Patient Care Needs identified how often the patient's needs for care such as activities of daily living, instrumental activities of daily living, treatments in the home or facility, and supervision were being met. The intent of *JJ0110. Patient Safety* was to identify how often patient needs associated with safety were being met, such as those related to risk for injury, for example, or falls or other adverse events patients at end of life may experience. SWs collected these data elements at both admission and discharge.

Validity

Descriptive statistics suggest face validity. SWs indicated care needs were met for the majority of patients at both admission and discharge (78.8 percent and 89.5 percent, respectively). Similarly, for patient safety SWs indicated patient safety needs were met for 75.1 percent at admission and 94.7 percent at discharge. See Exhibit 7-6 and Exhibit 7-7.

Exhibit 7-6. *JJ0100. Patient Care Needs*

Based on your assessment, are the patient's needs for care (e.g., ADLs, IADLs, treatments, supervision) being met?				
	Admission		Discharge	
	Number	Percent	Number	Percent
Not at all	0	0%	0	0%
Occasionally	3	1.2%	0	0%
Sometimes	16	6.6%	0	0%
Most of the time	26	10.8%	2	10.5%
All of the time	190	78.8%	17	89.5%
Not assessed	4	1.7%	0	0%
Missing	2	0.8%	0	0%

[12] For analysis, Abt collapsed the categories for patient need identified, caregiver need identified, and patient and caregiver need identified because of relatively small numbers when these were evaluated separately.

Total	241	100%	19	100%

This data element initially had a skip pattern that directed the SW to complete this data element only for patients or caregivers with a complete psychosocial assessment (n=230 at admission and n=19 at discharge; see data element *JJ 0050*). Partway through testing, this skip pattern was no longer applied, making the total assessments for the data elements 241.

Source: Assessor-initiated Beta Test HOPE SW Admission and Discharge forms.

Exhibit 7-7. *JJ0110. Patient Safety*

Based on your assessment, are the patient's needs for safety (e.g., prevention of complications, adverse events, or injuries; overcoming challenges to care; risk mitigation) being met?				
	Admission		Discharge	
	Number	Percent	Number	Percent
Not at all	0	0%	0	0%
Occasionally	2	0.8%	0	0%
Sometimes	14	5.8%	0	0%
Most of the time	38	15.8%	1	5.3%
All of the time	181	75.1%	18	94.7%
Not assessed	3	1.2%	0	0%
Missing	3	1.2%	0	0%
Total	241	100%	19	100%

This data element initially had a skip pattern that directed the SW to complete this data element only for patients or caregivers with a complete psychosocial assessment (n=230 at admission and n=19 at discharge; see data element JJ0050). Partway through testing, this skip pattern was no longer applied, making the total assessments for the data elements 241.

Source: Assessor-initiated Beta Test HOPE SW Admission and Discharge forms.

Feasibility

Missingness rates were very low for these data elements, suggesting **no feasibility challenges**. The proportion missing at admission for care needs was 0.8 percent, and for safety needs was 1.2 percent. These data elements were not missing any data at discharge. Hospice SWs did not identify any feasibility issues for these data elements.

Reliability

Kappa statistics indicated **good rater agreement** for both data elements (0.65 for both).

7.4.3 Financial Resources (JJ0120), Social Support (JJ0130), and *Cultural Values (JJ0140)*

JJ0120. Financial Resources evaluates whether and how often financial resource needs of both the patient and the caregiver are being met. Similarly, *JJ0130. Social Support* identifies the frequency with which the patient and family/caregiver needs for social support are being met. The intent of *JJ0140. Cultural Values* is for the SW to determine, based on their assessment, whether the patient and their family/caregiver are experiencing congruence between the care they receive and their cultural values (e.g., beliefs, customs). These were new data elements developed for beta testing and collected at admission and discharge.

Validity

One SW noted **potential challenge with content validity**. The SW noted that she does not routinely assess financial stability and resources of the caregiver.

Descriptive statistics support face validity. Overall, financial, social support, and cultural needs were met most or all of the time for a majority of patients and family/caregivers (82.6 percent for financial resource needs, 66.4 percent for social support need, and 75.9 percent of the time for cultural values). Few patients or caregivers experienced needs that were not met at all, or only occasionally. No patients and family/caregivers were discharged without these needs being met. Refer to Exhibit 7-8 and Exhibit 7-9.

Exhibit 7-8. *JJ0120. Financial Resources*

Based on your assessment, are the financial resource needs of the patient and caregiver (including family) being met?				
A. Patient needs are being met.	Admission		Discharge	
	Number	Percent	Number	Percent
Not at all	4	1.7%	0	0%
Occasionally	3	1.2%	0	0%
Sometimes	6	2.5%	0	0%
Most of the time	18	7.5%	1	5.3%
All of the time	199	82.6%	17	89.5%
Not assessed	8	3.3%	1	5.3%
Missing	3	1.2%	0	0%
Total	241	100%	19	100%
B. Caregiver needs are being met.	Admission		Discharge	
	Number	Percent	Number	Percent
Not at all	3	1.2%	0	0%
Occasionally	1	0.4%	0	0%
Sometimes	9	3.7%	1	5.3%
Most of the time	41	17%	0	0%
All of the time	154	63.9%	11	57.9%
Not assessed	15	6.2%	2	10.5%
Not applicable (caregiver not available)	15	6.2%	5	26.3%
Missing	3	1.2%	0	0%
Total	241	100%	19	100%

This data element initially had a skip pattern that directed the SW to complete this data element only for patients or caregivers with a complete psychosocial assessment (n=230 at admission and n=19 at discharge; see data element *JJ0050*). Partway through testing, this skip pattern was no longer applied, making the total assessments for the data elements 241.

Source: Assessor-initiated Beta Test HOPE SW Admission and Discharge forms.

Exhibit 7-9. *JJ0130. Social Support*

Based on your assessment, are the patient and caregiver's (including family) needs for social support being met?				
A. Patient needs being met.	Admission		Discharge	
	Number	Percent	Number	Percent
Not at all	2	0.8%	0	0%
Occasionally	4	1.7%	0	0%
Sometimes	11	4.6%	0	0%
Most of the time	54	22.4%	2	10.5%
All of the time	160	66.4%	17	89.5%
Not assessed	6	2.5%	0	0%
Missing	4	1.7%	0	0%
Total	241	100%	19	100%
B. Caregiver needs being met.	Admission		Discharge	
	Number	Percent	Number	Percent
Not at all	2	0.8%	0	0%
Occasionally	3	1.2%	0	0%
Sometimes	13	5.4%	1	5.3%
Most of the time	57	23.7%	1	5.3%
All of the time	138	57.3%	11	57.9%
Not assessed	10	4.1%	2	10.5%
Not applicable (caregiver not available)	16	6.6%	4	21.1%
Missing	2	0.8%	0	0%
Total	241	100%	19	100%

This data element initially had a skip pattern that directed the SW to complete this data element only for patients or caregivers with a complete psychosocial assessment (n=230 at admission and n=19 at discharge; see data element *JJ0050*). Partway through testing, this skip pattern was no longer applied, making the total assessments for the data elements 241.

Based on your assessment, are the patient and caregiver's (including family) needs for social support being met?

Source: Assessor-initiated Beta Test HOPE SW Admission and Discharge forms.

Exhibit 7-10. *JJ0140. Cultural Values*

Based on your assessment, are the patient and caregiver (including family) experiencing congruence between the care and their cultural values (e.g., beliefs, customs)?				
A. Patient experiencing congruence	Admission		Discharge	
	Number	Percent	Number	Percent
Not at all	2	0.8%	0	0%
Occasionally	1	0.4%	0	0%
Sometimes	3	1.2%	0	0%
Most of the time	25	10.4%	0	0%
All of the time	183	75.9%	19	100%
Not assessed	25	10.4%	0	0%
Missing	2	0.8%	0	0%
Total	241	100%	19	100%
B. Caregiver experiencing congruence	Admission		Discharge	
	Number	Percent	Number	Percent
Not at all	1	0.4%	0	0%
Occasionally	1	0.4%	0	0%
Sometimes	1	0.4%	0	0%
Most of the time	32	13.3%	0	0%
All of the time	169	70.1%	14	73.7%
Not assessed	19	7.9%	1	5.3%
Not applicable (caregiver not available)	15	6.2%	4	21.1%
Missing	3	1.2%	0	0%
Total	241	100%	19	100%

This data element initially had a skip pattern that directed the SW to complete this data element only for patients or caregivers with a complete psychosocial assessment (n=230 at admission and n=19 at discharge; see data element *JJ0050*). Partway through testing, this skip pattern was no longer applied, making the total assessments for the data elements 241.

Source: Assessor-initiated Beta Test HOPE SW Admission and Discharge forms.

Feasibility

Missingness rates were lower than 2 percent across all data elements, suggesting **no feasibility challenges**. For *JJ0120. Financial Resources*, missingness rates were 1.2 percent for both patient and caregiver. For *JJ1030. Social Support*, missingness rates were 1.7 percent for the patient and 0.8 percent for the caregiver. For *JJ0140. Cultural Values*, missingness rates were 0.8 percent for the patient and 1.2 percent for the caregiver. See Appendix D for more information.

Qualitative data suggests some feasibility challenges. SWs noted that patients and family caregivers may not be prepared for in-depth conversations during the first visit, such as those including finances. Some SWs asked whether cultural values were expected to be aligned across patient and family/caregivers. Abt clarified there was no expectation of alignment, as individuals may have different values and beliefs.

Reliability

Kappa statistics indicated **good rater agreement for whether caregiver social support needs are being met** (0.64), and **moderate rater agreement for the remainder** of the data element components (0.47 to 0.56). See Appendix E for more information.

7.4.4 Awareness of Prognosis (*JJ0150*) and Coping Related to Anticipatory Grief (*JJ0160*)

SWs collected *JJ0150. Awareness of Prognosis* and *JJ0160. Coping Related to Anticipatory Grief* at admission and discharge for both the patient and the family/caregiver. These were among the new psychosocial data elements developed for beta testing. The intent of *JJ0105* was to identify whether the

patient and family/caregiver were aware of and understood the patient's prognosis. This data element used a yes/no response with an additional *Not Assessed* option. *JJ1060* identified how often the patients' and family/caregivers' coping needs related to anticipatory grief were met.

Validity

Descriptive statistics suggest face validity. SWs indicated that both patients and caregivers were aware of and understood the patient's prognosis at admission (59.8 percent of patients and 89.2 percent of caregivers). Similarly at discharge, 78.9 percent of both patients and caregivers were indicated as aware and understanding of the patient's prognosis. Refer to Exhibit 7-11.

SWs also indicated that, at admission, patients were having their coping needs related to anticipatory grief met most or all of the time (74.3 percent for patients and 81.3 percent for caregivers). These proportions were also high at discharge, with 84.2 percent of patients and 63.2 percent of caregivers having this need met. Refer to Exhibit 7-12.

Exhibit 7-11. *JJ0150. Awareness of Prognosis*

Based on your assessment, are the patient and caregiver (including family and facility staff) aware of the patient's prognosis?				
A. Patient is aware of and understands their prognosis	Admission		Discharge	
	Number	Percent	Number	Percent
No	53	22%	4	21.1%
Yes	144	59.8%	15	78.9%
Not assessed	41	17%	0	0%
Missing	3	1.2%	0	0%
Total	241	100%	19	100%
B. Caregiver is aware of and understands the patient's prognosis	Admission		Discharge	
	Number	Percent	Number	Percent
No	6	2.5%	0	0%
Yes	215	89.2%	15	78.9%
Not assessed	6	2.5%	1	5.3%
Not applicable (caregiver not available)	12	5%	3	15.8%
Missing	2	0.8%	0	0%
Total	241	100%	19	100%

This data element initially had a skip pattern that directed the SW to complete this data element only for patients or caregivers with a complete psychosocial assessment (n=230 at admission and n=19 at discharge; see data element *JJ0050*). Partway through testing, this skip pattern was no longer applied, making the total assessments for the data elements 241.

Source: Assessor-initiated Beta Test HOPE SW Admission and Discharge forms.

Exhibit 7-12. *JJ0160. Coping Related to Anticipatory Grief*

Based on your assessment, are the patient and caregiver's (including family) needs for coping related to anticipatory grief being met?				
A. Patient needs are being met.	Admission		Discharge	
	Number	Percent	Number	Percent
Not at all	1	0.4%	0	0%
Occasionally	1	0.4%	0	0%
Sometimes	22	9.1%	1	5.3%
Most of the time	57	23.7%	1	5.3%
All of the time	122	50.6%	15	78.9%
Not assessed	34	14.1%	2	10.5%
Missing	4	1.7%	0	0%
Total	241	100%	19	100%
B. Caregiver needs are being met.	Admission		Discharge	
	Number	Percent	Number	Percent

Based on your assessment, are the patient and caregiver's (including family) needs for coping related to anticipatory grief being met?				
Not at all	1	0.4%	0	0%
Occasionally	2	0.8%	1	5.3%
Sometimes	17	7.1%	0	0%
Most of the time	73	30.3%	1	5.3%
All of the time	123	51%	11	57.9%
Not assessed	10	4.1%	2	10.5%
Not applicable (caregiver not available)	13	5.4%	4	21.1%
Missing	2	0.8%	0	0%
Total	241	100%	19	100%

This data element initially had a skip pattern that directed the SW to complete this data element only for patients or caregivers with a complete psychosocial assessment (n=230 at admission and n=19 at discharge; see data element *JJ0050*). Partway through testing, this skip pattern was no longer applied, making the total assessments for the data elements 241.

Source: Assessor-initiated Beta Test HOPE SW Admission and Discharge forms.

Feasibility

Missingness rates were very low for awareness of prognosis and coping related to anticipatory grief data elements at SW admission, and there was no missing data for these data elements at discharge, suggesting **no feasibility challenges**. For *JJ0150. Awareness of Prognosis*, the percent with a missing response was 1.2 percent (patient) and 0.8 percent (caregiver). For *JJ0160. Coping Related to Anticipatory Grief*, the percent with a missing response was 1.7 percent (patient) and 0.8 percent (caregiver). See Appendix D for additional information.

Hospice SWs did not identify feasibility challenges for these data elements.

Reliability

Kappa statistics indicated **good rater agreement for the patient-related portions** of the data elements (0.67 for *JJ0150* and 0.61 for *JJ0160*). Kappa statistics indicated **moderate rater agreement for the caregiver-related portions** of the data element (0.45 for *JJ0150* and 0.54 for *JJ0160*). See Appendix E for additional information.

7.5 Psychosocial Needs

This section presents results for *JJ0050. Psychosocial Assessment Completed*, *JJ0180. Identification of Psychosocial Needs*, and *JJ0200. Establish Psychosocial Plan of Care*. The SW collects these data elements at admission only.

7.5.1 Psychosocial Assessment Completed (*JJ0050*)

JJ0050. Psychosocial Assessment Completed indicated whether the SW completed a psychosocial assessment with the patient and/or caregiver(s). Abt included this data element for its possible use in support of a process quality measure. *Yes* was selected when all the psychosocial data elements on the form were completed.

Validity

Descriptive statistics support face validity. SWs indicated that 90.9 percent of patients at admission and 79.2 percent at discharge had a psychosocial assessment completed.

Exhibit 7-13. *JJ0050. Psychosocial Assessment Completed*

At the time of this assessment, is a psychosocial assessment completed with the patient and/or caregiver that addresses psychosocial needs (e.g., care needs, financial needs, social support, cultural values related to end-of- life care)?				
	Admission		Discharge	
	Number	Percent	Number	Percent

No, psychosocial assessment not completed	19	7.5%	5	20.8%
Yes, psychosocial assessment completed	230	90.9%	19	79.2%
Missing	4	1.6%	0	0.0%
Total	253	100%	24	100.0%

This data element initially had a skip pattern that directed the SW to complete this data element only for patients or caregivers with a complete psychosocial assessment (n=230 at admission and n=19 at discharge; see data element *JJ0050*). Partway through testing, this skip pattern was no longer applied, making the total assessments for the data elements 241.

Source: Assessor-initiated Beta Test HOPE SW Admission and Discharge forms.

Feasibility

Missingness rates were low for *JJ0050. Psychosocial Assessment Completed* (1.6 percent), **suggesting no feasibility challenges**. See Appendix D for more information.

Hospice SWs expressed confusion about when to select "yes" for this data element, asking whether a completed psychosocial assessment referred to their comprehensive assessment. Abt clarified that for beta test purposes, the psychosocial assessment was completed when all the SW Admission or Discharge form data elements were completed, not the SW's entire comprehensive assessment.

Reliability

Kappa statistics indicate **moderate rater agreement** (0.59) for *JJ0050. Psychosocial Assessment Completed*. See Appendix E for more information.

7.5.2 Identification of Psychosocial Needs (JJ0180) and *Establish Psychosocial Plan of Care (JJ0200)*

SWs collect *JJ0180. Identification of Psychosocial Need* and *JJ0200. Establish Psychosocial Plan of Care* at admission. *JJ0180* had two components, one for the patient and one for the family/caregiver, while *JJ0200* was a single question that applied to both patient and family/caregiver.

Validity

Descriptive statistics suggest face validity. SWs indicated identifying psychosocial needs for 59.3 percent of patients and 55.6 percent of caregivers. Of those who had identified psychosocial needs, 91.5 percent had a care psychosocial care plan indicated as having been established. See Exhibit 7-14 and Exhibit 7-15.

Exhibit 7-14. *JJ0180. Identification of Psychosocial Needs*

At the time of this assessment, did you identify any psychosocial needs (e.g., care needs, awareness of prognosis, coping strategies, connecting with community resources) for the patient and caregiver (including family)?		
A. Patient	Number	Percent
No, psychosocial needs not identified	95	39.4%
Yes, psychosocial needs identified	143	59.3%
Missing	3	1.2%
Total	241	100%
B. Caregiver	Number	Percent
No, psychosocial needs not identified	85	35.3%
Yes, psychosocial needs identified	134	55.6%
Not applicable (caregiver not available)	19	7.9%
Missing	3	1.2%
Total	241	100%

This data element initially had a skip pattern that directed the SW to complete this data element only for patients or caregivers with a complete psychosocial assessment (n=230 at admission and n=19 at discharge; see data element *JJ0050*). Partway through testing, this skip pattern was no longer applied, making the total assessments for the data elements 241.

Source: Assessor-initiated Beta Test HOPE SW Admission forms.

Exhibit 7-15. *JJ0200. Establish Psychosocial Plan of Care*

If psychosocial needs are identified at the time of this assessment, is there a plan of care to address the identified needs?		
	Number	Percent
No, plan of care addressing psychosocial needs not established	4	2.3%
Yes, plan of care addressing psychosocial needs established	161	91.5%
Not applicable (no psychosocial needs identified at the time of this assessment)	6	3.4%
Missing	5	2.8%
Total	176	100%

SWs completed this data element only for patients or caregivers with an identified psychosocial need. Note that the *JJ0200* total is not equal to the sum of patients and caregivers with identified needs (n=143 and 134, respectively), because those counts are not mutually exclusive (see data element *JJ0180*).

Source: Assessor-initiated Beta Test HOPE SW Admission forms.

Feasibility

Missingness was very low for both data elements, suggesting **no feasibility challenges**. *JJ0180. Identification of Psychosocial Need* had a missingness rate of 1.2 percent for both patient and family/caregiver. *JJ0200. Establish Psychosocial Plan of Care* had a missingness rate of 2.8 percent. See Appendix D for more information.

Hospice SWs identified no feasibility challenges for these data elements.

Reliability

Kappa statistics indicated **moderate rater agreement** for identification of patient psychosocial needs (0.48), identification of family/caregiver psychosocial needs (0.50), and establishment of a psychosocial plan of care (0.57). See Appendix E for more information.

8. Beta Results: Chaplain Forms

Based on the feedback from the pilot and alpha tests, the data elements for the chaplain forms were completely revised for the beta test. Hospice chaplains and spiritual care counselors provided feedback in alpha testing that the chaplain data elements did not reflect their scope of practice.

The Abt team conducted an accelerated data element development process, consistent with the CMS Blueprint, to develop new chaplain data elements for beta testing. The data elements developed for the beta test aligned with concepts central to the patient-centered hospice care the chaplains provided. They include whether the patient is at peace and able to find meaning and joy; and whether the patient and family/caregiver are experiencing spiritual or religious struggles, deriving comfort and strength from faith, or need visits or support from a faith community. The chaplain completes these data elements based on their comprehensive assessment, using multiple assessment strategies such as observation and clinical judgment, and with input from the patient, family, and/or caregiver(s), as applicable. The beta test guidance manual included instructions and strategies for completing each data element.

8.1 Overall Chaplain Form Validity and Feasibility

Chaplain feedback suggested **both content validity and feasibility challenges** for the Chaplain Admission and Discharge forms. Chaplains reported that the Chaplain Admission form did not fit their workflow, as their process with patients and families was grounded in development of a relationship over time that allowed introduction of sensitive topics gently and gradually.

Most chaplains reported that they did not ask standardized questions in their assessment. While most chaplains agreed that the domains addressed in the HOPE spiritual assessment aligned with the content of their current assessments, their own assessments were often more in depth than the questions on the Chaplain Admission and Discharge form. Some chaplains noted that the Chaplain Discharge form was not typically within their scope of work, though one found the form useful. Chaplains in general thought the Chaplain forms did not align well with their usual assessment.

Some chaplains mentioned challenges with the terminology used in the assessment, particularly for patients who do not identify as spiritual or religious. The wording implies a religious world view and many patients don't have a religious world view (e.g., anger may be experienced but not toward a higher power). Although one chaplain stated that the scope was appropriate and provided a springboard to discuss patient strengths, struggles, and support systems, they also remarked that these might not be feasible for patients/families who decline spiritual care. Other comments included that the chaplain data elements were a little invasive, did not adequately reflect the scope of spiritual care, and did not work well with all populations/situations. Improvement suggestions included adding in the term "existential," throughout the form and having a greater focus on hopes, goals, fears, and values.

As with the SW assessors, some chaplains found challenges in completing the spiritual assessment at admission because the first visit is usually more about the patient's and the family/caregiver's emotional response – the topics are "personal" and may require more time to build a rapport. One commented that "chaplaincy is about relationship building … as a patient and caregiver gain trust, over time, they share more."

Chaplains expressed challenges with incorporating all the topics the data elements represent into their first visit. Some reported no issues obtaining the information but noted a lack of clarity in identifying which family/caregivers to include, since one family member may not represent the views of all family members.

Hospices also had challenges identifying enough chaplains to provide both an assessor and an observer for inter-rater reliability testing. Many hospices have few chaplains on staff (one to two), part-time

chaplains, or territory-based chaplains. With the testing period coinciding with the COVID-19 Public Health Emergency pairing chaplains was particularly difficult. These challenges were so significant that the Abt team permitted RNs or SWs to serve as the observer for joint visits with the chaplain as the assessor to ensure enough paired observations for reliability testing.

8.2 Spiritual or Religious Needs

8.2.1 *Patient Response (AA0050), Patient at Peace (AA0010),* and *Meaning and Joy (AA0100)*

AA0050 indicated whether the patient is both able and willing to participate in the assessment. *AA0010* identified the level at which the patient was at peace in the face of their illness, for example, considering whether the patient has had a chance to say goodbye to others, if the patient has unaddressed concerns about dying, or if there is a sense of being unready for death. *AA0110* identified the extent to which the patient was experiencing meaning or joy in their life, in the face of illness, or if the patient expressed despair or hopelessness. Chaplains collected these data elements at admission and discharge.

Validity

Some chaplains suggested **potential content validity challenges**. Two chaplains specifically mentioned the Meaning and Joy data element (*AA0110*), with one noting it was not something they typically assess but that they perceived these questions to be positive additions, as they "opened venues for discussion." Another chaplain suggested that the term "joy" was a difficult word to use for patients who are very sick and suggested the term "meaning and purpose."

Descriptive statistics support face validity. Chaplains indicated that, at admission, 71.2 percent of patients were able to respond, and 91 percent of those patients were willing to participate in the assessment. The proportion of patients indicated as able to respond increased to 88.2 percent at discharge, with 86.7 percent of them indicated as willing to participate in the assessment. Chaplains indicated that most patients were at peace most or all of the time (75.5 percent at admission and 84.6 percent at discharge). Chaplains indicated that most patients experience meaning and joy most or all of the time at both admission and discharge (72.2 percent and 92.3 percent, respectively). See Exhibit 8-1 through Exhibit 8-3.

Exhibit 8-1. *AA0050. Patient Response*

A. At the time of the assessment is the patient able to respond (e.g., patient unresponsive)	Admission		Discharge	
	Number	Percent	Number	Percent
No, the patient is not able to respond (e.g., patient unresponsive).	62	26.6%	1	5.9%
Yes, the patient is able to respond.	166	71.2%	15	88.2%
Not assessed	4	1.7%	1	5.9%
Missing	1	0.4%	0	0%
Total	233	100%	17	100%
B. At the time of the assessment is the patient willing to participate in the spiritual assessment?	Admission		Discharge	
	Number	Percent	Number	Percent
No, the patient is not willing to participate.	10	6%	2	13.3%
Yes, the patient is willing to participate.	151	91%	13	86.7%
Not assessed	3	1.8%	0	0%
Missing	2	1.2%	0	0%
Total	166	100%	15	100%

Source: Assessor-initiated Beta Test HOPE Chaplain Admission and Discharge forms.

Exhibit 8-2. *AA0100. Patient at Peace*

Based on your assessment, is the patient at peace in the face of illness?				
	Admission		Discharge	
	Number	Percent	Number	Percent
Not at all	7	4.6%	0	0%

Based on your assessment, is the patient at peace in the face of illness?				
	Admission		Discharge	
	Number	Percent	Number	Percent
Occasionally	5	3.3%	0	0%
Sometimes	24	15.9%	2	15.4%
Most of the time	60	39.7%	3	23.1%
All of the time	54	35.8%	8	61.5%
Not assessed	1	0.7%	0	0%
Missing	0	0%	0	0%
Total	151	100%	13	100%

Chaplain completed this data element only for patients or caregivers able and willing to participate (n=151 at admission and n=13 at discharge; see data element *AA050.B*).

Source: Assessor-initiated Beta Test HOPE Chaplain Admission and Discharge forms.

Exhibit 8-3. *AA0110. Meaning and Joy*

Based on your assessment, is the patient experiencing meaning and joy in his or her life?				
	Admission		Discharge	
	Number	Percent	Number	Percent
Not at all	8	5.3%	0	0%
Occasionally	12	7.9%	0	0%
Sometimes	21	13.9%	1	7.7%
Most of the time	64	42.4%	4	30.8%
All of the time	45	29.8%	8	61.5%
Not assessed	1	0.7%	0	0%
Missing	0	0%	0	0%
Total	151	100%	13	100%

Chaplain completed this data element only for patients or caregivers able and willing to participate (n=151 at admission and n=13 at discharge; see data element *AA050.B*).

Source: Assessor-initiated Beta Test HOPE Chaplain Admission and Discharge forms.

Feasibility

At admission, the missingness rate was low both for patient able to respond (0.4 percent) and patient willing to participate (1.2 percent) and there was no missing data for patient at peace or meaning and joy. There was also no missing data for these data elements at discharge. This suggests **no feasibility challenges**. See Appendix D for more information.

Reliability

Kappa statistics indicated **good rater agreement** for *AA0010. Patient at Peace* (0.69) and *AA0110. Meaning and Joy* (0.70), and **very good rater agreement** for patient ability and willingness to respond (0.90 and 0.89, respectively). See Appendix E for more information.

8.2.2 Spiritual or Religious Struggles (AA0120), Comfort and Strength (AA0130), and *Visits or Support from Faith Community (AA0140)*

Chaplains collected *AA0102. Spiritual or Religious Struggles*, *AA0130. Comfort and Strength*, and *AA0140. Visits or Support from Faith Community* at admission and discharge. These data elements identified whether the patient and family/caregiver were experiencing spiritual or religious struggles (*AA0120*) and comfort and strength from their faith (*AA0130*), or needed visits or support from their faith community (*AA0140*) always, most of the time, occasionally, sometimes, or not at all. These data elements were collected for the Chaplain Admission and Discharge forms.

Validity

Qualitative data suggests challenges with content validity. Chaplains questioned whether assessing the family/caregiver's experience of spiritual or religious struggles was meaningful or relevant for their

assessment and care plan, suggesting that this data element should focus on the patient only. A few chaplains expressed concern about addressing potentially sensitive topics during the admission visit, without first building a rapport. Some also noted that the terms "spiritual" and "religious" were too direct, sensitive, and potentially invasive and might cause patients to shut down. Overall, the chaplains reported that they typically ask more open-ended questions that are conversational, and for HOPE testing they individualized or reworded terms to focus the discussion based on the patient's perspective and preferences. Additionally, some chaplains noted that the patient was the focus of their assessment for spiritual distress, not the caregiver.

Descriptive statistics support face validity. At admission, chaplains reported most patients and caregivers as not experiencing spiritual or religious struggles at all (58.4 percent and 52.4 percent, respectively). At discharge, this percentage declined to 41.2 percent for patients and 35.3 percent for caregivers. At admission, chaplains indicated that 66.1 percent of patients received comfort and strength from spirituality or religion most or all the time, as did 56.2 percent of caregivers. At discharge, 76.4 percent of patients received comfort and strength from spirituality or religion most or all the time, as did 58.9 percent of caregivers. Chaplains indicated that while most patients wanted support from a faith community at admission (60.9 percent), fewer did so at discharge (41.2 percent). Fewer caregivers than patients were indicated as wanting support from a faith community (49.4 percent at admission and 29.4 percent at discharge). See Exhibit 8-4 through Exhibit 8-6.

Exhibit 8-4. *AA0120. Spiritual or Religious Struggles*

Based on your assessment, do the patient and caregiver (including family) have what might be described as spiritual or religious struggles (e.g., trouble or doubts with spiritual or religious beliefs, anger, or disappointment with a higher power)?				
A. Patient experiencing spiritual or religious struggles	Admission		Discharge	
	Number	Percent	Number	Percent
Not at all	136	58.4%	7	41.2%
Occasionally	31	13.3%	3	17.6%
Sometimes	21	9%	3	17.6%
Most of the time	10	4.3%	0	0%
All of the time	11	4.7%	2	11.8%
Not assessed	23	9.9%	2	11.8%
Missing	1	0.4%	0	0%
Total	233	100%	17	100%
B. Caregiver experiencing spiritual or religious struggles	Admission		Discharge	
	Number	Percent	Number	Percent
Not at all	122	52.4%	6	35.3%
Occasionally	27	11.6%	3	17.6%
Sometimes	23	9.9%	2	11.8%
Most of the time	9	3.9%	0	0%
All of the time	4	1.7%	0	0%
Not assessed	15	6.4%	2	11.8%
Not applicable (caregiver not available)	32	13.7%	4	23.5%
Missing	1	0.4%	0	0%
Total	233	100%	17	100%

Source: Assessor-initiated Beta Test HOPE Chaplain Admission and Discharge forms.

Exhibit 8-5. *AA0130. Comfort and Strength*

Based on your assessment, do the patient and caregiver's (including family) spirituality or religion provide them with comfort and strength?				
A. Patient receives comfort and strength from spirituality or religion.	Admission		Discharge	
	Number	Percent	Number	Percent

Based on your assessment, do the patient and caregiver's (including family) spirituality or religion provide them with comfort and strength?				
Not at all	12	5.2%	0	0%
Occasionally	16	6.9%	1	5.9%
Sometimes	30	12.9%	1	5.9%
Most of the time	59	25.3%	3	17.6%
All of the time	95	40.8%	10	58.8%
Not assessed	20	8.6%	2	11.8%
Missing	1	0.4%	0	0%
Total	233	100%	17	100%
B. Caregiver receives comfort and strength from spirituality or religion	Admission		Discharge	
	Number	Percent	Number	Percent
Not at all	14	6%	0	0%
Occasionally	15	6.4%	0	0%
Sometimes	20	8.6%	1	5.9%
Most of the time	37	15.9%	2	11.8%
All of the time	94	40.3%	8	47.1%
Not assessed	21	9%	2	11.8%
Not applicable (caregiver not available)	31	13.3%	4	23.5%
Missing	1	0.4%	0	0%
Total	233	100%	17	100%

Source: Assessor-initiated Beta Test HOPE Chaplain Admission and Discharge forms.

Exhibit 8-6. *AA0140 Visits* or *Support from Faith Community*

Based on your assessment, do the patient and caregiver (including family) want visits or support from a faith community (i.e., external to the hospice, internal to the hospice, or both)?				
A. Patient wants visits or support from a faith community.	Admission		Discharge	
	Number	Percent	Number	Percent
No	77	33%	8	47.1%
Yes	142	60.9%	7	41.2%
Not assessed	13	5.6%	2	11.8%
Missing	1	0.4%	0	0%
Total	233	100%	17	100%
B. Caregiver wants visits or support from a faith community.	Admission		Discharge	
	Number	Percent	Number	Percent
No	72	30.9%	7	41.2%
Yes	115	49.4%	5	29.4%
Not assessed	18	7.7%	1	5.9%
Not applicable (caregiver not available)	26	11.2%	4	23.5%
Missing	2	0.9%	0	0%
Total	233	100%	17	100%

Source: Assessor-initiated Beta Test HOPE Chaplain Admission and Discharge forms.

Feasibility

Missingness rates were very low for these data elements, suggesting **no feasibility issues**. For *AA0102. Spiritual or Religious Struggles,* the proportion of the missing data element at admission was very low for both patient and family/caregiver (0.4 percent for each). *AA0130. Comfort and Strength* also had a missingness rate at admission of 0.4 percent for each of the patient and caregiver components. *AA0140. Visits or Support from Faith Community* had a missingness rate at admission of 0.4 percent for patients, and 0.9 percent for caregivers. There was no missing data for the discharge data elements. See Appendix D for more information.

Qualitative data suggest limited feasibility issues. Hospice staff asked multiple questions about how to assess the caregiver's experience of spiritual or religious struggles, wondering whether the intent was to capture the caregiver's concerns separate from those of the patient.

Reliability

For *AA0102. Spiritual or Religious Struggles* kappa statistics indicated **moderate rater agreement** for the patient-related portion (0.52) and **fair rater agreement** for the caregiver portion (0.31). Kappa statistics for all of the other data elements had **good rater agreement** (0.61 to 0.64).

8.2.3 Identification of Spiritual or Religious Needs (AA0150) and *Establish Spiritual Plan of Care (AA0200)*

At the conclusion of the Chaplain Admission form, chaplains completed *AA0150. Identification or Spiritual and Religious Needs* and *AA0200. Establish Spiritual Plan of Care*. *AA01050* identified any spiritual or religious needs for the patient or the caregiver and *AA0200* identified whether a spiritual plan of care had been established. These data elements were not collected at discharge.

Validity

Descriptive statistics support face validity. Chaplains indicated they identified spiritual or religious needs for approximately half of patients and caregivers (56.7 percent and 46.4 percent, respectively). Of the 203 patients and care givers for which a spiritual plan of care was indicated (i.e., the response was neither *Not Applicable* nor missing) patients with a need identified, 85 percent had a plan of care established.

Exhibit 8-7. *AA0150. Identification of Spiritual or Religious Needs*

At the time of this assessment, did you identify any spiritual or religious needs for the patient and caregiver (including family)?		
A. Patient's needs identified	Number	Percent
No, spiritual or religious needs not identified	96	41.2%
Yes, spiritual, or religious needs identified	132	56.7%
Missing	5	2.2%
Total	233	100%
B. Caregiver's needs identified	Number	Percent
No, spiritual or religious needs not identified	85	36.5%
Yes, spiritual, or religious needs identified	108	46.4%
Not applicable (caregiver not available)	38	16.3%
Missing	2	0.9%
Total	233	100%

Source: Assessor-initiated Beta Test HOPE Chaplain Admission forms.

Exhibit 8-8. *AA0200. Establish Spiritual Plan of Care*

If spiritual or religious needs are identified at the time of this assessment, is there a plan of care to address the identified needs?		
	Number	Percent
No, plan of care addressing spiritual or religious needs not established	30	12.9%
Yes, plan of care addressing spiritual or religious needs established	173	74.2%
Not applicable (no spiritual or religious needs identified at the time of this assessment)	27	11.6%
Missing	3	1.3%
Total	233	100%

Source: Assessor-initiated Beta Test HOPE Chaplain Admission forms.

Feasibility

Missingness rates were low for these data elements, suggesting **no feasibility challenges**. The proportion missing for patient spiritual or religious needs was 2.2 percent, and 0.9 percent for family/caregiver. The

proportion missing for plan of care established was 1.3 percent. See Appendix D for additional information.

Like the questions SWs asked about the psychosocial needs identified and plan of care established data elements, chaplains asked whether the identification of needs in data element *AA0150* was intended to capture their complete assessment or only the HOPE data elements, which were a subset of their comprehensive assessment. They also wanted to know whether the response to plan of care established was based only on the HOPE data elements, and what constituted an acceptable plan of care for the purposes of that data element.

Reliability

Kappa statistics indicated **moderate rater agreement** for *AA0150. Identification or Spiritual and Religious Needs* (0.58 for patient and 0.43 for caregiver) and *AA0200. Establish Spiritual Plan of Care* (0.46). See Appendix E for additional information.

9. Discussion

The goal of HOPE development and testing was to produce a standardized clinical assessment tool yielding high-quality, meaningful, and relevant data that CMS, hospice providers, and patients and families can use with confidence. Potential HOPE data uses include quality measure development, including measures that may be publicly reported as part of the HQRP to support patient and family choice of a hospice provider. HOPE was designed to reflect the traditional multidisciplinary approach to hospice care and HOPE content areas were aligned with the CAHPS® Hospice Survey (e.g., help with pain symptoms, emotional and spiritual support, etc.). However, HOPE assess these facets of care in real time, throughout the hospice stay, and as such, collecting standardized and ongoing patient data during a patient stay supports patient- and hospice-level decisions about care provided, informs adjustments in practice, and drives quality improvement activities. HOPE data may also support potential future updates to the hospice payment model, among other purposes. Following HOPE development and testing, CMS expects to propose HOPE in rulemaking for national implementation in Medicare-certified hospices.

Throughout all phases of development and testing, concluding with beta testing as documented in this report, CMS and Abt considered factors that would support ease of use and successful implementation for HOPE, including:

- The multidisciplinary approach used in hospice settings (e.g., HOPE included data elements for completion by a multidisciplinary team including RNs, SWs, and chaplains) where the patient and family are the unit of care, and where the patient's status is expected to decline.
- Core concepts of hospice care, including symptom management and relief of suffering.
- Typical hospice length of stay patterns, where a substantial proportion of patients have a short length of stay in hospice, while others may be long-stay patients.
- Alignment with the hospice workflow and Medicare hospice Conditions of Participation.
- Existing CMS post-acute care standardized data elements that may be relevant and meaningful in the hospice setting.
- Timepoints for each data element needed to support development of outcome-focused quality measures and assessment of patient outcomes, suggesting at least two data collection timepoints are needed for outcome data elements. Including data elements at other timepoints could support potential risk adjustment of outcome quality measures.

Abt gained insights about implications for HOPE implementation through successive phases of development and testing, working intensively with participating hospice staff. To the extent possible, testing sought to gain insight into the hospice workflow and the training and support needed by the RNs, SWs, and chaplains to accurately complete their data elements. Additionally, testing sought to identify and resolve issues related to HOPE as a whole and its integration into hospice staff workflow, as well as individual HOPE data elements.

9.1 HOPE and Hospice Workflow

Beta test findings suggest potential areas of needed guidance and support to facilitate successful national implementation of HOPE data collection. For example, guidance for hospice staff should emphasize that HOPE is to be completed as part of their usual comprehensive assessment of the patient, not as a separate activity or an extended verbatim interview with the patient or caregiver. In addition, a consistent approach to using and defining terminology may reduce hospice staff confusion about which family member or caregiver is the intended focus for data elements that rely on family/caregiver input and/or assess the caregiver.

With support and guidance from Abt during beta testing to clarify these and other issues, most hospice staff were able to successfully integrate HOPE into their comprehensive assessment workflow, though SWs and chaplains reported more challenges than did RNs. While both SWs and chaplains found that most topics covered in HOPE were within their scope, they said that their initial visits and conversations are generally more organic and are focused on relationship building and gathering information while providing support to often overwhelmed patients and families. Some described challenges with obtaining information from caregivers when they may not be present during their visits.

Some SW and chaplain participants found some HOPE topics intrusive, and noted specific challenges with data elements with standardized responses that variously interrupted the flow of discussion, were related to potentially invasive topics such as finances, or were spiritual questions that were too direct or focused on "religion," especially for their hospice patients and families that "don't have a religious world view." This feedback highlights the challenges social workers and spiritual care providers encounter when trying to use standardized tools and data elements, suggesting these disciplines need data collection tools that can adapt the needs and preferences of each individual hospice patient or caregiver.

9.2 HOPE Data Elements

The HOPE beta test successfully tested 64 data elements, and where applicable, their individual components (e.g., a single data element may require a response for a patient component and a caregiver component) for potential inclusion in HOPE. Testing assessed validity, feasibility, and reliability, demonstrating that:

- Across all disciplines, many of the data elements aligned with the scope and content generally collected by hospice staff during their current assessment processes. However, assessor feedback received during and after the beta test indicated that some elements exhibited potential content validity challenges – for example, because of terminology used, construction of the item, and, in some cases, conflicts with the discipline's typical approach to information gathering during hospice assessment visits.
- Few data elements or components had missingness rates above 10 percent, and hospice staff did not generally note substantial feasibility challenges. The highest rates of missingness (15 to 32 percent) were found for the *Other* response option for three check-all-that-apply data elements, where hospice staff mistakenly thought the option did not apply if other response options were selected.
- Nearly all data elements and their components (96 percent; n=163) had at least moderate rater agreement (i.e., a Kappa statistic greater than 0.40). Eighty-two percent of data elements for RNs had good to very good rater agreement, with lower percentages among SW data elements (42 percent) and chaplain data elements (62 percent).

Overall, more than 90 percent of data elements evaluated in the beta test, including cross-setting items (i.e., those used in other post-acute care QRPs), were found to be reliable, valid, and feasible. Adjusting guidance and training, data element design, and skip patterns will likely improve usability for the minority of data elements that presented challenges to hospice staff in the beta test.

9.3 Potential HOPE-Based Quality Measures

Several specific RN data elements were developed and prioritized by CMS and Abt as data elements that could potentially support future outcome-focused HQRP quality measures:

- *J2050. Symptom Impact*
- *J2060. Patient Desired Tolerance Level for Symptoms*

- *J2070. Patient Preferences for Symptom Management*
- *J2080. Follow-Up Symptom Control*
- *J0915. Neuropathic Pain*
- *J1410. Death is Imminent*

At admission, RNs documented pain impact as moderate or severe in more than 40 percent of instances. Non-pain symptoms were similarly coded in 6 to 36 percent of instances, with shortness of breath, anxiety, and agitation most often reported at the *Moderate* or *Severe* levels. These rates suggest that a quality measure focusing on instances of moderate or severe symptom impact would yield high reportability. While beta testing did not require forms to be completed for the same patient at different time points, there was little difference in percentage of patients for whom the RN indicated *Moderate* to *Severe* pain impact at admission relative to symptom reassessment (44% vs 42%)[13]. This suggests a symptom management measure would be far from "topped-out." In other words, there is room for improvement among hospices in lowering symptom impact.

Throughout HOPE development, federal stakeholders, the technical expert panel, and hospice staff have expressed that acknowledging and considering patient preferences is important for symptom management. This input drove the development of *J2060. Patient Desired Tolerance Level* and *J2070. Patient Preferences for Symptom Management*, and analyses of how these data elements interact with *J2050. Symptom Impact*. The beta test results indicated a desired symptom tolerance level of "None" or "Slight" for most patients on admission, including those reporting a higher actual level of pain, and that patients continued to highly prioritize pain reduction on reassessment. Although it is not certain how CMS may integrate these data elements into a future quality measure, the patterns underscore that preferences are meaningful to patients, and future quality efforts could further consider this information to better ensure care that respects the dignity and wishes of those being treated.

In addition to a variety of other physical assessment items, the RNs tested new data elements that included *Neuropathic Pain* (*J0915*). Neuropathic pain is a specific pain type that develops when the nervous system is damaged due to disease or injury, and requires medication be administered more slowly and over more days than medication used for other types of pain.[xvi] Those experiencing neuropathic pain often do not have it formally documented as a diagnosis, and evidence of its prevalence in the hospice population is limited at best. Collecting a data element like *J0915* could both inform prevalence estimates in the hospice setting and allow for quality measure concepts that explicitly consider neuropathic pain as distinct from other types of pain.

RNs also tested *Death is Imminent (J1410)* and *Signs of Imminent Death (J1420*) to identify those who may be actively dying. These were tested for their potential to trigger a skip pattern that would allow nurses to complete only a subset of HOPE for actively dying patients, reducing assessor burden. While nurses found *J1410* straightforward to complete, some had questions about *J1420*, since some of the data elements signs and symptoms can actually occur much earlier in illness trajectory. Just as data collection approaches should vary for those who are actively dying, so too might expected patient outcomes. Including data elements that consider whether a patient is actively dying can inform future potential measure concepts.

[13] These percentages reflect the total number of patients for whom RNs indicated pain impact as *Moderate* or *Severe* out of the number of assessments in which the data element was not indicated as *Not Applicable* or missing. See Exhibit 6-18.

HOPE test results will inform continued development and specification of quality measures in both symptom management and other domains. Any quality measures eventually proposed in rulemaking for incorporation into the HQRP may use HOPE, claims, or a combination of both as the data source.

9.4 Conclusions

Beta test findings will inform CMS in implementing data elements that are appropriate for hospice patients and the HQRP in HOPE version 1.0. The addition of assessment-based data elements in the future will align hospice with other patient care settings and assist CMS in differentiating hospices while improving the overall quality of hospice services. While some data elements outperformed others, the results of the beta test provide a firm basis for an initial implementation version of HOPE.

Appendix A: HOPE Development and Testing Details

This appendix provides further details on methods and findings from HOPE development and testing phases conducted prior to beta testing, beginning in 2019 with information gathering activities that supported development of the first draft of HOPE, followed by cognitive, pilot, and alpha testing to support further HOPE data element refinement, culminating in development of Beta HOPE.

Information Gathering

Beginning in 2019, Abt conducted multiple information gathering activities to support the development of the HOPE tool.[xvii,xviii,xix,xx] The team obtained input via:

- Listening sessions with multiple hospice experts and stakeholders, including provider associations, federal staff, subject matter experts and caregivers. The Abt team solicited their input on a draft list of hospice care domains, the proposed timing of data collection and general considerations around hospice quality measurement.
- Review of relevant clinical practice guidelines, legislation and regulations related to hospice care.
- Environmental scans of existing items, instruments, scales, and tools to measure hospice quality.
- Literature reviews of the published and grey literature on validated, reliable, and applicable measures, instruments and/or tools used in a post-acute care setting.
- Interviews with experts and other key informants about what comprises quality hospice care and how to measure it.
- Focus groups with hospice staff to obtain their feedback on key hospice care domains, specific data elements, frequency of data collection, and interoperability.
- Surveys of hospice providers and electronic health record vendors to understand the tools they use.

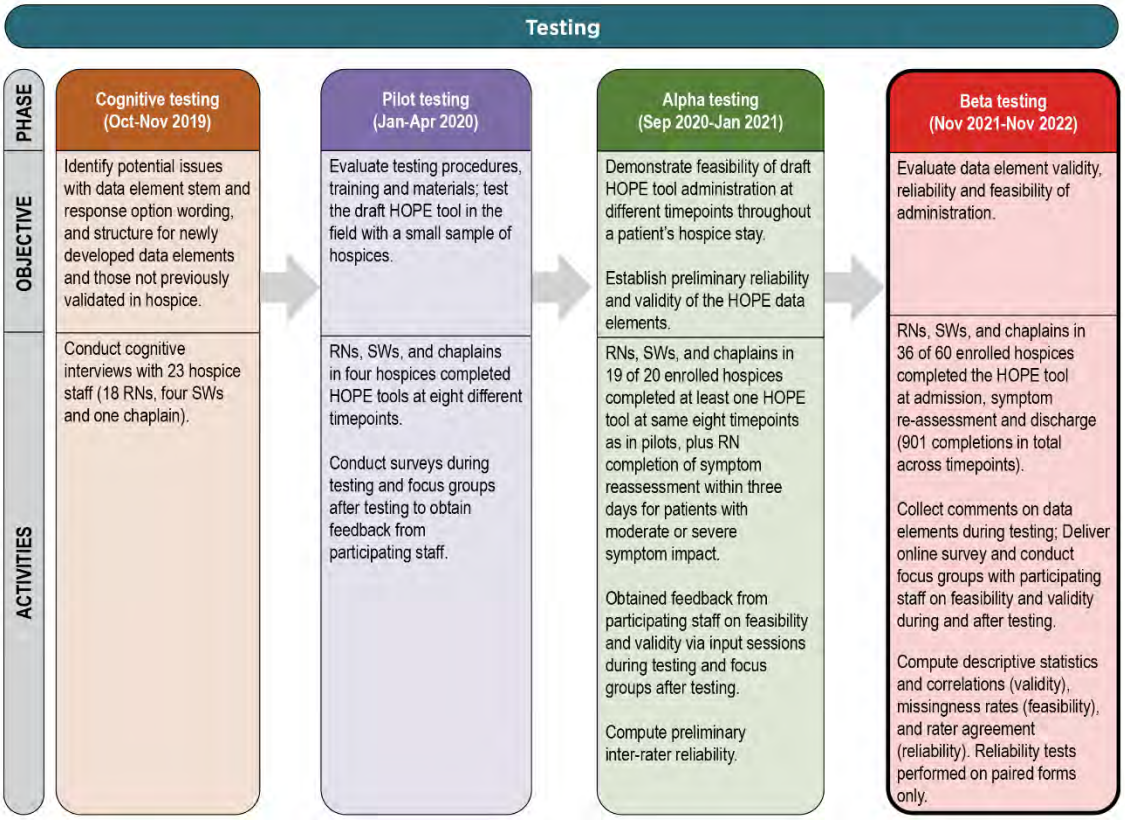
Additionally, Abt convened a Technical Expert Panel to provide input on hospice quality measurement concepts. Engagement between Abt and the panel continued throughout the development process.[xxi,xxii,xxiii]

These information gathering activities informed the identification of relevant care domains for hospice quality. From this foundation, Abt reviewed existing data elements in each domain for any inclusion in HOPE either directly or in a modified form. When existing data elements did not capture the desired domain or concept, Abt developed *de novo* data elements. Input from Dr. Irene Higginson and Dr. Mevhibe Hocaoglu supported Abt's development of data elements based on the Integrated Palliative Outcome Scale (IPOS).[xxiv] These modified IPOS data elements reflected symptom impact on patients' day-to-day activities, anxiety, feeling depressed and feeling at peace. Abt developed *de novo* data elements to assess patients' preferences for symptom management, desired tolerance level for symptoms, follow-up symptom impact, neuropathic pain, emergency room use, psychosocial care needs, spiritual needs and whether death is imminent (i.e., likely to occur within three days). The resulting existing, modified, and *de novo* data elements comprised the first draft of the HOPE tool.

HOPE Testing

The Abt team developed and tested HOPE in an overlapping and iterative process, during which stakeholder input and testing results were integrated into successive drafts. Abt completed four phases of HOPE development and testing from late 2019 through 2022: cognitive, pilot, alpha and beta. Results of each phase of testing informed the content and design of the following phase. Exhibit A-1 provides an overview of testing objectives and activities for each phase of HOPE testing.

Exhibit A-1. HOPE Testing Objectives and Activities by Phase



Notes: RN – registered nurse; SW – social worker.

The remainder of this section provides additional details on methods and findings for each testing phase.

Cognitive Testing

Cognitive testing evaluated hospice staff's understanding of a subset of the draft HOPE data elements and identified potential issues with stem and response option wording and data element structure. Hospice staff participated in cognitive interviews in October and November 2019.

Participants

Abt maintained a database of all hospice providers interested in HOPE development activities. Any provider not selected for one activity was eligible to participate in future opportunities. Abt reviewed eligible providers in the database and identified a purposive convenience sample of potential interviewees (n=38), including hospice registered nurses (RNs), social workers (SWs) and chaplains (from a mix of nonprofit, for-profit, rural, and urban hospices. Twenty-three hospice staff (18 RNs, 4 SWs and 1 chaplain) participated in cognitive interviews.

Methods

For cognitive testing, Abt selected data elements that were newly developed, adapted from other sources, and/or not previously validated in hospice settings. Cognitive interviews gathered feedback from hospice staff on their comprehension of the data elements. The interview guide also addressed and incorporated

issues raised during data element and guidance manual development. Respondents were asked to think of a current or past patient and to respond to the interviewer's questions with that patient in mind, considering the process by which they would complete the data element for that patient. Question topics included:

- Comprehension and interpretation of data element stem and response options to highlight any respondent confusion or questions about the data element and guidance manual section.
- Understanding of specific terms used in the data elements and guidance sections.
- Learning about how the respondent's hospice agency might use information collected by the data element.
- Identification of which sources of information the respondent would need to complete the data element.
- Understanding of respondents' thought processes about completing the items.

Using a verbal probing approach,[xxv] Abt conducted cognitive interviews in two phases (i.e., Round 1 and Round 2) to allow for data elements and guidance revision between rounds. Based on respondent feedback in Round 1 and prior to Round 2 interviews, the team revised four data elements and the guidance for six data elements.

Results

Respondents described their process of considering data elements with a patient in mind. Respondents also detailed how they would draw from sources such as discussion with the patient and caregiver, observation of the patient and the setting, and review of the patient's medical record to complete the data elements. Respondents were generally positive about the data elements' standardization and intent. Respondents had some questions about the guidance manual instructions for some data elements, such as the use of specific terms or phrases. Results from cognitive testing informed HOPE tool revisions for the pilot test.

Pilot Testing

The pilot test evaluated the draft HOPE tool and tested the procedures, training and materials with a small sample of hospices in preparation for the larger alpha and beta tests. The pilot test version of HOPE was one document (i.e., tool) with sections for the RN, SW, and chaplain to complete. Pilot testing occurred from January 2020 through April 2020.

Participants

To identify potential hospices, Abt reviewed an internal database of providers that had expressed interest in participating in HOPE development and asked for professional organizations recommendations. Four hospices enrolled and participated in the pilot test. Each hospice identified a staff person to act as a liaison, the primary point of contact with the Abt team. The liaisons identified hospice staff to participate in the pilot test, and organized and tracked the HOPE tools completed at their hospice.

Methods

Abt trained hospice RNs, SWs, and chaplains to identify eligible patients, obtain verbal consent, and complete the HOPE tool. Patients 18 and older who could speak and understand English were eligible to participate. A family caregiver or other authorized representative could provide verbal consent on behalf of patients unable to respond due to their condition. Patient eligibility criteria and consent processes remained the same throughout testing. Abt provided training using a combination of self-study modules and live webinars (Exhibit A-2). Each hospice started data collection as soon as they completed training.

Exhibit A-2. Pilot Test Training Topics

- Pilot test purpose and requirements
- Testing and data collection procedures
- Data security, privacy, and confidentiality
- Obtaining verbal consent
- HOPE data element training and practice scenarios

Abt asked hospice staff to complete HOPE data collection during regular patient visits at multiple timepoints: admission, symptom reassessment, interdisciplinary group (IDG) reassessment, level of care change, recertification, and discharge (Exhibit A-3). The Abt team asked each hospice to complete four HOPE tools at each timepoint. To evaluate the process required to produce data for inter-rater reliability calculations, Abt asked the hospice staff to conduct joint visits for two of the four HOPE sections completed at each timepoint. For joint visits, two hospice staff visited the patient at the same time and completed HOPE independently. The Abt team instructed RNs to visit the patient first and enroll the patient in the pilot test, obtain verbal consent and complete the RN section of HOPE. The SWs and chaplains visited after the RN and completed their sections of HOPE.

Exhibit A-3. Pilot Test HOPE Tool Timepoints

Timepoint	Description	Disciplines Completing a HOPE Tool Section at Each Timepoint
Admission	At the patient's admission to hospice.	All
Interdisciplinary Group	Every 14 days while the patient continues to receive hospice care, starting 14 days after the first IDG meeting.	All
Level of Care Change	When the patient transitions to a higher level of care.	All
Recertification	At the patient's recertification for hospice.	All
Symptom Reassessment	Within 3 days following any HOPE timepoint (except discharge) where *J2050. Symptom Impact* was rated moderate or severe for any one or more of the symptoms assessed; *or J0900C. Pain Severity* was rated moderate or severe.	RN
Unplanned Discharge	When the patient is discharged from hospice alive, and the patient is not available for the RN and SW to visit to complete an in-person assessment.	RN, SW
Planned Discharge	When the patient is discharged from hospice alive and is available for the RN and SW to visit to complete an in-person assessment.	RN, SW
Expired	When the patient is discharged due to death.	RN

Note: IDG –Interdisciplinary Group; RN – registered nurse; SW – social worker

During the pilot test, and while HOPE data collection was ongoing, Abt administered four online surveys to collect hospice staff feedback on the enrollment process for hospices, the training and resources provided, the data collection procedures, and the HOPE tool, respectively. After hospice's HOPE data collection was completed, they each participated in a focus group discussion of the HOPE tool, the

timepoints for HOPE administration, and the data collection process including alignment with existing workflows.

Results

The online surveys and focus groups identified several strengths in the pilot test procedures as well as areas for improvement. The enrollment process, training, and the ability of sites to incorporate HOPE into their workflow stood out as strengths. Hospice leadership reported it was relatively easy for them to identify a liaison from their staff. Hospice liaisons and leadership reported that the information they received during the enrollment process was sufficient to make participation decisions. These participants also noted that Abt provided clarification and additional information when needed to support their decision about participation in testing.

Respondents reported the training modules and resources were helpful overall. After completing the training, hospice staff were confident that they could identify eligible patients and complete the HOPE tool, keep pilot test information confidential and secure, and report adverse events, if one occurred. Similarly, liaisons reported feeling prepared to support the hospice sites in reporting adverse events, keeping pilot test information confidential and secure, identifying eligible hospice patients, obtaining patient/caregiver agreement to participate, and scheduling and tracking patient assessments.

Hospice staff stated that HOPE fit into their existing workflow. The planned discharge, death at discharge, change in level of care and IDG assessments were all described as "routine workflow" for RNs. Hospice staff described the IDG timepoint as "the most consistent with routine assessments," as its frequency aligned with the IDG care plan review frequency Medicare requires in their hospice Conditions of Participation. Medicare-certified hospice providers must meet the Conditions of Participation to receive Medicare reimbursement for care provided to Medicare beneficiaries.

Areas for improvement identified included clarification of training and resources related to conducting joint visits for inter-rater reliability, multidisciplinary scheduling, training for liaisons and revisions for some items. All sites expressed difficulty scheduling and completing the joint visits for inter-rater reliability, and few completed joint visits during the pilot test. Hospice staff recommended developing discipline-specific self-study online modules for RNs, SWs, and chaplains. Additionally, participants recommended that Abt provide a live demonstration of the web-based data collection tool, a walkthrough of a clinical scenario, and websites with tips to facilitate joint visits and visits made by each of the disciplines. Liaisons recommended that Abt provide additional training to hospice staff who would act as liaisons in future testing, including interactive training to verify comprehension. Liaisons suggested that any HOPE-related resources be disseminated to the liaisons before sharing with the hospice staff, to help them prepare to answer questions and provide support to their staff.

Hospice staff recommended reducing redundancy between data elements in the pilot test's *Health Conditions* and *Spirituality* sections. They also suggested clarity and wording revisions to improve the patient's comfort with being asked questions. The hospice staff also recommended highlighting whether the RN, SW or chaplain should complete each data element across the various timepoints.

Based on the pilot test results, Abt revised some HOPE data elements and the guidance manual for the alpha test version of HOPE.

Alpha Testing

The alpha test evaluated preliminary reliability and validity of the alpha test version of data elements, and the feasibility of administering HOPE at different timepoints throughout a patient's hospice stay. The alpha test version of HOPE was one document with three sections, one each for the RN, the SW, and the chaplain. Alpha test data collection started October 5, 2020, and ended January 29, 2021.

Participants

CMS and Abt announced recruitment of Medicare-certified hospice providers for participation in the alpha test beginning in December 2019, and concluded outreach and recruitment following an informational webinar in March 2020. CMS disseminated the recruitment announcement broadly via email to interested parties, listservs, newsletters and posting to CMS websites. Abt invited interested providers to complete a short online survey with their contact information.

Abt selected Medicare-certified hospices from the pool of applicants, prioritizing variation in geographic region (i.e., Midwest, Northeast, South, and West), urbanicity (i.e., serving only urban areas, serving only rural areas, and serving both), ownership (i.e., for-profit and nonprofit) and service location (i.e., patient's homes, nursing homes, skilled nursing facilities, assisted living facilities, and inpatient hospitals). To determine the minimum sample size needed, Abt conducted power analyses for the inter-rater reliability measure, which estimated how many observations are needed to be confident in the results. Abt calculated that 20 hospices of medium-to-large size would enable the collection of sufficient data to conduct preliminary reliability analyses. For this reason, hospices were excluded from sampling if they were very small, specifically if they reported fewer than 10 average weekly referrals or had fewer than 200 hospice admissions in FY 2019 Medicare claims data. Abt re-sampled replacement hospices for any sampled hospice that declined to participate to maintain variation across the characteristics of interest to the extent possible.

Abt enrolled 20 hospices for alpha testing, and 19 of these completed at least one HOPE tool. Each hospice identified one or two staff members to serve as the liaison at their hospice, to manage data collection at their site and to communicate and coordinate with the Abt team. In the first month following hospice enrollment, the liaisons participated in a planning and preparation webinar. This webinar addressed equipment needs, the use of telehealth, and the training and data collection requirements.

Abt provided approximately 16 hours of required training to the hospice staff in September 2020. Training included: an introduction to the alpha test; a description of Abt and hospice staff roles and responsibilities; and review of procedures and requirements, including web-based data collection, data management and security; and individual data element and scenario-based training for HOPE completion. Abt assigned team members to each participating hospice site to serve as the hospice's primary point of contact, answer questions and support the hospice's progress with data collection. Abt also provided regular, structured guidance to hospice staff throughout the alpha test via virtual weekly or biweekly office hours for questions and answers, reinforcement and clarification of procedures and data element guidance, and weekly or biweekly e-newsletters with updates and frequently asked questions.

After training, participating RNs, SWs, and chaplains completed their HOPE sections with a convenience sample of consenting patients and caregivers. Abt asked hospice staff to complete HOPE data collection at the same timepoints introduced in the pilot test (Exhibit A-3): admission, IDG assessment, level of care change, recertification, and discharge. RNs also completed a symptom reassessment within 3 days for patients with moderate or severe symptom impact.

Methods

Alpha HOPE included data elements that reflected the patient's health status, symptom management and advance care planning preferences, and psychosocial, spiritual, and nursing care needs (Exhibit A-4). In addition, refining data elements and related guidance based on pilot test results, CMS and Abt, in collaboration with the Office of Minority Health, reviewed social determinants of health data elements and determined which would be included in the alpha test. The data elements include *Ethnicity, Race, Language* (preferred language and need for interpreter), *Sex* (also known as sex assigned at birth), *Sexual Orientation* and two versions of gender (self-reported *Gender Identity*).

Exhibit A-4. The Alpha Test Version of the HOPE Tool with Nurse, Social Work, and Chaplain Sections

HOPE Tool Sections	Data Elements
Nurse Section	• Diagnoses • Symptom Assessment (screening, severity, impact) • Patient Preferences for Symptom Management • Medication Management • Skin Conditions • Self-care and Mobility • Living Arrangements and Availability of Assistance • Education and Training; Resource Needs • Falls • Transfer of Health Information
Social Work Section	• Ethnicity, Race, Language • Sex, Sexual Orientation, Gender Identity • Resource Needs • Depression Screening • Patient and Family Anxiety/Worry
Chaplain Section	• Religion/Spirituality/Faith is Challenged • Evidence of Unmet Spiritual Need • Identification of Practical Problems

Abt analyzed alpha test data to evaluate the feasibility of each timepoint; assess data element reliability and validity; and assess feasibility of administration. To determine whether items could be completed with acceptable reliability, the team calculated the level of agreement between data element responses of hospice staff conducting a joint visit to the same patient.

During testing, Abt obtained preliminary hospice staff feedback about HOPE and the alpha test through input sessions, and near the end of data collection conducted focus groups for additional hospice staff feedback. The input sessions focused on the overall content and scope of HOPE and the integration of RN, SW, and chaplain sections. Additional topics included workflow processes, timepoints for HOPE completion and hospice staff perspectives about future implementation. The focus groups gathered specific hospice staff feedback about their experiences completing HOPE with patients and families/caregivers and the integration of the data elements into their clinical workflow. The focus group also assessed how hospice staff perceived the feasibility of completing the data elements.

Results

Abt's analysis of hospice staff feedback, missing data and convergent validity of data elements measuring similar constructs supported data element validity and feasibility at multiple timepoints during a patient's hospice stay. Data element rater agreement ranged from moderate to very good. The magnitude of agreement was determined by conventional criteria, in that kappa values of 0.41 to 0.60 were considered moderate agreement and everything above that was considered good or very good agreement.[xxvi]

Hospice staff strongly supported a multidisciplinary assessment and reported that HOPE was generally well received by patients and family/caregivers. RNs considered the information captured by the data elements relevant for hospice and provided strong consensus feedback that HOPE's scope and content aligned with their current practices, including the symptoms they typically assess. SWs and chaplains provided strong consensus feedback that their HOPE sections were too brief and did not sufficiently reflect their scope of practice.

The hospice staff supported HOPE completed by RNs, SWs, and chaplains at the admission and recertification timepoints. They recommended a brief RN reassessment instead of a SW or chaplain reassessment at the IDG timepoint. Hospice staff suggested that only RNs reassess when the patient's

status change required transition to a higher level of care. For the alpha test, most data elements were completed at discharge to evaluate their usefulness at this timepoint. Some hospice staff supported assessment of patient status when the patient was discharged alive from hospice, to provide up-to-date information to the next provider, but others did not feel this was necessary and recommended a brief RN discharge section or form only.

Results highlighted priority data elements for next draft HOPE draft tool, drew attention to data elements that needed revision or reformatting to improve their usability, and pointed to the need for further development of the psychosocial and spiritual tools. Findings from the alpha test informed revisions to HOPE and the guidance manual prior to the beta test.

Appendix B: Beta HOPE Forms

Beta testing included seven distinct data collection forms: three for registered nurses (RNs) (RN Admission, RN Symptom Reassessment and RN Discharge); two for social workers (SWs) (SW Admission and SW Discharge); and two for chaplains (Chaplain Admission and Chaplain Discharge).

Beta test participants completed these forms in the Research Electronic Data Capture (REDCap®), application, an electronic data collection tool; therefore, there may be some minor variation in the PDFs presented here and the electronic version of the tool.

For the SW and Chaplain disciplines, this appendix includes only the SW and Chaplain Admission forms. HOPE data elements are the same at admission and discharge, except for needs identified and plan of care established, which are collected at admission only.

Some data elements were revised during the beta test. This appendix includes the most recent version of the beta test HOPE forms.

Beta HOPE RN Admission Form

RN ADMISSION	
Patient study identifier (system generated, pre-populated)	Date of birth (MM/DD/YYYY)
	Gender (M/F)
Assessment date and time started (system generated)	Discipline completing assessment (RN, SW, CH)

Administrative Information

Date Assessment was Started

We need to know the day and time you started your assessment with the patient (not the day and time you started documentation or data entry):

Month Day Year

HH : MM AM/PM

A0220. Admission Date

Month Day Year

A0205. Site of Service at Admission

Enter Code

01. Hospice provided in patient's home/residence
02. Hospice provided in Assisted Living Facility
03. Hospice provided in Nursing Long Term Care (LTC) or Non-skilled Nursing Facility (NF)
04. Hospice provided in a Skilled Nursing Facility (SNF)
05. Hospice provided in Inpatient Hospital
06. Hospice provided in Inpatient Hospice Facility
07. Hospice provided in Long Term Care Hospital (LTCH)
08. Hospice provided in Inpatient Psychiatric Facility
09. Hospice provided in place not otherwise specified (NOS)
10. Hospice home care provided in a hospice facility

A1005. Ethnicity
Are you of Hispanic, Latino/a, or Spanish origin?

↓	**Check all that apply**
	A. No, not of Hispanic, Latino/a, or Spanish origin
	B. Yes, Mexican, Mexican American, Chicano/a
	C. Yes, Puerto Rican
	D. Yes, Cuban
	E. Yes, Another Hispanic, Latino, or Spanish origin
	X. Patient unable to respond

A1010. Race
What is your race?

↓	**Check all that apply**
	A. White
	B. Black or African American
	C. American Indian or Alaska Native

Hospice Outcomes and Patient Evaluation (HOPE) RN Admission Form.
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	D. Asian Indian
	E. Chinese
	F. Filipino
	G. Japanese
	H. Korean
	I. Vietnamese
	J. Other Asian
	K. Native Hawaiian
	L. Guamanian or Chamorro
	M. Samoan
	N. Other Pacific Islander
	X. Patient Unable to Respond
A1110. Language	
	A. What is your preferred language? **B. Do you need or want an interpreter to communicate with a doctor or healthcare staff?** 01. No 02. Yes 09. Unable to determine
J1410. Death is Imminent	
Enter Code	At the time of this assessment and based on your assessment, does the patient appear to have a life expectancy of 3 days or less? 00. No – Skip to F0900. Living Arrangements 01. Yes – Continue to J1420. Signs of Imminent Death
J1420. Signs of Imminent Death	
↓	**Check all that apply at the time of this assessment**
	A. Cheyne-Stokes respirations
	B. Apnea
	C. Pulselessness of radial artery
	D. Peripheral cyanosis
	E. Decreased urine output
	F. Terminal respiratory secretions (death rattle)
	G. Respiration with mandibular movement
	H. Non-reactive pupils
	I. Decreased response to verbal stimuli
	J. Drooping of nasolabial fold

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	K. Low oxygen saturation
	L. New dysphagia of liquids
	M. Decrease in blood pressure
	N. None of the above
Preferences for Customary Routine and Activities	
F0900. Living Arrangements	
Enter Code	Based on your assessment, identify the patient's living arrangement at the time of this assessment. 01. Person lives alone- no other residents in the home 02. Person lives with others in the home (e.g., family, friends, or paid caregiver) 03. Person lives in congregate home (e.g., assisted living or residential care home) 04. Person is in an inpatient facility (e.g., skilled nursing facility, nursing home, inpatient hospice, hospital) 05. Person does not have a permanent home or is homeless
F0915. Availability of Assistance	
Enter Code	Based on your assessment, code the level of in-person assistance from available and willing caregiver(s), excluding hospice staff, at the time of the assessment. 01. No assistance available 02. Occasional short-term assistance (with infrequent exceptions) 03. Regular nighttime (all night every night with infrequent exceptions) 04. Regular daytime (all day every day with infrequent exceptions) 05. Around-the-clock (24 hours a day with infrequent exceptions)
F1000. Advance Care Planning Preferences	
↓	**Check all that apply at the time of this assessment** Identify the patient's preferences for the following based upon the discussion with the patient and/or caregiver.
	A. Do not attempt chest compressions
	B. Do not intubate
	C. Do not hospitalize unless for the patient's comfort
	D. None of the above
	X. Not discussed
Functional Abilities and Goals	
GG0130. Self-Care	
Code the patient's usual performance at Admission foreach activity using the 6-point scale· If activity was not attempted at Admission, code the reason.	

Coding:
Safety and Quality of Performance – If helper assistance is required because patient's performance is unsafe or of poor quality, score according to amount of assistance provided.
Activities may be completed with or without assistive devices.

06. Independent – Patient completes the activity by him/herself with no assistance from a helper.
05. Setup or clean-up assistance – Helper sets up or cleans up; patient completes activity. Helper assists only prior to or following the activity.
04. Supervision or touching assistance – Helper provides verbal cues and/or touching/steadying and/or contact guard assistance as patient completes activity. Assistance may be provided throughout the activity or intermittently.
03. Partial/moderate assistance – Helper does LESS THAN Half the effort. Helper lifts, holds or supports trunk or limbs, but provides less than half the effort.
02. Substantial/maximal assistance – Helper does MORE THAN HALF the effort. Helper lifts or holds trunk or limbs and provides more than half the effort.
01. Dependent – Helper does ALL of the effort. Patient does none of the effort to complete the activity. Or, the assistance of 2 or more helpers is required for the patient to complete the activity.

If activity was not attempted, code reason:

07. Patient refused.
09. Not applicable – Not attempted and the patient did not perform this activity prior to the current illness, exacerbation or injury.
10. Not attempted due to environmental limitations (e.g., lack of equipment, weather constraints).
88. Not attempted due to medical conditions or safety concerns.

↓	Enter Codes in Boxes
	A. Eating: The ability to use suitable utensils to bring food and/or liquid to the mouth and swallow food and/or liquid once the meal is placed before the patient.
	B. Oral Hygiene: The ability to use suitable items to clean teeth. Dentures (if applicable): The ability to insert and remove dentures into and from mouth and manage denture soaking and rinsing with use of equipment.
	C. Toileting Hygiene: The ability to maintain perineal hygiene, adjust clothes before and after voiding or having a bowel movement. If managing an ostomy, include wiping the opening but not managing equipment.
	D. Shower/bathe self: The ability to bathe self, including washing, rinsing, and drying self (excludes washing of back and hair). Does not include transferring in/out of tub/shower.

GG0170. Mobility

Code the patient's usual performance for each activity at Admission using the 6-point scale. If activity was not attempted at Admission, code the reason.

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Coding:
Safety and Quality of Performance – If helper assistance is required because patient's performance is unsafe or of poor quality, score according to amount of assistance provided.
Activities may be completed with or without assistive devices.

06 Independent – Patient completes the activity by him/herself with no assistance from a helper.
05. Setup or clean-up assistance – Helper sets up or cleans up; patient completes activity. Helper assists only prior to or following the activity.
04. Supervision or touching assistance – Helper provides verbal cues and/or touching/steadying and/or contact guard assistance as patient completes activity. Assistance may be provided throughout the activity or intermittently.
03. Partial/moderate assistance – Helper does LESS THAN HALF the effort. Helper lifts, holds or supports trunk or limbs, but provides less than half the effort.
02. Substantial/maximal assistance – Helper does MORE THAN HALF the effort. Helper lifts or holds trunk or limbs and provides more than half the effort.
01. Dependent – Helper does ALL of the effort. Patient does none of the effort to complete the activity. Or the assistance of 2 or more helpers is required for the patient to complete the activity.

If activity was not attempted, code reason:

07. Patient refused.
09. Not applicable – Not attempted and the patient did not perform this activity prior to the current illness, exacerbation or injury.
10. Not attempted due to environmental limitations (e.g., lack of equipment, weather constraints).
88. Not attempted due to medical conditions or safety concerns.

↓	Enter Codes in Boxes
	A. Roll left and right: The ability to roll from lying on back to left and right side and return to lying on back on the bed.
	D. Sit to stand: The ability to come to a standing position from sitting in a chair, wheelchair, or on the side of the bed.
	E. Chair/bed-to-chair transfer: The ability to transfer to and from a bed to a chair (or wheelchair).
	F. Toilet transfer: The ability to get on and off a toilet or commode.
	I. Walk 10 feet: Once standing, the ability to walk at least 10 feet in a room, corridor, or similar space.

Active Diagnoses

I0030. Primary Medical Condition Category

Enter Code	Indicate the patient's primary medical condition category.
	01. Cancer 02. Heart Failure 03. Cardiovascular (excluding heart failure) 04. Liver Disease 05. Renal Disease 06. Stroke 07. Dementia (including Alzheimer's disease) 08. Neurological Condition (e.g., Parkinson's disease, multiple sclerosis, amyotrophic lateral sclerosis (ALS)) 09. Chronic Obstructive Pulmonary Disease (COPD) 10. Other Medical Condition

I0050. Comorbidities and Co-existing Conditions

↓	Check all that apply
	Cancer
	I0100. Cancer

	Heart/Circulation
	I0600. Heart Failure (e.g., congestive heart failure (CHF) and pulmonary edema)
	I0900. Peripheral Vascular Disease (PVD) or Peripheral Arterial Disease (PAD)
	I0950. Cardiovascular (excluding heart failure)
	Gastrointestinal
	I1101. Liver disease (e.g., cirrhosis)
	Genitourinary
	I1510. Renal disease
	Infections
	I2102. Sepsis
	Metabolic
	I2900. Diabetes Mellitus (DM)
	I2910. Neuropathy
	Neurological
	I4501. Stroke
	I4801. Dementia (including Alzheimer's disease)
	I5150. Neurological Conditions (e.g., Parkinson's disease, multiple sclerosis, ALS)
	I5401. Seizure Disorder
	Pulmonary
	I6202. Chronic Obstructive Pulmonary Disease (COPD)
	Other
	I8005. Other Medical Conditions

Health Conditions	
J0900. Pain Screening	
Enter Code	A. Was the patient screened for pain? 00. No — Skip to J0905. Pain Active Problem 01. Yes
Enter Code	C. The patient's pain severity was: 00. None 01. Mild 02. Moderate 03. Severe 08. Not assessed
J0905. Pain Active Problem	
Is pain an active problem for the patient?	
Enter Code	00. No 01. Yes

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J0915. Neuropathic Pain	
Does the patient have neuropathic pain? (e.g., pain with burning, tingling, pins and needles, hypersensitivity to touch)	
Enter Code	00. No 01. Yes

J2050. Symptom Impact

Over the past 2 days, how has the patient been affected by each of the following symptoms? Base this on your clinical assessment (including input from patient and/or caregiver). Symptoms may impact multiple patient activities including, but not limited to, sleep, concentration, day to day activities, or ability to interact with others.

01. Not at all – symptom does not affect the patient, including symptoms well-controlled with current treatment
02. Slight
03. Moderate
04. Severe
09. Not applicable (the patient is not experiencing the symptom)

	Enter Code ↓
A. Pain	
B. Shortness of breath	
C. Anxiety	
D. Nausea	
E. Vomiting	
F. Diarrhea	
G. Constipation	
H. Agitation	

J2060. Patient Desired Tolerance Level for Symptoms

At the time of the assessment, what is the patient's desired tolerance level for each of the following symptoms? Base this on your clinical assessment (including input from patient and/or caregiver).

Coding:

01. None – patient prefers not to experience the symptom at all
02. Slight
03. Moderate
04. High
10. Not applicable (the patient is not experiencing the symptom)

	Enter code ↓
A. Pain	
B. Shortness of breath	
C. Anxiety	
D. Nausea	
E. Vomiting	
F. Diarrhea	
G. Constipation	

H. Agitation	

J2070. Patient Preferences for Symptom Management

At the time of the assessment, does the patient prioritize reduction in their symptoms, even with potential treatment side-effects or inconvenience? Base this on your clinical assessment (including input from patient and/or caregiver).
Coding:

00. No
01. Yes
09. Not applicable (the patient is not experiencing the symptom)

	Enter code ↓
A. Pain	
B. Shortness of breath	
C. Anxiety	
D. Nausea	
E. Vomiting	
F. Diarrhea	
G. Constipation	
H. Agitation	

Patient and Family Needs

Q1000. Patient and Caregiver Education and Training

At the time of this assessment does the patient and/or caregiver(s) (family and non-family) need education or training to meet the needs of the patient?

	Column 1: Code who needs education and training 01. Patient 02. Caregiver 03. Both 04. No education or training needs 0.9. Not applicable (e.g., patient unconscious or caregiver not available)	Column 2: Code if education and training was initiated at this visit or ongoing from a prior visit. 05. Yes 06. No
Education and Training Needs	**1. Enter code**	**2. Enter code**
A. Communication (e.g., hospice contact information, when to contact hospice)		
B. Basic caregiving skills (e.g., feeding, bathing, repositioning, changing an occupied bed)		
C. Wound care		
D. Mouth and/or oral care		
E. Infection control (e.g., wound care, handwashing, universal precautions)		

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F. Equipment use and management (e.g., oxygen tanks, nebulizer, feeding pump, mechanical lift, patient-controlled analgesia pumps)		
G. Medication Management		
H. Symptom Management (current and anticipated)		
I. Signs and symptoms of patient decline		
J. Other		

Q1100. Patient and Caregiver Resource Needs (Nurse Assessment)

At the time of this assessment does the patient and/or caregiver (including family and non-family) have any of the following re- source needs?

	Column 1: Code who needs resources 01. Patient 02. Caregiver 03. Both 04. No resource needs 09. Not applicable (e.g., patient unconscious or caregiver not available)	Column 2: Code if a referral was made or declined. 01. Yes, request made 02. No, service declined
Resource Needs	**1. Enter code**	**2. Enter code**
A. Volunteer support		
B. Aide support		
C. DME and/or medical equipment		
D. Inpatient respite care		
E. General inpatient care or continuous homecare		
F. Other		

JJ0010. Chaplain/Spiritual Care Offered

Enter Code	At the time of this assessment, were hospice chaplain/spiritual care services offered to the patient and/or caregiver (family caregiver and non-family caregiver)?
	01. Yes, offered and accepted — hospice chaplain/spiritual care services were offered and accepted 02. Yes, offered but declined as active with non-hospice spiritual care services — chaplain/spiritual care services were offered from the hospice, but declined due to receiving non-hospice services 03. Yes, offered and declined—hospice chaplain/spiritual care services were offered but declined 04. No, not offered — hospice chaplain/spiritual care services were not offered 05. Currently active with hospice chaplain/spiritual care— chaplain/spiritual care is currently an active service with the hospice 09. Not assessed

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JJ0015. Social Work Offered	
Enter Code	At the time of this assessment, were hospice social work services offered to the patient and/or caregiver (family caregiver and non-family caregiver)? 06. Yes, offered and accepted — hospice social work services were offered and accepted 07. Yes, offered but declined as active with non-hospice social services — social work services were offered from the hospice, but declined due to receiving non-hospice services 08. Yes, offered and declined— hospice social work services were offered but declined 09. No, not offered — hospice social work services were not offered 10. Currently active with hospice social services — social work is currently an active service with the hospice 11. Not assessed
Skin Conditions	
M0210. Unhealed Pressure Ulcers/Injuries	
Enter Code	Does this patient have one or more unhealed pressure ulcers/injuries? 00. No — Skip to M1085. Other Skin Conditions. 01. Yes
M0300. Current Number of Unhealed Pressure Ulcers/Injuries at Each Stage	
Enter Number	**A. Stage 1:** Intact skin with non-blanchable redness of a localized area usually over a bony prominence. Darkly pigmented skin may not have a visible blanching; in dark skin tones only it may appear with persistent blue or purple hues **1. Number of Stage 1 pressure injuries**
Enter Number	**B. Stage 2:** Partial thickness loss of dermis presenting as a shallow open ulcer with a red or pink wound bed, without slough. May also present as an intact or open/ruptured blister. **1. Number of Stage 2 pressure ulcers**
Enter Number	**C. Stage 3:** Full thickness tissue loss. Subcutaneous fat may be visible but bone, tendon, or muscle is not exposed. Slough may be present but does not obscure the depth of tissue loss. May include undermining and tunneling. **1. Number of Stage 3 pressure ulcers**
Enter Number	**D. Stage 4:** Full thickness tissue loss with exposed bone, tendon, or muscle. Slough or eschar may be present on some parts of the wound bed. Often includes undermining and tunneling. **1. Number of Stage 4 pressure ulcers**
Enter Number	**E. Unstageable:** Non-removable dressing/device: Known but not stageable due to non-removable dressing/ device. **1. Number of unstageable pressure ulcers/injuries due to non-removable dressing/device**
Enter Number	**F. Unstageable: Slough and/or eschar:** Known but not stageable due to coverage of wound bed by slough and/or eschar. **1. Number of unstageable pressure ulcers due to coverage of wound bed by slough and/or eschar**
Enter Number	**G. Unstageable: Deep tissue injury** **1. Number of unstageable pressure injuries presenting as deep tissue injury**

M1085. Other Skin Conditions	
At the time of this assessment, the patient has which of the following other skin conditions?	**Check all that apply**
A. Surgical Wound	
B. Ulcers other than Pressure Ulcers/Injuries (e.g., Kennedy ulcer, venous stasis ulcer, arterial ulcer, diabetic ulcer)	

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C. Other Skin Conditions (e.g., rash, skin tear)	
D. None of the above	

M1090. Characteristics of Pressure Ulcers/Injuries and Other Skin Conditions

Indicate the characteristics of the pressure ulcers/injuries and other skin conditions identified at the time of this assessment.

↓	Check all that apply
	A. Wound discharge
	B. Signs and symptoms of infection
	C. Pain including with wound assessment and/or treatment
	D. Odor
	E. None of the above
	F. Not applicable (no pressure ulcers/injuries or other skin conditions)

M1095. Interventions for Pressure Ulcers/Injuries and Other Skin Conditions

Indicate the interventions that are on the plan of care at the time of this assessment, for identified pressure ulcers/injuries and other skin conditions.

↓	Check all that apply
	A. Debridement
	B. Dressing change
	C. Incontinence management
	D. Medicate prior to wound care
	E. Negative pressure wound therapy
	F. Pressure relief items
	G. Repositioning
	H. Topical medication
	I. Other
	J. None of the above
	K. Not applicable (no pressure ulcers/injuries or other skin conditions)

Medications

N0471. Medication Management—Patient

At the time of this assessment, indicate the level of assistance from another person required by the patient to prepare and take medication(s) and proper dosage(s) at the correct times safely and accurately.

Instructions: If level of assistance varies between the medications, select the response based on the medication that requires the most assistance.

Enter Code	
	00. **Independent**: Patient does not require assistance from another person. 01. **Needs some assistance:** Patient requires some assistance from another person (e.g., if individual does are prepared in advance by another person, if another person sets up a reminder system allowing the patient to take medications correctly). 02. **Dependent**: Patient is unable to complete task(s) related to preparation and administration of their medications and relies completely on another person.

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	09. **Not applicable**: Patient is not taking any medications
N0471. Medication Management—Caregiver	
At the time of this assessment, indicate the level of assistance required by the caregiver to prepare and administer the patient's medication(s) safely and accurately. **The caregiver includes family caregivers, non-family caregivers, or, for patients residing in any facility setting, such as assisted living or long-term care, caregivers include the facility staff.** Instructions: If level of assistance varies between the medications, select the response based on the medication that requires the most assistance.	
Enter Code	00. **Independent**: Caregiver does not require assistance from another person. 01. **Needs some assistance**: Caregiver requires some assistance from another person (e.g., if individual does are prepared in advance by another person, if another person sets up a reminder system allowing the caregiver to administer medications correctly). 02. **Dependent**: Caregiver is unable to complete task(s) related to preparation and administration of their medications and relies completely on another person. 09. **Not applicable**: Patient is not taking any medication(s) or the patient does not required assistance from another person to prepare and take medication(s) and proper dosage(s) at the correct time.
Administrative Information	
M0090. Date Assessment was Completed	
	We need to know the day and time you started your assessment with the patient (not the day and time you started documentation or data entry): Month Day Year HH MM AM/PM

Beta HOPE RN Symptom Reassessment Form

RN SYMPTOM REASSESSMENT	
Patient study identifier (System generated, pre-populated)	Date of birth (MM/DD/YYYY)
	Gender (M/F)
Assessment date and time started (system generated)	Discipline completing assessment (RN, SW, CH)

Administrative Information

Date Assessment was Started

We need to know the day and time you started your assessment with the patient (not the day and time you started documentation or data entry):

Month Day Year

HH : MM AM/PM

Health Conditions

J0900. Pain Screening

Enter Code	A. Was the patient screened for pain? 00. No — *Skip to J2050. Symptom Impact* 01. Yes
Enter Code	C. The patient's pain severity was: 00 .None 01. Mild 02. Moderate 03. Severe 09.Not assessed

J2050. Symptom Impact

Over the past 2 days, how has the patient been affected by each of the following symptoms? Base this on your clinical assessment (including input from patient and/or caregiver). Symptoms may impact multiple patient activities including, but not limited to, sleep, concentration, day to day activities, or ability to interact with others.

01. Not at all – symptom does not affect the patient, including symptoms well-controlled with current treatment
02. Slight
03. Moderate
04. Severe
09. Not applicable (the patient is not experiencing the symptom)

	↓ Enter code
A. Pain	
B. Shortness of breath	
C. Anxiety	
D. Nausea	
E. Vomiting	
F. Diarrhea	
G. Constipation	
H. Agitation	

J2060. Patient Desired Tolerance Level for Symptoms	
At the time of the assessment, what is the patient's desired tolerance level for each of the following symptoms? Base this on your clinical assessment (including input from patient and/or caregiver). 01. None (The patient prefers not to experience the symptom at all) 02. Slight 03. Moderate 04. High 09. Not applicable (the patient is not experiencing the symptom)	
	↓ Enter code
A. Pain	
B. Shortness of breath	
C. Anxiety	
D. Nausea	
E. Vomiting	
F. Diarrhea	
G. Constipation	
H. Agitation	

J2070. Patient Preferences for Symptom Management	
At the time of the assessment, does the patient prioritize reduction in their symptoms, even with potential treatment side-effects or inconvenience? Base this on your clinical assessment (including input from patient and/or caregiver). 00. No 01. Yes 09. Not applicable (the patient is not experiencing the symptom)	
	↓ Enter code
A. Pain	
B. Shortness of breath	
C. Anxiety	
D. Nausea	
E. Vomiting	
F. Diarrhea	
G. Constipation	
H. Agitation	

J2080. Follow-up Symptom Control	
At the time of this assessment, has the patient achieved symptom control? Base this on your clinical assessment (including input from patient and/or caregiver) 00. No 01. Yes 09. Not applicable (the patient is not experiencing the symptom)	
	↓ Enter code
A. Pain	

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B. Shortness of breath	
C. Anxiety	
D. Nausea	
E. Vomiting	
F. Diarrhea	
G. Constipation	
H. Agitation	
Administrative Information	
M0090. Date Assessment was Completed	
	We need to know the day and time you started your assessment with the patient (not the day and time you started documentation or data entry): Month Day Year HH : MM AM/PM

Beta HOPE RN Discharge Form

RN DISCHARGE	
Patient study identifier (System generated, pre-populated)	Date of birth (MM/DD/YYYY)
	Gender (M/F)
Assessment date and time started (system generated)	Discipline completing assessment (RN, SW, CH)
After this assessment, the patient will not receive additional visits from this hospice. (Y/N)	

Administrative Information

A0270. Discharge Date

We need to know the day and time you started your assessment with the patient (not the day and time you started documentation or data entry):

Month Day Year

HH MM AM/PM

A2115. Reason for Discharge

Enter Code

01. Expired *Skip to J1800. Any Falls Since Admission or Recertification*
02. Revoked
03. No longer terminally ill
04. Moved out of hospice service area
05. Transferred to another hospice
06. Discharged for cause

Reason for Discharge

Functional Abilities and Goals

GG0130. Self-Care

Code the patient's usual performance at Discharge for each activity using the 6-point scale. If activity was not attempted at Discharge, code the reason.

Coding:

Safety and Quality of Performance – If helper assistance is required because patient's performance is unsafe or of poor quality, score according to amount of assistance provided.

Activities may be completed with or without assistive devices.

06. Independent – Patient completes the activity by him/herself with no assistance from a helper.
05. Setup or clean-up assistance – Helper sets up or cleans up; patient completes activity. Helper assists only prior to or following the activity.
04. Supervision or touching assistance – Helper provides verbal cues and/or touching/steadying and/or contact guard assistance as patient completes activity. Assistance may be provided throughout the activity or intermittently.
03. Partial/moderate assistance – Helper does LESS THAN HALF the effort. Helper lifts, holds or supports trunk or limbs, but provides less than half the effort.
02. Substantial/maximal assistance – Helper does MORE THAN HALF the effort. Helper lifts or holds trunk or limbs and provides more than half the effort.
01. Dependent – Helper does ALL of the effort. Patient does none of the effort to complete the activity. Or the assistance of 2 or more helpers is required for the patient to complete the activity.

If activity was not attempted, code reason:

07. Patient refused.
09. Not applicable – Not attempted and the patient did not perform this activity prior to the current illness, exacerbation or injury.
10. Not attempted due to environmental limitations (e.g., lack of equipment, weather constraints).
88. Not attempted due to medical conditions or safety concerns.

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↓	Enter Codes in Boxes
	A. Eating: The ability to use suitable utensils to bring food and/or liquid to the mouth and swallow food and/or liquid once the meal is placed before the patient.
	B. Oral Hygiene: The ability to use suitable items to clean teeth. Dentures (if applicable): The ability to insert and remove dentures into and from mouth, and manage denture soaking and rinsing with use of equipment.
	C. Toileting Hygiene: The ability to maintain perineal hygiene, adjust clothes before and after voiding or having a bowel movement. If managing an ostomy, include wiping the opening but not managing equipment.
	E. Shower/bathe self: The ability to bathe self, including washing, rinsing, and drying self (excludes washing of back and hair). Does not include transferring in/out of tub/shower.

GG0170. Mobility

Code the patient's usual performance for each activity at Discharge using the 6-point scale. If activity was not attempted at Discharge, code the reason.

Coding:

Safety and Quality of Performance – If helper assistance is required because patient's performance is unsafe or of poor quality, score according to amount of assistance provided.

Activities may be completed with or without assistive devices.

06. Independent – Patient completes the activity by him/herself with no assistance from a helper.
05. Setup or clean-up assistance – Helper sets up or cleans up; patient completes activity. Helper assists only prior to or following the activity.
04. Supervision or touching assistance – Helper provides verbal cues and/or touching/steadying and/or contact guard assistance as patient completes activity. Assistance may be provided throughout the activity or intermittently.
03. Partial/moderate assistance – Helper does LESS THAN HALF the effort. Helper lifts, holds or supports trunk or limbs, but provides less than half the effort.
02. Substantial/maximal assistance – Helper does MORE THAN HALF the effort. Helper lifts or holds trunk or limbs and provides more than half the effort.
01. Dependent – Helper does ALL of the effort. Patient does none of the effort to complete the activity. Or, the assistance of 2 or more helpers is required for the patient to complete the activity.

If activity was not attempted, code reason:

07. Patient refused.
09. Not applicable – Not attempted and the patient did not perform this activity prior to the current illness, exacerbation or injury.
10. Not attempted due to environmental limitations (e.g., lack of equipment, weather constraints).
88. Not attempted due to medical conditions or safety concerns.

↓	Enter Codes in Boxes
	A. Roll left and right: The ability to roll from lying on back to left and right side, and return to lying on back on the bed.
	D. Sit to stand: The ability to come to a standing position from sitting in a chair, wheelchair, or on the side of the bed.
	E. Chair/bed-to-chair transfer: The ability to transfer to and from a bed to a chair (or wheelchair).
	F. Toilet transfer: The ability to get on and off a toilet or commode.
	I. Walk 10 feet: Once standing, the ability to walk at least 10 feet in a room, corridor, or similar space.

Health Conditions

J2050. Symptom Impact

Over the past 2 days, how has the patient been affected by each of the following symptoms? Base this on your clinical assessment (including input from patient and/or caregiver). Symptoms may impact multiple patient activities including, but not limited to, sleep, concentration, day to day activities, or ability to interact with others.

01. Not at all – symptom does not affect the patient, including symptoms well-controlled with current treatment Slight
02. Moderate
03. Severe
09. Not applicable (the patient is not experiencing the symptom)

	Enter code ↓
A. Pain	
B. Shortness of breath	
C. Anxiety	
D. Nausea	
E. Vomiting	
F. Diarrhea	
G. Constipation	
H. Agitation	

Skin Conditions

M0210. Unhealed Pressure Ulcers/Injuries

Enter Code	Does this patient have one or more unhealed pressure ulcers/injuries? 00. No — *Skip to M1085. Other Skin Conditions* 01. Yes

M0300. Current Number of Unhealed Pressure Ulcers/Injuries at Each Stage

Enter Number	**A. Stage 1:** Intact skin with non-blanchable redness of a localized area usually over a bony prominence. Darkly pigmented skin may not have a visible blanching; in dark skin tones only it may appear with persistent blue or purple hues. **1. Number of Stage 1 pressure injuries**
Enter Number	**B. Stage 2:** Partial thickness loss of dermis presenting as a shallow open ulcer with a red or pink wound bed, without slough. May also present as an intact or open/ruptured blister. **1. Number of Stage 2 pressure ulcers**
Enter Number	**C. Stage 3:** Full thickness tissue loss. Subcutaneous fat may be visible but bone, tendon, or muscle is not exposed. Slough may be present but does not obscure the depth of tissue loss. May include undermining and tunneling. **1. Number of Stage 3 pressure ulcers**
Enter Number	**D. Stage 4:** Full thickness tissue loss with exposed bone, tendon, or muscle. Slough or eschar may be present on some parts of the wound bed. Often includes undermining and tunneling. **1. Number of Stage 4 pressure ulcers**
Enter Number	**E. Unstageable:** Non-removable dressing/device: Known but not stageable due to non-removable dressing/ device **1. Number of unstageable pressure ulcers/injuries due to non-removable dressing/device**
Enter Number	**F. Unstageable: Slough and/or eschar:** Known but not stageable due to coverage of wound bed by slough and/or eschar **1. Number of unstageable pressure ulcers due to coverage of wound bed by slough and/or eschar**

Enter Number	G. Unstageable: Deep tissue injury 1. Number of unstageable pressure injuries presenting as deep tissue injury

M1085. Other Skin Conditions	
At the time of this assessment, the patient has which of the following other skin conditions?	Check all that apply
A. Surgical Wound	
B. Ulcers other than Pressure Ulcers/Injuries (e.g., Kennedy ulcer, venous stasis ulcer, arterial ulcer, diabetic ulcer)	
C. Other Skin Conditions (e.g., rash, skin tear)	
D. None of the above	

M1090. Characteristics of Pressure Ulcers/Injuries and Other Skin Conditions	
Indicate the characteristics of the pressure ulcers/injuries and other skin conditions identified at the time of this assessment.	
↓	Check all that apply
	A. Wound discharge
	B. Signs and symptoms of infection
	C. Pain including with wound assessment and/or treatment
	D. Odor
	E. None of the above
	F. Not applicable (no pressure ulcers/injuries or other skin conditions)

M1095. Interventions for Pressure Ulcers/Injuries and Other Skin Conditions	
Indicate the interventions that are on the plan of care at the time of this assessment, for identified pressure ulcers/injuries and other skin conditions.	
↓	Check all that apply
	A. Debridement
	B. Dressing change
	C. Incontinence management
	D. Medicate prior to wound care
	E. Negative pressure wound therapy
	F. Pressure relief items
	G. Repositioning
	H. Topical medication
	I. Other
	J. None of the above
	K. Not applicable (no pressure ulcers/injuries or other skin conditions)

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Medications	
N0471. Medication Management—Patient	
At the time of this assessment, indicate the level of assistance from another person required by the patient to prepare and take medication(s) and proper dosage(s) at the correct times safely and accurately. Instructions: If level of assistance varies between the medications, select the response based on the medication that requires the most assistance.	
Enter Code	00. **Independent**: Patient does not require assistance from another person. 01. **Needs some assistance**: Patient requires some assistance from another person (e.g., if individual does are prepared in advance by another person, if another person sets up a reminder system allowing the patient to take medications correctly). 02. **Dependent**: Patient is unable to complete task(s) related to preparation and administration of their medications and relies completely on another person. 09. **Not applicable**: Patient is not taking any medications
N0471. Medication Management—Caregiver	
At the time of this assessment, indicate the level of assistance required by the caregiver to prepare and administer the patient's medication(s) safely and accurately. **The caregiver includes family caregivers, non-family caregivers, or, for patients residing in any facility setting, such as assisted living or long-term care, caregivers include the facility staff.** Instructions: If level of assistance varies between the medications, select the response based on the medication that requires the most assistance.	
Enter Code	00. **Independent**: Caregiver does not require assistance from another person. 01. **Needs some assistance**: Caregiver requires some assistance from another person (e.g., if individual does are prepared in advance by another person, if another person sets up a r minder system allowing the caregiver to administer medications correctly). 02. **Dependent**: Caregiver is unable to complete task(s) related to preparation and administration of their medications and relies completely on another person. 09. **Not applicable**: Patient is not taking any medication(s) or the patient does not required assistance from another person to prepare and take medication(s) and proper dosage(s) at the correct time.
A2105. Discharge Location	
Enter Code	01. Home/Community (e.g., private home/apt., board/care, assisted living, group home, transitional living, other residential care arrangements) — *Skip to A2123. Provision of Current Reconciled Medication List to Patient at Discharge* 02. Nursing home (long-term care facility) 03. Skilled Nursing Facility (SNF, swing beds) 04. Short-Term General Hospital (acute hospital, IPPS) 05. Long-Term Care Hospital (LTCH) 06. Inpatient Rehabilitation Facility (IRF, free standing facility or unit) 07. Inpatient Psychiatric Facility (psychiatric hospital or unit) 08. Intermediate Care Facility (ID/DD facility) 09. Hospice (home/non-institutional) 10. Hospice (institutional facility) 11. Critical Access Hospital (CAH) 12. Home under care of organized home health service organization 99. Not Listed

BOLD THINKERS DRIVING REAL-WORLD IMPACT

A2105. Discharge Location	
Enter Code	01. Home/Community (e.g., private home/apt., board/care, assisted living, group home, transitional living, other residential care arrangements) — *Skip to A2123. Provision of Current Reconciled Medication List to Patient at Discharge* 02. Nursing home (long-term care facility) 03. Skilled Nursing Facility (SNF, swing beds) 04. Short-Term General Hospital (acute hospital, IPPS) 05. Long-Term Care Hospital (LTCH) 06. Inpatient Rehabilitation Facility (IRF, free standing facility or unit) 07. Inpatient Psychiatric Facility (psychiatric hospital or unit) 08. Intermediate Care Facility (ID/DD facility) 09. Hospice (home/non-institutional) 10. Hospice (institutional facility) 11. Critical Access Hospital (CAH) 12. Home under care of organized home health service organization 99. Not Listed

A2121. Provision of Current Reconciled Medication List to Subsequent Provider at Discharge At the time of discharge to another provider, did your agency provide the patient's current reconciled medication list to the subsequent provider?	
Enter Code	00. No – Current reconciled medication list not provided to the subsequent provider — *Skip to J1800. Any Falls Since Admission or Recertification, whichever is more recent* 01. Yes – Current reconciled medication list provided to the subsequent provider— *Continue to A2122. Route of Current Reconciled Medication List Transmission to Subsequent Provider*

A2122. Route of Current Reconciled Medication List Transmission to Subsequent Provider

Indicate the route(s) of transmission of the current reconciled medication list to the subsequent provider.

Route of Transmission	↓ Check all that apply
A. Electronic Health Record	
B. Health Information Exchange Organization	
C. Verbal (e.g., in-person, telephone, video conferencing)	
D. Paper-based(e.g., fax, copies, printouts)	
E. Other Methods (e.g., texting, email, CDs)	

A2105. Discharge Location	
Enter Code	01. Home/Community (e.g., private home/apt., board/care, assisted living, group home, transitional living, other residential care arrangements) — *Skip to A2123. Provision of Current Reconciled Medication List to Patient at Discharge* 02. Nursing home (long-term care facility) 03. Skilled Nursing Facility (SNF, swing beds) 04. Short-Term General Hospital (acute hospital, IPPS) 05. Long-Term Care Hospital (LTCH) 06. Inpatient Rehabilitation Facility (IRF, free standing facility or unit) 07. Inpatient Psychiatric Facility (psychiatric hospital or unit) 08. Intermediate Care Facility (ID/DD facility) 09. Hospice (home/non-institutional) 10. Hospice (institutional facility) 11. Critical Access Hospital (CAH) 12. Home under care of organized home health service organization 99. Not Listed

BOLD THINKERS DRIVING REAL-WORLD IMPACT

A2121. Provision of Current Reconciled Medication List to Subsequent Provider at Discharge **At the time of discharge to another provider, did your agency provide the patient's current reconciled medication list to the subsequent provider?**	
Enter Code ☐	00. No – Current reconciled medication list not provided to the subsequent provider — *Skip to J1800. Any Falls Since Admission or Recertification, whichever is more recent* 01. Yes – Current reconciled medication list provided to the subsequent provider— *Continue to A2122. Route of Current Reconciled Medication List Transmission to Subsequent Provider*

A2122. Route of Current Reconciled Medication List Transmission to Subsequent Provider **Indicate the route(s) of transmission of the current reconciled medication list to the subsequent provider.**	
Route of Transmission	**↓ Check all that apply**
A. Electronic Health Record	☐
B. Health Information Exchange Organization	☐
C. Verbal (e.g., in-person, telephone, video conferencing)	☐
D. Paper-based(e.g., fax, copies, printouts)	☐
E. Other Methods (e.g., texting, email, CDs)	☐

Other RN Discharge Items

A2123. Provision of Current Reconciled Medication List to Patient at Discharge **At the time of discharge, did your agency provide the patient's current reconciled medication list to the patient, family and/or caregiver?**	
Enter Code ☐	00. No– Current reconciled medication list not provided to the patient, family and/or caregiver — Skip to J1800. Any Falls Since Admission or Recertification 01. Yes – Current reconciled medication list provided to the patient, family and/or caregiver— Continue to A2124. Route of Current Reconciled Medication List Transmission to Patient

A2124. Route of Current Reconciled Medication List Transmission to Patient **Indicate the route(s) of transmission of the current reconciled medication list to the patient/family/caregiver.**	
Route of Transmission	**↓ Check all that apply**
A. Electronic Health Record	☐
B. Health Information Exchange Organization	☐
C. Verbal (e.g., in-person, telephone, video conferencing)	☐
D. Paper-based(e.g., fax, copies, printouts)	☐
E. Other Methods (e.g., texting, email, CDs)	☐

J1800. Any Falls Since Admission or Recertification, whichever is more recent	
Enter Code ☐	00. No — Skip to A1850. Emergency Room Use 01. Yes — Continue to J1900. Number of Falls

J1900. Number of Falls		
Number of Falls Since Admission or Recertification, whichever is more recent		
Coding: 00. None 01. One 02. Two or more	**↓** ☐	**Enter Codes in Boxes** A. No injury: No evidence of any injury is noted on physical assessment by the nurse or primary care clinician; no complaints of pain or injury by the patient; no change in the patient's behavior is noted after the fall

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		B. Injury (except major): Skin tears, abrasions, lacerations, superficial bruises, hematomas and sprains; or any fall-related injury that causes the patient to complain of pain
		C. Major injury: Bone fractures, joint dislocations, closed head injuries with altered consciousness, subdural hematoma

A2123. Provision of Current Reconciled Medication List to Patient at Discharge

At the time of discharge, did your agency provide the patient's current reconciled medication list to the patient, family and/or caregiver?

Enter Code	
	00. No– Current reconciled medication list not provided to the patient, family and/or caregiver — Skip to J1800. Any Falls Since Admission or Recertification 01. Yes – Current reconciled medication list provided to the patient, family and/or caregiver— Continue to A2124. Route of Current Reconciled Medication List Transmission to Patient

A2124. Route of Current Reconciled Medication List Transmission to Patient

Indicate the route(s) of transmission of the current reconciled medication list to the patient/family/caregiver.

Route of Transmission	↓ Check all that apply
A. Electronic Health Record	
B. Health Information Exchange Organization	
C. Verbal (e.g., in-person, telephone, video conferencing)	
D. Paper-based(e.g., fax, copies, printouts)	
E. Other Methods (e.g., texting, email, CDs)	

J1800. Any Falls Since Admission or Recertification, whichever is more recent

Enter Code	
	00. No — *Skip to A1850. Emergency Room Use* 01. Yes — *Continue to J1900. Number of Falls*

J1900. Number of Falls

Number of Falls Since Admission or Recertification, whichever is more recent

Coding:	↓	Enter Codes in Boxes
00. None 01. One 02. Two or more		A. No injury: No evidence of any injury is noted on physical assessment by the nurse or primary care clinician; no complaints of pain or injury by the patient; no change in the patient's behavior is noted after the fall
		B. Injury (except major): Skin tears, abrasions, lacerations, superficial bruises, hematomas and sprains; or any fall-related injury that causes the patient to complain of pain
		C. Major injury: Bone fractures, joint dislocations, closed head injuries with altered consciousness, subdural hematoma

A1850. Emergency Room Use

Enter Code	At any time during this admission has the patient utilized an emergency room (including holding/observation status)? 01. No *Skip to F1010.Advance Care Planning Preferences Follow-up* 02. Yes, used emergency room but not admitted to hospital 09. Yes, used emergency room and admitted to hospital

A1855. Date of Emergency Room Use Care

	Enter date(s) starting with most recent: A. Month Day Year

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B.
Month Day Year

C.
Month Day Year

D.
Month Day Year

E.
Month Day Year

F.
Month Day Year

G.
Month Day Year

H.
Month Day Year

I.
Month Day Year

J.
Month Day Year

F1010. Advance Care Planning Preferences Follow-up

Were patient preferences followed throughout this hospice stay?
Coding:

01. Yes, preferences did not change throughout the hospice stay and were followed
02. Yes, preferences changed during the hospice stay and were followed
03. No, preferences were not followed throughout the hospice stay
04. Not applicable: Not discussed at any time during the hospice stay

↓	Enter Codes in Boxes
	F1010A. Chest Compression
	F1010B. Intubation
	F1010C. Hospitalization

F1010. Advance Care Planning Preferences Follow-up	
Were patient preferences followed throughout this hospice stay? **Coding:** 01. Yes, preferences did not change throughout the hospice stay and were followed 02. Yes, preferences changed during the hospice stay and were followed 03. No, preferences were not followed throughout the hospice stay 04. Not applicable: Not discussed at any time during the hospice stay	
↓	**Enter Codes in Boxes**
	F1010A. Chest Compression
	F1010B. Intubation
	F1010C. Hospitalization

Administrative Information

M0090. Date Assessment was Completed	
	We need to know the day and time you started your assessment with the patient (not the day and time you started documentation or data entry): Month Day Year HH : MM AM/PM

Beta HOPE SW Admission Form

SOCIAL WORKER ADMISSION	
Patient study identifier (System generated, pre-populated)	Date of birth (MM/DD/YYYY)
	Gender (M/F)
Assessment date and time started (system generated)	Discipline completing assessment (RN, SW, CH)

Administrative Information

Date Assessment was Started

We need to know the day and time you started your assessment with the patient (not the day and time you started documentation or data entry):

Month Day Year

HH MM AM/PM

Mood

D0150. Patient Mood Interview (PHQ-2)

Say to patient: "*Over the last 2 weeks have you been bothered by any of the following problems?*"

If symptom is present enter 1 (yes) in column 1, Symptom Presence
If yes in column 1 then ask the patient: "*About how often have you been bothered by this?*"
Read and show the patient a card with the symptom frequency choices. Indicate response in column 2, Symptom Frequency

1. Symptom Present **0. No** (enter 0 in column 2) **1. Yes** (enter 0-3 in column 2) **9. No response** (leave column 2 blank	**2. Symptom Frequency** **0. Never or 1 day** **1. 2-6 days** (several days) **2. 7-11 days** (half or more of the days) **3. 12-14 days** (nearly every day(	**1. Symptom Presence**	**2. Symptom Frequency**
		Enter Scores in Boxes	
A. Little interest or pleasure in doing things			
B. Feeling down, depressed, or hopeless			

D0160. Total Severity Score

Enter Score	Add scores for all frequency responses in Column 2, Symptom Frequency. Total score must be between 0 and 6.
	Check box here if unable to complete the interview.

D0180. Patient Feeling Anxious or Worried

Enter Code

Over the past three days, and based on your assessment, has the patient been feeling anxious or worried about his/ her illness or treatment?

00. Not at all
01. Occasionally
02. Sometimes
03. Most of the time
04. Always
09. Not applicable (Cannot assess, e.g., unconscious)

D0190. Family Feeling Anxious or Worried

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Enter Code	Over the past three days, and based on your assessment, how often has the family felt anxious or worried about the patient? 00. Not at all 01. Occasionally 02. Sometimes 03. Most of the time 04. Always 09. Not applicable

Patient and Family Needs

Q1200. Patient and Caregiver Resource Needs (Social Worker Assessment)

At the time of this assessment does the patient and/or caregiver (including family and non-family) have any of the following resource needs?

	Column 1. Code who needs resources: 01. Patient 02. Caregiver 03. Both 04. No resource needs 05. Not applicable (e.g., patient unconscious or caregiver not available)	Column 2: Code if a referral was made or declined. 01. Yes, a referral was made 02. No, a referral was declined.
Resource Needs	**1. Enter Code**	**2. Enter Code**
A. Mental health counseling		
B. Social worker support		
C. Chaplain and/or spiritual support		
D. Cultural support		
E. Financial		
F. Connection to community resources		
G. Transportation		
H. Other		

JJ0100. Care Needs

Enter Number	Based on your assessment, are the patient's needs for care (e.g., ADLs, IADLs, treatments, supervision) being met? 00. Not at all 01. Occasionally 02. Sometimes 03. Most of the time 04. All of the time 09. Not assessed

JJ0110. Safety

Enter Number	Based on your assessment, are the patient's needs for safety (e.g., prevention of complications, adverse events, or injuries; overcoming challenges to care; risk mitigation) being met? 00. Not at all 01. Occasionally 02. Sometimes 03. Most of the time 04. All of the time 09. Not assessed

JJ0120. Financial Resources

Enter Code	Based on your assessment, are the financial resource needs of the patient and caregiver (including family) being met? A. Patient needs are being met. 00. Not at all 01. Occasionally 02. Sometimes 03. Most of the time 04. All of the time 05. Not assessed
Enter Code	B. Caregiver needs are being met. 00. Not at all 01. Occasionally 02. Sometimes 03. Most of the time 04. All of the time 05. Not assessed 09. Not applicable (Caregiver not available)
JJ0130. Social Support	
Enter Code	Based on your assessment, are the patient and caregiver's (including family) needs for social support being met? A. Patient needs are being met. 00. Not at all 01. Occasionally 02. Sometimes 03. Most of the time 04. All of the time 05. Not assessed
Enter Code	B. Caregiver needs are being met. 00. Not at all 01. Occasionally 02. Sometimes 03. Most of the time 04. All of the time 05. Not assessed 09. Not applicable (Caregiver not available)
JJ0140. Cultural Values	
Enter Code	Based on your assessment, are the patient and caregiver (including family) experiencing congruence between the care and their cultural values (e.g., beliefs, customs)? A. Patient experiencing congruence. 00. Not at all 01. Occasionally 02. Sometimes 03. Most of the time 04. All of the time 09. Not assessed
Enter Code	B. Caregiver experiencing congruence. 00. Not at all 01. Occasionally 02. Sometimes 03. Most of the time 04. All of the time 05. Not assessed 09. Not applicable (Caregiver not available)
JJ0150. Awareness of Prognosis	

Enter Code	Based on your assessment, are the patient and caregiver (including family and facility staff) aware of the patient's prognosis? A. Patient is aware of and understands their prognosis. 00. No 01. Yes 02. Not assessed
Enter Code	B. Caregiver is aware of and understands the patient's prognosis. 00. No 01. Yes 02. Not assessed 09. Not applicable (Caregiver not available)
JJ0160. Coping Related to Anticipatory Grief	
Enter Code	Based on your assessment, are the patient and caregiver's (including family) needs for coping, related to anticipatory grief, being met? A. Patient needs are being met. 00. Not at all 01. Occasionally 02. Sometimes 03. Most of the time 04. All of the time 09. Not assessed
Enter Code	B. Caregiver needs are being met. 00. Not at all 01. Occasionally 02. Sometimes 03. Most of the time 04. All of the time 05. Not assessed 09. Not applicable (Caregiver not available)
JJ0180. Identification of Psychosocial Needs	
Enter Code	At the time of this assessment, did you identify any psychosocial needs (e.g., care needs, awareness of prognosis, coping strategies, connecting with community resources) for the patient and caregiver (including family)? A. Patient 00. No, psychosocial needs not identified 01. Yes, psychosocial needs identified
Enter Code	B. Caregiver 00. No, psychosocial needs not identified 01. Yes, psychosocial needs identified 09. Not applicable (Caregiver not available)
JJ0050. Psychosocial Assessment Completed	
Enter Number	At the time of this assessment, is a psychosocial assessment completed with the patient and/or caregiver that addresses psychosocial needs (e.g., care needs, financial needs, social support, cultural values related to end-of- life care)? 1. No, psychosocial assessment not completed 2. Yes, psychosocial assessment completed
JJ0200. Establish Psychosocial Plan of Care	

BOLD THINKERS DRIVING REAL-WORLD IMPACT

Enter Code	If psychosocial needs are identified at the time of this assessment, is there a plan of care to address the identified needs? 00. No, plan of care addressing psychosocial needs not established 01. Yes, plan of care addressing psychosocial needs established 09. Not applicable (No psychosocial needs identified at the time of this assessment)

Administrative Information

M0090. Date Assessment was Completed

We need to know the day and time you started your assessment with the patient (not the day and time you started documentation or data entry):

Month Day Year

HH : MM AM/PM

Beta HOPE Chaplain Admission form

CHAPLAIN ADMISSION	
Patient study identifier (System generated, pre-populated)	Date of birth (MM/DD/YYYY)
	Gender (M/F)
Assessment date and time started (system generated)	Discipline completing assessment (RN, SW, CH)

Administrative Information

Date Assessment was Started

We need to know the day and time you started your assessment with the patient (not the day and time you started documentation or data entry):

Month Day Year

HH MM AM/PM

Spiritual or Religious Needs

AA0050. Patient Response

Enter Code

A. At the time of the assessment is the patient **able** to respond?
- 00. No, the patient is not able to respond (e.g., patient unresponsive) — Skip to AA0120 Spiritual or Religious Struggles
- 01. Yes, the patient is able to respond.
- 09. Not assessed

Enter Code

B. At the time of the assessment is the patient **willing** to participate in the spiritual assessment?
- 00. No, the patient is not willing to participate — Skip to AA0120 Spiritual or Religious Struggles
- 01. Yes, the patient is willing to participate.
- 09. Not assessed

AA0100. Patient at Peace

Enter Code

Based on your assessment, is the patient at peace in the face of illness?
- 00. Not at all
- 01. Occasionally
- 02. Sometimes
- 03. Most of the time
- 04. All of the time
- 09. Not assessed

AA0110. Meaning and Joy

Enter Code

Based on your assessment, is the patient experiencing meaning and joy in his or her life?
- 00. Not at all
- 01. Occasionally
- 02. Sometimes
- 03. Most of the time
- 04. All of the time
- 09. Not assessed

AA0120. Spiritual or Religious Struggles

Enter Code

Based on your assessment, do the patient and caregiver (including family) have what might be described as spiritual or religious struggles (e.g., trouble or doubts with spiritual or religious beliefs, anger, or disappointment with a higher power)?

A. Patient experiencing spiritual or religious struggles.
- 00. Not at all
- 01. Occasionally
- 02. Sometimes
- 03. Most of the time
- 04. All of the time
- 09. Not assessed

BOLD THINKERS DRIVING REAL-WORLD IMPACT

Enter Code	B. Caregiver experiencing spiritual or religious struggles. 00. Not at all 01. Occasionally 02. Sometimes 03. Most of the time 04. All of the time 05. Not assessed 09. Not applicable (Caregiver not available)
AA0130. Comfort and Strength	
Enter Code	Based on your assessment, do the patient and caregiver's (including family) spirituality or religion provide them with comfort and strength? A. Patient receives comfort and strength from spirituality or religion. 00. Not at all 01. Occasionally 02. Sometimes 03. Most of the time 04. All of the time 09. Not assessed
Enter Code	B. Caregiver receives comfort and strength from spirituality or religion. 00. Not at all 01. Occasionally 02. Sometimes 03. Most of the time 04. All of the time 05. Not assessed 09. Not applicable (Caregiver not available)
AA0140. Visits or Support from Faith Community	
Enter Code	Based on your assessment, do the patient and caregiver (including family) want visits or support from a faith community (i.e., external to the hospice, internal to the hospice, or both)? A. Patient wants visits or support from a faith community. 00. No 01. Yes 09. Not assessed
Enter Code	B. Caregiver wants visits or support from a faith community. 00. No 01. Yes 05. Not assessed 09. Not applicable (Caregiver not available)
AA0150. Identification of Spiritual or Religious Needs	
Enter Code	At the time of this assessment, did you identify any spiritual or religious needs for the patient and caregiver (including family)? A. Patient's needs identified 00. No, spiritual or religious needs not identified 01. Yes, spiritual or religious needs identified
Enter Code	B. Caregiver's needs identified 00. No, spiritual or religious needs not identified 01. Yes, spiritual or religious needs identified 09. Not applicable (Caregiver not available)

BOLD THINKERS DRIVING REAL-WORLD IMPACT

AA0200. Establish Spiritual Plan of Care	
Enter Code	If spiritual or religious needs are identified at the time of this assessment, is there a plan of care to address the identified needs? 00. No, plan of care addressing spiritual or religious needs not established 01. Yes, plan of care addressing spiritual or religious needs established 09. Not applicable (No spiritual or religious needs identified at the time of this assessment)
Administrative Information	
M0090. Date Assessment was Completed	
	We need to know the day and time you started your assessment with the patient (not the day and time you started documentation or data entry): Month Day Year HH : MM AM/PM

Appendix C: Detailed Methods

This appendix provides additional details on HOPE beta testing methods, including sampling and recruitment, data collection, and the analytic approach to assessing validity, feasibility, and reliability of Beta HOPE data elements.

Sampling and Recruitment

This section describes sampling and recruitment methods used to identify a geographically diverse national sample of hospices to participate in HOPE beta testing.

Sample Size Requirements

To assess sample size requirements for beta testing, Abt first performed power calculations using paired forms (i.e., two staff administering the HOPE tool for the same patient) collected during alpha testing. These calculations sought to identify the minimum number of paired forms that would be needed to determine whether inter-rater reliability for each included Beta HOPE data element exceeded 0.4, the minimum reliability to achieve a moderate rating.

Assuming 80 percent power and a 95 percent confidence level, this analysis indicated that 300 paired HOPE admission tools for each type of hospice staff (i.e., registered nurse (RN), social worker (SW), and chaplain) would be sufficient to calculate inter-rater reliability for more than 90 percent of data elements associated with quality measure concepts in development. The power analysis further demonstrated that increasing the number of paired tools beyond 300 was associated with rapidly diminishing returns, in that small boosts in reliability for certain data elements would require large numbers of additional paired tools. For the data elements that were collected only on the RN symptom reassessment and discharge forms, Abt estimated that 60 paired tools were needed.

Abt considered the rate of data collection in the alpha test (i.e., one to two paired tools per week, on average) and the planned duration of data collection (34 weeks) to estimate the number of hospices needed to collect the needed number of paired tools over that interval. Abt estimated conservatively a minimum of 29 hospices should participate. Given the importance of testing outcomes to the Center for Medicare & Medicaid Services' (CMS') objectives for HOPE development, and to adjust for potentially higher than expected attrition, Abt aimed for a total of 33 hospices for beta test participation.

Hospice Provider Sampling and Selection

Medicare-certified hospices that agreed to meet staff participation and HOPE completion requirements were eligible to participate in the beta test. Outreach methods to solicit interest from eligible hospices included announcements posted to the CMS Hospice QRP Announcements & Spotlight webpage,[14] with each linking to a detailed recruitment announcement and a brief application. National provider associations and state/regional organizations disseminated recruitment announcements and materials to their membership.

Abt then designed a multi-step sampling strategy to select beta testing participants from among eligible hospices responding to outreach efforts. Characteristics of interest considered in sampling included geographic region (i.e., Midwest, Northeast, South, and West), urbanicity (i.e., serving only urban areas, serving only rural areas, and serving both), ownership type (i.e., for-profit and nonprofit) and service location (i.e., patient's homes, inpatient facilities, and inpatient hospice facilities). CMS and Abt were particularly interested in securing the participation of up to four very small hospices, and oversampling hospices that only served patients in rural areas, to ensure their unique perspectives were represented in HOPE feedback.

[14] https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Hospice-Quality-Reporting/Spotlight

The strategy called for re-sampling to replace any hospice that declined participation to maintain the characteristics of interest, to the extent possible.

Enrollment and Training

Abt contacted selected hospices with a welcome letter introducing Abt and a participation agreement that detailed HOPE beta test requirements. The participation agreement described Abt's support to the hospice staff throughout the beta test. Any hospice that declined participation when notified of their selection was replaced by the re-sampling process.

For selected hospices that agreed to participate, Abt arranged conference calls or WebEx meetings to explain beta test requirements to hospice leadership, confirming their interest in participation and their commitment to meeting data collection targets. At that time, each hospice identified one or two staff to serve as the liaison and to manage their participating hospice staff members throughout the beta test. Abt shared strategies for successful testing preparation with the liaisons. Abt also provided introductory information about training to facilitate scheduling staff time to attend the webinars and complete the required independent study content. Hospice leadership officially agreed, via email, to the participation agreement requirements.

Hospice staff completed the required beta test training (Exhibit C-1) within 2 months of enrollment and prior to beginning data collection. The training consisted of three live sessions conducted via WebEx, independent study of tool content and scenarios, and supplemental supporting materials. Abt recorded the three WebEx sessions for hospice staff members with scheduling conflicts. Supporting materials included test procedures and detailed guidance for each HOPE data element. Abt updated the training webinars and materials as needed throughout the beta test, based on feedback from the hospice staff and Abt's analysis of training effectiveness (e.g., questions received from hospice staff collecting data, review of tool data). After each live training webinar, Abt distributed a Frequently Asked Questions (FAQ) handout to all liaisons and instructed them to share the information with their team.

Exhibit C-1. HOPE Beta Test Training Topics

- Introduction to the HOPE Beta Test
  - Hospice staff roles and responsibilities
  - Procedures: identify eligible patients (inclusion/exclusion); obtain verbal consent; enroll patients; track enrollment and attrition; conduct HOPE assessments (joint visits)
  - Data management and security; adverse events; communication and coordination; support available from Abt
  - Supplemental materials: HOPE Beta Test Procedures, Agreement to Participate scripts and HOPE Beta Test Information Form
- HOPE Assessments
  - Item-by-item training with scenarios and polling
  - Supplemental materials: HOPE Guidance Manual; HOPE Admission Practice Scenario (Case Study); assessment forms
- Data Collection Tool
  - Supplemental materials: Data Collection Tool Tips

Participating Hospice Characteristics

A total of 60 hospices participated in the beta test. Hospice staff in 38 of these 60 hospices (63 percent) initiated at least one HOPE form. Reasons for not initiating a form varied, but staffing shortages, heightened by the COVID-19 pandemic, were the most common reason provided. Abt included all initiated HOPE forms even if they were not completed.

Participating hospice provider characteristics are summarized in Exhibit C-2. Slightly more for-profit hospices (53percent) than nonprofit hospices (45 percent) enrolled. Most enrolled hospices were located in the southern United States (39 percent) with the remaining three regions representing approximately 20 percent each.

Sixteen percent of participating hospices served patients only in rural areas. Hospice size, based on self-reported average daily census averaged 157 and ranged from four to 690.

Exhibit C-2. Participating Hospice Provider Characteristics

Hospice Characteristics	Enrolled in Beta Test		Initiated at Least One Beta HOPE Form	
	Number	Percent	Number	Percent
Total	60	100%	38	100%
Ownership				
For-profit	32	53%	20	53%
Nonprofit	27	45%	17	45%
Other	1	2%	1	3%
Region				
West	12	20%	7	18%
Midwest	14	23%	9	24%
Northeast	12	20%	8	21%
South	23	38%	15	39%
Urbanicity				
Both urban and rural	43	72%	29	76%
Urban only	6	10%	3	8%
Rural only	11	18%	6	16%

Notes: Characteristics self-reported by hospice staff. The sample was not designed to representative. Percentages may sum to more than 100% due to rounding. One participating hospice operated in two different regions; numbers for this characteristic sum to one more than the total.

Hospice Staff Participants

Upon beta test enrollment, each hospice identified at least one (and preferably two) staff who would serve as liaisons between the hospice staff and Abt during the beta test. The liaisons were the main points of contact for Abt. The liaisons identified the staff at their hospice who would participate in the beta test, either by completing HOPE forms or by supporting data collection. Hospice staff completing tools consisted of RNs, SWs, and chaplains. Abt recommended a minimum of four RNs, two SWs and two chaplains at the start of the beta test. To achieve data collection targets, Abt increased this number to six RNs, three SWs and three chaplains as beta recruitment progressed. While Beta testing did include a few small rural hospice providers, they found it difficult to meet these recommendations and were more likely to complete a smaller number of forms than requested.

Data Collection

The beta test included quantitative and qualitative data collection. Completed HOPE forms provided quantitative data, while qualitative data consisted of informal feedback (e.g., through mailbox submissions or training discussions) an online survey and focus groups. Abt analyzed completed HOPE forms data to directly assess validity, feasibility, and reliability of the data elements.

HOPE Data Collection

Abt staff programmed the beta test version of the HOPE into the Research Electronic Data Capture (REDCap®)[xxvii,xxviii] application, which was the beta test's primary data collection tool. Designed for online and offline research study data capture, REDCap® is a secure web-based software application run by Vanderbilt University that is compliant with Title 21 Code of Federal Regulations Part 11 (21 CFR 11), Federal Information Security Modernization Act of 2014 (FISMA), Health Insurance Portability and

Accountability Act of 1996 (HIPAA) and General Data Protection Regulation (GDPR).[15] Hospice staff were offered a practice environment in REDCap®, in which they could practice data entry and familiarize themselves with the REDCap® tool before entering live data in the beta test environment.

Hospice staff enrolled a total of 381 patients in the beta test. Participating staff identified eligible patients and obtained verbal consent from patients or, for patients unable to respond due to their condition, obtaining the consent of a caregiver such as a family member or an authorized representative. To be eligible for the beta test, patients were required to be current or new hospice patients, 18 years of age or older, covered by any payer, and speak and understand English (or have a consenting caregiver who could speak and understand English for patients unable to respond). Hospice staff documented the patient's or caregiver's verbal consent in a demographic form in REDCap®, at which point the patient was assigned a unique beta test identifier. Hospice staff then selected the appropriate HOPE form (i.e., admission, symptom reassessment, or discharge) and staff discipline (i.e., RN, SW, or chaplain). Once entered by hospice staff, data in REDCap® were immediately available to the Abt analytic team.

Some patients ended their beta test participation. If a patient had consented to participate (rather than an authorized representative or caregiver) only the patient could withdraw. For patients who became incapable of response during the testing period, a family member or caregiver could choose to withdraw the patient from the beta test. Any family or authorized representative who agreed to beta test participation on behalf of a patient could withdraw that patient from testing. Over the course of the beta test, 27 patients withdrew or were withdrawn from testing (Exhibit C-3) Hospice staff documented attrition in REDCap®, noting whether a patient (or family/caregiver on behalf of the patient) stopped participating, the date they stopped, and the reason, if provided. Most attrition was because the patient died (44 percent) or was too ill or overwhelmed (Exhibit C-4). Only two patients, who changed their mind soon after providing consent, did not have any HOPE forms initiated (e.g., a form with a discipline-specific data element entered).

Exhibit C-3. Patient/Caregiver Stopped Participating

	Number	Percent
Patient stopped participating	21	77.8%
Caregiver stopped participating	5	18.5%
Missing	1	3.7%
Total	27	100%

Exhibit C-4. Reason Patient/Caregiver Stopped Participating

Reason	Number	Percent
Patient died	12	44.4%
Patient is too ill or overwhelmed	6	22.2%
Hospice admission was not finalized	4	14.8%
Patient declined a pre-arranged visit, typically from the social worker or chaplain, after providing consent and completing the RN Admission form	3	11.1%
Declined to give consent	1	3.7%
Other things to do and not really interested.	1	3.7%
Total	27	100%

Note: RN – registered nurse

In all, 381 hospice patients enrolled in HOPE beta testing, and hospice staff ultimately initiated at least one Beta HOPE form (i.e., the form had at least one data element completed by the applicable hospice discipline) for 371 of these patients. In total, hospice staff initiated a total of 901 forms across disciplines (i.e., RN, SW,

[15] REDCap (project-redcap.org)

chaplain) and timepoints (i.e., admission, symptom reassessment, discharge).[16] To support computation of inter-rater reliability, whenever feasible, two hospice staff members (an assessor and an observer) completed the HOPE form separately; 778 such paired forms were successfully completed by both staff. Abt used the paired forms for inter-rater reliability analyses only. Feasibility and validity analyses (described below) used only data from assessor-completed forms. Exhibit C-5 shows the number of completed forms for each discipline and timepoint.

Exhibit C-5: Number of Initiated Beta HOPE Forms by Discipline

Initiated Forms[1]	Admission			Symptom Reassessment	Discharge			Total
	RN	SW	CH	RN	RN	SW	CH	
Total	289	253	233	55	30	24	17	901
Paired[2]	250	218	205	40	28	21	16	778

Note: RN – registered nurse; SW – social worker; CH – chaplain. [1]Multiple Beta HOPE forms were completed per patient; therefore, the number of forms completed does not reflect the number of patients. A form is initiated if at least one data element is completed by the applicable hospice discipline. [2]Paired forms are forms completed separately by two staff, an observer and an assessor.

Hospice Staff Feedback

Abt obtained hospice staff feedback about Beta HOPE through several means during and immediately following completion of data collection to ensure their perspectives on validity and feasibility would be reflected in further revisions to the tool.

Informal Feedback

Abt encouraged hospice staff to ask questions and provide feedback about the HOPE forms and testing throughout the beta test. Abt triaged and responded to all requests, questions, and feedback received via a dedicated study mailbox. The team also conducted weekly scheduled virtual Office Hours in the earlier months of data collection. About midway through data collection, to better suit participants' schedules and information needs, Abt altered the Office Hours format, reduced the frequency to bimonthly, and renamed them Beta Education, Support, and Training (BEST) sessions. Abt recorded BEST sessions and shared the recording link with all hospice liaisons to distribute to their staff, so that any who were unable to attend the session could still benefit from the updates and question-and-answer session.

In addition, hospice staff could enter comments directly into the HOPE form in REDCap® using a comment feature available next to the data elements. Abt reviewed comments entered in REDCap® and responded to any questions submitted. When Abt analysis of form data indicated the hospice staff were not completing a data element as intended, the liaisons were asked to contact their teams for specific feedback about their understanding and interpretation of the data element and guidance. Hospice staff responses to these requests informed future follow-up education with hospice staff and updates to the data element and/or guidance to clarify data element intent and response-specific instructions. Updates were then shared in handouts distributed to all hospice staff participants. Abt synthesized item-related feedback from the 65 REDCap® comments with all other hospice staff feedback in the qualitative analysis.

Online Survey

Abt evaluated the performance of the HOPE data elements and the REDCap® data collection tool with an online survey launched early in data collection using the Confirmit[17] survey platform. This timing was chosen

[16] The RN Reassessment form and the SW Admission form each had a small number of patients for whom the forms were started but not completed (two and one, respectively). Note that a completed form is one which the final administrative data elements on the form were completed, not necessarily that all applicable fields with the form were completed.

[17] Forsta now owns what was previously Confirmit. https://www.forsta.com/.

to optimize data accuracy and completeness, particularly for the new psychosocial and spiritual tool items, and to ensure hospice staff used the REDCap® data collection tool correctly. Abt drafted the survey questions and revised them based on CMS feedback. The survey first collected information on respondent discipline, years of experience working in hospice and whether the respondent had completed any HOPE forms with patients during the beta test. Respondents were then asked to provide feedback about the HOPE data elements at admission, symptom reassessment and discharge. Specifically, the survey asked about:

- Clinical usefulness of the data elements.
- Ease and burden of data collection for both assessors and patients/families.
- Factors that affected respondent ability to collect information for the HOPE tool.
- Time to complete the HOPE tool.
- Additional questions or comments related to the HOPE tool.

Abt launched the online survey on April 14, 2022, and requested that hospice staff complete the survey within one week, with one reminder sent prior to the survey closing. Overall, 52 staff completed the survey; 21 of these respondents were RNs, 10 were SWs and nine were chaplains. One respondent was both a SW and a chaplain. Thirteen respondents did not report their discipline. Among all the respondents, 94 percent had completed at least one HOPE form with patients.

Focus Groups

Abt invited all hospice staff who completed HOPE forms to participate in focus groups. In collaboration with CMS, Abt developed semi-structured interview guides for a 60- to 90-minute focus group session, along with a discussion topic handout for hospice staff to review in advance of the focus groups. Abt conducted nine virtual focus groups from May through June 2022, via WebEx, with hospice staff and liaisons from 19 participating hospices. In November 2022, just after data collection ended, Abt conducted six additional focus groups with 16 hospices to elicit experiences from later in the beta test when hospice staff had more experience with HOPE (Exhibit C-6).

Exhibit C-6. Focus Group Participants by Discipline

Discipline	Total Hospice Staff Spring 2022	Total Hospice Staff Fall 2022	Total Hospice Staff Total
Registered nurses	30	27	57
Social workers	17	27	44
Chaplains	14	16	30
Other (liaisons, administrators)	6	6	12
Total	67	76	143

Each focus group had a dedicated note-taker and was audio-recorded with participant permission. Facilitators invited all focus group participants to provide feedback on HOPE (i.e., feasibility, alignment with current processes), the training or support that was most helpful and what could be improved. The RN focus groups covered clinical HOPE data elements, challenges in completing the data elements, alignment of the RN Symptom Reassessment form with usual practice for symptom reassessment, the most important items in the RN Admission Symptom Reassessment forms and use of the RN Discharge form. The SW and chaplain focus groups covered the HOPE psychosocial and spiritual data elements, challenges in completing data elements and the most important data elements in the SW and chaplain forms. Abt synthesized focus group results with survey results and all informal hospice staff feedback. Analysis of qualitative feedback informed determination of data element validity and feasibility.

Analytic Approach

Abt used quantitative and qualitative methods to assess validity, feasibility, and reliability of Beta HOPE data elements.

Validity

Abt conducted a series of descriptive and qualitative analyses to determine face and content validity.

Descriptive univariate response distributions (i.e., descriptive statistics) showed whether the responses selected were what one would logically expect. For example, if the response distribution for *J2050. Symptom Impact* revealed that 90 percent of patients in the sample experienced no impact of any symptom, this suggests an issue with data element content given that it does not align with expectations for this end-of-life population.

Questions asked of hospice staff to inform content validity included, for example: Is this item (these items) relevant and meaningful for hospice? Do these items support care planning and patient care?

To examine convergent validity, Abt analyzed results of cross-tabulations and Chi-square statistics for selected conceptually related items. These analyses allowed for examination of whether anticipated relationships existed between items measuring the same or similar constructs (e.g., pain impact and pain severity). Convergent validity analyses reflect associations but not direction or causality.

Feasibility

Both quantitative and qualitative data informed the feasibility analyses, which focused on two areas: 1) an assessment of the extent of missing data, and 2) hospice staff perspectives on, for example, clarity of item purpose, and how easy or challenging a data element was to complete.

High levels of missing data suggest items may not be feasible to collect, either due to an issue with the data element concept, content or structure, or because hospice staff perceived challenges completing the data element or collecting the data from patients and family/caregivers. Some evidence suggests that more than 10 percent of missing data is likely to cause bias in analyses.[xxix] Abt computed missing data frequencies in a multi-step analysis that first considered the forms (i.e., admission, symptom reassessment and/or discharge) in which the hospice staff collected the data elements. Data were then adjusted so that legitimate skip patterns were not counted as missing data.

In total, Abt calculated 235 missingness rates, reflecting data elements and their related individual components across timepoints (e.g., if the same data element was collected at admission and discharge, separate missingness calculations were calculated for each timepoint). Abt did not calculate missingness rates for data elements that required a drop-down or free text entry (*A1100.A Language* and *M0300. Number of Unhealed Pressure Ulcers/Injuries at Each Stage*). These data elements are neither binary nor check all that apply. Missingness rates cannot determine whether the entry was meaningful (e.g., whether the language entered was "Portuguese" or "unknown"), making it a poor indicator of feasibility for such data elements. Abt also did not calculate missingness rates for data element *D0160. Total Severity Score.* This data element is automatically calculated based on previous answers about the patient's mood.

In addition to missingness rates, Abt drew on hospice staff feedback and focus group results to understand data element feasibility, including whether the data element's purpose and intent were easy to understand, whether the data elements were easy or challenging to complete, and whether the forms were similar to their current assessments and fit their current workflow.

Reliability

Beta testing also sought to establish the reliability of individual data elements. Data element reliability supports the overall quality of the HOPE-collected data – and the quality measures calculated from those data. Statistical reliability occurs when the same results are consistently yielded across multiple trials.

To measure inter-rater reliability, two raters (an assessor and an observer) completed the same data elements for the same patient. Inter-rater reliability reflects the extent to which two raters select the same response for each item, across all trials. For example, if the assessor selects the response option "severe" for *J2050A Symptom Impact: Pain*, agreement exists when the observer also selects the response option "severe." This is one trial of the item. Inter-rater reliability is a useful means of assessing statistical reliability because it ensures that two different raters are coding the same responses for the same participant independently; that is, they are receiving the same information, processing that information independently and producing the same response.

Abt used Cohen's Kappa to assess inter-rater reliability for Beta HOPE data elements. This statistic, unlike simple percent agreement, is a method of estimating inter-rater reliability that considers that raters might agree purely by chance. By discounting chance agreements, kappa provides more certainty that observed strong agreement for a data element means that data element is more likely to be reliable. Kappa values range from -1.0 (perfect disagreement) to 1.0 (perfect agreement). A kappa of zero indicates that any agreement occurred by chance. For the purposes of the beta test, kappa values of 0.41 to 0.60 are considered moderate agreement and everything above that is considered good or very good agreement.[xxx]

Reliability estimates such as inter-rater reliability consider agreement as occurring when the responses are the same. But when there are multiple possible responses, such as in items that ask users to "check all that apply," the definition of agreement can take many forms. Abt used a summary approach to calculate inter-rater reliability for these items called pooled kappa. In this approach, the components of the kappa calculation (i.e., proportions of observed and chance agreement) are calculated for each response option. Then, the meaning of each response-level component is calculated, and an item-level kappa is calculated using the new mean inputs. This approach preserves the most information about how raters chose responses while allowing for a single pooled kappa value to be reported for the data element[xxxi]. Compared to calculating a simple average kappa – where response-level kappas are calculated and averaged into a single kappa – pooled kappa offers more precise estimates of inter-rater reliability across all sample sizes.[xxxii]

Abt calculated 171 Kappa statistics, reflecting data elements and their related individual components. Unlike missingness rates, Kappa statistics pooled data elements across timepoints (e.g., data elements that are part of both an admission and discharge form have a single Kappa statistic). While feasibility may vary depending on when a form is completed (e.g., the availability of a family or caregiver may be different at admission than at discharge), whether an assessor and observer agreed would not be expected to be different at different time periods. In addition, pooling across timepoints facilitated computation of Kappa statistics for data elements subject to skip patterns, and therefore collected only for a subset of participating patients, for which sample sizes might otherwise be too small to support this analysis. Kappa statistics are not presented for *D0160. Total Severity Score*, as it is automatically calculated based on previous answers about the patient's mood.

Appendix D: Feasibility Results

High levels of missing data suggest items may not be feasible to collect, either due to an issue with the data element concept, content or structure, or because hospice staff perceived challenges completing the data element or collecting the data from patients and family/caregivers.

This appendix details the proportion of missing data for each Beta HOPE data element, which only used assessor-completed forms (i.e., observer forms were excluded). The proportion missing is the percent of responses missing where the data element should have been completed (i.e., the HOPE tool was started and skip patterns were not triggered to skip the data element).

For data elements that require the user to *Check All That Apply* the data element is considered missing if none of the available options is selected.

Missingness was not calculated for D0160 because it is a calculated field rather than a social worker entered field. Missingness rates were not calculated for data elements that required a drop-down or free text entry (*A1100.A Language* and *M0300. Number of Unhealed Pressure Ulcers/Injuries at Each Stage*). These data elements are neither binary nor check all that apply; missingness rates cannot determine whether the entry was meaningful, making it a poor indicator of feasibility.

RN Admission Form: Missing Data

Data Element	Expected (n)	Missing (n)	Missing (%)
A0205. Site of Service at Admission	289	21	7.3
A1005. Ethnicity: Are you of Hispanic, Latino/a, or Spanish origin?	289	5	1.7
A1010. Race: What is your race?	289	5	1.7
A1110 B. Interpreter	289	1	0.3
F0900. Living Arrangements	289	1	0.3
F0915. Availability of Assistance	289	1	0.3
F1000. Advance Care Planning Preferences	289	4	1.4
GG0130A. Eating	289	0	0.0
GG0130B. Oral Hygiene	289	0	0.0
GG0130C. Toileting Hygiene	289	0	0.0
GG0130E. Shower/Bathe Self	289	1	0.3
GG0170A. Roll Left And Right	289	0	0.0
GG0170D. Sit To Stand	289	0	0.0
GG0170E. Chair/bed-to-chair transfer	289	0	0.0
GG0170F. Toilet Transfer	289	1	0.3
GG0170I. Walk 10 Feet	289	0	0.0
I0030. Primary Medical Condition Category	289	10	3.5
I0050. Comorbidities and Co-existing Conditions	289	17	5.9
J0900A. Patient Screened for Pain	289	0	0.0
J0900C. Pain Severity	278	1	0.4
J0905. Pain Active Problem	289	3	1.0
J0915. Neuropathic Pain	289	3	1.0
J1410. Death is Imminent	289	3	1.0
J1420. Signs of Imminent Death	15	1	6.7
J2050A. Symptom Impact: Pain	289	2	0.7
J2050B. Symptom Impact: Shortness of breath	289	2	0.7

Data Element	Expected (n)	Missing (n)	Missing (%)
J2050C. Symptom Impact: Anxiety	289	2	0.7
J2050D. Symptom Impact: Nausea	289	2	0.7
J2050E. Symptom Impact: Vomiting	289	2	0.7
J2050F. Symptom Impact: Diarrhea	289	2	0.7
J2050G. Symptom Impact: Constipation	289	2	0.7
J2050H. Symptom Impact: Agitation	289	2	0.7
J2060A. Desired Tolerance: Pain	289	5	1.7
J2060B. Desired Tolerance: Shortness of breath	289	5	1.7
J2060C. Desired Tolerance: Anxiety	289	5	1.7
J2060D. Desired Tolerance: Nausea	289	5	1.7
J2060E. Desired Tolerance: Vomiting	289	5	1.7
J2060F. Desired Tolerance: Diarrhea	289	5	1.7
J2060G. Desired Tolerance: Constipation	289	5	1.7
J2060H. Desired Tolerance: Agitation	289	6	2.1
J2070A. Preferences for Symptom Management: Pain	289	4	1.4
J2070B. Preferences for Symptom Management: Shortness of Breath	289	3	1.0
J2070C. Preferences for Symptom Management: Anxiety	289	3	1.0
J2070D. Preferences for Symptom Management: Nausea	289	3	1.0
J2070E. Preferences for Symptom Management: Vomiting	289	3	1.0
J2070F. Preferences for Symptom Management: Diarrhea	289	3	1.0
J2070G. Preferences for Symptom Management: Constipation	289	3	1.0
J2070H. Preferences for Symptom Management: Agitation	289	3	1.0
JJ0010. Chaplain/Spiritual Care Offered	289	2	0.7
JJ0015. Social Work Offered	289	2	0.7
M0210. Unhealed Pressure Ulcers/Injuries	274	2	0.7
M1085. Other Skin Conditions	274	11	4.0
M1090. Characteristics of Pressure Ulcers /Injuries and Other Skin Conditions	274	16	5.8
M1095. Interventions for Pressure Ulcers/Injuries and Other Skin Conditions	274	15	5.5
N0470. Medication Management	216	2	0.9
N0471. Medication Management - Patient	73	0	0.0
N0472. Medication Management - Caregiver	73	1	1.4
Q1000A1. Education & Training Needs: Communication	289	2	0.7
Q1000A2. Education & Training Initiated/Ongoing: Communication	215	6	2.8
Q1000B1. Education & Training Needs: Basic caregiving skills	289	2	0.7
Q1000B2. Education & Training Initiated/Ongoing: Basic caregiving skills	139	2	1.4
Q1000C1. Education & Training Needs: Wound care	289	2	0.7
Q1000C2. Education & Training Initiated/Ongoing: Wound care	43	1	2.3
Q1000D1. Education & Training Needs: Mouth and/or oral care	289	2	0.7
Q1000D2. Education & Training Initiated/Ongoing: Mouth and/or Oral Care	91	1	1.1
Q1000E1. Education & Training Needs: Infection control	289	2	0.7
Q1000E2. Education & Training Initiated/Ongoing: Infection Control	150	7	4.7
Q1000F1. Education & Training Needs: Equipment Use And Management	289	2	0.7
Q1000F2. Education & Training Initiated/Ongoing: Equipment Use And Management	133	4	3.0

Data Element	Expected (n)	Missing (n)	Missing (%)
Q1000G1. Education & Training Needs: Medication Management	289	2	0.7
Q1000G2. Education & Training Initiated/Ongoing: Medication Management	189	5	2.6
Q1000H1. Education & Training Needs: Symptom Management	289	2	0.7
Q1000H2. Education & Training Initiated/Ongoing: Symptom Management	237	3	1.3
Q1000I1. Education & Training Needs: Signs & Symptoms Of Patient Decline	289	2	0.7
Q1000I2. Education & Training Initiated/Ongoing: Signs & Symptoms Of Patient Decline	237	7	3.0
Q1000J1. Education & Training Needs: Other	289	92	31.8
Q1000J2. Education & Training Initiated/Ongoing: Other	10	0	0.0
Q1100A1. Resource Needs: Volunteer support	289	4	1.4
Q1100A2. Referral Given: Volunteer support	74	3	4.1
Q1100B1. Resource Needs: Aide support	289	3	1.0
Q1100B2. Referral Given: Aide support	216	11	5.1
Q1100C1. Resource Needs: DME and/or medical equipment	289	3	1.0
Q1100C2. Referral Given: DME and/or medical equipment	191	9	4.7
Q1100D1. Resource Needs: Inpatient respite care	289	4	1.4
Q1100D2. Referral Given: Inpatient respite care	22	1	4.6
Q1100E1. Resource Needs: General inpatient care or continuous home care	289	4	1.4
Q1100E2. Referral Given: General inpatient care or continuous home care	20	2	10.0
Q1100F1. Resource Needs: Other	289	91	31.5
Q1100F2. Referral Given: Other	1	0	0.0

Missingness was not calculated for date fields because they are not entered by the RN, have an unknown expected rate, or the RN is forced to complete it to submit the assessment.
Missingness rates were not calculated for data elements that required a drop-down or free text entry (*A1100.A Language* and *M0300. Number of Unhealed Pressure Ulcers/Injuries at Each Stage*). These data elements are neither binary nor check all that apply; missingness rates cannot determine whether the entry was meaningful making it a poor indicator of feasibility.
Source: Assessor-initiated Beta Test HOPE RN Admission forms.

RN Discharge Form: Missing Data

Data Element	Expected (n)	Missing (n)	Missing (%)
A1850. Emergency Room Use	30	1	3.3
A2105. Discharge Location	28	1	3.6
A2115. Reason for Discharge	30	1	3.3
A2121. Provision of Current Reconciled Medication List to Subsequent Provider at Discharge	11	0	0.0
A2122. Route of Current Reconciled Medication List Transmission to Subsequent Provider	8	0	0.0
A2123. Provision of Current Reconciled Medication List to Patient at Discharge	16	0	0.0
A2124. Route of Current Reconciled Medication List Transmission to Patient	13	0	0.0
F1010A. Advance Care Planning Preferences Follow-up: Chest compression	30	1	3.3
F1010B. Advance Care Planning Preferences Follow-up: Intubation	30	1	3.3
F1010C. Advance Care Planning Preferences Follow-up: Hospitalization	30	1	3.3
GG0130A. Eating	28	1	3.6
GG0130B. Oral Hygiene	28	1	3.6
GG0130C. Toileting Hygiene	28	1	3.6
GG0130E. Shower/bathe self	28	1	3.6
GG0170A. Roll left and right	28	1	3.6
GG0170D. Sit to stand	28	1	3.6
GG0170E. Chair/bed-to-chair transfer	28	1	3.6
GG0170F. Toilet transfer	28	1	3.6
GG0170I. Walk 10 feet	28	1	3.6
J1800. Any Falls	30	2	6.7
J1900A. Number of Falls: No injury	5	0	0.0
J1900B. Number of Falls: Injury (except major)	5	0	0.0
J1900C. Number of Falls: Major injury	5	0	0.0
J2050A. Symptom Impact: Pain	30	2	6.7
J2050B. Symptom Impact: Shortness of breath	30	2	6.7
J2050C. Symptom Impact: Anxiety	30	2	6.7
J2050D. Symptom Impact: Nausea	30	2	6.7
J2050E. Symptom Impact: Vomiting	30	2	6.7
J2050F. Symptom Impact: Diarrhea	30	2	6.7
J2050G. Symptom Impact: Constipation	30	2	6.7
J2050H. Symptom Impact: Agitation	30	2	6.7
M0210. Unhealed Pressure Ulcers/Injuries	28	0	0.0
M1085. Other Skin Conditions	28	2	7.1
M1090. Characteristics of Pressure Ulcers/Injuries and Other Skin Conditions	28	2	7.1
M1095. Interventions for Pressure Ulcers/Injuries and Other Skin Conditions	28	2	7.1
N0470. Medication Management	28	0	0.0
N0471. Medication Management; Patient	0	0	0.0
N0472. Medication Management: Caregiver	0	0	0.0

Data Element	Expected (n)	Missing (n)	Missing (%)

Missingness was not calculated for date fields because they are not entered by the RN, have an unknown expected rate, or the RN is forced to complete it to submit the assessment.
Missingness rates were not calculated for data element(s) that required a free text entry (*M0300. Number of Unhealed Pressure Ulcers/Injuries at Each Stage*). These data elements are neither binary nor check all that apply; missingness rates cannot determine whether the entry was meaningful making it a poor indicator of feasibility.
Source: Assessor-initiated Beta Test HOPE RN Discharge forms.

RN Symptom Reassessment Form: Missing Data

Data Element	Expected (n)	Missing (n)	Missing (%)
J0900A. Patient Screened for Pain	55	3	5.5
J0900C. Pain Severity	48	1	2.1
J2050A. Symptom Impact: Pain	55	4	7.3
J2050B. Symptom Impact: Shortness of breath	55	4	7.3
J2050C. Symptom Impact: Anxiety	55	4	7.3
J2050D. Symptom Impact: Nausea	55	4	7.3
J2050E. Symptom Impact: Vomiting	55	4	7.3
J2050F. Symptom Impact: Diarrhea	55	4	7.3
J2050G. Symptom Impact: Constipation	55	4	7.3
J2050H. Symptom Impact: Agitation	55	4	7.3
J2060A. Desired Tolerance: Pain	55	3	5.5
J2060B. Desired Tolerance: Shortness of breath	55	3	5.5
J2060C. Desired Tolerance: Anxiety	55	3	5.5
J2060D. Desired Tolerance: Nausea	55	3	5.5
J2060E. Desired Tolerance: Vomiting	55	3	5.5
J2060F. Desired Tolerance: Diarrhea	55	3	5.5
J2060G. Desired Tolerance: Constipation	55	3	5.5
J2060H. Desired Tolerance: Agitation	55	3	5.5
J2070A. Preferences for Symptom Management: Pain	55	4	7.3
J2070B. Preferences for Symptom Management: Shortness of breath	55	4	7.3
J2070C. Preferences for Symptom Management: Anxiety	55	4	7.3
J2070D. Preferences for Symptom Management: Nausea	55	4	7.3
J2070E. Preferences for Symptom Management: Vomiting	55	4	7.3
J2070F. Preferences for Symptom Management: Diarrhea	55	4	7.3
J2070G. Preferences for Symptom Management: Constipation	55	4	7.3
J2070H. Preferences for Symptom Management: Agitation	55	4	7.3
J2080A. Follow-up Symptom Control: Pain	55	3	5.5
J2080B. Follow-up Symptom Control: Shortness of breath	55	3	5.5
J2080C. Follow-up Symptom Control: Anxiety	55	3	5.5
J2080D. Follow-up Symptom Control: Nausea	55	3	5.5
J2080E. Follow-up Symptom Control: Vomiting	55	3	5.5
J2080F. Follow-up Symptom Control: Diarrhea	55	3	5.5
J2080G. Follow-up Symptom Control: Constipation	55	3	5.5
J2080H. Follow-up Symptom Control: Agitation	55	4	7.3

Missingness was not calculated for date fields because they are not entered by the RN, have an unknown expected rate, or the RN is forced to complete it to submit the assessment.
Source: Assessor-initiated Beta Test HOPE RN Symptom Reassessment forms.

Chaplain Admission Form: Missing Data

Data Element	Expected (n)	Missing (n)	Missing (%)
AA0050A. Patient able to respond	233	1	0.4
AA0050B. Patient willing to participate	166	2	1.2
AA0100. Patient at Peace	151	0	0.0
AA0110. Meaning and Joy	151	0	0.0
AA0120A. Spiritual or Religious Struggles: Patient	233	1	0.4
AA0120B. Spiritual or Religious Struggles: Caregiver	233	1	0.4
AA0130A. Comfort and Strength: Patient	233	1	0.4
AA0130B. Comfort and Strength: Caregiver	233	1	0.4
AA0140A. Visits/Support from Faith Community: Patient	233	1	0.4
AA0140B. Visits/Support from Faith Community: Caregiver	233	2	0.9
AA0150A. Spiritual or Religious Needs: Patient	233	5	2.2
AA0150B. Spiritual or Religious Needs: Caregiver	233	2	0.9
AA0200. Spiritual Plan of Care	233	3	1.3

Missingness was not calculated for date fields because they are not entered by the chaplain, have an unknown expected rate, or the chaplain is forced to complete it to submit the assessment.
Source: Assessor-initiated Beta Test HOPE Chaplain Admission forms.

Chaplain Discharge Form: Missing Data

Data Element	Expected (n)	Missing (n)	Missing (%)
AA0050A. Patient able to respond	17	0	0.0
AA0050B. Patient willing to participate	15	0	0.0
AA0100. Patient at Peace	13	0	0.0
AA0110. Meaning and Joy	13	0	0.0
AA0120A. Spiritual or Religious Struggles: Patient	17	0	0.0
AA0120B. Spiritual or Religious Struggles: Caregiver	17	0	0.0
AA0130A. Comfort and Strength: Patient	17	0	0.0
AA0130B. Comfort and Strength: Caregiver	17	0	0.0
AA0140A. Visits/Support from Faith Community: Patient	17	0	0.0
AA0140B. Visits/Support from Faith Community: Caregiver	17	0	0.0

Missingness was not calculated for date fields because they are not entered by the chaplain, have an unknown expected rate, or the chaplain is forced to complete it to submit the assessment.
Relatively early in Beta HOPE testing data collection, because of reported hospice staffing challenges, Abt directed chaplains to complete only the admission form instead of both admission and discharge forms
Source: Assessor-initiated Beta Test HOPE Chaplain Discharge forms.

SW Admission Form: Missing Data

Data Element	Expected (n)	Missing (n)	Missing (%)
D0150A1. PHQ2: Symptom A: Little interest or pleasure in doing things	253	7	2.8
D0150A2. PHQ2: Frequency A: Little interest or pleasure in doing things	86	1	1.2
D0150B1. PHQ2: Symptom B: Feeling down, depressed, or hopeless	253	7	2.8
D0150B2. PHQ2: Frequency B: Feeling down, depressed, or hopeless	74	1	1.4
D0180. Patient Feeling Anxious or Worried	253	7	2.8
D0190. Family Feeling Anxious or Worried	253	6	2.4
JJ0050. Psychosocial Assessment Completed	253	4	1.6
JJ0100. Care Needs	241	2	0.8
JJ0110. Safety	241	3	1.2
JJ0120A. Financial Resources: Patient	241	3	1.2
JJ0120B. Financial Resources: Caregiver	241	3	1.2
JJ0130A. Social Support: Patient	241	4	1.7
JJ0130B. Social Support: Caregiver	241	2	0.8
JJ0140A. Cultural Values: Patient	241	2	0.8
JJ0140B. Cultural Values: Caregiver	241	3	1.2
JJ0150A. Awareness of Prognosis: Patient	241	3	1.2
JJ0150B. Awareness of Prognosis: Caregiver	241	2	0.8
JJ0160A. Coping Related to Anticipatory Grief: Patient	241	4	1.7
JJ0160B. Coping Related to Anticipatory Grief: Caregiver	241	2	0.8
JJ0180A. Psychosocial Needs: Patient	241	3	1.2
JJ0180B. Psychosocial Needs: Caregiver	241	3	1.2
JJ0200. Psychosocial Plan of Care	176	5	2.8
Q1200A1. Resource Needs: Mental Health Counseling	253	7	2.8
Q1200A2. Referral Given: Mental Health Counseling	20	2	10.0
Q1200B1. Resource Needs: Social worker support	253	6	2.4
Q1200B2. Referral Given: Social worker support	177	8	4.5
Q1200C1. Resource Needs: Chaplain and/or spiritual counselor	253	8	3.2
Q1200C2. Referral Given: Chaplain and/or spiritual counselor	146	6	4.1
Q1200D1. Resource Needs: Cultural support	253	7	2.8
Q1200D2. Referral Given: Cultural support	5	0	0.0
Q1200E1. Resource Needs: Financial	253	7	2.8
Q1200E2. Referral Given: Financial	21	0	0.0
Q1200F1. Resource Needs: Connection to community resources	253	7	2.8
Q1200F2. Referral Given: Connection to community resources	52	0	0.0
Q1200G1. Resource Needs: Transportation	253	7	2.8
Q1200G2. Referral Given: Transportation	9	0	0.0
Q1200H1. Resource Needs: Other	253	37	14.6
Q1200H2. Referral Given: Other	7	0	0.0

Missingness was not calculated for date fields because they are not entered by the SW, have an unknown expected rate, or the SW is forced to complete it to submit the assessment.
Missingness was not calculated for D0160 because it is a calculated field rather than a social worker entered field.
Source: Assessor-initiated Beta Test HOPE SW Admission forms.

SW Discharge Form: Missing Data

Data Element	Expected (n)	Missing (n)	Missing (%)
JJ0050. Psychosocial Assessment Completed	24	0	0.0
JJ0100. Care Needs	19	0	0.0
JJ0110. Safety	19	0	0.0
JJ0120A. Financial Resources: Patient	19	0	0.0
JJ0120B. Financial Resources: Caregiver	19	0	0.0
JJ0130A. Social Support: Patient	19	0	0.0
JJ0130B. Social Support: Caregiver	19	0	0.0
JJ0140A. Cultural Values: Patient	19	0	0.0
JJ0140B. Cultural Values: Caregiver	19	0	0.0
JJ0150A. Awareness of Prognosis: Patient	19	0	0.0
JJ0150B. Awareness of Prognosis: Caregiver	19	0	0.0
JJ0160A. Coping Related to Anticipatory Grief: Patient	19	0	0.0
JJ0160B. Coping Related to Anticipatory Grief: Caregiver	19	0	0.0

Missingness was not calculated for date fields because they are not entered by the SW, have an unknown expected rate, or the SW is forced to complete it to submit the assessment.
Relatively early in Beta HOPE testing data collection, because of reported hospice staffing challenges, Abt directed SWs and chaplains to complete only the admission form instead of both admission and discharge forms.
Source: Assessor-initiated Beta Test HOPE SW Discharge forms.

Appendix E: Reliability Results

Abt used Cohen's Kappa to assess inter-rater reliability for Beta HOPE data elements. This statistic, unlike simple percent agreement, is a method of estimating inter-rater reliability that considers that raters might agree purely by chance. By discounting chance agreements, kappa provides more certainty that observed strong agreement for a data element means that data element is more likely to be reliable. Kappa values range from -1.0 (perfect disagreement) to 1.0 (perfect agreement). A kappa of zero indicates that any agreement occurred by chance.

For responses that require the user to *Check All That Apply* Abt used a summary approach to calculate inter-rater reliability called pooled kappa. In this approach, the components of the kappa calculation (i.e., proportions of observed and chance agreement) are calculated for each response option.

For *Q1000*, *Q1100* and *Q1200*, Abt collapsed the categories for patient need identified, caregiver need identified, and patient and caregiver need identified because of relatively small numbers when evaluated separately. Results reflect any education/training need identified for each topic.

The maximum number of paired assessments were: 250 for RN admission; 271 for RN Admission & RN Discharge; 40 for RN Symptom Reassessment; 250 for RN Admission & RN Symptom Reassessment; 28 for RN Discharge; 237 for RN Admission, RN Symptom Reassessment & RN Discharge; 218 for SW Admission; 232 for SW Admission & SW Discharge; 204 for Chaplain Admission; 216 for CH Admission & CH Discharge. Only those paired assessments for which both the assessor and observer completed the data element/component have been used in the inter-rater reliability calculation.

Inter-rater Reliability: RN Data Elements

Data Element	HOPE Form(s)	Paired HOPE Forms (n)	Kappa	Kappa Classification
A0205. Site of Service at Admission	RN Admission	217	0.91	Very Good
A1005. Ethnicity	RN Admission	241	0.99	Very Good
A1010. Race	RN Admission	243	0.99	Very Good
A1110 A. Language	RN Admission	247	0.99	Very Good
A1110 B. Interpreter	RN Admission	242	0.66	Good
A1850. Emergency Room Use	RN Discharge	27	0.99	Very Good
A2105. Discharge Location	RN Discharge	27	0.88	Very Good
A2115. Reason for Discharge	RN Discharge	28	0.92	Very Good
A2121. Provision of Current Reconciled Medication List to Subsequent Provider at	RN Discharge	28	0.86	Very Good
A2122. Route of Transmission to Subsequent Provider	RN Discharge	7	0.84	Very Good
A2123. Provision of Current Reconciled Medication List to Patient at Discharge	RN Discharge	28	0.68	Good
A2124. Route of Transmission to Patient	RN Discharge	11	0.89	Very Good

Data Element	HOPE Form(s)	Paired HOPE Forms (n)	Kappa	Kappa Classification
F0900. Living Arrangements	RN Admission	249	0.88	Very Good
F0915. Availability of Assistance	RN Admission	247	0.77	Good
F1000. Advance Care Planning Preferences	RN Admission	245	0.99	Very Good
F1010A. Advance Care Planning Preferences Follow-up: Chest compression	RN Discharge	28	0.65	Good
F1010B. Advance Care Planning Preferences Follow-up: Intubation	RN Discharge	28	0.99	Very Good
F1010C. Advance Care Planning Preferences Follow-up: Hospitalization	RN Discharge	28	0.99	Very Good
GG0130A. Eating	RN Admission RN Discharge	242	0.68	Good
GG0130B. Oral Hygiene	RN Admission RN Discharge	246	0.74	Good
GG0130C. Toileting Hygiene	RN Admission RN Discharge	244	0.75	Good
GG0130E. Shower/bathe self	RN Admission RN Discharge	241	0.71	Good
GG0170A. Roll left and right	RN Admission RN Discharge	244	0.55	Moderate
GG0170D. Sit to stand	RN Admission RN Discharge	210	0.64	Good
GG0170E. Chair/bed-to-chair transfer	RN Admission RN Discharge	203	0.66	Good
GG0170F. Toilet transfer	RN Admission RN Discharge	196	0.70	Good
GG0170I. Walk 10 feet	RN Admission RN Discharge	152	0.64	Good
I0030. Primary Medical Condition Category	RN Admission	234	0.90	Very Good
I0050. Comorbidities	RN Admission	227	0.99	Very Good
J0900A. Patient Screened for Pain	RN Admission RN Symptom Reassessment	250	0.27	Fair
J0900C. Pain Severity	RN Admission RN Symptom Reassessment	248	0.75	Good
J0905. Pain Active Problem	RN Admission	249	0.78	Good
J0915. Neuropathic Pain	RN Admission	245	0.78	Good

Data Element	HOPE Form(s)	Paired HOPE Forms (n)	Kappa	Kappa Classification
J1410. Death is Imminent	RN Admission	244	0.88	Very Good
J1420. Signs of Imminent Death	RN Admission	12	0.89	Very Good
J1800. Any Falls	RN Discharge	27	0.86	Very Good
J1900A. Number of Falls: No injury	RN Discharge	28	0.95	Very Good
J1900B. Number of Falls: Injury (except major)	RN Discharge	28	0.66	Good
J1900C. Number of Falls: Major injury	RN Discharge	28	0.88	Very Good
J2050A. Symptom Impact: Pain	RN Admission RN Symptom Reassessment RN Discharge	237	0.71	Good
J2050B. Symptom Impact: Shortness of breath	RN Admission RN Symptom Reassessment RN Discharge	210	0.65	Good
J2050C. Symptom Impact: Anxiety	RN Admission RN Symptom Reassessment RN Discharge	209	0.60	Good
J2050D. Symptom Impact: Nausea	RN Admission RN Symptom Reassessment RN Discharge	164	0.61	Good
J2050E. Symptom Impact: Vomiting	RN Admission RN Symptom Reassessment RN Discharge	144	0.59	Moderate
J2050F. Symptom Impact: Diarrhea	RN Admission RN Symptom Reassessment RN Discharge	148	0.59	Moderate
J2050G. Symptom Impact: Constipation	RN Admission RN Symptom Reassessment RN Discharge	169	0.51	Moderate
J2050H. Symptom Impact: Agitation	RN Admission RN Symptom Reassessment RN Discharge	185	0.45	Moderate
J2060A. Desired Tolerance: Pain	RN Admission RN Symptom Reassessment	201	0.55	Moderate
J2060B. Desired Tolerance: Shortness of breath	RN Admission RN Symptom Reassessment	162	0.70	Good
J2060C. Desired Tolerance: Anxiety	RN Admission RN Symptom Reassessment	166	0.57	Moderate

Data Element	HOPE Form(s)	Paired HOPE Forms (n)	Kappa	Kappa Classification
J2060D. Desired Tolerance: Nausea	RN Admission RN Symptom Reassessment	117	0.60	Good
J2060E. Desired Tolerance: Vomiting	RN Admission RN Symptom Reassessment	85	0.71	Good
J2060F. Desired Tolerance: Diarrhea	RN Admission RN Symptom Reassessment	91	0.59	Moderate
J2060G. Desired Tolerance: Constipation	RN Admission RN Symptom Reassessment	111	0.70	Good
J2060H. Desired Tolerance: Agitation	RN Admission RN Symptom Reassessment	134	0.60	Good
J2070A. Preferences for Symptom Management: Pain	RN Admission RN Symptom Reassessment	177	0.66	Good
J2070B. Preferences for Symptom Management: Shortness of breath	RN Admission RN Symptom Reassessment	140	0.65	Good
J2070C. Preferences for Symptom Management: Anxiety	RN Admission RN Symptom Reassessment	141	0.67	Good
J2070D. Preferences for Symptom Management: Nausea	RN Admission RN Symptom Reassessment	80	0.73	Good
J2070E. Preferences for Symptom Management: Vomiting	RN Admission RN Symptom Reassessment	51	0.71	Good
J2070F. Preferences for Symptom Management: Diarrhea	RN Admission RN Symptom Reassessment	49	0.71	Good
J2070G. Preferences for Symptom Management: Constipation	RN Admission RN Symptom Reassessment	85	0.73	Good
J2070H. Preferences for Symptom Management: Agitation	RN Admission RN Symptom Reassessment	99	0.64	Good
J2080A. Follow-up Symptom Control: Pain	RN Symptom Reassessment	40	0.79	Good
J2080B. Follow-up Symptom Control: Shortness of breath	RN Symptom Reassessment	40	0.95	Very Good
J2080C. Follow-up Symptom Control: Anxiety	RN Symptom Reassessment	40	0.82	Very Good
J2080D. Follow-up Symptom Control: Nausea	RN Symptom Reassessment	40	0.87	Very Good
J2080E. Follow-up Symptom Control: Vomiting	RN Symptom Reassessment	40	0.72	Good
J2080F. Follow-up Symptom Control: Diarrhea	RN Symptom Reassessment	40	0.53	Moderate
J2080G. Follow-up Symptom Control: Constipation	RN Symptom Reassessment	40	0.84	Very Good

Data Element	HOPE Form(s)	Paired HOPE Forms (n)	Kappa	Kappa Classification
J2080H. Follow-up Symptom Control: Agitation	RN Symptom Reassessment	39	0.81	Very Good
JJ0010. Chaplain/Spiritual Care Offered	RN Admission	250	0.70	Good
JJ0015. Social Work Offered	RN Admission	250	0.66	Good
M0210. Unhealed Pressure Ulcers/Injuries	RN Admission RN Discharge	270	0.88	Very Good
M0300A. Number of Stage 1 Pressure Ulcers	RN Admission RN Discharge	13	0.84	Very Good
M0300B. Number of Stage 2 Pressure Ulcers	RN Admission RN Discharge	18	0.68	Good
M0300C. Number of Stage 3 Pressure Ulcers	RN Admission RN Discharge	10	0.99	Very Good
M0300D. Number of Stage 4 Pressure Ulcers	RN Admission RN Discharge	10	0.99	Very Good
M0300E. Number of Unstageable: Non-removable dressing/device	RN Admission RN Discharge	10	0.99	Very Good
M0300F. Number of Unstageable: Slough and/or eschar	RN Admission RN Discharge	10	0.99	Very Good
M0300G. Number of Unstageable: Deep tissue injury	RN Admission RN Discharge	11	0.99	Very Good
M1085. Other Skin Conditions	RN Admission RN Discharge	236	0.99	Very Good
M1090. Characteristics of Skin Conditions	RN Admission RN Discharge	230	0.99	Very Good
M1095. Interventions for Skin Conditions	RN Admission RN Discharge	234	0.99	Very Good
N0470. Medication Management	RN Admission RN Discharge	269	0.84	Very Good
N0471. Medication Management: Caregiver	RN Admission RN Discharge	269	0.96	Very Good
N0472. Medication Management: Patient	RN Admission RN Discharge	271	0.96	Very Good
Q1000A1. Education & Training Needs: Communication	RN Admission	246	0.63	Good
Q1000A2. Education & Training Initiated/Ongoing: Communication	RN Admission	240	0.66	Good

Data Element	HOPE Form(s)	Paired HOPE Forms (n)	Kappa	Kappa Classification
Q1000B1. Education & Training Needs: Basic caregiving skills	RN Admission	241	0.64	Good
Q1000B2. Education & Training Initiated/Ongoing: Basic caregiving skills	RN Admission	246	0.63	Good
Q1000C1. Education & Training Needs: Wound care	RN Admission	164	0.83	Very Good
Q1000C2. Education & Training Initiated/Ongoing: Wound care	RN Admission	249	0.70	Good
Q1000D1. Education & Training Needs: Mouth and/or oral care	RN Admission	233	0.72	Good
Q1000D2. Education & Training Initiated/Ongoing: Mouth and/or oral care	RN Admission	249	0.68	Good
Q1000E1. Education & Training Needs: Infection control	RN Admission	233	0.65	Good
Q1000E2. Education & Training Initiated/Ongoing: Infection control	RN Admission	242	0.64	Good
Q1000F1. Education & Training Needs: Equipment use and management	RN Admission	227	0.68	Good
Q1000F2. Education & Training Initiated/Ongoing: Equipment use and management	RN Admission	244	0.66	Good
Q1000G1. Education & Training Needs: Medication management	RN Admission	245	0.63	Good
Q1000G2. Education & Training Initiated/Ongoing: Medication management	RN Admission	243	0.63	Good
Q1000H1. Education & Training Needs: Symptom management	RN Admission	246	0.53	Moderate
Q1000H2. Education & Training Initiated/Ongoing: Symptom management	RN Admission	238	0.52	Moderate
Q1000I1. Education & Training Needs: Signs & symptoms of patient decline	RN Admission	243	0.53	Moderate
Q1000I2. Education & Training Initiated/Ongoing: Signs & symptoms of patient decline	RN Admission	239	0.46	Moderate
Q1000J1. Education & Training Needs: Other	RN Admission	85	0.47	Moderate
Q1000J2. Education & Training Initiated/Ongoing: Other	RN Admission	250	0.24	Fair

Data Element	HOPE Form(s)	Paired HOPE Forms (n)	Kappa	Kappa Classification
Q1100A1. Resource Needs: Volunteer support	RN Admission	231	0.68	Good
Q1100A2. Referral Given: Volunteer support	RN Admission	245	0.67	Good
Q1100B1. Resource Needs: Aide support	RN Admission	243	0.82	Very Good
Q1100B2. Referral Given: Aide support	RN Admission	228	0.80	Good
Q1100C1. Resource Needs: DME and/or medical equipment	RN Admission	241	0.68	Good
Q1100C2. Referral Given: DME and/or medical equipment	RN Admission	230	0.67	Good
Q1100D1. Resource Needs: Inpatient respite care	RN Admission	215	0.45	Moderate
Q1100D2. Referral Given: Inpatient respite care	RN Admission	247	0.44	Moderate
Q1100E1. Resource Needs: General inpatient care or continuous home care	RN Admission	212	0.59	Moderate
Q1100E2. Referral Given: General inpatient care or continuous home care	RN Admission	247	0.54	Moderate
Q1100F1. Resource Needs: Other	RN Admission	90	0.00	Poor
Q1100F2. Referral Given: Other	RN Admission	250	0.00	Poor

Inter-rater Reliability: SW Data Elements

Data Element	HOPE Form(s)	Paired HOPE Forms (n)	Kappa	Kappa Classification
D0150A1. PHQ2: Symptom A: Little interest or pleasure in doing things	SW Admission	159	0.76	Good
D0150A2. PHQ2: Frequency A: Little interest or pleasure in doing things	SW Admission	217	0.78	Good
D0150B1. PHQ2: Symptom B: Feeling down, depressed, or hopeless	SW Admission	158	0.83	Very Good
D0150B2. PHQ2: Frequency B: Feeling down, depressed, or hopeless	SW Admission	216	0.82	Very Good
D0160. PHQ2 Score	SW Admission	73	0.87	Very Good
D0180. Patient Feeling Anxious or Worried	SW Admission	169	0.67	Good
D0190. Family Feeling Anxious or Worried	SW Admission	188	0.52	Moderate
Q1200A1. Resource Needs: Mental health counseling	SW Admission	200	0.57	Moderate
Q1200A2. Referral Given: Mental health counseling	SW Admission	215	0.48	Moderate
Q1200B1. Resource Needs: Social worker support	SW Admission	213	0.70	Good
Q1200B2. Referral Given: Social worker support	SW Admission	204	0.68	Good

Data Element	HOPE Form(s)	Paired HOPE Forms (n)	Kappa	Kappa Classification
Q1200C1. Resource Needs: Chaplain and/or spiritual counselor	SW Admission	209	0.72	Good
Q1200C2. Referral Given: Chaplain and/or spiritual counselor	SW Admission	206	0.71	Good
Q1200D1. Resource Needs: Cultural support	SW Admission	205	0.48	Moderate
Q1200D2. Referral Given: Cultural support	SW Admission	217	0.44	Moderate
Q1200E1. Resource Needs: Financial	SW Admission	203	0.48	Moderate
Q1200E2. Referral Given: Financial	SW Admission	216	0.51	Moderate
Q1200F1. Resource Needs: Connection to community resources	SW Admission	209	0.75	Good
Q1200F2. Referral Given: Connection to community resources	SW Admission	216	0.71	Good
Q1200G1. Resource Needs: Transportation	SW Admission	204	0.56	Moderate
Q1200G2. Referral Given: Transportation	SW Admission	218	0.56	Moderate
Q1200H1. Resource Needs: Other	SW Admission	133	-0.01	Poor
Q1200H2. Referral Given: Other	SW Admission	217	-0.01	Poor
JJ0050. Psychosocial Assessment Completed	SW Admission	21	0.59	Moderate
JJ0100. Care Needs	SW Admission SW Discharge	232	0.65	Good
JJ0110. Safety	SW Admission SW Discharge	231	0.65	Good
JJ0120A. Financial Resources: Patient	SW Admission SW Discharge	226	0.55	Moderate
JJ0120B. Financial Resources: Caregiver	SW Admission SW Discharge	198	0.56	Moderate
JJ0130A. Social Support: Patient	SW Admission SW Discharge	228	0.47	Moderate
JJ0130B. Social Support: Caregiver	SW Admission SW Discharge	202	0.64	Good
JJ0140A. Cultural Values: Patient	SW Admission SW Discharge	210	0.51	Moderate
JJ0140B. Cultural Values: Caregiver	SW Admission SW Discharge	191	0.51	Moderate
JJ0150A. Awareness of Prognosis: Patient	SW Admission SW Discharge	188	0.67	Good
JJ0150B. Awareness of Prognosis: Caregiver	SW Admission SW Discharge	208	0.45	Moderate
JJ0160A. Coping Related to Anticipatory Grief: Patient	SW Admission SW Discharge	197	0.61	Good
JJ0160B. Coping Related to Anticipatory Grief: Caregiver	SW Admission SW Discharge	206	0.54	Moderate
JJ0180A. Psychosocial Needs: Patient	SW Admission	217	0.48	Moderate
JJ0180B. Psychosocial Needs: Caregiver	SW Admission	195	0.50	Moderate
JJ0200. Psychosocial Plan of Care	SW Admission	214	0.57	Moderate

Inter-rater Reliability: Chaplain Data Elements

Data Element	HOPE Form(s)	Paired HOPE Forms (n)	Kappa	Kappa Classification
AA0050A. Patient able to respond	Chaplain Admission Chaplain Discharge	211	0.90	Very Good
AA0050B. Patient willing to participate	Chaplain Admission Chaplain Discharge	216	0.89	Very Good
AA0100. Patient at Peace	Chaplain Admission Chaplain Discharge	216	0.69	Good
AA0110. Meaning and Joy	Chaplain Admission Chaplain Discharge	216	0.70	Good
AA0120A. Spiritual or Religious Struggles: Patient	Chaplain Admission Chaplain Discharge	192	0.52	Moderate
AA0120B. Spiritual or Religious Struggles: Caregiver	Chaplain Admission Chaplain Discharge	166	0.31	Fair
AA0130A. Comfort and Strength: Patient	Chaplain Admission Chaplain Discharge	193	0.61	Good
AA0130B. Comfort and Strength: Caregiver	Chaplain Admission Chaplain Discharge	160	0.64	Good
AA0140A. Visits/Support from Faith Community: Patient	Chaplain Admission Chaplain Discharge	195	0.64	Good
AA0140B. Visits/Support from Faith Community: Caregiver	Chaplain Admission Chaplain Discharge	168	0.62	Good
AA0150A. Spiritual or Religious Needs: Patient	Chaplain Admission	203	0.58	Moderate
AA0150B. Spiritual or Religious Needs: Caregiver	Chaplain Admission	162	0.43	Moderate
AA0200. Spiritual Plan of Care	Chaplain Admission	204	0.46	Moderate

Appendix F: Convergent Validity Results

For instances where the Abt team anticipated a relationship between two data elements, we conducted a Pearson's Chi-square. Absence of a statistically significant relationship (i.e., $p > 0.05$) might indicate issues with the question and response options in one or both data elements, indicating they do not capture the intended information. Additionally, for data elements collected at multiple timepoints, absence of a statistically significant relationship at each timepoint may indicate a validity challenge at one of the timepoints. These analyses were only completed for the Admission and Symptom Readmission timepoint because the Discharge timepoint had an inadequate sample size. Note that the HOPE Beta test was designed to test the validity of a data collection tool—not how a patient's treatment progressed over time.

Correlation of J0900.C Pain Severity and J2050.A Pain Impact

J0900.C. Pain Severity										
J2050.A. Pain Impact	None		Mild		Moderate		Severe		Total	
	N	%	N	%	N	%	N	%	N	%
Not applicable	27	100%	0	0.0%	0	0.0%	0	0.0%	27	100%
Not at all	68	94.4%	3	4.2%	1	1.4%	0	0.0%	72	100%
Slight	34	52.3%	28	43.1%	3	4.6%	0	0.0%	65	100%
Moderate	22	27.5%	15	18.8%	42	52.5%	1	1.2%	80	100%
Severe	4	12.5%	4	12.5%	2	2.2%	22	68.8%	32	100%
Total	155	56.2%	50	18.1%	48	17.4%	23	8.3%	276	100%

Pearson's Chi-Square test indicates statistically significant correlation: $\chi 2 = 325.35$; p-value <0.001.
Source: Assessor-initiated Beta Test HOPE RN Admission and Symptom Reassessment forms

Correlation of J2050. Symptom Impact with J2060. Patient Desired Tolerance Level for Symptoms and J2070. Patient Preferences for Symptom Management

	J2060. Patient and Desired Tolerance Level		J2070. Patient Preferences for Symptom Management	
J2050. Symptom Impact	Test Statistic (χ^2)	P-value	Test Statistic (χ^2)	P-value
Pain	127.4	<0.001	151.5	<0.001
Shortness of breath	186.7	<0.001	192.4	<0.001
Anxiety	162.6	<0.001	151.0	<0.001
Nausea	243.7	<0.001	131.1	<0.001
Vomiting	159.7	<0.001	78.67	<0.001
Diarrhea	164.0	<0.001	103.7	<0.001
Constipation	190.4	<0.001	162.1	<0.001
Agitation	153.2	<0.001	159.2	<0.001

Test statistics reflect Pearson's Chi-Square test. P-value of < 0.05 indicates statistical significance. Responses options were the same J2050, J2060, and J2070.
Source: Assessor-initiated Beta Test HOPE RN Admission forms.

Correlation of N0471. Patient Medication Management – Patient with F0900. Living Arrangements

	N0471. Medication Management - Patient							
F0900. Living Arrangements	Independent		Needs Assistance		Dependent		Total	
	N	%	N	%	N	%	N	%
Person lives alone	6	100%	0	0.0%	0	0.0%	6	100%
Person lives with others in the home	3	11.5%	3	11.5%	20	76.9%	26	100%
Person lives in congregate home	0	0.0%	2	16.7%	10	83.3%	12	100%

Person is in an inpatient facility	0	0.0%	1	3.4%	28	96.6%	29	100%
Person does not have a permanent home or is homeless	0	0.0%	0	0.0%	0	0.0%	0	100%
Missing	0	0.0%	0	0.0%	0	0.0%	0	100%
Total	9	12.3%	6	8.2%	58	79.5%	73	100%

Pearson's Chi-Square test indicates statistically significant correlation: $\chi 2 = 51.0$; p-value <0.001. No patients had data elements indicated as *Not Applicable* or missing.
Source: The 73 RN assessor-initiated Beta Test HOPE RN Admission forms in which *N0471. Medication Management - Patient* was collected.

Correlation of N0471. Patient Medication Management – Patient with F0915. Availability of Assistance

F0915. Availability of Assistance	N0471. Medication Management - Patient							
	Independent		Needs assistance		Dependent		Total Patients	
	N	%	N	%	N	%	N	%
No assistance available	0	0.0%	0	0.0%	2	100%	2	100%
Occasional short-term assistance	5	62.5%	1	12.5%	2	25.0%	8	100%
Regular nighttime	1	33.3%	1	33.3%	1	33.3%	3	100%
Regular daytime	0	0.0%	0	0.0%	1	100%	1	100%
Around-the-clock	3	5.1%	4	6.8%	52	88.1%	59	100%
Missing	0	0.0%	0	0.0%	0	0%	0	100%
Total Patients	9	12.3%	6	8.2%	58	79.5%	73	100%

Pearson's Chi-Square test indicates statistically significant correlation: $\chi 2 = 27.7$; p-value <0.001. No patients had data elements indicated as *Not Applicable* or missing.
Source: The 73 RN assessor-initiated Beta Test HOPE RN Admission forms in which *N0471. Medication Management - Patient* was collected.

Correlation of Data Elements at Admission and Symptom Reassessment

Data Element and Component	Test Statistic (χ^2)	P-value
J0090. Pain Screening (Admission and Reassessment)		
Pain Screening	29.7	< 0.01
Pain Severity	157.8	< 0.01
J2050. Symptom Impact (Admission and Reassessment)		
Pain	67.1	< 0.01
Shortness of Breath	43.2	< 0.01
Anxiety	30.4	0.02
Nausea	79.1	< 0.01
Vomiting	37.1	< 0.01
Diarrhea	19.2	< 0.01
Constipation	52.5	< 0.01
Agitation	36.9	< 0.01
J2060. Patient Desired Tolerance Level for Symptoms (Admission and Reassessment)		
Pain	64.1	< 0.01
Shortness of Breath	60.6	< 0.01
Anxiety	54.0	< 0.01
Nausea	31.2	< 0.01
Vomiting	62.7	< 0.01
Diarrhea	22.3	< 0.01
Constipation	43.3	< 0.01
Agitation	69.1	< 0.01
J2070. Patient Preferences for Symptom Management		

Pain	19.9	< 0.01
Shortness of Breath	33.9	< 0.01
Anxiety	16.2	< 0.01
Nausea	25.8	< 0.01
Vomiting	23.3	< 0.01
Diarrhea	31.2	< 0.01
Constipation	20.8	< 0.01
Agitation	3.7	0.45

Test statistics reflect Pearson's Chi-Square test. P-value of < 0.05 indicates statistical significance.
Chi-test testing across timepoints was completed only for data elements that had sufficient forms completed at the respective timepoints. Testing was designed only to determine the validity to the Beta Test HOPE forms. Results should not be interpreted as reflecting patient progress over time.
Source: Assessor-initiated Beta Test HOPE RN Admission and Symptom Reassessment forms.

Appendix G: References

[i] Medicare Payment Advisory Commission. (2023). Report to the Congress: Medicare and the health care delivery system, Chapter 10: Hospice Services. Washington, DC: MedPAC.

[ii] Hospice Quality Reporting Program, https://www.cms.gov/medicare/quality-initiatives-patient-assessment-instruments/hospice-quality-reporting

[iii] Abt Associates. (2019). Information-Gathering Report: Hospice Quality Reporting Program – Base Year. https://www.cms.gov/files/document/hope-information-gathering-report-508pdf.pdf

[iv] Abt Associates. (2019). Information-Gathering Report – Focus Groups Addendum: Hospice Quality Reporting Program – Base Year. https://www.cms.gov/files/document/hopefocusgroupaddendumhqrp508pdf.pdf

[v] Abt Associates. (2020). Information-Gathering Report: Hospice Quality Reporting Program – Option Year 1. https://www.cms.gov/files/document/12042020-information-gathering-oy1508.pdf

[vi] Abt Associates. (2021). Information-Gathering Report: Hospice Quality Reporting Program – Option Year 2. https://www.cms.gov/files/document/12202021-information-gathering-report-2021.pdf

[vii] Abt Associates. (2020). November 2019 Technical Expert Panel: Hospice Quality Reporting Program Summary Report. https://www.cms.gov/files/document/2019hospice-qrptep-summary-reportfinalaugust-2020-002.pdf

[viii] Abt Associates. (2021). 2020 Technical Expert Panels: Hospice Quality Reporting Program Summary Report. https://www.cms.gov/files/document/2020-hqrp-tep-summary-report.pdf

[ix] Abt Associates. (2022). 2021 Technical Expert Panel Meetings: Hospice Quality Reporting Program Summary Report. https://www.cms.gov/files/document/2021-hqrp-tep-summary-reportfinal.pdf

[x] CMS Measures Management System. *Measure Implementation: Measure Selection.* Last updated May 2023. Accessed May 19, 2023 at Measure Selection | The Measures Management System (cms.gov).

[xi] Madley-Down P, Hughes R, Tilling K., Heron J. (2019). The Proportion of Missing Data Should Not Be Used To Guide Decisions on Multiple Imputation. Journal of Clinical Epidemiology June 2019; 110: 63-73. Available at www.sciencedirect.com/science/article/pii/S0895435618308710. Retrieved 4/7/2023.

[xii] Altman DG 1991. *Practical statistics for medical research*. Chapman and Hall.

[xiii] Palliative Care Outcomes Scale (POS). (n.d.). *Integrated POS (IPOS) in English*. Cicely Saunders Institute. Retrieved September 20, 2023, from Palliative care Outcome Scale (POS) - Integrated POS (IPOS) in English (pos-pal.org)/

[xiv] Kroenke K, Spitzer RL, Williams JB. The Patient Health Questionnaire-2: Validity of a Two-Item Depression Screener. *Med Care*. 2003; 41:1284-1292.

[xv] Palliative Care Outcomes Scale (POS). (n.d.). *Integrated POS (IPOS) in English*. Cicely Saunders Institute. Retrieved September 20, 2023, from Palliative care Outcome Scale (POS) - Integrated POS (IPOS) in English (pos-pal.org)/

[xvi] Abt Associates. (2020). Information-Gathering Report: Hospice Quality Reporting Program – Option Year 1. https://www.cms.gov/files/document/12042020-information-gathering-oy1508.pdf

[xvii] Abt Associates. (2019). Information-Gathering Report: Hospice Quality Reporting Program – Base Year. https://www.cms.gov/files/document/hope-information-gathering-report-508pdf.pdf

[xviii] Abt Associates. (2019). Information-Gathering Report – Focus Groups Addendum: Hospice Quality Reporting Program – Base Year. https://www.cms.gov/files/document/hopefocusgroupaddendumhqrp508pdf.pdf

[xix] Abt Associates. (2020). Information-Gathering Report: Hospice Quality Reporting Program – Option Year 1. https://www.cms.gov/files/document/12042020-information-gathering-oy1508.pdf

[xx] Abt Associates. (2021). Information-Gathering Report: Hospice Quality Reporting Program – Option Year 2. https://www.cms.gov/files/document/12202021-information-gathering-report-2021.pdf

[xxi] Abt Associates. (2020). November 2019 Technical Expert Panel: Hospice Quality Reporting Program Summary Report. https://www.cms.gov/files/document/2019hospice-qrptep-summary-reportfinalaugust-2020-002.pdf

[xxii] Abt Associates. (2021). 2020 Technical Expert Panels: Hospice Quality Reporting Program Summary Report. https://www.cms.gov/files/document/2020-hqrp-tep-summary-report.pdf

[xxiii] Abt Associates. (2022). 2021 Technical Expert Panel Meetings: Hospice Quality Reporting Program Summary Report. https://www.cms.gov/files/document/2021-hqrp-tep-summary-reportfinal.pdf

[xxiv] Palliative Care Outcome Scale (POS). Integrated Palliative Outcome Scale (IPOS) in English. Retrieved 4/17/2023. Available at Palliative care Outcome Scale (POS) - Integrated POS (IPOS) in English (pos-pal.org)

[xxv] Beatty Paul C, Willis Gordon B. Research Synthesis: The Practice of Cognitive Interviewing. Public Opinion Quarterly 2007;71(2):287-311. As of 12/6/2019: https://doi.org/10.1093/poq/nfm006

[xxvi] Altman, DG. Practical statistics for medical research. Chapman and Hall; 1991.

[xxvii] Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap). A metadata-driven methodology and workflow process for providing translational research informatics support. J Biomed Inform. 2009 Apr;42(2):377-81.

[xxviii] Harris PA, Taylor R, Minor L, Elliott V, Fernandez M, O'Neal L, McLeod L, Delacqua G, Delacqua F, Kirby J, Duda SN. REDCap Consortium. The Redcap Consortium: Building an International Community of Software Partners. J Biomed Inform. 2019 May 9 [doi:10.1016/j.jbi.2019.103208].

[xxix] Madley-Down P, Hughes R, Tilling K, Heron J. The Proportion of Missing Data Should Not Be Used To Guide Decisions on Multiple Imputation. Journal of Clinical Epidemiology, June 2019;110:63-73. Available at www.sciencedirect.com/science/article/pii/S0895435618308710. Retrieved 4/7/2023.

[xxx] Altman, D.G. (1991) Practical Statistics for Medical Research. Chapman & Hall, London, 285-288.

[xxxi] Bakeman, R, Quera V. Sequential analysis and observational methods for the behavioral sciences. Cambridge University Press; 2011. https://doi.org/10.1017/CBO9781139017343

[xxxii] De Vries H, Elliott MN, Kanouse DE, Teleki SS. Using Pooled Kappa To Summarize Interrater Agreement Across Many Items. Field Methods. 2008; 20(3), 272-282. https://doi.org/10.1177/1525822X08317166