

Supplementary Data: Implementation Worksheet and Data Collection Packet

This document contains two different components:

1. **Part 1 - Implementation Worksheet:** This worksheet will guide home health agencies in making decisions about how the intervention will be implemented at their agency. This worksheet guides home health agencies in making adaptations to the intervention protocol to make the intervention work for their agency. It gives guidance on what can be changed and what should be left intact to preserve effectiveness of the intervention.
2. **Part 2 - Data Collection Packet:** this packet can be modified and used by nurses (or other staff) to complete the screening at the patient bedside. This data collection packet was the exact intervention protocol used by Kirk et al. in their 2018 pilot test of the intervention. Note that this data collection packet is intended for use *after* eligible patients have been identified. Agencies may need to develop separate protocols for identifying eligible patients to supplement this data collection packet. The data collection packet contains language for patient consent and IRB follow-up; this may not be needed if you are not using this intervention as part of a research study.

It may be helpful to skim the data collection packet *first* to familiarize yourself with the intervention (what questions will be asked of patients, what follow-up is needed), then go back and complete the implementation worksheet once you have a better sense of what the intervention is and what might need to be changed about it to fit with your organization's needs and goals.

Part 1: Implementation Worksheet for Intervention to Improve Timeliness of Hospice/Palliative Care Referrals for Home Health Patients

This intervention is adapted from an intervention developed and tested by Casarett et al. in the nursing home setting in 2005. The intervention has been adapted for the home health setting, with input from home health & hospice agencies.

Overview of the intervention:

Overall, this intervention seeks to improve timeliness of referrals to hospice/palliative for the target population (home health patients). The intervention is a screening intervention where eligible patients are asked questions about 3 domains: 1) symptom/service needs 2) care goals 3) care preferences. Based on the results of the screening (i.e., if the patient screened positive by stating they had symptom/service needs and that their care goals/preferences aligned with a palliative approach), the patient is asked to give permission for the physician to be contacted to authorize a referral to hospice/palliative care. The physician is then contacted, notified of the screening results, and asked to initiate the appropriate order.

About this worksheet:

This worksheet outlines the main activities of the intervention step-by-step. For each step, procedures are outlined, as well as areas where home health & hospice agencies can tailor the intervention to suit their needs. Also noted are areas where it is NOT recommended that you tailor/change the intervention protocol. In these areas, changing the intervention protocol may compromise the effectiveness of the intervention.

Each step is accompanied by a worksheet to help you work through and document the decisions you make about how you may tailor this intervention to implement it successfully at your hospice. It is recommended that you complete these worksheets.

Potential Process for Implementing this intervention:

- *Review this protocol – decide if you want to implement the intervention*
- *Notify/recruit appropriate staff – gather the staff necessary to implement and carry out the intervention. Also notify staff at your agency who may not be directly involved, but should know that your agency is implementing the intervention (e.g., marketing staff).*
- *Work with appropriate staff to review this protocol and complete worksheets*
- *Based on worksheet responses, make the necessary procedural/systems changes (e.g., updating SoPs, updating EMR or documentation systems, updating clinical workflows)*
- *Train staff on intervention*
- *Conducting monitoring to ensure implementation is going well*
- *Modify processes as necessary – update your processes as needed, based on monitoring activities*
- *Track outcomes to see if this intervention is making a difference*

STEP 1: DETERMINE PATIENT ELIGIBILITY CRITERIA AND HOW ELIGIBLE PATIENTS WILL BE IDENTIFIED

Purpose of Step 1:

Not all home health patients will be appropriate to receive the hospice screener (e.g., would not be appropriate to screen patients who are on home health because of an acute injury, have no other co-morbidities/frailties, and are expected to make a full recovery). Thus, the purpose of this step is to determine and identify which home health patients may be eligible for the hospice screener

Procedures for Step 1:

Step 1a. Define eligible patients. In general, eligible patients would be those that are in some way “high-risk” or “frail”. There are many ways to define high risk or frail patients (see list below). To minimize burden, you could define your criteria using existing data fields/sources (e.g., OASIS data or existing clinical chart data fields). Choose at least one standardized criterion from the list below (or another criterion you create) – do not leave patient eligibility up to clinical judgement alone. **Although clinical judgement is important in interpreting data to determine whether a patient may truly be eligible or not, allowing eligibility to be determined solely based on clinical judgement is not recommended as it may result in potentially eligible patients falling through the cracks.**

By diagnosis (e.g., CHF, COPD, HIV/AIDS, Cancer, ESRD, dementia)	Patients who have voiced a preference for hospice/palliative services	Patients with multiple co-morbidities	Patients with a poor prognosis (could use OASIS M1034 Overall status, including those who are marked as fragile with serious risk of complications/death or death in 1 year)	Patients who are identified as having deteriorating health, using the Supportive and Palliative Care Indicators Tool (SPCIT™)
For agencies that have SHP software: patients who trigger the alert for moderate-high hospitalization risk or trigger the alert for potential candidate for hospice referral	Patients with a life expectancy less than 1 year	Patients with a high risk of hospitalization (could use OASIS M1033 including those at high risk)	Patients above a certain age (e.g., >90)	Or any combination of the above

Step 1b. Identifying eligible patients. Your home health agency may have procedures in place already for identifying high-risk patients as you’ve defined them above. If so, you use these procedures to make use of existing clinical workflows. For example, some software systems (like SHP) analyze OASIS data on diagnosis, re-hospitalization risk, and ADLs and will flag patients who are at risk and may benefit from hospice services. Other home health agencies may already have standardized procedures for identifying “bridge patients” or “fragile” consults; these procedures could be used for identifying eligible patients for the hospice screen. At a minimum, your process for identifying eligible patients should include: 1) how patients will be identified (chart review or other data source); 2) who will identify and flag eligible patients; 3) when eligibility will be defined (on admission, at re-certification, after a major change in status; at all OASIS timepoints); 4) how will the appropriate party be notified that a patient is eligible.

Worksheet For Step 1:

What eligibility criteria are you going to use (you should have at least 1 standardized criterion, beyond clinical judgement)

Eligibility criteria:

How will you find eligible patients?

How patients will be identified (e.g., existing data items; new data collection)	
Who will identify and flag patients (e.g., admitting clinician, marketing liaison at initial consult, case manager, office staff)	
When will patients be identified (e.g., on admission, at re-cert, after a major change in status)	
How will appropriate party be notified that patient is eligible (e.g., note in chart; telephone call; message in EMR portal)	

STEP 2: ASSESS COGNITIVE STATUS OF ELIGIBLE PATIENTS and IDENTIFY APPROPRIATE PROXY, AS-NEEDED

Purpose of Step 2:

This intervention screens patients for hospice appropriateness by asking them questions about their care goals, needs, and preferences. If the patient is cognitively impaired, they will not be able to respond themselves and will need to have a proxy/caregiver respond. Thus, assessing the cognitive status of the patient will inform who the respondent for the screening questions will be. If the patient is cognitively impaired, you will need to identify who the appropriate proxy is.

Procedures for Step 2:

Step 2a. Determine cognitive status of patient: Use OASIS item M1700. Cognitive Functioning. Patients scoring a 0 or 1 will be considered to have no cognitive impairment and could respond to the screening questions themselves. Patients scoring 2-4 have moderate-severe cognitive impairment and would need to have a proxy respond to the screening questions. Patients must be screened for cognitive status as cognitively impaired patients will not be able to participate in the main activity of the intervention (responding to the 3 hospice appropriateness screening questions). If you do not wish to use the OASIS item for whatever reason, develop your own process for determining cognitive status of the patient.

(M1700) Cognitive Functioning: Patient's current (day of assessment) level of alertness, orientation, comprehension, concentration, and immediate memory for simple commands.	
Enter Code <input type="checkbox"/>	0 Alert/oriented, able to focus and shift attention, comprehends and recalls task directions independently.
	1 Requires prompting (cuing, repetition, reminders) only under stressful or unfamiliar conditions.
	2 Requires assistance and some direction in specific situations (for example, on all tasks involving shifting of attention) or consistently requires low stimulus environment due to distractibility.
	3 Requires considerable assistance in routine situations. Is not alert and oriented or is unable to shift attention and recall directions more than half the time.
	4 Totally dependent due to disturbances such as constant disorientation, coma, persistent vegetative state, or delirium.

Step 2b. For cognitively impaired patients, determine appropriate proxy: if the patient is cognitively impaired, determine the appropriate proxy. The proxy should ideally be the HC POA, but if that person is not available, below are other choices for appropriate proxy. The first/second/third/fourth choice for appropriate proxy noted below is a suggestion; your agency's preferred order may depend on state law and may vary from patient-to-patient, depending on who knows the patient best (e.g., in some instances, HC POA may be a daughter in a different state but the paid caregiver has been with the patient for a considerable length of time and may understand patient's needs, goals, and preferences better).

- First choice: HC POA/legally authorized representative
- Second choice: next of kin
- Third choice: friend
- Fourth choice: paid caregiver (if caregiver knows the patient well enough to know their care needs and/or preferences)

Worksheet for Step 2:

How will you determine cognitive status of patient? (suggested: OASIS M1700)

For cognitively impaired patients, what is your preferred hierarchy for proxy? (suggested: HC POA, next of kin, friend, paid caregiver)

Any special notes about laws in your state or how to determine who may be most appropriate on a patient-by-patient basis?

STEP 3: DELIVER CARE GOALS, PREFERENCES, AND NEEDS SCREENING QUESTIONS

Purpose of Step 3:

Often, a clinician will identify using their own clinical judgement that a patient may be appropriate for hospice. Despite their clinical intuition, however, the “hospice conversation” often gets delayed in practice because the clinician doesn’t know how to start the conversation or broach the subject in a comfortable way. Re-framing the “hospice conversation” entirely was shown an effective way of overcoming this barrier in the original Casarett intervention. Re-framing the conversation as a conversation about care goals, needs, and preferences increases the clinician’s comfort in starting/having the conversation by removing “hospice” from the conversation. In this sense, we are still able to identify patients who are appropriate for hospice, but in a non-threatening way. The topic is introduced and discussion centers on care goals, needs, and preferences apart from hospice.

Procedures for Step 3:

Step 3a. Determine procedures for the screening conversation: First, your agency will need to determine the process for how these screening conversations will occur. This includes deciding who from the care team will deliver the screening, and when. You want to develop a procedure that is flexible enough to allow for individual patient situations, but rigid enough that responsibility is not overly diffused, causing patients to slip through the cracks. A suggested process is below, but you could modify this based on your agency’s needs.

- **Who:** admitting clinician (or case manager) introduces the screening conversation and starts asking the screening questions, getting through as much as they’re able. If admitting clinician unable to get through all screening questions due to time constraints or other patient factors (patient not comfortable with conversation), finish conversation at the next visit.
- **When:** at start of care or at a later visit, depending on patient factors. It is recommended that all questions be asked within the first 3 visits or within the first week of care, whichever comes first.
- **Mode:** suggested to introduce the conversation and ask the screening questions in person, to build trust. Additionally, older patients may not feel comfortable doing this over the phone.
- **Documentation:** you may wish to build the screening questions into existing clinical workflows (EMRs, assessment forms), or keep them separate (e.g., on paper)
- **Responsibility:** Although the conversation may be had by someone other than the case manager, ultimately, assign the responsibility for the screening questions getting asked to the case manager. At the end of 3 visits/1 week, it would be the case manager’s responsibility to ensure all questions were asked.

Step 3b. introduce the conversation: The person identified in Step 3a will introduce the conversation. A suggested script for introducing the conversation has been provided in the Data Collection Packet. Your agency may modify the script to suit your needs. The script may be helpful as you’re first implementing the intervention, and may prove less important over time as clinicians get comfortable/used to having these conversations. **If you modify the script, do not re-frame the introduction of the conversation to say you are screening patients for hospice. It’s important to keep the introduction “hospice neutral” and focus on more general aspects of care (discussing care goals, needs, and preferences) to maintain clinician and patient comfort with initiating and having this screening conversation.**

Step 3c. Ask screening questions: The person(s) identified in Step 3a will deliver the care goals, needs, and preferences screening questions. The questions are provided in the Data Collection Packet. You may modify the wording of questions as appropriate for your agency. **You may modify the number of questions, but eliminate questions with caution. Although asking more questions increases burden, it helps provide the most comprehensive picture of the patient’s care goals, needs, and preferences.** If you change the wording/number of questions, you want to make sure you maintain a comprehensive set of questions that aligns with the services hospice provides and the goals of hospice care.

That way, when you feed the results of the screening back to the patient, you can say “you said you want xyz – xyz is what hospice does”. In short, you will ask questions for the following care domains:

1. Symptom and Service Needs: 4 psychological symptoms; 6 physical symptoms; 8 service needs
2. Care Goals: 1 situational based question about whether your care goals focus on extending life or palliation to maximize QoL
3. Care Preferences: care preferences for CPR and mechanical ventilation

Step 3d. Record answers to screening questions: Somehow, you will need to record the patient or proxy’s answers to the screening questions. This could be done by building the screening questions (and a way to document responses) into existing EMRs or assessment forms, or could be done via a separate documentation process (separate paper form).

Worksheet for Step 3.

3a. What will be your procedures for introducing and delivering the screening questions? (see above for suggested process)

<p>Who will introduce conversation and who will delivery screening questions?</p>	
<p>When will the conversation be introduced and when will the questions be asked?</p>	
<p>What mode will you use (telephone, in person)?</p>	
<p>Where will the questions be housed (e.g., build into EMR/existing assessment form, keep separate)</p>	
<p>Who will ultimately be responsible for ensuring all questions are asked within specified timeframe:</p>	

3b. Introduce the screening conversation

- | |
|--|
| <ul style="list-style-type: none"> ✓ Review the script in the Data Collection Packet ✓ Decide if you want to modify it. If you do, mark-up the script. ✓ Be sure NOT to change the frame of the conversation (i.e., don’t introduce it as a screening |
|--|

for hospice).

3c. Screening questions

- ✓ Review the questions provided in the Data Collection Packet
- ✓ Decide if you want to modify it the wording of the questions. If you do, mark-up the script.
- ✓ Decide if you want to change the number/type of questions asked. If you do, be sure that you have enough questions that you feel comprehensively describe hospice's services and goals.

3d. Document answers to screening questions

<p>How will you document responses to screening questions (e.g., build fields into EMR or existing assessment form; create separate documentation workflow)</p>	
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STEP 4: SCORE RESULTS OF SCREEN TO DETERMINE IF PATIENT APPROPRIATE FOR HOSPICE

Purpose of Step 4:

Scoring the results of the screening ultimately determines which patients are potentially appropriate for hospice – and thus which patients will go on to receive physician follow-up and, potentially, a referral to hospice.

Procedures for Step 4:

The scoring sheet for the screening is presented in the Data Collection Packet. You'll need to determine:

- **Who will complete the scoring sheet:** will this be completed by the same person asking the screening questions? the person who asks the last screening question? The case manager?
- **What constitutes a “positive” screen:** it is recommended that a positive screen be defined as a patient having at least 1 of the following:
 - At least 1 symptom or service need
 - Care goals aligned with palliation
 - Preference to not have CPR or mechanical ventilation

You may decide a higher threshold is right for your agency, but know that the higher the threshold, the fewer patients that will receive follow-up with their physician and a possible referral. In our pilot, we found that if a patient has *only* a symptom need, they may not be appropriate for hospice. **It is NOT recommended that you require a preference to NOT have CPR/vent in order to screen positive. This is because you do not have to refuse CPR/vent to be admitted to hospice; all patients – including those on hospice – should have the right to choose their preference for life-sustaining treatment. As such, your threshold for a positive screen should not be 3/3.**

- **Documentation:** your agency will need to determine how you'll document the results of the screening. You may choose to build the scoring sheet into existing EMR or assessment forms or keep the documentation separate.
- **Notification to care team of patients who screen positive:** Your agency will need to determine how you'll notify the appropriate care team member(s) that the patient screened positive. This could be via phone call, note in the EMR portal, etc.

Worksheet for Step 4:

Who will complete scoring sheet?	
What is the threshold for a positive screen (1/3 suggested, or just considering symptom-need only patients as negative screen; do NOT recommend 3/3)	
How will you document scoring? (e.g., build scoring sheet into EMR; separate system)	
How will you notify the appropriate member(s) of the care team that a patient screened positive?	

STEP 5: REPORT “RESULTS” OF SCREENING TO PATIENT OR PROXY

Purpose of Step 5:

Reporting the results of the screening back to the patient allows you to eventually introduce hospice/palliative in a non-threatening (less threatening) way. In this intervention, hospice/palliative care is introduced as a response to the patient’s self-expressed needs and goals – not because something is “wrong” or “imminent”. Reporting the results of the screen back to the patient (e.g., “you said that you’re having trouble with pain and SOB, that you could use some more aide services, and that your care goals are focused on comfort”) allows the clinician to naturally introduce hospice/palliative care (“did you know there’s an extra set of services available to you that specializes in symptom management and comfort...it’s called hospice”). This keeps the conversation “neutral” – again – you’re not leading with hospice; you’re repeating back the patient’s needs and goals and then offering a potential solution to those needs/goals (hospice).

Procedures for Step 5:

After the screening questions have been scored, you will need to notify patients of the “results” of their screen and ultimately, introduce hospice/palliative care as appropriate. You will need to consider several factors, and some suggested processes and procedures are outlined below.

- **Who:** It is suggested that the case manager be the staff member to report the results back to the patient and introduce the notion of hospice, if applicable. Even if the case manager is not the staff member who asked the screening questions, they may be best to report back the results because this is the home health clinician the patient will build a relationship with throughout their stay. You may change this process to suit the needs of your agency, but do so with caution.
- **When:** It is suggested that the report back occur at a visit other than the admission visit. It also allows the introduction of hospice as a solution to the patient’s needs/wants to happen at a visit other than the hectic, busy admission visit, where the patient and family may be overwhelmed and not receptive to this conversation. You may change this process to suit the needs of your agency, but do so with caution.
- **To whom:** It is suggested that you report the results back to patients who screen positive and negative. It is recommended that you also report results back to patients that screen negative to familiarize the notion of hospice early – even if they’re not appropriate now, you can let them know hospice is an option and available to them at any time if their needs/preferences change. You may change this process to suit the needs of your agency, but do so with caution.

A script to report back the results of the screen is provided in the Data Collection Packet. You may modify this script to suit the needs of your hospice, but, for patients that have screened positive, you should always start this part of the conversation by reporting back what you heard from the patient (e.g., “you said that you’re having trouble with pain and SOB, that you could use some more aide services, and that your care goals are focused on comfort”) and you should present hospice as a solution to those identified goals/needs. Do not lead this portion of the conversation by stating something like “we think it might be time to consider hospice”. Part of the script is getting permission from the patient/proxy to contact the physician. It is suggested that this be maintained, though you could modify the wording of how you ask for permission.

Worksheet for Step 5:

Procedures:

Who will report the results of the screening back to patient/proxy (case manager suggested)?	
When will the results be presented (at a visit other than the initial admission visit suggested)?	
Will you report results to those that screen positive only? Or those that screen positive and negative? (both are suggested)	

Script:

- ✓ Review the script in the Data Collection Packet.
- ✓ Decide if you want to modify it. If you do, mark-up the script.

STEP 6: COMPLETE NECESSARY FOLLOW-UP WITH PHYSICIAN TO GET ORDER FOR HOSPICE

Purpose of Step 6:

After the patient is notified of their results and agrees to have physician contacted, physician will need to be contacted to get an order for hospice/palliative care, if patient is eligible. As such, step 6 initiates the formal referral to hospice/palliative care.

Procedures for Step 6:

At this point, the intervention largely reverts back to usual care, so your agency should use whatever processes is normally used to initiate/receive an order for hospice/palliative care from the patient's physician.

Worksheet for Step 6:

Outline your usual care process for contacting physicians to get orders for hospice/palliative care – note any changes you may need to make to this process for the purposes of this intervention.

Part 2: Data Collection Packet

Overview of process/checklist for each patient:

For each patient determined eligible for the pilot:

- ✓ STEP 1: Determine their cognitive status using OASIS M1700 – if cognitively impaired, all consents and questions will be asked of proxy
- ✓ STEP 2: Read verbal consent to patient or proxy
- ✓ STEP 3: Ask hospice appropriateness screening questions (care goals, needs, and preferences questions) of patient or proxy
- ✓ STEP 4: Record responses to screening questions in this packet
- ✓ STEP 5: Score screening questions and report results back to patient or proxy
- ✓ STEP 6: Give patient or proxy debrief sheet

Note: Also included at the end of this packet is a leave-behind info sheet for patients who say they don't want to answer now, but may want to answer later. If this happens, tear off the leave behind sheet and leave with patient.

STEP 1 - DETERMINE COGNITIVE STATUS OF PATIENT:

Through usual OASIS assessment processes, determine cognitive status of patient and enter the appropriate code in the item below.

(M1700) Cognitive Functioning: Patient's current (day of assessment) level of alertness, orientation, comprehension, concentration, and immediate memory for simple commands.	
Enter Code <input type="checkbox"/>	0 Alert/oriented, able to focus and shift attention, comprehends and recalls task directions independently.
	1 Requires prompting (cuing, repetition, reminders) only under stressful or unfamiliar conditions.
	2 Requires assistance and some direction in specific situations (for example, on all tasks involving shifting of attention) or consistently requires low stimulus environment due to distractibility.
	3 Requires considerable assistance in routine situations. Is not alert and oriented or is unable to shift attention and recall directions more than half the time.
	4 Totally dependent due to disturbances such as constant disorientation, coma, persistent vegetative state, or delirium.

- **If patient scores 0 or 1:**
 - Patient NOT cognitively impaired; proceed with consent and screening questions directly with patient
- **If patient scores 2, 3 or 4:**
 - Patient cognitively impaired; proceed with consent and screening questions with proxy
 - For pilot, proxy is defined as “The study follows the informed consent laws applicable to clinical care in North Carolina, identifying the person who has the highest level of legal decision-making authority. The person identified in the medical record with the highest level of legal decision-making authority will be the person who will authorize the patient's participation in the study.”

STEP 2: GET CONSENT FROM PATIENT OR PROXY

Verbal consent script for non-cognitively impaired patients – read the following to the patient:

Our home health agency is participating in an initiative to help us better address our patients' care needs. As part of this effort, we are asking our patients questions about their care goals, care preferences, and care needs. Knowing more about your care goals, needs, and preferences will help us ensure you receive all care and services that you may benefit from. It will also help us make sure the care we deliver aligns with your wants and needs.

Answering the questions will take about 5-10 minutes and your responses would be confidential. If you've never had a conversation with your healthcare provider about your care goals, preferences, and needs, then some of these questions may seem a bit strange, or you may not know the answer to some of the questions, and that's OK. You can skip over any question or stop responding to the questions at any time.

Would you be willing to answer a few questions about your care goals, preferences, and needs?

- Yes → proceed with Step 3 – asking hospice appropriateness screening questions
- No → thank participant and end pilot data collection/conversation
- Not now, but maybe later → thank participant and tear off “leave behind” sheet (page 9 of this document) to leave with patient

Verbal consent for cognitively impaired patients – read the following to the identified proxy:

Our home health agency is participating in an initiative to help us better address our patients' care needs. As part of this effort, we are asking our patients questions about their care goals, care preferences, and care needs. Knowing more about your care goals, needs, and preferences will help us ensure you receive all care and services that you may benefit from. It will also help us make sure the care we deliver aligns with your wants and needs.

Since (patient name) is unable to respond to questions about their care goals, preferences and needs, as (patient name)'s surrogate decision maker, we would like to ask you these questions on behalf of (patient name). Answering the questions will take about 5-10 minutes and your responses would be confidential. If you've never had a conversation with your healthcare provider about (patient name)'s care goals, preferences, and needs, then some of these questions may seem a bit strange, or you may not know the answer to some of the questions, and that's OK. You can skip over any question or stop responding to the questions at any time.

Would you be willing to answer a few questions about (patient name)'s care goals, preferences, and needs?

- Yes → proceed with Step 3 – asking hospice appropriateness screening questions
- No → thank participant and end pilot data collection/conversation
- Not now, but maybe later → thank participant and tear off “leave behind” sheet (page 9 of this document) to leave with patient

STEP 3 AND 4: ASK SCREENING QUESTIONS AND DOCUMENT RESPONSE TO QUESTIONS

Netsmart Patient Number: _____ SOC Date: _____ Who responded (highlight one): pt or proxy

Domain 1 – symptom and service needs:

Let's talk about symptoms that might be bothering you/your family member. (Highlight the response)

<i>Have [you/family member] been feeling sad?</i>					
0	1	2	3	4	9
None	Rarely	Occasionally	Frequently	Almost constantly	Don't know
<i>Have [you/family member] been worrying?</i>					
0	1	2	3	4	9
None	Rarely	Occasionally	Frequently	Almost constantly	Don't know
<i>Have [you/family member] been feeling irritable?</i>					
0	1	2	3	4	9
None	Rarely	Occasionally	Frequently	Almost constantly	Don't know
<i>Have [you/family member] been feeling nervous?</i>					
0	1	2	3	4	9
None	Rarely	Occasionally	Frequently	Almost constantly	Don't know

<i>Has lack of appetite been distressing or bothering [you/family member]?</i>					
0	1	2	3	4	9
Not at all	A little bit	Somewhat	Quite a bit	Very Much	Don't know
<i>Has lack of energy been distressing or bothering [you/family member]?</i>					
0	1	2	3	4	9
Not at all	A little bit	Somewhat	Quite a bit	Very Much	Don't know
<i>Has pain been distressing or bothering [you/family member]?</i>					
0	1	2	3	4	9
Not at all	A little bit	Somewhat	Quite a bit	Very Much	Don't know
<i>Has drowsiness or confusion been distressing or bothering [you/family member]?</i>					
0	1	2	3	4	9
Not at all	A little bit	Somewhat	Quite a bit	Very Much	Don't know
<i>Has constipation been distressing or bothering [you/family member]?</i>					
0	1	2	3	4	9
Not at all	A little bit	Somewhat	Quite a bit	Very Much	Don't know
<i>Has dyspnea/shortness of breath been distressing or bothering [you/family member]?</i>					
0	1	2	3	4	9
Not at all	A little bit	Somewhat	Quite a bit	Very Much	Don't know
<i>Has nausea been distressing or bothering [you/family member]?</i>					

0	1	2	3	4	9
Not at all	A little bit	Somewhat	Quite a bit	Very Much	Don't know

Service Needs

- *Ok, next I'll describe several services and I'll ask you to tell me whether you think these services could help.*
- *Would it help to have an **extra nurse** who could help treat symptoms that have been bothering [you/him/her]?*
 - Yes*
 - No*
 - Unsure*
- *Would it help to have an **extra doctor** who could help treat symptoms that have been bothering [you/him/her]?*
 - Yes*
 - No*
 - Unsure*
- *Would it help to have an **extra home health aide** come in to give [you/him/her] more help with bathing dressing and eating?*
 - Yes*
 - No*
 - Unsure*
- *Would it help to have an **extra social worker** who could work with [you/him/her] to arrange [your/his/her] finances and insurance?*
 - Yes*
 - No*
 - Unsure*
- *Would it help to have an extra social worker or **chaplain** who could provide counseling and emotional support?*
 - Yes*
 - No*
 - Unsure*
- *If [you/your family member] were to die, do you think it would be helpful for [family member] to have a **bereavement counselor** or support group?*
 - Yes*
 - No*
 - Unsure*
- *Would it help [family member] to have an extra **chaplain** who could provide spiritual support?*
 - Yes*
 - No*

- Unsure*
- *Would it help [you/your family member] to have a **volunteer** who would visit and spend time with [you/him/her]?*
 - Yes*
 - No*
 - Unsure*

Domain 2: Care Goals

- **If interviewing patient, ask the following (only read what is in italics):**
OK, now I'd like you to imagine that you had to make a decision right now about how your doctors should take care of you. If you had to make a decision right now, would you prefer a course of treatment that focuses on extending life as much as possible, even if it means having more pain and discomfort, or would you want a plan of care that focuses on relieving pain and discomfort as much as possible, even if that means not living as long?
- **(If they say both):** *OK, but if you had to choose just one, which would you choose? [READ OPTIONS AGAIN]*
Responses – check one:
 - Palliative Care:** *focus on keeping [him/her] comfortable as possible*
 - Extending life:** *focus on helping [him/her] live as long as possible*
 - Don't know**
- **If interviewing proxy, ask the following substituted judgement question:**
OK, now I'd like you to imagine that [your family member] had to make a decision right now about how [his/her] doctors should take care of [him/her]. If [he/she] had to make a decision right now, would [he/she] prefer a course of treatment that focuses on extending life as much as possible, even if it means having more pain and discomfort, or would [he/she] want a plan of care that focuses on relieving pain and discomfort as much as possible, even if that means not living as long?
- **(If they say both):** *OK, but if you had to choose just one, which would you choose? [READ OPTIONS AGAIN]*
Responses – check one:
 - Palliative Care:** *focus on keeping [him/her] comfortable as possible, or*
 - Extending life:** *focus on helping [him/her] live as long as possible?*
 - Don't know**

Domain 3: Care Preferences

- *Some people make plans about how they want their doctors to take care of them. So now, I'd like to talk about how [you/your family member] want [your/your family member's] doctors to take care of [you/him/her].*
 - **(CPR):** *For example, if [YOUR/PATIENT NAME] heart stops beating, do you want [your/his/her] doctors to try to restart it?*
 - Yes*
 - No*
 - Unsure*

- **(Vent):** *OK, if [YOU/PATIENT NAME] isn't able to breathe on [your/his/her] own, would you want [your/his/her] doctors to put [you/him/her] on a breathing machine?*

Yes

No

Unsure

STEP 5 – SCORING AND REPORTING RESULTS BACK TO PATIENT:

For each domain of questions, select “yes” or “no” from the right-hand column. Then add up the total number of “yes’s”.

Domain 1 – Symptom and Service Needs: <ul style="list-style-type: none"> Did patient have at least ONE symptom or service need? 	<input type="checkbox"/> Yes <input type="checkbox"/> No
Domain 2 – Care Goals: <ul style="list-style-type: none"> Did patient or proxy respond “palliative care” to care goals question? 	<input type="checkbox"/> Yes <input type="checkbox"/> No
Domain 3 – Care Preferences: <ul style="list-style-type: none"> Did respondent answer “no” to both the CPR and the Vent questions? 	<input type="checkbox"/> Yes <input type="checkbox"/> No
Add up “Yes’s” in the right column: if total score is 1 or greater, patient counts as “positive screen”	_____ total number of yes’s (1-3)

If patient screened positive (had a total score of 1 or greater):

- You said that [you/your family member] had some additional symptom and service needs [INSERT SOME OF IDENTIFIED SYMPTOM/SERVICE NEEDS HERE], and/or had care goals and preferences aligned with maximizing comfort and focusing on quality of life. Based on these responses, there may be some additional services [you/your family member] may benefit from. These additional services specialize in symptom management and psychological and spiritual service needs, as well as maximizing comfort and quality of life.*
- I don’t know whether these extra services are the right decision for [you/your family member] right now. That’s up to [your/your family member’s] doctor. If it’s OK with you, I’ll let [your/your family member’s] doctor know that we had this conversation so that they can give [you/your family member] more information. Is that OK?*
 - Yes → initiate appropriate follow-up with physician to get hospice or palliative care order
 - No → do not follow-up with physician; give patient debrief sheet

If patient screened negative (had a score of 0):

- Thanks for taking time to tell me more about your care goals and needs. Now we have a better understanding of what you want and what additional services you may be able to benefit from in the future. I’ll make a note of this in your chart and may ask you about your care goals, needs, and preferences again in the future, in case your needs change.*

STEP 6: MAKE SURE TO GIVE PATIENT DEBRIEF FORM. THIS IS REQUIRED BY THE IRB. → DEBRIEF FORM IS ON THE NEXT PAGE, WHICH YOU CAN TEAR OFF AND GIVE TO PATIENT/PROXY

Debrief Sheet:

Earlier, you responded to some questions about your care goals, needs, and preferences. Your home health nurse mentioned that responding to these questions was part of a larger research effort our agency is participating in to make sure our patients have access to all services that they may benefit from. Specifically, we used your responses to these questions to determine if you may benefit from some additional services that hospice or palliative care can provide.

We plan to ask these care goals, needs, and preferences questions of about 50 of our new patients. Pending the success of this initiative, we may integrate this into our standard care practices.

We appreciate your participation in this research initiative. All the information we received from you about your care goals, needs, and preferences is strictly confidential. The research team will not identify you or use any information that would make it possible for anyone to identify you in any presentation or written reports about this study. In any reports or presentations about this study, there will be no way to identify individual participants. The only risk to you might be if your identity were ever revealed.

If you have questions about this research study, you can contact the principal investigator, xxxxx, at xxx-xxx-xxxx with questions about the research study. All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject you may contact, anonymously if you wish, the Institutional Review Board at xxx-xxxx-xxxx or by email to xxxxx.

If you have any questions about hospice or would like to further discuss your care goals, needs, and preferences, please contact your home health nurse that provides care to you.

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