

Medical Record Abstraction

Record ID

(The Record ID is automatically generated. The Record ID will serve as the unique Study ID for this subject. It is recommended that you keep a key linking the Record ID with the patient's identity at your site for your future reference.)

Is this a NEW record or is this a DUPLICATE record being created for the purpose of QCing?

- ☐ New Record
☐ Duplicate Record for QC
(As part of a quality control measure, you may be asked to perform a re-abstraction of an already abstracted record in order to verify the accuracy of data abstractions. If you are creating a record in order to perform a QC, select "Duplicate Record." Otherwise, all records should be "New Record.")

If this is a duplicate record, what is the record ID of the original record that you are QCing?

(Please write in format: XXXX-XX)

Your site name:

- ☐ University of California San Diego
☐ University of Iowa
☐ UAB

Eligibility Check

Instructions: Please answer the following questions by looking in the patient's medical record.

What is the patient's date of birth?

What is the patient's date of death?

((Must be between 1/1/2013-12/31/2016 in order to be eligible for this study.))

Age at time of death (in years):

((Must be age 15-39 at time of death.))

Was the patient diagnosed with cancer?

- ☐ Yes
☐ No
((Must be yes.))

On what date was the patient diagnosed with cancer?

((Must be ≥ 30 days before date of death.))

Did the patient receive care at your site during the month of his/her death?

- ☐ Yes
☐ No
((Must be yes.))

Looking back over the responses from this section of the form, does this deceased patient meet all of the eligibility criteria for this medical record review?

- ☐ Yes
☐ No

Part A - Participant Demographic Information

Instructions: Please answer the following questions by looking in the patient's medical record.

Initials

(Example: for John Doe, enter J.D.)

Sex

- ☐ Male
☐ Female

Ethnicity

- ☐ Hispanic or Latino
☐ Not Hispanic or Latino
☐ Not documented / unknown

Race (select all that apply)

- ☐ White
☐ Black or African American
☐ Asian
☐ Native Hawaiian or Pacific Islander
☐ American Indian or Alaska Native
☐ Not documented / unknown
((Select all that apply.))

Which best describes the patient's highest level of education completed?

- ☐ Grade school or less
☐ High school graduate or GED
☐ Some vocational, business or trade school
☐ Some college
☐ College graduate
☐ Some graduate school, but no degree
☐ Graduate or professional degree
☐ Not documented / unknown

What type(s) of insurance did the patient have?

- ☐ No insurance
☐ Medicaid / CHIP
☐ Other safety net insurance
☐ TRICARE
☐ Private insurance
☐ Other (please specify)
((Select all that apply.))

Insurance other, please specify:

In what CITY or town was the patient's primary residence?

In what STATE was the patient's primary residence?

In what ZIP CODE was the patient's primary residence?

Patient's Marital Status at time of death

- ☐ Never Married
- ☐ Married
- ☐ Divorced
- ☐ Domestic Partnership/Living Together
- ☐ Separated
- ☐ Widowed
- ☐ Other (please specify)
- ☐ Not documented / unknown

Marital status other, please specify:

Part B: Cancer Diagnosis

Instructions: Please answer the following questions by looking in the patient's medical record.

What was the patient's Primary Cancer Site?

- ☐ Head and neck
- ☐ Thyroid
- ☐ Brain
- ☐ Lung
- ☐ Pancreas
- ☐ Other upper GI (liver, gastric, esophageal, carcinoid, etc.)
- ☐ Breast
- ☐ Colon, rectal, anal
- ☐ Ovarian/peritoneal
- ☐ Uterine, cervical, vaginal
- ☐ Renal
- ☐ Bladder (including urethral)
- ☐ Melanoma
- ☐ Lymphoma
- ☐ Leukemia (including MDS)
- ☐ Bone / Soft tissue (including sarcoma)
- ☐ Other cancer (please specify)

Other cancer, please specify:

What was the patient's cancer stage at diagnosis?

- ☐ I-III
- ☐ IV
- ☐ Not documented / unknown
- ☐ Not applicable (e.g., leukemia)

Part D - Use of Palliative and/or Hospice Services

In the patient's medical record, is there documentation that the patient received a REFERRAL to hospice?

- ☐ Yes
- ☐ No

On what date was the referral to hospice made?

Did the patient ENROLL in hospice?

- ☐ Yes
- ☐ No
- ☐ Not documented / unknown

On what date did the patient enroll in hospice?

Where did the patient receive hospice care?

☐ Inpatient
☐ Outpatient
☐ Home
☐ Skilled Nursing Facility / Rehab Facility
☐ Other (please specify)
☐ Unknown
((Select all that apply.))

Received hospice care in other location, please specify:

Enrolled in hospice at time of death?

☐ Yes
☐ No
☐ Not documented / unknown

In the patient's medical record, is there documentation that the patient received a palliative care consultation?

☐ Yes
☐ No

On what date did the first palliative care consultation occur?

Where did the patient receive palliative care services?

☐ Inpatient
☐ Outpatient
☐ Home
☐ Skilled Nursing Facility / Rehab Facility
☐ Other (please specify)
☐ Unknown
((Select all that apply.))

Received palliative care in other location, please specify:

Receiving palliative care at time of death?

☐ Yes
☐ No
☐ Not documented / unknown

Part E - Information at Time of Death

Did the patient designate a health care proxy (power of attorney)?

☐ Yes
☐ No

Is there documentation of a DNR/DNI order (do not resuscitate/do not intubate) in the patient's medical record?

☐ Yes
☐ No

In the last MONTH of the patient's life, did s/he receive any of the following?

☐ Chemotherapy
☐ Radiation therapy
☐ Surgery
☐ Treatment on a clinical trial
☐ None of the above
((Select all that apply.))

In the last WEEK of the patient's life, did s/he receive any of the following?

- ☐ Chemotherapy
☐ Radiation therapy
☐ Surgery
☐ Treatment on a clinical trial
☐ None of the above
(Select all that apply.)

Location of Death

- ☐ Inpatient acute care facility: general floor
☐ Inpatient acute care facility: ICU
☐ Inpatient acute care facility: palliative care unit
☐ Home
☐ Long-term care facility
☐ Outpatient (i.e., home, long-term care) hospice
☐ Inpatient hospice
☐ Assisted Living Facility
☐ Other (please specify)
☐ Not documented / unknown

Location of death other, please specify:

Questions to determine if the study packet should be mailed

Instructions: Please answer the following questions by looking in the patient's medical record.

Sometimes a patient has 0, 1, 2, 3, or more people who serve as his/her family caregiver and/or next of kin [hereinafter referred to collectively as "CAREGIVER"].

People who might serve as a patient's caregiver include, but are not limited to, the patient's: child, friend, parent, neighbor, sibling, in-law, spouse, etc.

For example, a patient might have a mom and a dad who both served as caregivers for the patient; in this case, the patient would have 2 caregivers. Furthermore, the mom and the dad may have the same or different mailing addresses. This section will ask you about the patient's caregiver(s).

How many caregiver(s) did this patient have?

- ☐ 0 - no caregivers/next of kin documented
☐ 1
☐ 2
☐ 3 or more

It appears that there is not a primary caregiver who would be eligible for this study. Please do NOT mail the study packet to anyone for this patient. END FORM

You selected 1. The next section will ask you about this 1 caregiver: CAREGIVER A.

You selected 2. The 2 next sections will ask you about these 2 caregivers: first about CAREGIVER A, then about CAREGIVER B.

You selected 3 or more. The 3 next sections will ask you about these 3+ caregivers: first about CAREGIVER A, then about CAREGIVER B, then about CAREGIVER C, then about all additional caregivers.

QUESTIONS ABOUT CAREGIVER A:

Looking at the patient's medical record, CAREGIVER A was the patient's...

- ☐ Child
- ☐ Friend
- ☐ Parent
- ☐ Grandchild
- ☐ Grandparent
- ☐ Life Partner
- ☐ Neighbor
- ☐ Sibling
- ☐ Son/daughter-in-law
- ☐ Spouse
- ☐ Other relative (please specify)
- ☐ Other non-relative (please specify)
- ☐ Not documented / unknown

Other caregiver A relationship, please specify:

What are CAREGIVER A's initials?

((For example: If CAREGIVER A's name is Jane Doe, then type J.D. here.))

QUESTIONS ABOUT CAREGIVER B:

Looking at the patient's medical record, CAREGIVER B was the patient's...

- ☐ Child
- ☐ Friend
- ☐ Parent
- ☐ Grandchild
- ☐ Grandparent
- ☐ Life Partner
- ☐ Neighbor
- ☐ Sibling
- ☐ Son/daughter-in-law
- ☐ Spouse
- ☐ Other relative (please specify)
- ☐ Other non-relative (please specify)
- ☐ Not documented / unknown

Other caregiver B relationship, please specify:

What are CAREGIVER B's initials?

((For example: If CAREGIVER B's name is Jane Doe, then type J.D. here.))

QUESTIONS ABOUT CAREGIVER C:

Looking at the patient's medical record, CAREGIVER C was the patient's...

- ☐ Child
- ☐ Friend
- ☐ Parent
- ☐ Grandchild
- ☐ Grandparent
- ☐ Life Partner
- ☐ Neighbor
- ☐ Sibling
- ☐ Son/daughter-in-law
- ☐ Spouse
- ☐ Other relative (please specify)
- ☐ Other non-relative (please specify)
- ☐ Not documented / unknown

Other caregiver C relationship, please specify:

What are CAREGIVER C's initials?

((For example: If CAREGIVER C's name is Jane Doe, then type J.D. here.))

Did the patient have more than these 3 caregivers?

- ☐ Yes
- ☐ No

Has it been ≥ 4 months since the patient passed away?

- ☐ Yes
- ☐ No

Please wait until it has been ≥ 4 months since the patient passed away before mailing the study packet to CAREGIVER A.

Once it as been ≥ 4 months since the patient passed away, please mail the study packet to CAREGIVER A.

Friendly reminder... The study packet should contain: (1) letter explaining the study and the collaboration with Dana-Farber Cancer Institute; (2) opt-out card; (3) informed consent document; and (4) prepaid return envelope. The study packet is available in English and in Spanish; please mail the appropriate version(s).

ACTION REQUIRED:

Please mail the study packet to CAREGIVER A now.

Friendly reminder... The study packet should contain: (1) letter explaining the study and the collaboration with Dana-Farber Cancer Institute; (2) opt-out card; (3) informed consent document; and (4) prepaid return envelope. The study packet is available in English and in Spanish; please mail the appropriate version(s).

Note: Please do NOT mail a study packet to CAREGIVER B (or C) at this time. If CAREGIVER A does not reply, then the study staff at Dana-Farber will contact you and ask you to mail a study packet to CAREGIVER B (or C).

On what date did you mail the study packet to CAREGIVER A?

Did you mail CAREGIVER A the study packet in English, Spanish, or both?

- ☐ English
- ☐ Spanish
- ☐ Both

RECOMMENDATION:

In 4 weeks, we will be asking you to log into REDCap and enter CAREGIVER A's:

First and last name
Phone number
Mailing address
E-mail address (if available)

In the future, we may request CAREGIVER B & C's name, phone number, address, & email.

We recommend that you go ahead and jot down this information for caregivers A, B, & C in a secure file or on a secure piece of paper so that you don't have to go back and look up this information from scratch.

4-Week Follow-up Form_CAREGIVER A

Did the CAREGIVER A return the opt-out card?

- ☐ Yes, s/he returned the opt out card; s/he does NOT want to be contacted further about this study.
- ☐ No, s/he did not return the opt out card.
- ☐ The mailing was returned to sender as undeliverable, but efforts are being made/will be made to ascertain a correct forwarding address.
- ☐ The mailing was returned to sender as undeliverable; no efforts are being made/will be made to ascertain a correct forwarding address. This caregiver is to be permanently marked as unreachable and an interview will not be pursued.

Thank you.

Since CAREGIVER A either declined to participate in this study OR their packet was undeliverable and no other address can be obtained, please mail a study packet to CAREGIVER B.

Friendly reminder... The study packet should contain: (1) letter explaining the study and the collaboration with Dana-Farber Cancer Institute; (2) opt-out card; (3) informed consent document; and (4) prepaid return envelope. The study packet is available in English and in Spanish, please mail the appropriate version(s).

On what date did you mail the study packet to CAREGIVER B?

Did you mail CAREGIVER B the study packet in English, Spanish, or both?

- ☐ English
- ☐ Spanish
- ☐ Both

What is CAREGIVER A's first and last name?

What is CAREGIVER A's phone number?

What is the CAREGIVER A's mailing address?

((Must include number, street name, apt # (if applicable), city, state, zip code.))

What is CAREGIVER A's e-mail address (if available)?

Did CAREGIVER A sign and return the Informed Consent Form?

- ☐ Yes
- ☐ No

Upload a copy of the signed Informed Consent Form here:

4-Week Follow-up Form_CAREGIVER B

Did the CAREGIVER B return the opt-out card?

- ☐ Yes, s/he returned the opt out card; s/he does NOT want to be contacted further about this study.
- ☐ No, s/he did not return the opt out card.
- ☐ The mailing was returned to sender as undeliverable, but efforts are being made/will be made to ascertain a correct forwarding address.
- ☐ The mailing was returned to sender as undeliverable; no efforts are being made/will be made to ascertain a correct forwarding address. This caregiver is to be permanently marked as unreachable and an interview will not be pursued.

Thank you.

Since CAREGIVER B either declined to participate in this study OR their packet was undeliverable and no other address can be obtained, please mail a study packet to CAREGIVER C.

Friendly reminder... The study packet should contain: (1) letter explaining the study and the collaboration with Dana-Farber Cancer Institute; (2) opt-out card; (3) informed consent document; and (4) prepaid return envelope. The study packet is available in English and in Spanish, please mail the appropriate version(s).

On what date did you mail the study packet to CAREGIVER C?

Did you mail CAREGIVER C the study packet in English, Spanish, or both?

- ☐ English
- ☐ Spanish
- ☐ Both

What is CAREGIVER B's first and last name?

What is CAREGIVER B's phone number?

What is the CAREGIVER B's mailing address?

((Must include number, street name, apt # (if applicable), city, state, zip code.))

What is CAREGIVER B's e-mail address (if available)?

Did CAREGIVER B sign and return the Informed Consent Form?

- ☐ Yes
- ☐ No

Upload a copy of the signed Informed Consent Form here:

4-Week Follow-up Form_CAREGIVER C

Did the CAREGIVER C return the opt-out card?

- ☐ Yes, s/he returned the opt out card; s/he does NOT want to be contacted further about this study.
- ☐ No, s/he did not return the opt out card.
- ☐ The mailing was returned to sender as undeliverable, but efforts are being made/will be made to ascertain a correct forwarding address.
- ☐ The mailing was returned to sender as undeliverable; no efforts are being made/will be made to ascertain a correct forwarding address. This caregiver is to be permanently marked as unreachable and an interview will not be pursued.

Thank you.

Since CAREGIVER C declined to participate in this study, OR their packet was undeliverable, please contact Overall Study PI Jenny Mack at jennifer_mack@dfci.harvard.edu to discuss whether or not to mail out additional study packets.

Thank you!

What is CAREGIVER C's first and last name?

What is CAREGIVER C's phone number?

What is the CAREGIVER C's mailing address?

((Must include number, street name, apt # (if applicable), city, state, zip code.))

What is CAREGIVER C's e-mail address (if available)?

Did CAREGIVER C sign and return the Informed Consent Form?

- ☐ Yes
- ☐ No

Upload a copy of the signed Informed Consent Form here:

Interview

Date of Interview

Interviewer ID

Surrogate ID

Patient Date of Birth

Patient Date of Death

Date of Admit to Hospital

Date of Discharge

Was patient under care of the hospital during all of the last 7 days of life?

Patient Diagnosis

Patient Karnofsky Score

Patient Marital Status

- ☐ Married
☐ Widowed
☐ Divorced
☐ Single, never married

Patient Sex

☐ M
☐ F

Patient Religious Preference

Surrogate's Full Name

Surrogate Sex

☐ M
☐ F

INTRODUCTION AND SCREENING

1. Can you tell me how you were related to [PATIENT NAME]?

- ☐ SPOUSE
☐ PARTNER
☐ CHILD
☐ DAUGHTER-IN-LAW/SON-IN-LAW
☐ PARENT
☐ SIBLING
☐ OTHER RELATIVE
☐ FRIEND
☐ OTHER

1a. Specify Other

2. Would you say you are one of the people who knows the most about how [PATIENT NAME] was doing during (his/her) last few weeks of life?

- ☐ Yes
☐ No

3. Who would know more about [PATIENT NAME] in (his/her) last few weeks of life than you? (Alternative person)

3a. What is this person's relationship to [PATIENT NAME]?

- ☐ SPOUSE
☐ PARTNER
☐ CHILD
☐ DAUGHTER-IN-LAW/SON-IN-LAW
☐ PARENT
☐ SIBLING
☐ OTHER RELATIVE
☐ FRIEND
☐ OTHER

3a. Specify Other

3b i. Alternative Person Name

3b ii. Alternative Person Address

3b iii. Alternative Person Phone Number

(INTERVIEWER: CORNFIRM THAT THE REFERRAL PERSON KNOWS MORE THAN THE RESPONDENT ABOUT THE PATIENT'S LAST FEW WEEKS. ***** THANK RESPONDENT AND TERMINATE INTERVIEW*****)

CHECKING THE FACTS

A. Where did [PATIENT'S] death take place?
([*INTERVIEWER*- IF NECESSARY, PROMPT UNTIL SITE IS IDENTIFIED])

- ☐ AT HOME
☐ IN A HOSPITAL
☐ NURSING HOME OR OTHER LONG-TERM CARE FACILITY
☐ HOSPICE
☐ IN TRANSIT TO A MEDICAL FACILITY
☐ SOMEWHERE ELSE
☐ DON'T KNOW

A i. If at home, was the home, the patient's own home, your home, or someone else's home?

- ☐ patient's own home
☐ your home
☐ someone else's home

A ii. If in the hospital, was that in the intensive care unit?

- ☐ Yes
☐ No

A iii. Was it in a palliative care or inpatient hospice unit?

- ☐ Yes
☐ No

A iv. Was it in an Inpatient Hospice Unit?

- ☐ Yes
☐ No

A v. Do you mean an inpatient hospice unit?

- ☐ Yes
☐ No

A vi. Do you mean residential housing provided by hospice?

- ☐ Yes
☐ No

A vii. Specify Somewhere Else

A1. And our information is that [PATIENT] died on [DATE OF DEATH]. Is this correct?

- ☐ Yes
☐ No

A1 i. In what month and year did (he/she) die?

A5. Place (30 days before) where [PATIENT] was.

A5a. Number of days

A5 i. [AS NEEDED: Did (he/she) go anywhere after that? Where was that?

A5 ii. Number of days there

A5 iii. [AS NEEDED: Did (he/she) go anywhere after that? Where was that?

A5 iv. Number of days there

A5 v. Last place

A5 vi. Number of days at last place

DOMAIN QUESTIONS

From cover sheet- "Was pt under care of the hospital during the last 7 days of his/her life?"

If YES use phrase "IN THAT LAST WEEK"

If NO use phrase "WHILE UNDER CARE OF THE HOSPITAL"

C1. (In [PATIENT'S] last week/While [PATIENT] was under care of the hospital), did you talk with any of [PATIENT'S] doctors yourself?

- ☐ Yes
☐ No

C1a. (In that last week/ While under care of the hospital), was there ever a problem understanding what any doctor was saying to you about what to expect from treatment?

- ☐ Yes
☐ No

C1b. (In that last week/ While under care of the hospital), did you feel that the doctors you talked to listened to your concerns about [PATIENT'S] medical treatment?

- ☐ YES
☐ NO
☐ HAD NO CONCERNS

C1c. (In that last week/ While under care of the hospital), how much information did the doctors provide you about [PATIENT'S] medical condition - would you say less information than was needed, just the right amount, or more than was needed?

- ☐ LESS THAN WAS NEEDED
☐ JUST RIGHT AMOUNT
☐ MORE THAN WAS NEEDED

C1d. (In that last week/ While under care of the hospital), how often did any doctor give confusing or contradictory information about [PATIENT'S] medical treatment - always, usually, sometimes, or never?

- ☐ ALWAYS
☐ USUALLY
☐ SOMETIMES
☐ NEVER

C2. (In that last week/ While under care of the hospital), was there always a doctor in charge of [PATIENT]'s care?

- ☐ Yes
☐ No

C2a. (In that last week/While under care of the hospital), was it always clear to you which doctor was in charge of (his/her) care?

- ☐ Yes
☐ No

D1. Did [PATIENT] have specific wishes or plans about the types of medical treatment (he/she) did or did not want while dying?

- ☐ YES
☐ NO
☐ DON'T KNOW

D2. To the best of your knowledge, did [PATIENT]'s doctor or the medical staff who cared for (him/her) while under care of the hospital speak to (him/her) or you about (his/her) wishes about medical treatment?

- ☐ Yes
☐ No

D3. Did (his/her) doctor or the medical staff who cared for (him/her) while under care of the hospital speak to (him/her) or you about making sure (his/her) care was consistent with (his/her) wishes?

- ☐ Yes
☐ No

D4. (In that last week/ While under care of the hospital), was there any medical procedure or treatment that happened to (him/her) that was inconsistent with (his/her) previously stated wishes?

- ☐ Yes
☐ No

D5. Did [PATIENT] have a signed Durable Power of Attorney for Health Care naming someone to make decisions about medical treatment if (he/she) could not speak for (him/her) self?

- ☐ YES
☐ NO
☐ DON'T KNOW

D6. Did [PATIENT] have a signed Living Will giving directions for the kind of medical treatment (he/she) would want if (he/she) could not speak for (him/her) self?

- ☐ YES
☐ NO
☐ DON'T KNOW

D7. Had you or [PATIENT] discussed (his/her) Living Will or Durable Power of Attorney for Health Care with a doctor caring for (him/her) while under care of the hospital?

- ☐ Yes
☐ No

A8. Did the patient lose consciousness for any number of days or any number of weeks?

- ☐ LOST CONSCIOUSNESS FOR A CERTAIN NUMBER OF DAYS
☐ LOST CONSCIOUSNESS FOR A CERTAIN NUMBER OF WEEKS
☐ NEVER LOST CONSCIOUSNESS

A8 i. How many days did patient lose consciousness?

A8 ii. For how many weeks did the patient lose consciousness?

D12. (In that last week/ While under care of the hospital), was [PATIENT] on medicines to treat (his/her) pain?

- ☐ YES
☐ NO
☐ DON'T KNOW

D12a. (In that last week/ While under care of the hospital), did (his/her) doctor or the medical staff who cared for (him/her) tell you about how (his/her) pain would be treated, in a way that you could understand?

- ☐ Yes
☐ No

D15. (In that last week/ While under care of the hospital), did [PATIENT] receive too much, too little, or just the right amount of medication for (his/her) pain?

- ☐ TOO MUCH
☐ TOO LITTLE
☐ RIGHT AMOUNT

D15a. (In that last week/ While under care of the hospital), was there ever a time when one doctor or nurse said one thing about treatment of (his/her) pain and another said something else?

- ☐ Yes
☐ No

D16. (In that last week/ While under care of the hospital), did (he/she) have trouble breathing?

- ☐ YES
☐ NO
☐ DON'T KNOW

D16b. How much help in dealing with (his/her) breathing did [PATIENT] receive - less than was needed, or about the right amount?

- ☐ LESS THAN NEEDED
☐ RIGHT AMOUNT

D17. (In that last week/ While under care of the hospital), did (he/she) have any feelings of anxiety or sadness?

- ☐ YES
☐ NO
☐ DON'T KNOW

D17b. How much help in dealing with these feelings did [PATIENT] receive - less than was needed or about the right amount?

- ☐ LESS THAN WAS NEEDED
☐ RIGHT AMOUNT

D18. (In that last week/ While under care of the hospital), was there any problem with doctors or nurses not knowing enough about [PATIENT'S] medical history to provide the best possible care?

- ☐ Yes
☐ No

D19. (In that last week/ While under care of the hospital), was there ever a decision made about (his/her) care without enough input from (him/her) or (his/her) family?

- ☐ Yes
☐ No

D21. (In that last week/ While under care of the hospital), how often were [PATIENT'S] personal care needs - such as bathing, dressing, and changing bedding - taken care of as well as they should have been - would you say always, usually, sometimes, or never?

- ☐ ALWAYS
☐ USUALLY
☐ SOMETIMES
☐ NEVER

D22. (In that last week/ While under care of the hospital), how often was (he/she) treated with respect by those who were taking care of (him/her) - always, usually, sometimes, or never?

- ☐ ALWAYS
☐ USUALLY
☐ SOMETIMES
☐ NEVER

D23. (In that last week/ While under care of the hospital), how often was [PATIENT] treated with kindness by those who were taking care of (him/her) - always, usually, sometimes, or never?

- ☐ ALWAYS
☐ USUALLY
☐ SOMETIMES
☐ NEVER

D24. (In that last week/ While under care of the hospital), was there enough help available to meet (his/her) personal care needs, like bathing, dressing, feeding, and going to the bathroom?

- ☐ Yes
☐ No

D25. (In that last week/ While under care of the hospital), was there enough help with medications and getting dressings changed?

- ☐ Yes
☐ No

D26. At any time while [PATIENT] was in the hospital did you or your family receive any information about what to expect while (he/she) was dying?

- ☐ Yes
☐ No

D26a. Would you have wanted (some/more) information about that?

- ☐ Yes
☐ No

D26b. How confident were you that you knew what to expect while [PATIENT] was dying - very confident, fairly confident, or not confident?

- ☐ VERY CONFIDENT
☐ FAIRLY CONFIDENT
☐ NOT CONFIDENT

D27. At any time while [PATIENT] was in the hospital did you or your family receive any information about what to do at the time of (his/her) death?

- ☐ Yes
☐ No

D27a. Would you have wanted (some/more) information about that?

- ☐ Yes
☐ No

D27b. How confident were you that you knew what to do at the time of death - very confident, fairly confident, or not confident?

- ☐ VERY CONFIDENT
☐ FAIRLY CONFIDENT
☐ NOT CONFIDENT

D28. At any time while [PATIENT] was in the hospital did you or your family receive any information about the medicines that would be used to manage (his/her) pain, shortness of breath, or other symptoms?

- ☐ Yes
☐ No

D28a. Would you have wanted (some/more) information about the medicines?

- ☐ Yes
☐ No

D28b. How confident were you that you understood about the medicines that would be used to manage (his/her) pain, shortness of breath, or other symptoms - very confident, fairly confident, or not confident?

- ☐ VERY CONFIDENT
☐ FAIRLY CONFIDENT
☐ NOT CONFIDENT

E1. (In [PATIENT'S] last week/ While [PATIENT] was under care of the hospital), how often were you or other family members kept informed about [PATIENT'S] condition - always, usually, sometimes, or never?

- ☐ ALWAYS
☐ USUALLY
☐ SOMETIMES
☐ NEVER

E2. (In [PATIENT'S] last week/ While [PATIENT] was under care of the hospital), how often did you have concerns about [PATIENT'S] personal care needs - such as bathing, dressing, and changing bedding - being met when you were not there - always, usually, sometimes, or never?

- ☐ ALWAYS
☐ USUALLY
☐ SOMETIMES
☐ NEVER

E4. (In [PATIENT'S] last week/ While [PATIENT] was under care of the hospital), did someone talk with you about your religious or spiritual beliefs?

- ☐ Yes
☐ No

E4a. Was this done in a sensitive manner?

- ☐ Yes
☐ No

E4b. Did you have as much contact of that kind as you wanted (in [PATIENT'S] last week/ while [PATIENT] was under care of hospital)?

☐ Yes
☐ No

E6. (In [PATIENT'S] last week/ While [PATIENT] was under care of the hospital), how much support in dealing with your feelings about [PATIENT'S] death did the doctors, nurses, and other professional staff taking care of (him/her) provide you - less support than was needed or about the right amount?

☐ LESS THAN WAS NEEDED
☐ RIGHT AMOUNT

E7. (In [PATIENT'S] last week/ While [PATIENT] was under care of the hospital), did a doctor, nurse, or other professional staff taking care of [PATIENT] talk about how you might feel after [PATIENT'S] death?

☐ Yes
☐ No

E7 i. Was it done in a sensitive manner?

☐ Yes
☐ No

E7 ii. Would you have wanted them too?

☐ Yes
☐ No

E8. (In [PATIENT'S] last week/ While [PATIENT] was under care of the hospital), did a doctor, nurse, or other professional staff taking care of [PATIENT] suggest someone you could turn to for help if you were feeling stressed?

☐ Yes
☐ No

RATINGS

F1. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of the hospital), how well did the doctors, nurses, and other professional staff who cared for [PATIENT] communicate with (him/her) and the family about the illness and the likely outcomes of care?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

F2. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of the hospital), how would you rate how well those taking care of [PATIENT] provided medical care that respected (his/her) wishes?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

F3. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of the hospital), how well did those taking care of [PATIENT] make sure (his/her) symptoms were controlled to a degree that was acceptable to (him/her)?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

F4. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of the hospital), how well did those taking care of [PATIENT] make sure that [PATIENT] died with dignity - that is, died on (his/her) own terms?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

F5. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of the hospital), how well did those taking care of [PATIENT] do at providing emotional support for you and [PATIENT'S] family and friends?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

F6. On a scale of 0 to 10, where 0 means the worst care possible and 10 means the best care possible, what number would you give the overall care that [PATIENT] received in [PATIENT'S] last week of life/ while [PATIENT] was under care of the hospital)?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

SOCIAL BACKGROUND

H1. At the time of (his/her) death, was [PATIENT] married, widowed, divorced, separated, or had he/she never been married?

- ☐ MARRIED
☐ WIDOWED
☐ DIVORCED
☐ SEPARATED
☐ NEVER MARRIED
☐ DON'T KNOW

H2. Was (he/she) living alone?

- ☐ YES
☐ NO
☐ DON'T KNOW

H3. What was the highest level of schooling [PATIENT] completed?

- ☐ LESS THAN HIGH SCHOOL
☐ HIGH SCHOOL GRADUATE
☐ TECHNICAL SCHOOL OR AA DEGREE
☐ COLLEGE GRADUATE
☐ ADVANCED DEGREE
☐ DON'T KNOW

H4. What was [PATIENT'S] religious preference - Protestant, Catholic, Jewish, none/Atheist, something else or don't know?

- ☐ PROTESTANT
☐ CATHOLIC
☐ JEWISH
☐ NONE / ATHEIST
☐ SOMETHING ELSE
☐ DON'T KNOW

H4 i. If Protestant, what denomination?

H4 ii. If Jewish, is that Orthodox, Conservative, Reformed, or something else?

- ☐ OTHODOX
☐ REFORM
☐ CONSERVATIVE
☐ OTHER

H4 iii. If [PATIENT'S] religious preference was something else please specify _____

H5. Was [PATIENT] Hispanic or Latino?

- ☐ Yes
☐ No

H6. (In addition to being Hispanic or Latino), Was [PATIENT] White, Black, Asian, or something else?

- ☐ WHITE
☐ BLACK
☐ ASIAN
☐ SOMETHING ELSE
☐ DON'T KNOW

H6 i. If something else, please specify. _____

MODULE: LAST MONTH OF LIFE QUESTIONS

B1. During the last month of [PATIENT'S] life, were there times when (he/she) experienced pain?

- ☐ YES
☐ NO
☐ DON'T KNOW

B1a. Did (he/she) get any help in dealing with (his/her) pain?

- ☐ Yes
☐ No

B1b. How much help in dealing with (his/her) pain did [PATIENT] receive - less than was needed or about the right amount?

- ☐ LESS THAN WAS NEEDED
☐ RIGHT AMOUNT

B2. During the last month of [PATIENT'S] life, were there times when (he/she) had trouble breathing?

- ☐ YES
☐ NO
☐ DON'T KNOW

B2a. Did (he/she) get any help in dealing with (his/her) trouble breathing?

- ☐ Yes
☐ No

B2b. How much help in dealing with (his/her) breathing did [PATIENT] receive - less than was needed or about the right amount?

- ☐ LESS THAN WAS NEEDED
☐ RIGHT AMOUNT

B3. During the last month of life, did [PATIENT] have any feelings of anxiety or sadness?

- ☐ YES
☐ NO
☐ DON'T KNOW

B3a. Did (he/she) get any help in dealing with (his/her) feelings of anxiety or sadness?

- ☐ Yes
☐ No

B3b. How much help in dealing with these feelings did [PATIENT] receive - less than was needed or about the right amount?

- ☐ LESS THAN WAS NEEDED
☐ RIGHT AMOUNT

- B4. During the last month of life, was there ever a decision made about [PATIENT'S] care or treatment without enough input from (him/her) or (his/her) family? ☐ Yes ☐ No
- B5. During the last month of life, was there any decision made about care or treatment that [PATIENT] would not have wanted? ☐ Yes ☐ No
- B6. During the last month of [PATIENT'S] life, how often were (his/her) personal care needs - such as bathing, dressing, and changing bedding - taken care of as well as they should have been - always, usually, sometimes, or never? ☐ ALWAYS ☐ USUALLY ☐ SOMETIMES ☐ NEVER
- B7. During the last month of life, how often was [PATIENT] treated with respect by those who were taking care of (him/her) - always, usually, sometimes, or never? ☐ ALWAYS ☐ USUALLY ☐ SOMETIMES ☐ NEVER
- B8. During the last month of life, how often were you or other family members kept informed about [PATIENT'S] condition - always, usually, sometimes, or never? ☐ ALWAYS ☐ USUALLY ☐ SOMETIMES ☐ NEVER
- B9. During the last month of life, was there always a doctor in charge of [PATIENT]'s care? ☐ Yes ☐ No
- B9a. During the last month of life, was it always clear to you which doctor was in charge of [PATIENT'S] care? ☐ Yes ☐ No
- B10. During the last month of life, do you think [PATIENT] had any interest in seeing or talking with a priest, rabbi, minister, or other religious person? ☐ Yes ☐ No
- B10a. During the last month of life, do you think (he/she) had as much contact of this kind as (he/she) wanted? ☐ Yes ☐ No
- B11. Now, on a scale of 0 to 10, where 0 means as badly as possible and 10 means as well as possible, overall, how would you rate the way things went for [PATIENT] in the last month of life?
- ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

Hospice Version-DOMAIN QUESTIONS

- C1. (In [PATIENT'S] last week/While [PATIENT] was under care of hospice), did you talk with any of [PATIENT'S] doctors yourself? ☐ Yes ☐ No
- C1a. (In that last week/ While under care of hospice), was there ever a problem understanding what any doctor was saying to you about what to expect from treatment? ☐ Yes ☐ No

C1b. (In that last week/ While under care of hospice), did you feel that the doctors you talked to listened to your concerns about [PATIENT'S] medical treatment?	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> HAD NO CONCERNS
C1c. (In that last week/ While under care of hospice), how much information did the doctors provide you about [PATIENT'S] medical condition - would you say less information than was needed, just the right amount, or more than was needed?	<input type="radio"/> LESS THAN WAS NEEDED <input type="radio"/> JUST THE RIGHT AMOUNT <input type="radio"/> MORE THAN WAS NEEDED
C1d. (In that last week/ While under care of hospice), how often did any doctor give confusing or contradictory information about [PATIENT'S] medical treatment - always, usually, sometimes, or never?	<input type="radio"/> ALWAYS <input type="radio"/> USUALLY <input type="radio"/> SOMETIMES <input type="radio"/> NEVER
C2. (In that last week/ While under care of hospice), was there always a doctor in charge of [PATIENT]'s care?	<input type="radio"/> Yes <input type="radio"/> No
C2a. (In that last week/While under care of hospice), was it always clear to you which doctor was in charge of (his/her) care?	<input type="radio"/> Yes <input type="radio"/> No
D1. Did [PATIENT] have specific wishes or plans about the types of medical treatment (he/she) did or did not want while dying?	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> DON'T KNOW
D2. To the best of your knowledge, did [PATIENT]'s doctor or the medical staff who cared for (him/her) while under care of hospice speak to (him/her) or you about (his/her) wishes about medical treatment?	<input type="radio"/> Yes <input type="radio"/> No
D3. Did (his/her) doctor or the medical staff who cared for (him/her) while under care of hospice speak to (him/her) or you about making sure (his/her) care was consistent with (his/her) wishes?	<input type="radio"/> Yes <input type="radio"/> No
D4. (In that last week/ While under care of hospice), was there any medical procedure or treatment that happened to (him/her) that was inconsistent with (his/her) previously stated wishes?	<input type="radio"/> Yes <input type="radio"/> No
D5. Did [PATIENT] have a signed Durable Power of Attorney for Health Care naming someone to make decisions about medical treatment if (he/she) could not speak for (him/her) self?	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> DON'T KNOW
D6. Did [PATIENT] have a signed Living Will giving directions for the kind of medical treatment (he/she) would want if (he/she) could not speak for (him/her) self?	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> DON'T KNOW
D7. Had you or [PATIENT] discussed (his/her) Living Will or Durable Power of Attorney for Health Care with a doctor caring for (him/her) while under care of hospice?	<input type="radio"/> Yes <input type="radio"/> No

Now I want to ask some specific questions about when [PATIENT]'s health started to get worse and (his/her) symptoms while (he/she) was under the care of hospice.

A8. Did the patient lose consciousness for any number of days or any number of weeks?

- ☐ LOST CONSCIOUSNESS FOR A CERTAIN NUMBER OF DAYS
☐ LOST CONSCIOUSNESS FOR A CERTAIN NUMBER OF WEEKS
☐ NEVER LOST CONSCIOUSNESS

A8 i. For how many days did the patient lose consciousness? _____

A8 ii. For how many weeks did the patient lose consciousness _____

D12. (In that last week/ While under care of hospice), was [PATIENT] on medicines to treat (his/her) pain? ☐ YES
☐ NO
☐ DON'T KNOW

D12a. (In that last week/ While under care of hospice), did (his/her) doctor or the medical staff who cared for (him/her) tell you about how (his/her) pain would be treated, in a way that you could understand? ☐ Yes
☐ No

D15. (In that last week/ While under care of hospice), did [PATIENT] receive too much, too little, or just the right amount of medication for (his/her) pain? ☐ TOO MUCH
☐ TOO LITTLE
☐ RIGHT AMOUNT

D15a. (In that last week/ While under care of hospice), was there ever a time when one doctor or nurse said one thing about treatment of (his/her) pain and another said something else? ☐ Yes
☐ No

D16. (In that last week/ While under care of hospice), did (he/she) have trouble breathing? ☐ YES
☐ NO
☐ DON'T KNOW

D16b. How much help in dealing with (his/her) breathing did [PATIENT] receive - less than was needed, or about the right amount? ☐ LESS THAN WAS NEEDED
☐ RIGHT AMOUNT

D17. (In that last week/ While under care of hospice), did (he/she) have any feelings of anxiety or sadness? ☐ YES
☐ NO
☐ DON'T KNOW

D17b. How much help in dealing with these feelings did [PATIENT] receive - less than was needed or about the right amount? ☐ LESS THAN WAS NEEDED
☐ RIGHT AMOUNT

D18. (In that last week/ While under care of hospice), was there any problem with doctors or nurses not knowing enough about [PATIENT'S] medical history to provide the best possible care? ☐ Yes
☐ No

D19. (In that last week/ While under care of hospice), was there ever a decision made about (his/her) care without enough input from (him/her) or (his/her) family?

- ☐ Yes
☐ No

D21. (In that last week/ While under care of hospice), how often were [PATIENT'S] personal care needs - such as bathing, dressing, and changing bedding - taken care of as well as they should have been - would you say always, usually, sometimes, or never?

- ☐ ALWAYS
☐ USUALLY
☐ SOMETIMES
☐ NEVER

D22. (In that last week/ While under care of hospice), how often was (he/she) treated with respect by those who were taking care of (him/her) - always, usually, sometimes, or never?

- ☐ ALWAYS
☐ USUALLY
☐ SOMETIMES
☐ NEVER

D23. In that last week/ While under care of hospice), how often was [PATIENT] treated with kindness by those who were taking care of (him/her) - always, usually, sometimes, or never?

- ☐ ALWAYS
☐ USUALLY
☐ SOMETIMES
☐ NEVER

D24. (In that last week/ While under care of hospice), was there enough help available to meet (his/her) personal care needs, like bathing, dressing, feeding, and going to the bathroom?

- ☐ Yes
☐ No

D25. (In that last week/ While under care of hospice), was there enough help with medications and getting dressings changed?

- ☐ Yes
☐ No

D26. At any time while [PATIENT] was involved with hospice did you or your family receive any information about what to expect while (he/she) was dying?

- ☐ Yes
☐ No

D26a. Would you have wanted (some/more) information about that?

- ☐ Yes
☐ No

D26b. How confident were you that you knew what to expect while [PATIENT] was dying - very confident, fairly confident, or not confident?

- ☐ VERY CONFIDENT
☐ FAIRLY CONFIDENT
☐ NOT CONFIDENT

D27. At any time while [PATIENT] was involved with hospice did you or your family receive any information about what to do at the time of (his/her) death?

- ☐ Yes
☐ No

D27a. Would you have wanted (some/more) information about that?

- ☐ Yes
☐ No

D27b. How confident were you that you knew what to do at the time of death - very confident, fairly confident, or not confident?

- ☐ VERY CONFIDENT
☐ FAIRLY CONFIDENT
☐ NOT CONFIDENT

D28. At any time while [PATIENT] was involved with hospice did you or your family receive any information about the medicines that would be used to manage (his/her) pain, shortness of breath, or other symptoms?

- ☐ Yes
☐ No

D28a. Would you have wanted (some/more) information about the medicines?

- ☐ Yes
☐ No

D28b. How confident were you that you understood about the medicine that would be used to manage (his/her) pain, shortness of breath, or other symptoms- very confident, fairly confident, or not confident?

- ☐ VERY CONFIDENT
☐ FAIRLY CONFIDENT
☐ NOT CONFIDENT

D29b. How confident did you feel about taking care of [PATIENT] at home - very confident, fairly confident, or not confident?

- ☐ VERY CONFIDENT
☐ FAIRLY CONFIDENT
☐ NOT CONFIDENT
(If patient did not die at home or someone else's home then skip D29b and go to E1)

These next questions are about YOUR experience during [PATIENT'S] last week/while under care of hospice).

- ☐ ALWAYS
☐ USUALLY
☐ SOMETIMES
☐ NEVER

E1. (In [PATIENT'S] last week/ While [PATIENT] was under care of hospice), how often were you or other family members kept informed about [PATIENT'S] condition - always, usually, sometimes, or never?

E2. (In [PATIENT'S] last week/ While [PATIENT] was under care of hospice), how often did you have concerns about [PATIENT'S] personal care needs - such as bathing, dressing, and changing bedding- being met when you were not there - always, usually, sometimes, or never

- ☐ ALWAYS
☐ USUALLY
☐ SOMETIMES
☐ NEVER

E5. (In [PATIENT'S] last week/ While [PATIENT] was under care of hospice), did someone from hospice talk with you about your religious or spiritual beliefs?

- ☐ Yes
☐ No

E5a. Was this done in a sensitive manner?

- ☐ Yes
☐ No

E5b. Did you have as much contact of that kind as you wanted (in [PATIENT'S] last week/ while [PATIENT] was under care of hospice)?

- ☐ Yes
☐ No

E6. (In [PATIENT'S] last week/ While [PATIENT] was under care of hospice), how much support in dealing with your feelings about [PATIENT]'s death did the doctors, nurses, and other professional staff taking care of (him/her) provide you - less support than was needed or about the right amount?

- ☐ LESS THAN WAS NEEDED
☐ RIGHT AMOUNT

E7. (In [PATIENT'S] last week/ While [PATIENT] was under care of hospice), did a doctor, nurse, or other professional staff taking care of [PATIENT] talk about how you might feel after [PATIENT'S] death?

- ☐ Yes
☐ No

E7 i. Was it done in a sensitive manner?

☐ Yes
☐ No

E7 ii. Would you have wanted them to?

☐ Yes
☐ No

E8. (In [PATIENT'S] last week/ While [PATIENT] was under care of hospice), did a doctor, nurse, or other professional staff taking care of [PATIENT] suggest someone you could turn to for help if you were feeling stressed?

☐ Yes
☐ No

RATINGS

F1. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of hospice), how well did the doctors, nurses, and other professional staff who cared for [PATIENT] communicate with (him/her) and the family about the illness and the likely outcomes of care?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

F2. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of hospice), how would you rate how well those taking care of [PATIENT] provided medical care that respected (his/her) wishes?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

F3. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of hospice), how well did those taking care of [PATIENT] make sure (his/her) symptoms were controlled to a degree that was acceptable to (him/her)?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

F4. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of hospice), how well did those taking care of [PATIENT] make sure that [PATIENT] died with dignity - that is, died on (his/her) own terms?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

F5. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of hospice), how well did those taking care of [PATIENT] do at providing emotional support for you and [PATIENT]'s family and friends?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

And now an overall rating...

F6. On a scale of 0 to 10, where 0 means the worst care possible and 10 means the best care possible, what number would you give the overall care that [PATIENT] received in [PATIENT'S] last week of life/ while [PATIENT] was under care of hospice)?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

SOCIAL BACKGROUND

H1. At the time of (his/her) death, was [PATIENT] married, widowed, divorced, separated, or had he/she never been married?

- ☐ MARRIED
- ☐ WIDOWED
- ☐ DIVORCED
- ☐ SEPARATED
- ☐ NEVER MARRIED
- ☐ DON'T KNOW

H2. Was (he/she) living alone?

- ☐ YES
- ☐ NO
- ☐ DON'T KNOW

H3. What was the highest level of schooling [PATIENT] completed?

- ☐ LESS THAN HIGH SCHOOL
- ☐ HIGH SCHOOL GRADUATE
- ☐ TECHNICAL SCHOOL OR AA DEGREE
- ☐ COLLEGE GRADUATE
- ☐ ADVANCED DEGREE
- ☐ DON'T KNOW

H4. What was [PATIENT'S] religious preference - Protestant, Catholic, Jewish, none/Atheist, something else or don't know?

- ☐ PROTESTANT
- ☐ CATHOLIC
- ☐ JEWISH
- ☐ NONE/ATHEIST
- ☐ SOMETHING ELSE
- ☐ DON'T KNOW

H4 i. If Protestant, what denomination if that?

H4 ii. If Jewish, what denomination?

- ☐ ORTHODOX
- ☐ REFORM
- ☐ CONSERVATIVE
- ☐ OTHER

H4 iii. If something else, specify

H5. Was [PATIENT] Hispanic or Latino?

- ☐ Yes
- ☐ No

H6. (In addition to being Hispanic or Latino), Was [PATIENT] White, Black, Asian, or something else?

- ☐ WHITE
- ☐ BLACK
- ☐ ASIAN
- ☐ SOMETHING ELSE
- ☐ DON'T KNOW

H6 i. If something else, specify _____

MODULE: Last Month of Life Questions**Now I was to ask about the care [PATIENT] received during (his/her) last month of life.**

B1. During the last month of [PATIENT'S] life, were there times when (he/she) experienced pain?

- ☐ YES
☐ NO
☐ DON'T KNOW

B1a. Did (he/she) get any help in dealing with (his/her) pain?

- ☐ Yes
☐ No

B1b. How much help in dealing with (his/her) pain did [PATIENT] receive - less than was needed or about the right amount?

- ☐ LESS THAN WAS NEEDED
☐ RIGHT AMOUNT

B2. During the last month of [PATIENT'S] life, were there times when (he/she) had trouble breathing?

- ☐ YES
☐ NO
☐ DON'T KNOW

B2a. Did (he/she) get any help in dealing with (his/her) trouble breathing?

- ☐ Yes
☐ No

B2b. How much help in dealing with (his/her) breathing did [PATIENT] receive - less than was needed or about the right amount?

- ☐ LESS THAN WAS NEEDED
☐ RIGHT AMOUNT

B3. During the last month of life, did [PATIENT] have any feelings of anxiety or sadness?

- ☐ YES
☐ NO
☐ DON'T KNOW

B3a. Did (he/she) get any help in dealing with (his/her) feelings of anxiety or sadness?

- ☐ Yes
☐ No

B3b. How much help in dealing with these feelings did [PATIENT] receive - less than was needed or about the right amount?

- ☐ LESS THAN WAS NEEDED
☐ RIGHT AMOUNT

B4. During the last month of life, was there ever a decision made about [PATIENT'S] care or treatment without enough input from (him/her) or (his/her) family?

- ☐ Yes
☐ No

B5. During the last month of life, was there any decision made about care or treatment that [PATIENT] would not have wanted?

- ☐ Yes
☐ No

B6. During the last month of [PATIENT'S] life, how often were (his/her) personal care needs - such as bathing, dressing, and changing bedding - taken care of as well as they should have been - always, usually, sometimes, or never

- ☐ ALWAYS
☐ USUALLY
☐ SOMETIMES
☐ NEVER

B7. During the last month of life, how often was [PATIENT] treated with respect by those who were taking care of (him/her) - always, usually, sometimes, or never?

- ☐ ALWAYS
☐ USUALLY
☐ SOMETIMES
☐ NEVER

B8. During the last month of life, how often were you or other family members kept informed about [PATIENT'S] condition - always, usually, sometimes, or never?

- ☐ ALWAYS
☐ USUALLY
☐ SOMETIMES
☐ NEVER

B9. During the last month of life, was there always a doctor in charge of [PATIENT]'s care?

- ☐ Yes
☐ No

B9a. During the last month of life, was it always clear to you which doctor was in charge of [PATIENT]'s care?

- ☐ Yes
☐ No

B10. During the last month of life, do you think [PATIENT] had any interest in seeing or talking with a priest, rabbi, minister, or other religious person?

- ☐ Yes
☐ No

B10a. During the last month of life, do you think (he/she) had as much contact of this kind as (he/she) wanted?

- ☐ Yes
☐ No

B11. Now, on a scale of 0 to 10, where 0 means as badly as possible and 10 means as well as possible, overall, how would you rate the way things went for [PATIENT] in the last month of life?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

Nursing Home Version-DOMAIN QUESTIONS

These next questions are about [PATIENT]'s experience during (his/her) (last week/while under care of the nursing home).

C1. (In [PATIENT'S] last week/While [PATIENT] was under care of the nursing home), did you talk with any of [PATIENT'S] doctors yourself?

- ☐ Yes
☐ No

C1a.(In that last week/ While under care of the nursing home), was there ever a problem understanding what any doctor was saying to you about what to expect from treatment?

- ☐ Yes
☐ No

C1b. (In that last week/ While under care of the nursing home), did you feel that the doctors you talked to listened to your concerns about [PATIENT'S] medical treatment?

- ☐ YES
☐ NO
☐ HAD NO CONCERNS

C1c. (In that last week/ While under care of the nursing home), how much information did the doctors provide you about [PATIENT'S] medical condition - would you say less information than was needed, just the right amount, or more than was needed?

- ☐ LESS THAN WAS NEEDED
☐ JUST THE RIGHT AMOUNT
☐ MORE THAN WAS NEEDED

C1d. (In that last week/ While under care of the nursing home), how often did any doctor give confusing or contradictory information about [PATIENT'S] medical treatment - always, usually, sometimes, or never?

- ☐ ALWAYS
☐ USUALLY
☐ SOMETIMES
☐ NEVER

C2. (In that last week/ While under care of the nursing home), was there always a doctor in charge of [PATIENT]'s care?

- ☐ Yes
☐ No

C2a. (In that last week/While under care of the nursing home), was it always clear to you which doctor was in charge of (his/her) care?

- ☐ Yes
☐ No

D1. Did [PATIENT] have specific wishes or plans about the types of medical treatment (he/she) did or did not want while dying?

- ☐ YES
☐ NO
☐ DON'T KNOW

D2. To the best of your knowledge, did [PATIENT]'s doctor or the medical staff who cared for (him/her) while under care of the nursing home speak to (him/her) or you about (his/her) wishes about medical treatment?

- ☐ Yes
☐ No

D3. Did (his/her) doctor or the medical staff who cared for (him/her) while under care of the nursing home speak to (him/her) or you about making sure (his/her) care was consistent with (his/her) wishes?

- ☐ Yes
☐ No

D4. (In that last week/ While under care of the nursing home), was there any medical procedure or treatment that happened to (him/her) that was inconsistent with (his/her) previously stated wishes?

- ☐ Yes
☐ No

D5. Did [PATIENT] have a signed Durable Power of Attorney for Health Care naming someone to make decisions about medical treatment if (he/she) could not speak for (him/her) self?

- ☐ YES
☐ NO
☐ DON'T KNOW

D6. Did [PATIENT] have a signed Living Will giving directions for the kind of medical treatment (he/she) would want if (he/she) could not speak for (him/her) self?

- ☐ YES
☐ NO
☐ DON'T KNOW

D7. Had you or [PATIENT] discussed (his/her) Living Will or Durable Power of Attorney for Health Care with a doctor caring for (him/her) while under care of the nursing home?

- ☐ Yes
☐ No

A8. Did the patient lose consciousness for any number of days or any number of weeks?

- ☐ LOST CONSCIOUSNESS FOR A CERTAIN NUMBER OF DAYS
☐ LOST CONSCIOUSNESS FOR A CERTAIN NUMBER OF WEEKS
☐ NEVER LOST CONSCIOUSNESS
 (If A8 is greater than or equal to 1 week or if less than a week but longer than the time the patient was under the care of the nursing home, skip to D18)

A8 i. For how many days did the patient lose consciousness?

A8 ii. For how many weeks did the patient lose consciousness? _____

D12. (In that last week/ While under care of the nursing home), was [PATIENT] on medicines to treat (his/her) pain?

- ☐ YES
☐ NO
☐ DONT' KNOW
-

D12a. (In that last week/ While under care of the nursing home), did (his/her) doctor or the medical staff who cared for (him/her) tell you about how (his/her) pain would be treated, in a way that you could understand?

- ☐ Yes
☐ No
-

D15. (In that last week/ While under care of the nursing home), did [PATIENT] receive too much, too little, or just the right amount of medication for (his/her) pain?

- ☐ TOO MUCH
☐ TOO LITTLE
☐ RIGHT AMOUNT
-

D15a. (In that last week/ While under care of the nursing home), was there ever a time when one doctor or nurse said one thing about treatment of (his/her) pain and another said something else?

- ☐ Yes
☐ No
-

D16. (In that last week/ While under care of the nursing home), did (he/she) have trouble breathing?

- ☐ YES
☐ NO
☐ DON'T KNOW
-

D16b. How much help in dealing with (his/her) breathing did [PATIENT] receive - less than was needed, or about the right amount?

- ☐ LESS THAN WAS NEEDED
☐ RIGHT AMOUNT
-

D17. (In that last week/ While under care of the nursing home), did (he/she) have any feelings of anxiety or sadness?

- ☐ YES
☐ NO
☐ DON'T KNOW
-

D17b. How much help in dealing with these feelings did [PATIENT] receive - less than was needed or about the right amount?

- ☐ LESS THAN WAS NEEDED
☐ RIGHT AMOUNT
-

D18. (In that last week/ While under care of the nursing home), was there any problem with doctors or nurses not knowing enough about [PATIENT'S] medical history to provide the best possible care?

- ☐ Yes
☐ No
-

D19. (In that last week/ While under care of the nursing home), was there ever a decision made about (his/her) care without enough input from (him/her) or (his/her) family?

- ☐ Yes
☐ No
-

D21. (In that last week/ While under care of the nursing home), how often were [PATIENT'S] personal care needs - such as bathing, dressing, and changing bedding - taken care of as well as they should have been - would you say always, usually, sometimes, or never?

- ☐ ALWAYS
☐ USUALLY
☐ SOMETIMES
☐ NEVER

D22. (In that last week/ While under care of the nursing home), how often was (he/she) treated with respect by those who were taking care of (him/her) - always, usually, sometimes, or never?

- ☐ ALWAYS
☐ USUALLY
☐ SOMETIMES
☐ NEVER

D23. (In that last week/ While under care of the nursing home), how often was [PATIENT] treated with kindness by those who were taking care of (him/her) - always, usually, sometimes, or never?

- ☐ ALWAYS
☐ USUALLY
☐ SOMETIMES
☐ NEVER

D24. In that last week/ While under care of the nursing home), was there enough help available to meet (his/her) personal care needs, like bathing, dressing, feeding, and going to the bathroom?

- ☐ Yes
☐ No

D25. (In that last week/ While under care of the nursing home), was there enough help with medications and getting dressings changed?

- ☐ Yes
☐ No

D26. At any time while [PATIENT] was in the nursing home did you or your family receive any information about what to expect while (he/she) was dying?

- ☐ Yes
☐ No

D26a. Would you have wanted (some/more) information about that?

- ☐ Yes
☐ No

D26b. How confident were you that you knew what to expect while [PATIENT] was dying - very confident, fairly confident, or not confident?

- ☐ VERY CONFIDENT
☐ FAIRLY CONFIDENT
☐ NOT CONFIDENT

D27. At any time while [PATIENT] was in the nursing home did you or your family receive any information about what to do at the time of (his/her) death?

- ☐ Yes
☐ No

D27a. Would you have wanted (some/more) information about that?

- ☐ Yes
☐ No

D27b. How confident were you that you knew what to do at the time of death - very confident, fairly confident, or not confident?

- ☐ VERY CONFIDENT
☐ FAIRLY CONFIDENT
☐ NOT CONFIDENT

D28. At any time while [PATIENT] was in the nursing home did you or your family receive any information about the medicines that would be used to manage (his/her) pain, shortness of breath, or other symptoms?

- ☐ Yes
☐ No

D28a. Would you have wanted (some/more) information about the medicines?

- ☐ Yes
☐ No

D28b. How confident were you that you understood about the medicines that would be used to manage (his/her) pain, shortness of breath, or other symptoms - very confident, fairly confident, or not confident?

- ☐ VERY CONFIDENT
☐ FAIRLY CONFIDENT
☐ NOT CONFIDENT

These next questions are about YOUR experience during [PATIENT]'s last week/while [PATIENT] was under the care of nursing home.

- ☐ ALWAYS
☐ USUALLY
☐ SOMETIMES
☐ NEVER

E1. (In [PATIENT'S] last week/ While [PATIENT] was under care of the nursing home), how often were you or other family members kept informed about [PATIENT'S] condition - always, usually, sometimes, or never?

E2. (In [PATIENT'S] last week/ While [PATIENT] was under care of the nursing home), how often did you have concerns about [PATIENT'S] personal care needs - such as bathing, dressing, and changing bedding-being met when you were not there - always, usually, sometimes, or never?

- ☐ ALWAYS
☐ USUALLY
☐ SOMETIMES
☐ NEVER

E4. (In [PATIENT'S] last week/ While [PATIENT] was under care of the nursing home), did someone talk with you about your religious or spiritual beliefs?

- ☐ Yes
☐ No

E4a. Was this done in a sensitive manner?

- ☐ Yes
☐ No

E4b. Did you have as much contact of that kind as you wanted (in [PATIENT'S] last week/ while [PATIENT] was under care of nursing home)?

- ☐ Yes
☐ No

E6. (In [PATIENT'S] last week/ While [PATIENT] was under care of the nursing home), how much support in dealing with your feelings about [PATIENT'S] death did the doctors, nurses, and other professional staff taking care of (him/her) provide you - less support than was needed or about the right amount?

- ☐ LESS THAN WAS NEEDED
☐ RIGHT AMOUNT

E7. (In [PATIENT'S] last week/ While [PATIENT] was under care of the nursing home), did a doctor, nurse, or other professional staff taking care of [PATIENT] talk about how you might feel after [PATIENT'S] death?

- ☐ Yes
☐ No

E7 i. Was this done in a sensitive manner?

- ☐ Yes
☐ No

E7 ii. Would you have wanted them to?

- ☐ Yes
☐ No

E8. (In [PATIENT'S] last week/ While [PATIENT] was under care of the nursing home), did a doctor, nurse, or other professional staff taking care of [PATIENT] suggest someone you could turn to for help if you were feeling stressed?

- ☐ Yes
☐ No

RATINGS

Now we would like you to rate some aspects of the care [PATIENT] received (in that last week/while he/she was under the care of the nursing home). For each of the following questions, I'm going to ask you to use a scale from 0 to 10, where 0 means the worst care possible and 10 means the best care possible.

F1. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of the nursing home), how well did the doctors, nurses, and other professional staff who cared for [PATIENT] communicate with (him/her) and the family about the illness and the likely outcomes of care?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

F2. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of the nursing home), how would you rate how well those taking care of [PATIENT] provided medical care that respected (his/her) wishes?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

F3. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of the nursing home), how well did those taking care of [PATIENT] make sure (his/her) symptoms were controlled to a degree that was acceptable to (him/her)?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

F4. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of the nursing home), how well did those taking care of [PATIENT] make sure that [PATIENT] died with dignity - that is, died on (his/her) own terms?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

F5. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of the nursing home), how well did those taking care of [PATIENT] do at providing emotional support for you and [PATIENT'S] family and friends

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

And now an overall rating...

F6. On a scale of 0 to 10, where 0 means the worst care possible and 10 means the best care possible, what number would you give the overall care that [PATIENT] received in [PATIENT'S] last week of life/ while [PATIENT] was under care of the nursing home)?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

SOCIAL BACKGROUND

Now I have a few background questions about [PATIENT].

H1. At the time of (his/her) death, was [PATIENT] married, widowed, divorced, separated, or had he/she never been married?

- ☐ MARRIED
☐ WIDOWED
☐ DIVORCED
☐ SEPARATED
☐ NEVER MARRIED
☐ DON'T KNOW

H2. Was (he/she) living alone?

- ☐ YES
☐ NO
☐ DON'T KNOW
-

H3. What was the highest level of schooling [PATIENT] completed?

- ☐ LESS THAN HIGH SCHOOL
☐ HIGH SCHOOL GRADUATE
☐ TECHNICAL SCHOOL OR AA DEGREE
☐ COLLEGE GRADUATE
☐ ADVANCED DEGREE
☐ DON'T KNOW
-

H4. What was [PATIENT'S] religious preference - Protestant, Catholic, Jewish, none/Atheist, something else or don't know

- ☐ PROTESTANT
☐ CATHOLIC
☐ JEWISH
☐ NONE/ATHEIST
☐ SOMETHING ELSE
☐ DON'T KNOW
-

H4 i. If Protestant, what denomination?

H4 ii. If Jewish, is that Orthodox, Conservative, Reformed, or something else

- ☐ ORTHODOX
☐ REFORM
☐ CONSERVATIVE
☐ OTHER
-

H4 iii. If something else, specify

H5. Was [PATIENT] Hispanic or Latino?

- ☐ Yes
☐ No
-

H6. (In addition to being Hispanic or Latino), Was [PATIENT] White, Black, Asian, or something else?

- ☐ WHITE
☐ BLACK
☐ ASIAN
☐ SOMETHING ELSE
☐ DON'T KNOW
-

If something else, please specify.

MODULE: Last Month of Life Questions

Now I want to ask about the care [PATIENT] received during his/her last month of life.

(If A8 is greater than or equal to 1 month then skip to B4)

B1. During the last month of [PATIENT'S] life, were there times when (he/she) experienced pain?

- ☐ YES
☐ NO
☐ DON'T KNOW

B1a. Did (he/she) get any help in dealing with (his/her) pain?

- ☐ Yes
☐ No

B1b. How much help in dealing with (his/her) pain did [PATIENT] receive - less than was needed or about the right amount?

- ☐ LESS THAN WAS NEEDED
☐ RIGHT AMOUNT

B2. During the last month of [PATIENT'S] life, were there times when (he/she) had trouble breathing?

- ☐ YES
☐ NO
☐ DON'T KNOW

B2a. Did (he/she) get any help in dealing with (his/her) trouble breathing?

- ☐ Yes
☐ No

B2b. How much help in dealing with (his/her) breathing did [PATIENT] receive - less than was needed or about the right amount?

- ☐ LESS THAN WAS NEEDED
☐ RIGHT AMOUNT

B3. During the last month of life, did [PATIENT] have any feelings of anxiety or sadness?

- ☐ YES
☐ NO
☐ DON'T KNOW

B3a. Did (he/she) get any help in dealing with (his/her) feelings of anxiety or sadness?

- ☐ Yes
☐ No

B3b. How much help in dealing with these feelings did [PATIENT] receive - less than was needed or about the right amount?

- ☐ LESS THAN WAS NEEDED
☐ RIGHT AMOUNT

B4. During the last month of life, was there ever a decision made about [PATIENT'S] care or treatment without enough input from (him/her) or (his/her) family?

- ☐ Yes
☐ No

B5. During the last month of life, was there any decision made about care or treatment that [PATIENT] would not have wanted?

- ☐ Yes
☐ No

B6. During the last month of [PATIENT'S] life, how often were (his/her) personal care needs - such as bathing, dressing, and changing bedding - taken care of as well as they should have been - always, usually, sometimes, or never?

- ☐ ALWAYS
☐ USUALLY
☐ SOMETIMES
☐ NEVER

B7. During the last month of life, how often was [PATIENT] treated with respect by those who were taking care of (him/her) - always, usually, sometimes, or never?

- ☐ ALWAYS
☐ USUALLY
☐ SOMETIMES
☐ NEVER

B8. During the last month of life, how often were you or other family members kept informed about [PATIENT'S] condition - always, usually, sometimes, or never?

- ☐ ALWAYS
☐ USUALLY
☐ SOMETIMES
☐ NEVER

B9. During the last month of life, was there always a doctor in charge of [PATIENT]'s care?

- ☐ Yes
☐ No

B9a. During the last month of life, was it always clear to you which doctor was in charge of [PATIENT'S] care?

- ☐ Yes
☐ No

B10. During the last month of life, do you think [PATIENT] had any interest in seeing or talking with a priest, rabbi, minister, or other religious person?

- ☐ Yes
☐ No
(Skip B10 if ans to A8 is greater than or equal to 1 month.)

B10a. During the last month of life, do you think (he/she) had as much contact of this kind as (he/she) wanted?

- ☐ Yes
☐ No

B11. Now, on a scale of 0 to 10, where 0 means as badly as possible and 10 means as well as possible, overall, how would you rate the way things went for [PATIENT] in the last month of life?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

FAMCARE Scale

Instructions: Think about the care that your family member has received. Please answer the questions below indicating how satisfied you are with the care received: Very Satisfied (VS), Satisfied (S), Undecided (U), Dissatisfied (D), or Very Dissatisfied (VD). Please circle the letters below that best match your experience.

	very satisfied	satisfied	undecided	dissatisfied	very dissatisfied
1. The patient's pain relief	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Information provided about the patient's prognosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Answers from health professionals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Information given about side effects	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Referrals to specialists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Availability of a hospital bed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Family conferences held to discuss the patient's illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Speed with which symptoms are treated	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Doctor's attention to patient's description of symptoms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. The way tests and treatments are performed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. Availability of doctors to the family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. Availability of nurses to the family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. Coordination of care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. Time required to make a diagnosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. The way the family is included in treatment and care decisions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. Information given about how to manage the patient's pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. Information given about the patient's tests	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. How thoroughly the doctor assess the patient's symptoms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. The way tests and treatments are followed up by the doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

20. Availability of the doctor to the patient

☐☐☐☐☐

Mack Items #1-23

1. Life Changes

Now we would like for you to think about how much your life has changed as a result of caring for [PATIENT] at the end of his/her care. For each question, think back too the time when [PATIENT] was alive and you were participating in his/her care. Think about whether your life changed for the best, did not change, or changed for the worst during that time.

	-3	-2	-1	0	+1	+2	+3
My self-esteem	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My physical health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My time for family activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My ability to cope with stress	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My relationship with friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My future outlook	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My emotional well-being	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My time for social activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My relationship with family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My relationship with [PATIENT]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Now we would like to learn more about you and [PATIENT].

2. Thinking back to the last 6 months of [PATIENT]'s life, who would you say he/she lived with most of the time when he/she was at home? [Mark all that apply]

- ☐ I lived with the patient [if patient lived with participant, specify relationship by also checking appropriate box below]
- ☐ Patient's partner/spouse/boyfriend/girlfriend
- ☐ Patient's mother
- ☐ Patient's father
- ☐ Patient's brother
- ☐ Patient's sister
- ☐ Patient's grandparent
- ☐ Patient's child(ren)
- ☐ Patient's other relative [please specify]
- ☐ Patient's friend
- ☐ Other [please specify]
- ☐ The patient lived alone

2 i. If patient lived with another relative, please specify

2 ii. If patient lived with other, please specify

3. As of January, [YEAR BEFORE DEATH], did [PATIENT] have a job for pay or own a business?

(Note: Do not count work around the house. Include work in a family farm or business, even if unpaid.)

- ☐ Yes
- ☐ No
- ☐ Refused
- ☐ Don't know

4.[If No] What is the main reason [PATIENT] was not working at that time?

- ☐ Patient did not need to work because he/she was still young
- ☐ Unable to work because ill/disabled
- ☐ Going to school
- ☐ Could not find work
- ☐ Retired
- ☐ On temporary layoff
- ☐ Maternity/paternity leave
- ☐ Taking care of home or family
- ☐ Wanted some time off
- ☐ Waiting to find work
- ☐ Other
- ☐ Refused
- ☐ Don't know

5. Did[PATIENT] live in your household in [calendar year before death]?

- ☐ Yes
- ☐ No

6. What is your best guess of [PATIENT]'s household income in [calendar year before death] from all sources before taxes were taken out? Was it...

- ☐ No income
- ☐ \$1-5,000
- ☐ \$5001-10,000
- ☐ \$10,001-15,000
- ☐ \$15,001-25,000
- ☐ \$25,001-50,000
- ☐ \$50,001-100,000
- ☐ \$100,001 or more
- ☐ Refused
- ☐ Don't know

7. As of [month of death], did [PATIENT] have a job for pay or own a business?

(Note: Do not count work around the house. Include work in a family farm or business, even if unpaid)

- ☐ Yes
- ☐ No
- ☐ Refused
- ☐ Don't know

8. [If No] What is the main reason [PATIENT] was not working at that time?

- ☐ Patient did not need to work because he/she was still young
- ☐ Unable to work because ill/disabled
- ☐ Going to school
- ☐ Could not find work
- ☐ Retired
- ☐ On temporary layoff
- ☐ Maternity/paternity leave
- ☐ Taking care of home or family
- ☐ Wanted some time off
- ☐ Waiting to find work
- ☐ Other
- ☐ Refused
- ☐ Don't know

9. What is your gender

- ☐ Male
- ☐ Female

10. What is the highest level of school you have completed?

Please check one.

- ☐ Less than high school
- ☐ High school graduate
- ☐ Technical school or AA (associate's) degree
- ☐ College graduate
- ☐ Advanced degree

11. As of January, [year before death], did you have a job or own a business?

(Note: Do NOT count work around the house. DO include work in family farm or business, even if unpaid)

- ☐ Yes
- ☐ No
- ☐ Refused
- ☐ Don't Know

12. [If no] What is the main reason you were not working at the time?

- ☐ Could not find work
- ☐ Retired
- ☐ Unable to work because ill/disabled
- ☐ Taking care of patient
- ☐ On temporary layoff
- ☐ Maternity/paternity leave
- ☐ Going to school
- ☐ Taking care of home or family, other than patient
- ☐ Wanted some time off
- ☐ Other
- ☐ Refused
- ☐ Don't Know

13. What is your best guess of your total household income in [calendar year before death] from all sources before taxes were taken out?

- ☐ No income
- ☐ \$1-5,000
- ☐ \$5,001-10,000
- ☐ \$10,001-15,000
- ☐ \$15,001-25,000
- ☐ \$25,001-50,000
- ☐ \$50,001-100,000
- ☐ \$100,001 or more
- ☐ Refused
- ☐ Don't know

14. As of [month of death], did you have a job or own a business?

(Note: Do NOT count work around the house. DO include work in family farm or business, even if unpaid)

- ☐ Yes
- ☐ No
- ☐ Refused
- ☐ Don't Know

15. [If No] What is the main reason you were not working at that time?

- ☐ Could not find work
- ☐ Retired
- ☐ Unable to work because ill/disabled
- ☐ Taking care of patient
- ☐ On temporary layoff
- ☐ Maternity/paternity leave
- ☐ Going to school
- ☐ Taking care of home or family, other than patient
- ☐ Wanted some time off
- ☐ Other
- ☐ Refused
- ☐ Don't Know

16. If you lost all of your current sources of income (for example your paycheck, Social Security or pension, public assistance) and had to live off of your savings how long could you continue to live at your current address and standard of living?

- ☐ LESS THAN 1 MONTH
- ☐ 1-2 MONTHS
- ☐ 3-6 MONTHS
- ☐ 7-12 MONTHS
- ☐ MORE THAN 1 YEAR
- ☐ DON'T KNOW
- ☐ REFUSED

17 i. Including yourself, how many people living in your household are supported by your total household income? _____

17 ii. Including yourself, how many people living in your household are supported by your total household income? _____

- ☐ DON'T KNOW
- ☐ REFUSE

18 i. How many of these people are under the age of 18? _____

18 ii. How many of these people are children under 18?

- ☐ DON'T KNOW
☐ REFUSED
-

19. Are you currently married, widowed, divorced, separated, or never married?

- ☐ Never married
☐ Married/living as married
☐ Widowed
☐ Separated
☐ Divorced
-

20. Do you consider yourself Hispanic/Latino?

- ☐ Yes
☐ No
-

21. What group best describes your racial background?

- ☐ White
☐ Black
☐ Asian/Pacific Islander
☐ Native American
☐ Other
-

21 i. Please specify other race

22. What language do you speak at home?

- ☐ English
☐ Spanish
☐ Other
-

22 i. Please specify other language

23. What is your religion?

- ☐ Catholic
☐ Protestant
☐ Jewish
☐ Other
☐ No religion
-

23 i. Please specify other religion
