

PCRC - HOSPICE AND PALLIATIVE CARE UTILIZATION AMONG ADOLESCENT AND YOUNG ADULT CANCER PATIENTS

[Codebook](#)

Data Dictionary Codebook

03/16/2020 11:21am

[^ Collapse all instruments](#)

	#	Variable / Field Name	Field Label <i>Field Note</i>	Field Attributes (Field Type, Validation, Choices, Calculations, etc.)
Instrument: Medical Record Abstraction (medical_record_abstraction) <div>⤴ Collapse</div>				
	1	record_id	Record ID <i>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.</i>	text
	2	qcyesno	Is this a NEW record or is this a DUPLICATE record being created for the purpose of QCing? <i>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."</i>	radio <div><div>1 New Record</div><div>2 Duplicate Record for QC</div></div>
	3	qcyesid Show the field ONLY if: [qcyesno] = '2'	If this is a duplicate record, what is the record ID of the original record that you are QCing? <i>Please write in format: XXXX-XX</i>	text
	4	sitename	Your site name:	radio, Required <div><div>1 University of California San Diego</div><div>2 University of Iowa</div><div>3 UAB</div></div>
	5	dob	Section Header: Eligibility Check Instructions: Please answer the following questions by looking in the patient's medical record. What is the patient's date of birth?	text (date_mdy), Required, Identifier
	6	dod	What is the patient's date of death? <i>(Must be between 1/1/2013-12/31/2016 in order to be eligible for this study.)</i>	text (date_mdy, Min: 2013-01-01, Max: 2016-12-31), Required, Identifier
	7	age_at_death	Age at time of death (in years): <i>(Must be age 15-39 at time of death.)</i>	text, Required
	8	cancer	Was the patient diagnosed with cancer? <i>(Must be yes.)</i>	radio, Required <div><div>1 Yes</div><div>2 No</div></div>
	9	cancer_dx_date	On what date was the patient diagnosed with cancer? <i>(Must be >=30 days before date of death.)</i>	text (date_mdy), Required, Identifier
	10	site_care	Did the patient receive care at your site during the month of his/her death? <i>(Must be yes.)</i>	radio, Required <div><div>1 Yes</div><div>2 No</div></div>
	11	elx	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?	yesno, Required <div><div>1 Yes</div><div>0 No</div></div>
	12	aya_initials	Section Header: Part A - Participant Demographic Information Instructions: Please answer the following questions by looking in the patient's medical record. Initials <i>Example: for John Doe, enter J.D.</i>	text, Required
	13	sex	Sex	radio, Required <div><div>1 Male</div><div>2 Female</div></div>
	14	ethnicity	Ethnicity	radio, Required <div><div>1 Hispanic or Latino</div><div>2 Not Hispanic or Latino</div><div>3 Not documented / unknown</div></div>

15	race	Race (select all that apply) (Select all that apply.)	checkbox, Required <table border="1"> <tr><td>1</td><td>race__1</td><td>White</td></tr> <tr><td>2</td><td>race__2</td><td>Black or African American</td></tr> <tr><td>3</td><td>race__3</td><td>Asian</td></tr> <tr><td>4</td><td>race__4</td><td>Native Hawaiian or Pacific Islander</td></tr> <tr><td>5</td><td>race__5</td><td>American Indian or Alaska Native</td></tr> <tr><td>6</td><td>race__6</td><td>Not documented / unknown</td></tr> </table>	1	race__1	White	2	race__2	Black or African American	3	race__3	Asian	4	race__4	Native Hawaiian or Pacific Islander	5	race__5	American Indian or Alaska Native	6	race__6	Not documented / unknown
1	race__1	White																			
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3	race__3	Asian																			
4	race__4	Native Hawaiian or Pacific Islander																			
5	race__5	American Indian or Alaska Native																			
6	race__6	Not documented / unknown																			
16	education	Which best describes the patient's highest level of education completed?	radio, Required <table border="1"> <tr><td>1</td><td>Grade school or less</td></tr> <tr><td>2</td><td>High school graduate or GED</td></tr> <tr><td>3</td><td>Some vocational, business or trade school</td></tr> <tr><td>4</td><td>Some college</td></tr> <tr><td>5</td><td>College graduate</td></tr> <tr><td>6</td><td>Some graduate school, but no degree</td></tr> <tr><td>7</td><td>Graduate or professional degree</td></tr> <tr><td>8</td><td>Not documented / unknown</td></tr> </table>	1	Grade school or less	2	High school graduate or GED	3	Some vocational, business or trade school	4	Some college	5	College graduate	6	Some graduate school, but no degree	7	Graduate or professional degree	8	Not documented / unknown		
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5	College graduate																				
6	Some graduate school, but no degree																				
7	Graduate or professional degree																				
8	Not documented / unknown																				
17	insurance	What type(s) of insurance did the patient have? (Select all that apply.)	checkbox, Required <table border="1"> <tr><td>1</td><td>insurance__1</td><td>No insurance</td></tr> <tr><td>2</td><td>insurance__2</td><td>Medicaid / CHIP</td></tr> <tr><td>3</td><td>insurance__3</td><td>Other safety net insurance</td></tr> <tr><td>4</td><td>insurance__4</td><td>TRICARE</td></tr> <tr><td>5</td><td>insurance__5</td><td>Private insurance</td></tr> <tr><td>6</td><td>insurance__6</td><td>Other (please specify)</td></tr> </table>	1	insurance__1	No insurance	2	insurance__2	Medicaid / CHIP	3	insurance__3	Other safety net insurance	4	insurance__4	TRICARE	5	insurance__5	Private insurance	6	insurance__6	Other (please specify)
1	insurance__1	No insurance																			
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5	insurance__5	Private insurance																			
6	insurance__6	Other (please specify)																			
18	pt_other_insurance Show the field ONLY if: [insurance(6)] = '1'	Insurance other, please specify:	text, Required																		
19	city	In what CITY or town was the patient's primary residence?	text, Required, Identifier																		
20	state	In what STATE was the patient's primary residence?	text, Required																		
21	zip_code	In what ZIP CODE was the patient's primary residence?	text, Required, Identifier																		
22	marital	Patient's Marital Status at time of death	radio, Required <table border="1"> <tr><td>1</td><td>Never Married</td></tr> <tr><td>2</td><td>Married</td></tr> <tr><td>3</td><td>Divorced</td></tr> <tr><td>4</td><td>Domestic Partnership/Living Together</td></tr> <tr><td>5</td><td>Separated</td></tr> <tr><td>6</td><td>Widowed</td></tr> <tr><td>7</td><td>Other (please specify)</td></tr> <tr><td>8</td><td>Not documented / unknown</td></tr> </table>	1	Never Married	2	Married	3	Divorced	4	Domestic Partnership/Living Together	5	Separated	6	Widowed	7	Other (please specify)	8	Not documented / unknown		
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7	Other (please specify)																				
8	Not documented / unknown																				
23	marital_other Show the field ONLY if: [marital] = '7'	Marital status other, please specify:	text, Required																		

24	cancer_site	<p>Section Header: Part B: Cancer Diagnosis Instructions: Please answer the following questions by looking in the patient's medical record.</p> <p>What was the patient's Primary Cancer Site?</p>	<p>radio, Required</p> <table border="1"> <tr><td>1</td><td>Head and neck</td></tr> <tr><td>2</td><td>Thyroid</td></tr> <tr><td>3</td><td>Brain</td></tr> <tr><td>4</td><td>Lung</td></tr> <tr><td>5</td><td>Pancreas</td></tr> <tr><td>6</td><td>Other upper GI (liver, gastric, esophageal, carcinoid, etc.)</td></tr> <tr><td>7</td><td>Breast</td></tr> <tr><td>8</td><td>Colon, rectal, anal</td></tr> <tr><td>9</td><td>Ovarian/peritoneal</td></tr> <tr><td>10</td><td>Uterine, cervical, vaginal</td></tr> <tr><td>11</td><td>Renal</td></tr> <tr><td>12</td><td>Bladder (including urethral)</td></tr> <tr><td>13</td><td>Melanoma</td></tr> <tr><td>14</td><td>Lymphoma</td></tr> <tr><td>15</td><td>Leukemia (including MDS)</td></tr> <tr><td>16</td><td>Bone / Soft tissue (including sarcoma)</td></tr> <tr><td>17</td><td>Other cancer (please specify)</td></tr> </table>	1	Head and neck	2	Thyroid	3	Brain	4	Lung	5	Pancreas	6	Other upper GI (liver, gastric, esophageal, carcinoid, etc.)	7	Breast	8	Colon, rectal, anal	9	Ovarian/peritoneal	10	Uterine, cervical, vaginal	11	Renal	12	Bladder (including urethral)	13	Melanoma	14	Lymphoma	15	Leukemia (including MDS)	16	Bone / Soft tissue (including sarcoma)	17	Other cancer (please specify)
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17	Other cancer (please specify)																																				
25	other_cancer Show the field ONLY if: [cancer_site] = '17'	Other cancer, please specify:	text, Required																																		
26	stage	What was the patient's cancer stage at diagnosis?	<p>radio, Required</p> <table border="1"> <tr><td>1</td><td>I-III</td></tr> <tr><td>2</td><td>IV</td></tr> <tr><td>3</td><td>Not documented / unknown</td></tr> <tr><td>4</td><td>Not applicable (e.g., leukemia)</td></tr> </table>	1	I-III	2	IV	3	Not documented / unknown	4	Not applicable (e.g., leukemia)																										
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3	Not documented / unknown																																				
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27	pt_hospice_referral	<p>Section Header: Part D - Use of Palliative and/or Hospice Services</p> <p>In the patient's medical record, is there documentation that the patient received a REFERRAL to hospice?</p>	<p>radio, Required</p> <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>2</td><td>No</td></tr> </table>	1	Yes	2	No																														
1	Yes																																				
2	No																																				
28	pt_hospice_referral_date Show the field ONLY if: [pt_hospice_referral] = '1'	On what date was the referral to hospice made?	text (date_mdy), Required, Identifier																																		
29	hospice	Did the patient ENROLL in hospice?	<p>radio, Required</p> <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>2</td><td>No</td></tr> <tr><td>3</td><td>Not documented / unknown</td></tr> </table>	1	Yes	2	No	3	Not documented / unknown																												
1	Yes																																				
2	No																																				
3	Not documented / unknown																																				
30	pt_hospice_enroll_date Show the field ONLY if: [hospice] = '1'	On what date did the patient enroll in hospice?	text (date_mdy), Required, Identifier																																		
31	hospice_loc	<p>Where did the patient receive hospice care?</p> <p>(Select all that apply.)</p>	<p>checkbox</p> <table border="1"> <tr><td>1</td><td>hospice_loc__1</td><td>Inpatient</td></tr> <tr><td>2</td><td>hospice_loc__2</td><td>Outpatient</td></tr> <tr><td>3</td><td>hospice_loc__3</td><td>Home</td></tr> <tr><td>4</td><td>hospice_loc__4</td><td>Skilled Nursing Facility / Rehab Facility</td></tr> <tr><td>5</td><td>hospice_loc__5</td><td>Other (please specify)</td></tr> <tr><td>6</td><td>hospice_loc__6</td><td>Unknown</td></tr> </table>	1	hospice_loc__1	Inpatient	2	hospice_loc__2	Outpatient	3	hospice_loc__3	Home	4	hospice_loc__4	Skilled Nursing Facility / Rehab Facility	5	hospice_loc__5	Other (please specify)	6	hospice_loc__6	Unknown																
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32	hosp_loc_other Show the field ONLY if: [hospice_loc(5)] = '1'	Received hospice care in other location, please specify:	text, Required																																		
33	hosp_tod	Enrolled in hospice at time of death?	<p>radio, Required</p> <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>2</td><td>No</td></tr> <tr><td>3</td><td>Not documented / unknown</td></tr> </table>	1	Yes	2	No	3	Not documented / unknown																												
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34	pc_doc_consult	In the patient's medical record, is there documentation that the patient received a palliative care consultation?	radio, Required <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>2</td><td>No</td></tr> </table>	1	Yes	2	No																
1	Yes																						
2	No																						
35	pt_first_date_palliative Show the field ONLY if: [pc_doc_consult] = '1'	On what date did the first palliative care consultation occur?	text (date_mdy), Required, Identifier																				
36	pc_loc	Where did the patient receive palliative care services? (Select all that apply.)	checkbox <table border="1"> <tr><td>1</td><td>pc_loc__1</td><td>Inpatient</td></tr> <tr><td>2</td><td>pc_loc__2</td><td>Outpatient</td></tr> <tr><td>3</td><td>pc_loc__3</td><td>Home</td></tr> <tr><td>4</td><td>pc_loc__4</td><td>Skilled Nursing Facility / Rehab Facility</td></tr> <tr><td>5</td><td>pc_loc__5</td><td>Other (please specify)</td></tr> <tr><td>6</td><td>pc_loc__6</td><td>Unknown</td></tr> </table>	1	pc_loc__1	Inpatient	2	pc_loc__2	Outpatient	3	pc_loc__3	Home	4	pc_loc__4	Skilled Nursing Facility / Rehab Facility	5	pc_loc__5	Other (please specify)	6	pc_loc__6	Unknown		
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5	pc_loc__5	Other (please specify)																					
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37	pc_loc_other Show the field ONLY if: [pc_loc(5)] = '1'	Received palliative care in other location, please specify:	text, Required																				
38	pc_tod	Receiving palliative care at time of death?	radio, Required <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>2</td><td>No</td></tr> <tr><td>3</td><td>Not documented / unknown</td></tr> </table>	1	Yes	2	No	3	Not documented / unknown														
1	Yes																						
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39	pt_health_proxy	Section Header: Part E - Information at Time of Death Did the patient designate a health care proxy (power of attorney)?	radio, Required <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>2</td><td>No</td></tr> </table>	1	Yes	2	No																
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2	No																						
40	pt_dnr_document	Is there documentation of a DNR/DNI order (do not resuscitate/do not intubate) in the patient's medical record?	radio, Required <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>2</td><td>No</td></tr> </table>	1	Yes	2	No																
1	Yes																						
2	No																						
41	pt_tx_last_month	In the last MONTH of the patient's life, did s/he receive any of the following? (Select all that apply.)	checkbox, Required <table border="1"> <tr><td>1</td><td>pt_tx_last_month__1</td><td>Chemotherapy</td></tr> <tr><td>2</td><td>pt_tx_last_month__2</td><td>Radiation therapy</td></tr> <tr><td>3</td><td>pt_tx_last_month__3</td><td>Surgery</td></tr> <tr><td>4</td><td>pt_tx_last_month__4</td><td>Treatment on a clinical trial</td></tr> <tr><td>5</td><td>pt_tx_last_month__5</td><td>None of the above</td></tr> </table>	1	pt_tx_last_month__1	Chemotherapy	2	pt_tx_last_month__2	Radiation therapy	3	pt_tx_last_month__3	Surgery	4	pt_tx_last_month__4	Treatment on a clinical trial	5	pt_tx_last_month__5	None of the above					
1	pt_tx_last_month__1	Chemotherapy																					
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3	pt_tx_last_month__3	Surgery																					
4	pt_tx_last_month__4	Treatment on a clinical trial																					
5	pt_tx_last_month__5	None of the above																					
42	pt_tx_last_week	In the last WEEK of the patient's life, did s/he receive any of the following? (Select all that apply.)	checkbox, Required <table border="1"> <tr><td>1</td><td>pt_tx_last_week__1</td><td>Chemotherapy</td></tr> <tr><td>2</td><td>pt_tx_last_week__2</td><td>Radiation therapy</td></tr> <tr><td>3</td><td>pt_tx_last_week__3</td><td>Surgery</td></tr> <tr><td>4</td><td>pt_tx_last_week__4</td><td>Treatment on a clinical trial</td></tr> <tr><td>5</td><td>pt_tx_last_week__5</td><td>None of the above</td></tr> </table>	1	pt_tx_last_week__1	Chemotherapy	2	pt_tx_last_week__2	Radiation therapy	3	pt_tx_last_week__3	Surgery	4	pt_tx_last_week__4	Treatment on a clinical trial	5	pt_tx_last_week__5	None of the above					
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3	pt_tx_last_week__3	Surgery																					
4	pt_tx_last_week__4	Treatment on a clinical trial																					
5	pt_tx_last_week__5	None of the above																					
43	loc_death	Location of Death	radio, Required <table border="1"> <tr><td>1</td><td>Inpatient acute care facility: general floor</td></tr> <tr><td>2</td><td>Inpatient acute care facility: ICU</td></tr> <tr><td>3</td><td>Inpatient acute care facility: palliative care unit</td></tr> <tr><td>4</td><td>Home</td></tr> <tr><td>5</td><td>Long-term care facility</td></tr> <tr><td>6</td><td>Outpatient (i.e., home, long-term care) hospice</td></tr> <tr><td>7</td><td>Inpatient hospice</td></tr> <tr><td>8</td><td>Assisted Living Facility</td></tr> <tr><td>9</td><td>Other (please specify)</td></tr> <tr><td>10</td><td>Not documented / unknown</td></tr> </table>	1	Inpatient acute care facility: general floor	2	Inpatient acute care facility: ICU	3	Inpatient acute care facility: palliative care unit	4	Home	5	Long-term care facility	6	Outpatient (i.e., home, long-term care) hospice	7	Inpatient hospice	8	Assisted Living Facility	9	Other (please specify)	10	Not documented / unknown
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44	loc_death_other Show the field ONLY if: [loc_death] = '9'	Location of death other, please specify:	text, Required																				

45	pt_number_caregivers	<p>Section Header: Questions to determine if the study packet should be mailed <i>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).</i></p> <p>How many caregiver(s) did this patient have?</p>	<p>radio, Required</p> <table border="1"> <tr> <td>0</td> <td>0 - no caregivers/next of kin documented</td> </tr> <tr> <td>1</td> <td>1</td> </tr> <tr> <td>2</td> <td>2</td> </tr> <tr> <td>3</td> <td>3 or more</td> </tr> </table>	0	0 - no caregivers/next of kin documented	1	1	2	2	3	3 or more																		
0	0 - no caregivers/next of kin documented																												
1	1																												
2	2																												
3	3 or more																												
46	no_caregiver_end_form Show the field ONLY if: [pt_number_caregivers] = '0'	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	descriptive																										
47	one_caregiver Show the field ONLY if: [pt_number_caregivers] = '1'	You selected 1. The next section will ask you about this 1 caregiver: CAREGIVER A.	descriptive																										
48	two_caregivers Show the field ONLY if: [pt_number_caregivers] = '2'	You selected 2. The 2 next sections will ask you about these 2 caregivers: first about CAREGIVER A, then about CAREGIVER B.	descriptive																										
49	three_caregivers Show the field ONLY if: [pt_number_caregivers] = '3'	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.	descriptive																										
50	questions_caregiver_a Show the field ONLY if: [pt_number_caregivers] = '1' or [p t_number_caregivers] = '2' or [pt_ number_caregivers] = '3'	QUESTIONS ABOUT CAREGIVER A:	descriptive																										
51	relationship_caregiver_a Show the field ONLY if: [pt_number_caregivers] = '1' or [p t_number_caregivers] = '2' or [pt_ number_caregivers] = '3'	Looking at the patient's medical record, CAREGIVER A was the patient's...	<p>radio, Required</p> <table border="1"> <tr> <td>1</td> <td>Child</td> </tr> <tr> <td>2</td> <td>Friend</td> </tr> <tr> <td>3</td> <td>Parent</td> </tr> <tr> <td>4</td> <td>Grandchild</td> </tr> <tr> <td>5</td> <td>Grandparent</td> </tr> <tr> <td>6</td> <td>Life Partner</td> </tr> <tr> <td>7</td> <td>Neighbor</td> </tr> <tr> <td>8</td> <td>Sibling</td> </tr> <tr> <td>9</td> <td>Son/daughter-in-law</td> </tr> <tr> <td>10</td> <td>Spouse</td> </tr> <tr> <td>11</td> <td>Other relative (please specify)</td> </tr> <tr> <td>12</td> <td>Other non-relative (please specify)</td> </tr> <tr> <td>13</td> <td>Not documented / unknown</td> </tr> </table>	1	Child	2	Friend	3	Parent	4	Grandchild	5	Grandparent	6	Life Partner	7	Neighbor	8	Sibling	9	Son/daughter-in-law	10	Spouse	11	Other relative (please specify)	12	Other non-relative (please specify)	13	Not documented / unknown
1	Child																												
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3	Parent																												
4	Grandchild																												
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8	Sibling																												
9	Son/daughter-in-law																												
10	Spouse																												
11	Other relative (please specify)																												
12	Other non-relative (please specify)																												
13	Not documented / unknown																												
52	other_caregiver_a Show the field ONLY if: [relationship_caregiver_a] = '11' o r [relationship_caregiver_a] = '12'	Other caregiver A relationship, please specify:	text, Required																										
53	caregiver_a_initials Show the field ONLY if: [pt_number_caregivers] = '1' or [p t_number_caregivers] = '2' or [pt_ number_caregivers] = '3'	<p>What are CAREGIVER A's initials?</p> <p><i>(For example: If CAREGIVER A's name is Jane Doe, then type J.D. here.)</i></p>	text, Required, Identifier																										
54	questions_caregiver_b Show the field ONLY if: [pt_number_caregivers] = '2' or [p t_number_caregivers] = '3'	QUESTIONS ABOUT CAREGIVER B:	descriptive																										

55	relationship_caregiver_b Show the field ONLY if: [pt_number_caregivers] = '2' or [p t_number_caregivers] = '3'	Looking at the patient's medical record, CAREGIVER B was the patient's...	radio, Required <table><tr><td>1</td><td>Child</td></tr><tr><td>2</td><td>Friend</td></tr><tr><td>3</td><td>Parent</td></tr><tr><td>4</td><td>Grandchild</td></tr><tr><td>5</td><td>Grandparent</td></tr><tr><td>6</td><td>Life Partner</td></tr><tr><td>7</td><td>Neighbor</td></tr><tr><td>8</td><td>Sibling</td></tr><tr><td>9</td><td>Son/daughter-in-law</td></tr><tr><td>10</td><td>Spouse</td></tr><tr><td>11</td><td>Other relative (please specify)</td></tr><tr><td>12</td><td>Other non-relative (please specify)</td></tr><tr><td>13</td><td>Not documented / unknown</td></tr></table>	1	Child	2	Friend	3	Parent	4	Grandchild	5	Grandparent	6	Life Partner	7	Neighbor	8	Sibling	9	Son/daughter-in-law	10	Spouse	11	Other relative (please specify)	12	Other non-relative (please specify)	13	Not documented / unknown
1	Child																												
2	Friend																												
3	Parent																												
4	Grandchild																												
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10	Spouse																												
11	Other relative (please specify)																												
12	Other non-relative (please specify)																												
13	Not documented / unknown																												
56	other_caregiver_b Show the field ONLY if: [relationship_caregiver_b] = '11' o r [relationship_caregiver_b] = '12'	Other caregiver B relationship, please specify:	text, Required																										
57	caregiver_b_initials Show the field ONLY if: [pt_number_caregivers] = '2' or [p t_number_caregivers] = '3'	What are CAREGIVER B's initials? <i>(For example: If CAREGIVER B's name is Jane Doe, then type J.D. here.)</i>	text, Required, Identifier																										
58	questions_caregiver_c Show the field ONLY if: [pt_number_caregivers] = '3'	QUESTIONS ABOUT CAREGIVER C:	descriptive																										
59	relationship_caregiver_c Show the field ONLY if: [pt_number_caregivers] = '3'	Looking at the patient's medical record, CAREGIVER C was the patient's...	radio, Required <table><tr><td>1</td><td>Child</td></tr><tr><td>2</td><td>Friend</td></tr><tr><td>3</td><td>Parent</td></tr><tr><td>4</td><td>Grandchild</td></tr><tr><td>5</td><td>Grandparent</td></tr><tr><td>6</td><td>Life Partner</td></tr><tr><td>7</td><td>Neighbor</td></tr><tr><td>8</td><td>Sibling</td></tr><tr><td>9</td><td>Son/daughter-in-law</td></tr><tr><td>10</td><td>Spouse</td></tr><tr><td>11</td><td>Other relative (please specify)</td></tr><tr><td>12</td><td>Other non-relative (please specify)</td></tr><tr><td>13</td><td>Not documented / unknown</td></tr></table>	1	Child	2	Friend	3	Parent	4	Grandchild	5	Grandparent	6	Life Partner	7	Neighbor	8	Sibling	9	Son/daughter-in-law	10	Spouse	11	Other relative (please specify)	12	Other non-relative (please specify)	13	Not documented / unknown
1	Child																												
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12	Other non-relative (please specify)																												
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60	other_caregiver_c Show the field ONLY if: [relationship_caregiver_c] = '11' o r [relationship_caregiver_c] = '12'	Other caregiver C relationship, please specify:	text, Required																										
61	caregiver_c_initials Show the field ONLY if: [pt_number_caregivers] = '3'	What are CAREGIVER C's initials? <i>(For example: If CAREGIVER C's name is Jane Doe, then type J.D. here.)</i>	text, Required																										
62	more_than_3_caregivers Show the field ONLY if: [pt_number_caregivers] = '3'	Did the patient have more than these 3 caregivers?	radio, Required <table><tr><td>1</td><td>Yes</td></tr><tr><td>2</td><td>No</td></tr></table>	1	Yes	2	No																						
1	Yes																												
2	No																												
63	four_months_after_pt_death Show the field ONLY if: [pt_number_caregivers] = '1' or [p t_number_caregivers] = '2' or [pt_ number_caregivers] = '3'	Has it been >= 4 months since the patient passed away?	radio, Required <table><tr><td>1</td><td>Yes</td></tr><tr><td>2</td><td>No</td></tr></table>	1	Yes	2	No																						
1	Yes																												
2	No																												

64	mail_to_caregiver_a Show the field ONLY if: [four_months_after_pt_death] = '2'	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).	descriptive						
65	mail_caregiver_a Show the field ONLY if: [four_months_after_pt_death] = '1'	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).	descriptive						
66	mail_date_caregiver_a Show the field ONLY if: [four_months_after_pt_death] = '1'	On what date did you mail the study packet to CAREGIVER A?	text (date_mdy), Required						
67	study_packet_language Show the field ONLY if: [four_months_after_pt_death] = '1'	Did you mail CAREGIVER A the study packet in English, Spanish, or both?	radio, Required <table><tr><td>1</td><td>English</td></tr><tr><td>2</td><td>Spanish</td></tr><tr><td>3</td><td>Both</td></tr></table>	1	English	2	Spanish	3	Both
1	English								
2	Spanish								
3	Both								
68	recommend_caregiver_a_b_c Show the field ONLY if: [four_months_after_pt_death] = '1'	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.	descriptive						
69	medical_record_abstraction_complete	Section Header: <i>Form Status</i> Complete?	dropdown <table><tr><td>0</td><td>Incomplete</td></tr><tr><td>1</td><td>Unverified</td></tr><tr><td>2</td><td>Complete</td></tr></table>	0	Incomplete	1	Unverified	2	Complete
0	Incomplete								
1	Unverified								
2	Complete								

Instrument: **4-Week Follow-up Form CAREGIVER A** (week_followup_form_caregiver_a)[^ Collapse](#)

	70	cg_a_return_card	Did the CAREGIVER A return the opt-out card?	<table><tr><td colspan="2">radio, Required</td></tr><tr><td>1</td><td>Yes, s/he returned the opt out card; s/he does NOT want to be contacted further about this study.</td></tr><tr><td>2</td><td>No, s/he did not return the opt out card.</td></tr><tr><td>3</td><td>The mailing was returned to sender as undeliverable, but efforts are being made/will be made to ascertain a correct forwarding address.</td></tr><tr><td>4</td><td>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.</td></tr></table>	radio, Required		1	Yes, s/he returned the opt out card; s/he does NOT want to be contacted further about this study.	2	No, s/he did not return the opt out card.	3	The mailing was returned to sender as undeliverable, but efforts are being made/will be made to ascertain a correct forwarding address.	4	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.
radio, Required														
1	Yes, s/he returned the opt out card; s/he does NOT want to be contacted further about this study.													
2	No, s/he did not return the opt out card.													
3	The mailing was returned to sender as undeliverable, but efforts are being made/will be made to ascertain a correct forwarding address.													
4	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.													

71	<div>end_a_form</div> <div>Show the field ONLY if: [cg_a_return_card] = '1' or [cg_a_return_card] = '4'</div>	<div>Thank you.</div> <div>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.</div> <div>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).</div>	descriptive
72	<div>cg_b_study_packet</div> <div>Show the field ONLY if: [cg_a_return_card] = '1' or [cg_a_return_card] = '4'</div>	On what date did you mail the study packet to CAREGIVER B?	text (date_mdy), Required
73	<div>study_packet_b_language</div> <div>Show the field ONLY if: [cg_a_return_card] = '1' or [cg_a_return_card] = '4'</div>	Did you mail CAREGIVER B the study packet in English, Spanish, or both?	radio, Required <div><div>1English</div><div>2Spanish</div><div>3Both</div></div>
74	<div>caregiver_a_name</div> <div>Show the field ONLY if: [cg_a_return_card] = '2' or [cg_a_return_card] = '3'</div>	What is CAREGIVER A's first and last name?	text, Required, Identifier
75	<div>caregiver_a_phone_number</div> <div>Show the field ONLY if: [cg_a_return_card] = '2' or [cg_a_return_card] = '3'</div>	What is CAREGIVER A's phone number?	text, Required, Identifier
76	<div>caregiver_a_address</div> <div>Show the field ONLY if: [cg_a_return_card] = '2'</div>	<div>What is the CAREGIVER A's mailing address?</div> <div><i>(Must include number, street name, apt # (if applicable), city, state, zip code.)</i></div>	text, Required, Identifier
77	<div>caregiver_a_email</div> <div>Show the field ONLY if: [cg_a_return_card] = '2' or [cg_a_return_card] = '3'</div>	What is CAREGIVER A's e-mail address (if available)?	text, Required, Identifier
78	<div>cg_a_informed_consent</div> <div>Show the field ONLY if: [cg_a_return_card] = '2'</div>	Did CAREGIVER A sign and return the Informed Consent Form?	radio, Required <div><div>1Yes</div><div>2No</div></div>
79	<div>cg_a_upload</div> <div>Show the field ONLY if: [cg_a_informed_consent] = '1'</div>	Upload a copy of the signed Informed Consent Form here:	file, Required
80	<div>week_followup_form_caregiver_a_complete</div>	<div>Section Header: <i>Form Status</i></div> <div>Complete?</div>	dropdown <div><div>0Incomplete</div><div>1Unverified</div><div>2Complete</div></div>

Instrument: **4-Week Follow-up Form CAREGIVER B** (week_followup_form_caregiver_b)[^ Collapse](#)

81	cg_b_return_card	Did the CAREGIVER B return the opt-out card?	<table><tr><td colspan="2">radio, Required</td></tr><tr><td>1</td><td>Yes, s/he returned the opt out card; s/he does NOT want to be contacted further about this study.</td></tr><tr><td>2</td><td>No, s/he did not return the opt out card.</td></tr><tr><td>3</td><td>The mailing was returned to sender as undeliverable, but efforts are being made/will be made to ascertain a correct forwarding address.</td></tr><tr><td>4</td><td>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.</td></tr></table>	radio, Required		1	Yes, s/he returned the opt out card; s/he does NOT want to be contacted further about this study.	2	No, s/he did not return the opt out card.	3	The mailing was returned to sender as undeliverable, but efforts are being made/will be made to ascertain a correct forwarding address.	4	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.
radio, Required													
1	Yes, s/he returned the opt out card; s/he does NOT want to be contacted further about this study.												
2	No, s/he did not return the opt out card.												
3	The mailing was returned to sender as undeliverable, but efforts are being made/will be made to ascertain a correct forwarding address.												
4	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.												

82	end_b_form Show the field ONLY if: [cg_b_return_card] = '1' or [cg_b_return_card] = '4'	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).	descriptive						
83	cg_c_study_packet Show the field ONLY if: [cg_b_return_card] = '1' or [cg_b_return_card] = '4'	On what date did you mail the study packet to CAREGIVER C?	text (date_mdy), Required						
84	study_packet_c_language Show the field ONLY if: [cg_b_return_card] = '1' or [cg_b_return_card] = '4'	Did you mail CAREGIVER C the study packet in English, Spanish, or both?	radio, Required <table><tr><td>1</td><td>English</td></tr><tr><td>2</td><td>Spanish</td></tr><tr><td>3</td><td>Both</td></tr></table>	1	English	2	Spanish	3	Both
1	English								
2	Spanish								
3	Both								
85	caregiver_b_name Show the field ONLY if: [cg_b_return_card] = '2' or [cg_b_return_card] = '3'	What is CAREGIVER B's first and last name?	text, Required, Identifier						
86	caregiver_b_phone_number Show the field ONLY if: [cg_b_return_card] = '2' or [cg_b_return_card] = '3'	What is CAREGIVER B's phone number?	text, Required, Identifier						
87	caregiver_b_address Show the field ONLY if: [cg_b_return_card] = '2'	What is the CAREGIVER B's mailing address? <i>(Must include number, street name, apt # (if applicable), city, state, zip code.)</i>	text, Required, Identifier						
88	caregiver_b_email Show the field ONLY if: [cg_b_return_card] = '2' or [cg_b_return_card] = '3'	What is CAREGIVER B's e-mail address (if available)?	text, Required, Identifier						
89	cg_b_informed_consent Show the field ONLY if: [cg_b_return_card] = '2'	Did CAREGIVER B sign and return the Informed Consent Form?	radio, Required <table><tr><td>1</td><td>Yes</td></tr><tr><td>2</td><td>No</td></tr></table>	1	Yes	2	No		
1	Yes								
2	No								
90	cg_b_upload Show the field ONLY if: [cg_b_informed_consent] = '1'	Upload a copy of the signed Informed Consent Form here:	file, Required						
91	week_followup_form_caregiver_b_complete	Section Header: <i>Form Status</i> Complete?	dropdown <table><tr><td>0</td><td>Incomplete</td></tr><tr><td>1</td><td>Unverified</td></tr><tr><td>2</td><td>Complete</td></tr></table>	0	Incomplete	1	Unverified	2	Complete
0	Incomplete								
1	Unverified								
2	Complete								

Instrument: **4-Week Follow-up Form_CAREGIVER C** (week_followup_form_caregiver_c)[^ Collapse](#)

92	cg_c_return_card	Did the CAREGIVER C return the opt-out card?	radio, Required	
			1	Yes, s/he returned the opt out card; s/he does NOT want to be contacted further about this study.
			2	No, s/he did not return the opt out card.
			3	The mailing was returned to sender as undeliverable, but efforts are being made/will be made to ascertain a correct forwarding address.
			4	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.

93	end_c_form Show the field ONLY if: [cg_c_return_card] = '1'	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!	descriptive						
94	caregiver_c_name Show the field ONLY if: [cg_c_return_card] = '2' or [cg_c_return_card] = '3'	What is CAREGIVER C's first and last name?	text, Required, Identifier						
95	caregiver_c_phone_number Show the field ONLY if: [cg_c_return_card] = '2' or [cg_c_return_card] = '3'	What is CAREGIVER C's phone number?	text, Required, Identifier						
96	caregiver_c_address Show the field ONLY if: [cg_c_return_card] = '2'	What is the CAREGIVER C's mailing address? <i>(Must include number, street name, apt # (if applicable), city, state, zip code.)</i>	text, Required, Identifier						
97	caregiver_c_email Show the field ONLY if: [cg_c_return_card] = '2' or [cg_c_return_card] = '3'	What is CAREGIVER C's e-mail address (if available)?	text, Required, Identifier						
98	cg_c_informed_consent Show the field ONLY if: [cg_c_return_card] = '2'	Did CAREGIVER C sign and return the Informed Consent Form?	radio, Required <table><tr><td>1</td><td>Yes</td></tr><tr><td>2</td><td>No</td></tr></table>	1	Yes	2	No		
1	Yes								
2	No								
99	cg_c_upload Show the field ONLY if: [cg_c_informed_consent] = '1'	Upload a copy of the signed Informed Consent Form here:	file, Required						
100	week_followup_form_caregiver_c_complete	Section Header: <i>Form Status</i> Complete?	dropdown <table><tr><td>0</td><td>Incomplete</td></tr><tr><td>1</td><td>Unverified</td></tr><tr><td>2</td><td>Complete</td></tr></table>	0	Incomplete	1	Unverified	2	Complete
0	Incomplete								
1	Unverified								
2	Complete								

Instrument: **Interview** (interview)[^ Collapse](#)

	101	date_interview	Date of Interview	text (date_mdy), Required								
	102	interviewer_id	Interviewer ID	text, Required								
	103	surrogate_id	Surrogate ID	text, Required								
	104	patient_birth	Patient Date of Birth	text (date_mdy), Required, Identifier								
	105	death_date	Patient Date of Death	text (date_mdy), Required, Identifier								
	106	date_admit	Date of Admit to Hospital	text (date_mdy), Required, Identifier								
	107	date_discharge	Date of Discharge	text (date_mdy), Required, Identifier								
	108	hospital_last_seven_days	Was patient under care of the hospital during all of the last 7 days of life?	text, Required								
	109	diagnosis	Patient Diagnosis	text, Required								
	110	karnofsky_score	Patient Karnofsky Score	text								
	111	patient_marital_status	Patient Marital Status	radio <table border="1"><tr><td>1</td><td>Married</td></tr><tr><td>2</td><td>Widowed</td></tr><tr><td>3</td><td>Divorced</td></tr><tr><td>4</td><td>Single, never married</td></tr></table> Custom alignment: LV	1	Married	2	Widowed	3	Divorced	4	Single, never married
1	Married											
2	Widowed											
3	Divorced											
4	Single, never married											
	112	patient_sex	Patient Sex	radio, Required <table border="1"><tr><td>1</td><td>M</td></tr><tr><td>2</td><td>F</td></tr></table>	1	M	2	F				
1	M											
2	F											
	113	religious_preference	Patient Religious Preference	text								
	114	surrogate_name	Surrogate's Full Name	text, Required, Identifier								

115	surrogate_sex	Surrogate Sex	radio, Required <table border="1"> <tr><td>1</td><td>M</td></tr> <tr><td>2</td><td>F</td></tr> </table>	1	M	2	F														
1	M																				
2	F																				
116	relation_to_patient	Section Header: <i>INTRODUCTION AND SCREENING</i> 1. Can you tell me how you were related to [PATIENT NAME]?	radio <table border="1"> <tr><td>1</td><td>SPOUSE</td></tr> <tr><td>2</td><td>PARTNER</td></tr> <tr><td>3</td><td>CHILD</td></tr> <tr><td>4</td><td>DAUGHTER-IN-LAW/SON-IN-LAW</td></tr> <tr><td>5</td><td>PARENT</td></tr> <tr><td>6</td><td>SIBLING</td></tr> <tr><td>7</td><td>OTHER RELATIVE</td></tr> <tr><td>8</td><td>FRIEND</td></tr> <tr><td>9</td><td>OTHER</td></tr> </table> Custom alignment: LV	1	SPOUSE	2	PARTNER	3	CHILD	4	DAUGHTER-IN-LAW/SON-IN-LAW	5	PARENT	6	SIBLING	7	OTHER RELATIVE	8	FRIEND	9	OTHER
1	SPOUSE																				
2	PARTNER																				
3	CHILD																				
4	DAUGHTER-IN-LAW/SON-IN-LAW																				
5	PARENT																				
6	SIBLING																				
7	OTHER RELATIVE																				
8	FRIEND																				
9	OTHER																				
117	specify_other	1a. Specify Other	text																		
118	knowledge_of_patient	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?	yesno, Required <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No														
1	Yes																				
0	No																				
119	who_more_knowledge_patient	3. Who would know more about [PATIENT NAME] in (his/her) last few weeks of life than you? (Alternative person)	text																		
120	relation_other_to_patient	3a. What is this person's relationship to [PATIENT NAME]?	radio <table border="1"> <tr><td>1</td><td>SPOUSE</td></tr> <tr><td>2</td><td>PARTNER</td></tr> <tr><td>3</td><td>CHILD</td></tr> <tr><td>4</td><td>DAUGHTER-IN-LAW/SON-IN-LAW</td></tr> <tr><td>5</td><td>PARENT</td></tr> <tr><td>6</td><td>SIBLING</td></tr> <tr><td>7</td><td>OTHER RELATIVE</td></tr> <tr><td>8</td><td>FRIEND</td></tr> <tr><td>9</td><td>OTHER</td></tr> </table> Custom alignment: LV	1	SPOUSE	2	PARTNER	3	CHILD	4	DAUGHTER-IN-LAW/SON-IN-LAW	5	PARENT	6	SIBLING	7	OTHER RELATIVE	8	FRIEND	9	OTHER
1	SPOUSE																				
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6	SIBLING																				
7	OTHER RELATIVE																				
8	FRIEND																				
9	OTHER																				
121	specify_other_part_2	3a. Specify Other	text																		
122	alternative_person	3b i. Alternative Person Name	text, Identifier																		
123	alternative_person_address	3b ii. Alternative Person Address	notes, Identifier																		
124	alteranative_person_number	3b iii. Alternative Person Phone Number <i>INTERVIEWER: CORNFIRM THAT THE REFERRAL PERSON KNOWS MORE THAN THE RESPONDENT ABOUT THE PATIENT'S LAST FEW WEEKS. ***** THANK RESPONDENT AND TERMINATE INTERVIEW*****</i>	text, Identifier																		
125	location_death	Section Header: <i>CHECKING THE FACTS</i> A. Where did [PATIENT'S] death take place? <i>[*INTERVIEWER*- IF NECESSARY, PROMPT UNTIL SITE IS IDENTIFIED]</i>	radio <table border="1"> <tr><td>1</td><td>AT HOME</td></tr> <tr><td>2</td><td>IN A HOSPITAL</td></tr> <tr><td>3</td><td>NURSING HOME OR OTHER LONG-TERM CARE FACILITY</td></tr> <tr><td>4</td><td>HOSPICE</td></tr> <tr><td>5</td><td>IN TRANSIT TO A MEDICAL FACILITY</td></tr> <tr><td>6</td><td>SOMEWHERE ELSE</td></tr> <tr><td>7</td><td>DON'T KNOW</td></tr> </table> Custom alignment: LV	1	AT HOME	2	IN A HOSPITAL	3	NURSING HOME OR OTHER LONG-TERM CARE FACILITY	4	HOSPICE	5	IN TRANSIT TO A MEDICAL FACILITY	6	SOMEWHERE ELSE	7	DON'T KNOW				
1	AT HOME																				
2	IN A HOSPITAL																				
3	NURSING HOME OR OTHER LONG-TERM CARE FACILITY																				
4	HOSPICE																				
5	IN TRANSIT TO A MEDICAL FACILITY																				
6	SOMEWHERE ELSE																				
7	DON'T KNOW																				
126	which_home_patient_die	A i. If at home, was the home, the patient's own home, your home, or someone else's home?	radio <table border="1"> <tr><td>1</td><td>patient's own home</td></tr> <tr><td>2</td><td>your home</td></tr> <tr><td>3</td><td>someone else's home</td></tr> </table>	1	patient's own home	2	your home	3	someone else's home												
1	patient's own home																				
2	your home																				
3	someone else's home																				
127	intensive_care_death	A ii. If in the hospital, was that in the intensive care unit?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No														
1	Yes																				
0	No																				

128	palliative_hospice_care	A iii. Was it in a palliative care or inpatient hospice unit?	yesno 1 Yes 0 No
129	inpatient_hospice_unit	A iv. Was it in an Inpatient Hospice Unit?	yesno 1 Yes 0 No
130	inpatient_hospice_unit2	A v. Do you mean an inpatient hospice unit?	yesno 1 Yes 0 No
131	hospice_residential_house	A vi. Do you mean residential housing provided by hospice?	yesno 1 Yes 0 No
132	specify_somewhere_else	A vii. Specify Somewhere Else	text
133	correct_date_death	A1. And our information is that [PATIENT] died on [DATE OF DEATH]. Is this correct?	yesno 1 Yes 0 No
134	patient_death_confirmation	A1 i. In what month and year did (he/she) die?	text (date_mdy), Identifier
135	place_30_days_before_death	A5. Place (30 days before) where [PATIENT] was.	text
136	number_days_at_place	A5a. Number of days	text
137	additional_place1_patient	A5 i. [AS NEEDED: Did (he/she) go anywhere after that? Where was that?	text
138	number_days_other_place1	A5 ii. Number of days there	text
139	additional_place_2_patient	A5 iii. [AS NEEDED: Did (he/she) go anywhere after that? Where was that?	text
140	number_days_at_place2	A5 iv. Number of days there	text
141	last_place_patient	A5 v. Last place	text
142	number_days_last_place	A5 vi. Number of days at last place	text
143	interviewee_talk_with_dr	Section Header: 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?	yesno 1 Yes 0 No
144	issue_understanding_doctor	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?	yesno 1 Yes 0 No
145	doctors_listened_concerns	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?	radio 1 YES 2 NO 3 HAD NO CONCERNS
146	amount_info_from_doctors	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?	radio 2 LESS THAN WAS NEEDED 3 JUST RIGHT AMOUNT 4 MORE THAN WAS NEEDED
147	amount_confusing_info	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?	radio 1 ALWAYS 2 USUALLY 3 SOMETIMES 4 NEVER
148	doctor_incharge_care	C2. (In that last week/ While under care of the hospital), was there always a doctor in charge of [PATIENT]'s care?	yesno 1 Yes 0 No
149	clear_doctor_incharge	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?	yesno 1 Yes 0 No

150	patient_wishes_treatment	D1. Did [PATIENT] have specific wishes or plans about the types of medical treatment (he/she) did or did not want while dying?	radio <table border="1"> <tr><td>1</td><td>YES</td></tr> <tr><td>2</td><td>NO</td></tr> <tr><td>3</td><td>DON'T KNOW</td></tr> </table>	1	YES	2	NO	3	DON'T KNOW
1	YES								
2	NO								
3	DON'T KNOW								
151	dr_spoke_w_patient_wishes	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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No		
1	Yes								
0	No								
152	treatment_consist_wishes	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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No		
1	Yes								
0	No								
153	treatment_inconsist_wishes	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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No		
1	Yes								
0	No								
154	durable_power_decisions	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?	radio <table border="1"> <tr><td>1</td><td>YES</td></tr> <tr><td>2</td><td>NO</td></tr> <tr><td>3</td><td>DON'T KNOW</td></tr> </table>	1	YES	2	NO	3	DON'T KNOW
1	YES								
2	NO								
3	DON'T KNOW								
155	signed_living_will	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?	radio <table border="1"> <tr><td>1</td><td>YES</td></tr> <tr><td>2</td><td>NO</td></tr> <tr><td>3</td><td>DON'T KNOW</td></tr> </table>	1	YES	2	NO	3	DON'T KNOW
1	YES								
2	NO								
3	DON'T KNOW								
156	patient_discussed_will_dr	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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No		
1	Yes								
0	No								
157	when_lose_consciousness	A8. Did the patient lose consciousness for any number of days or any number of weeks?	radio <table border="1"> <tr><td>2</td><td>LOST CONSCIOUSNESS FOR A CERTAIN NUMBER OF DAYS</td></tr> <tr><td>3</td><td>LOST CONSCIOUSNESS FOR A CERTAIN NUMBER OF WEEKS</td></tr> <tr><td>4</td><td>NEVER LOST CONSCIOUSNESS</td></tr> </table> <p>Custom alignment: LV</p>	2	LOST CONSCIOUSNESS FOR A CERTAIN NUMBER OF DAYS	3	LOST CONSCIOUSNESS FOR A CERTAIN NUMBER OF WEEKS	4	NEVER LOST CONSCIOUSNESS
2	LOST CONSCIOUSNESS FOR A CERTAIN NUMBER OF DAYS								
3	LOST CONSCIOUSNESS FOR A CERTAIN NUMBER OF WEEKS								
4	NEVER LOST CONSCIOUSNESS								
158	days_lose_consciousness	A8 i. How many days did patient lose consciousness?	text						
159	weeks_lose_consciousness	A8 ii. For how many weeks did the patient lose consciousness?	text						
160	meds_for_pain_last_week	D12. (In that last week/ While under care of the hospital), was [PATIENT] on medicines to treat (his/her) pain?	radio <table border="1"> <tr><td>1</td><td>YES</td></tr> <tr><td>2</td><td>NO</td></tr> <tr><td>3</td><td>DON'T KNOW</td></tr> </table>	1	YES	2	NO	3	DON'T KNOW
1	YES								
2	NO								
3	DON'T KNOW								
161	dr_explain_pain_treatment	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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No		
1	Yes								
0	No								
162	amount_medication_for_pain	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?	radio <table border="1"> <tr><td>1</td><td>TOO MUCH</td></tr> <tr><td>2</td><td>TOO LITTLE</td></tr> <tr><td>3</td><td>RIGHT AMOUNT</td></tr> </table>	1	TOO MUCH	2	TOO LITTLE	3	RIGHT AMOUNT
1	TOO MUCH								
2	TOO LITTLE								
3	RIGHT AMOUNT								
163	discrepancies_pain_med	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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No		
1	Yes								
0	No								
164	trouble_breathing	D16. (In that last week/ While under care of the hospital), did (he/she) have trouble breathing?	radio <table border="1"> <tr><td>1</td><td>YES</td></tr> <tr><td>2</td><td>NO</td></tr> <tr><td>3</td><td>DON'T KNOW</td></tr> </table>	1	YES	2	NO	3	DON'T KNOW
1	YES								
2	NO								
3	DON'T KNOW								
165	help_with_breathing	D16b. How much help in dealing with (his/her) breathing did [PATIENT] receive - less than was needed, or about the right amount?	radio <table border="1"> <tr><td>1</td><td>LESS THAN NEEDED</td></tr> <tr><td>2</td><td>RIGHT AMOUNT</td></tr> </table>	1	LESS THAN NEEDED	2	RIGHT AMOUNT		
1	LESS THAN NEEDED								
2	RIGHT AMOUNT								

166	patient_feels_anxiety_sad	D17. (In that last week/ While under care of the hospital), did (he/she) have any feelings of anxiety or sadness?	radio <table border="1"> <tr><td>1</td><td>YES</td></tr> <tr><td>2</td><td>NO</td></tr> <tr><td>3</td><td>DON'T KNOW</td></tr> </table>	1	YES	2	NO	3	DON'T KNOW		
1	YES										
2	NO										
3	DON'T KNOW										
167	amount_help_w_feelings	D17b. How much help in dealing with these feelings did [PATIENT] receive - less than was needed or about the right amount?	radio <table border="1"> <tr><td>1</td><td>LESS THAN WAS NEEDED</td></tr> <tr><td>2</td><td>RIGHT AMOUNT</td></tr> </table>	1	LESS THAN WAS NEEDED	2	RIGHT AMOUNT				
1	LESS THAN WAS NEEDED										
2	RIGHT AMOUNT										
168	dr_do_not_know_med_hist	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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No				
1	Yes										
0	No										
169	decision_care_wo_family	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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No				
1	Yes										
0	No										
170	personal_care_needs_met	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?	radio <table border="1"> <tr><td>1</td><td>ALWAYS</td></tr> <tr><td>2</td><td>USUALLY</td></tr> <tr><td>3</td><td>SOMETIMES</td></tr> <tr><td>4</td><td>NEVER</td></tr> </table>	1	ALWAYS	2	USUALLY	3	SOMETIMES	4	NEVER
1	ALWAYS										
2	USUALLY										
3	SOMETIMES										
4	NEVER										
171	patient_treated_respect	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?	radio <table border="1"> <tr><td>1</td><td>ALWAYS</td></tr> <tr><td>2</td><td>USUALLY</td></tr> <tr><td>3</td><td>SOMETIMES</td></tr> <tr><td>4</td><td>NEVER</td></tr> </table>	1	ALWAYS	2	USUALLY	3	SOMETIMES	4	NEVER
1	ALWAYS										
2	USUALLY										
3	SOMETIMES										
4	NEVER										
172	patient_treated_kindness	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?	radio <table border="1"> <tr><td>1</td><td>ALWAYS</td></tr> <tr><td>2</td><td>USUALLY</td></tr> <tr><td>3</td><td>SOMETIMES</td></tr> <tr><td>4</td><td>NEVER</td></tr> </table>	1	ALWAYS	2	USUALLY	3	SOMETIMES	4	NEVER
1	ALWAYS										
2	USUALLY										
3	SOMETIMES										
4	NEVER										
173	enough_help_personal_needs	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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No				
1	Yes										
0	No										
174	enough_help_meds_dressings	D25. (In that last week/ While under care of the hospital), was there enough help with medications and getting dressings changed?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No				
1	Yes										
0	No										
175	info_what_to_expect_dying	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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No				
1	Yes										
0	No										
176	want_more_info_dying	D26a. Would you have wanted (some/more) information about that?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No				
1	Yes										
0	No										
177	knew_what_to_expect_dying	D26b. How confident were you that you knew what to expect while [PATIENT] was dying - very confident, fairly confident, or not confident?	radio <table border="1"> <tr><td>1</td><td>VERY CONFIDENT</td></tr> <tr><td>2</td><td>FAIRLY CONFIDENT</td></tr> <tr><td>3</td><td>NOT CONFIDENT</td></tr> </table>	1	VERY CONFIDENT	2	FAIRLY CONFIDENT	3	NOT CONFIDENT		
1	VERY CONFIDENT										
2	FAIRLY CONFIDENT										
3	NOT CONFIDENT										
178	info_what_to_do_time_death	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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No				
1	Yes										
0	No										
179	more_info_what_do_time_die	D27a. Would you have wanted (some/more) information about that?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No				
1	Yes										
0	No										

180	knew_what_to_do_time_death	D27b. How confident were you that you knew what to do at the time of death - very confident, fairly confident, or not confident?	radio 1 VERY CONFIDENT 2 FAIRLY CONFIDENT 3 NOT CONFIDENT
181	info_med_for_symptoms	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?	yesno 1 Yes 0 No
182	want_more_info_meds	D28a. Would you have wanted (some/more) information about the medicines?	yesno 1 Yes 0 No
183	understood_meds_used	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?	radio 1 VERY CONFIDENT 2 FAIRLY CONFIDENT 3 NOT CONFIDENT
184	informed_about_patient	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?	radio 1 ALWAYS 2 USUALLY 3 SOMETIMES 4 NEVER
185	concern_patient_prsnl_care	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?	radio 1 ALWAYS 2 USUALLY 3 SOMETIMES 4 NEVER
186	spoke_spiritual_beliefs	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?	yesno 1 Yes 0 No
187	spoke_beliefs_sensatively	E4a. Was this done in a sensitive manner?	yesno 1 Yes 0 No
188	enough_contact_beliefs	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)?	yesno 1 Yes 0 No
189	support_after_patient_die	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?	radio 1 LESS THAN WAS NEEDED 2 RIGHT AMOUNT
190	talk_feelings_after_death	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?	yesno 1 Yes 0 No
191	sensitively_handled	E7 i. Was it done in a sensitive manner?	yesno 1 Yes 0 No
192	want_to_discuss_feelings	E7 ii. Would you have wanted them too?	yesno 1 Yes 0 No
193	suggest_person_help_cg	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?	yesno 1 Yes 0 No

194	communication_with_family	<p>Section Header: <i>RATINGS</i></p> <p>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?</p>	<p>radio</p> <table border="1"> <tr><td>0</td><td>0</td></tr> <tr><td>1</td><td>1</td></tr> <tr><td>2</td><td>2</td></tr> <tr><td>3</td><td>3</td></tr> <tr><td>4</td><td>4</td></tr> <tr><td>5</td><td>5</td></tr> <tr><td>6</td><td>6</td></tr> <tr><td>7</td><td>7</td></tr> <tr><td>8</td><td>8</td></tr> <tr><td>9</td><td>9</td></tr> <tr><td>10</td><td>10</td></tr> </table> <p>Custom alignment: LH</p>	0	0	1	1	2	2	3	3	4	4	5	5	6	6	7	7	8	8	9	9	10	10
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195	med_care_respects_wishes	<p>F2. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of the hospital), how well would you rate how well those taking care of [PATIENT] provided medical care that respected (his/her) wishes?</p>	<p>radio</p> <table border="1"> <tr><td>0</td><td>0</td></tr> <tr><td>1</td><td>1</td></tr> <tr><td>2</td><td>2</td></tr> <tr><td>3</td><td>3</td></tr> <tr><td>4</td><td>4</td></tr> <tr><td>5</td><td>5</td></tr> <tr><td>6</td><td>6</td></tr> <tr><td>7</td><td>7</td></tr> <tr><td>8</td><td>8</td></tr> <tr><td>9</td><td>9</td></tr> <tr><td>10</td><td>10</td></tr> </table> <p>Custom alignment: LH</p>	0	0	1	1	2	2	3	3	4	4	5	5	6	6	7	7	8	8	9	9	10	10
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5	5																								
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8	8																								
9	9																								
10	10																								
196	how_well_control_symptoms	<p>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)?</p>	<p>radio</p> <table border="1"> <tr><td>0</td><td>0</td></tr> <tr><td>1</td><td>1</td></tr> <tr><td>2</td><td>2</td></tr> <tr><td>3</td><td>3</td></tr> <tr><td>4</td><td>4</td></tr> <tr><td>5</td><td>5</td></tr> <tr><td>6</td><td>6</td></tr> <tr><td>7</td><td>7</td></tr> <tr><td>8</td><td>8</td></tr> <tr><td>9</td><td>9</td></tr> <tr><td>10</td><td>10</td></tr> </table> <p>Custom alignment: LH</p>	0	0	1	1	2	2	3	3	4	4	5	5	6	6	7	7	8	8	9	9	10	10
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197	did_patient_die_w_dignity	<p>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?</p>	<p>radio</p> <table border="1"> <tr><td>0</td><td>0</td></tr> <tr><td>1</td><td>1</td></tr> <tr><td>2</td><td>2</td></tr> <tr><td>3</td><td>3</td></tr> <tr><td>4</td><td>4</td></tr> <tr><td>5</td><td>5</td></tr> <tr><td>6</td><td>6</td></tr> <tr><td>7</td><td>7</td></tr> <tr><td>8</td><td>8</td></tr> <tr><td>9</td><td>9</td></tr> <tr><td>10</td><td>10</td></tr> </table> <p>Custom alignment: LH</p>	0	0	1	1	2	2	3	3	4	4	5	5	6	6	7	7	8	8	9	9	10	10
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198	emocional_support_provided	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?	<div>radio</div> <table><tr><td>0</td><td>0</td></tr><tr><td>1</td><td>1</td></tr><tr><td>2</td><td>2</td></tr><tr><td>3</td><td>3</td></tr><tr><td>4</td><td>4</td></tr><tr><td>5</td><td>5</td></tr><tr><td>6</td><td>6</td></tr><tr><td>7</td><td>7</td></tr><tr><td>8</td><td>8</td></tr><tr><td>9</td><td>9</td></tr><tr><td>10</td><td>10</td></tr></table> <div>Custom alignment: LH</div>	0	0	1	1	2	2	3	3	4	4	5	5	6	6	7	7	8	8	9	9	10	10
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199	overall_care_last_week	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)?	<div>radio</div> <table><tr><td>0</td><td>0</td></tr><tr><td>1</td><td>1</td></tr><tr><td>2</td><td>2</td></tr><tr><td>3</td><td>3</td></tr><tr><td>4</td><td>4</td></tr><tr><td>5</td><td>5</td></tr><tr><td>6</td><td>6</td></tr><tr><td>7</td><td>7</td></tr><tr><td>8</td><td>8</td></tr><tr><td>9</td><td>9</td></tr><tr><td>10</td><td>10</td></tr></table> <div>Custom alignment: LH</div>	0	0	1	1	2	2	3	3	4	4	5	5	6	6	7	7	8	8	9	9	10	10
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200	patient_marital_status2	<div>Section Header: <i>SOCIAL BACKGROUND</i></div> <div>H1. At the time of (his/her) death, was [PATIENT] married, widowed, divorced, separated, or had he/she never been married?</div>	<div>radio</div> <table><tr><td>1</td><td>MARRIED</td></tr><tr><td>2</td><td>WIDOWED</td></tr><tr><td>3</td><td>DIVORCED</td></tr><tr><td>4</td><td>SEPARATED</td></tr><tr><td>5</td><td>NEVER MARRIED</td></tr><tr><td>6</td><td>DON'T KNOW</td></tr></table> <div>Custom alignment: LV</div>	1	MARRIED	2	WIDOWED	3	DIVORCED	4	SEPARATED	5	NEVER MARRIED	6	DON'T KNOW										
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3	DIVORCED																								
4	SEPARATED																								
5	NEVER MARRIED																								
6	DON'T KNOW																								
201	patient_living_alone	H2. Was (he/she) living alone?	<div>radio</div> <table><tr><td>1</td><td>YES</td></tr><tr><td>2</td><td>NO</td></tr><tr><td>3</td><td>DON'T KNOW</td></tr></table> <div>Custom alignment: LV</div>	1	YES	2	NO	3	DON'T KNOW																
1	YES																								
2	NO																								
3	DON'T KNOW																								
202	patient_highest_schooling	H3. What was the highest level of schooling [PATIENT] completed?	<div>radio</div> <table><tr><td>1</td><td>LESS THAN HIGH SCHOOL</td></tr><tr><td>2</td><td>HIGH SCHOOL GRADUATE</td></tr><tr><td>3</td><td>TECHNICAL SCHOOL OR AA DEGREE</td></tr><tr><td>4</td><td>COLLEGE GRADUATE</td></tr><tr><td>5</td><td>ADVANCED DEGREE</td></tr><tr><td>6</td><td>DON'T KNOW</td></tr></table> <div>Custom alignment: LV</div>	1	LESS THAN HIGH SCHOOL	2	HIGH SCHOOL GRADUATE	3	TECHNICAL SCHOOL OR AA DEGREE	4	COLLEGE GRADUATE	5	ADVANCED DEGREE	6	DON'T KNOW										
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4	COLLEGE GRADUATE																								
5	ADVANCED DEGREE																								
6	DON'T KNOW																								

203	patient_religion	H4. What was [PATIENT'S] religious preference - Protestant, Catholic, Jewish, none/Atheist, something else or don't know?	radio <table border="1"> <tr><td>1</td><td>PROTESTANT</td></tr> <tr><td>2</td><td>CATHOLIC</td></tr> <tr><td>3</td><td>JEWISH</td></tr> <tr><td>5</td><td>NONE / ATHEIST</td></tr> <tr><td>4</td><td>SOMETHING ELSE</td></tr> <tr><td>6</td><td>DON'T KNOW</td></tr> </table> Custom alignment: LV	1	PROTESTANT	2	CATHOLIC	3	JEWISH	5	NONE / ATHEIST	4	SOMETHING ELSE	6	DON'T KNOW
1	PROTESTANT														
2	CATHOLIC														
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5	NONE / ATHEIST														
4	SOMETHING ELSE														
6	DON'T KNOW														
204	protestant_denomination	H4 i. If Protestant, what denomination?	text												
205	jewish_denomination	H4 ii. If Jewish, is that Orthodox, Conservative, Reformed, or something else?	radio <table border="1"> <tr><td>1</td><td>ORTHODOX</td></tr> <tr><td>2</td><td>REFORM</td></tr> <tr><td>3</td><td>CONSERVATIVE</td></tr> <tr><td>4</td><td>OTHER</td></tr> </table>	1	ORTHODOX	2	REFORM	3	CONSERVATIVE	4	OTHER				
1	ORTHODOX														
2	REFORM														
3	CONSERVATIVE														
4	OTHER														
206	religion_specify_other	H4 iii. If [PATIENT'S] religious preference was something else please specify	text												
207	hispanic_latino	H5. Was [PATIENT] Hispanic or Latino?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No								
1	Yes														
0	No														
208	patient_race	H6. (In addition to being Hispanic or Latino), Was [PATIENT] White, Black, Asian, or something else?	radio <table border="1"> <tr><td>1</td><td>WHITE</td></tr> <tr><td>2</td><td>BLACK</td></tr> <tr><td>3</td><td>ASIAN</td></tr> <tr><td>4</td><td>SOMETHING ELSE</td></tr> <tr><td>5</td><td>DON'T KNOW</td></tr> </table> Custom alignment: LV	1	WHITE	2	BLACK	3	ASIAN	4	SOMETHING ELSE	5	DON'T KNOW		
1	WHITE														
2	BLACK														
3	ASIAN														
4	SOMETHING ELSE														
5	DON'T KNOW														
209	race_specify_other	H6 i. If something else, please specify.	text												
210	patient_pain_last_month	Section Header: <i>MODULE: LAST MONTH OF LIFE QUESTIONS</i> B1. During the last month of [PATIENT'S] life, were there times when (he/she) experienced pain?	radio <table border="1"> <tr><td>1</td><td>YES</td></tr> <tr><td>2</td><td>NO</td></tr> <tr><td>3</td><td>DON'T KNOW</td></tr> </table>	1	YES	2	NO	3	DON'T KNOW						
1	YES														
2	NO														
3	DON'T KNOW														
211	patient_had_help_pain	B1a. Did (he/she) get any help in dealing with (his/her) pain?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No								
1	Yes														
0	No														
212	how_much_help_w_pain	B1b. How much help in dealing with (his/her) pain did [PATIENT] receive - less than was needed or about the right amount?	radio <table border="1"> <tr><td>1</td><td>LESS THAN WAS NEEDED</td></tr> <tr><td>2</td><td>RIGHT AMOUNT</td></tr> </table>	1	LESS THAN WAS NEEDED	2	RIGHT AMOUNT								
1	LESS THAN WAS NEEDED														
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213	trouble_breath_last_month	B2. During the last month of [PATIENT'S] life, were there times when (he/she) had trouble breathing?	radio <table border="1"> <tr><td>1</td><td>YES</td></tr> <tr><td>2</td><td>NO</td></tr> <tr><td>3</td><td>DON'T KNOW</td></tr> </table>	1	YES	2	NO	3	DON'T KNOW						
1	YES														
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214	help_w_trouble_breathing	B2a. Did (he/she) get any help in dealing with (his/her) trouble breathing?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No								
1	Yes														
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215	amount_help_trouble_breath	B2b. How much help in dealing with (his/her) breathing did [PATIENT] receive - less than was needed or about the right amount?	radio <table border="1"> <tr><td>1</td><td>LESS THAN WAS NEEDED</td></tr> <tr><td>2</td><td>RIGHT AMOUNT</td></tr> </table>	1	LESS THAN WAS NEEDED	2	RIGHT AMOUNT								
1	LESS THAN WAS NEEDED														
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216	patient_sad_last_month	B3. During the last month of life, did [PATIENT] have any feelings of anxiety or sadness?	radio <table border="1"> <tr><td>1</td><td>YES</td></tr> <tr><td>2</td><td>NO</td></tr> <tr><td>3</td><td>DON'T KNOW</td></tr> </table>	1	YES	2	NO	3	DON'T KNOW						
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2	NO														
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217	patient_get_help_when_sad	B3a. Did (he/she) get any help in dealing with (his/her) feelings of anxiety or sadness?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No																		
1	Yes																								
0	No																								
218	amount_help_sad_patient	B3b. How much help in dealing with these feelings did [PATIENT] receive - less than was needed or about the right amount?	radio <table border="1"> <tr><td>1</td><td>LESS THAN WAS NEEDED</td></tr> <tr><td>2</td><td>RIGHT AMOUNT</td></tr> </table>	1	LESS THAN WAS NEEDED	2	RIGHT AMOUNT																		
1	LESS THAN WAS NEEDED																								
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219	patient_care_w_o_fam_input	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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No																		
1	Yes																								
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220	decision_patient_not_want	B5. During the last month of life, was there any decision made about care or treatment that [PATIENT] would not have wanted?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No																		
1	Yes																								
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221	frequency_prsnl_needs_met1	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?	radio <table border="1"> <tr><td>1</td><td>ALWAYS</td></tr> <tr><td>2</td><td>USUALLY</td></tr> <tr><td>3</td><td>SOMETIMES</td></tr> <tr><td>4</td><td>NEVER</td></tr> </table>	1	ALWAYS	2	USUALLY	3	SOMETIMES	4	NEVER														
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222	patient_treated_w_respect	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?	radio <table border="1"> <tr><td>1</td><td>ALWAYS</td></tr> <tr><td>2</td><td>USUALLY</td></tr> <tr><td>3</td><td>SOMETIMES</td></tr> <tr><td>4</td><td>NEVER</td></tr> </table>	1	ALWAYS	2	USUALLY	3	SOMETIMES	4	NEVER														
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4	NEVER																								
223	frequency_fam_informed	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?	radio <table border="1"> <tr><td>1</td><td>ALWAYS</td></tr> <tr><td>2</td><td>USUALLY</td></tr> <tr><td>3</td><td>SOMETIMES</td></tr> <tr><td>4</td><td>NEVER</td></tr> </table>	1	ALWAYS	2	USUALLY	3	SOMETIMES	4	NEVER														
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4	NEVER																								
224	always_dr_incharge_patient	B9. During the last month of life, was there always a doctor in charge of [PATIENT]'s care?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No																		
1	Yes																								
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225	clear_which_dr_incharge	B9a. During the last month of life, was it always clear to you which doctor was in charge of [PATIENT'S] care?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No																		
1	Yes																								
0	No																								
226	patient_want_religion_pers	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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No																		
1	Yes																								
0	No																								
227	enough_time_w_relig_pers	B10a. During the last month of life, do you think (he/she) had as much contact of this kind as (he/she) wanted?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No																		
1	Yes																								
0	No																								
228	patient_life_in_last_month	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?	radio <table border="1"> <tr><td>0</td><td>0</td></tr> <tr><td>1</td><td>1</td></tr> <tr><td>2</td><td>2</td></tr> <tr><td>3</td><td>3</td></tr> <tr><td>4</td><td>4</td></tr> <tr><td>5</td><td>5</td></tr> <tr><td>6</td><td>6</td></tr> <tr><td>7</td><td>7</td></tr> <tr><td>8</td><td>8</td></tr> <tr><td>9</td><td>9</td></tr> <tr><td>10</td><td>10</td></tr> </table> Custom alignment: LH	0	0	1	1	2	2	3	3	4	4	5	5	6	6	7	7	8	8	9	9	10	10
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229	talk_dr_in_hospice	Section Header: <i>Hospice Version- DOMAIN QUESTIONS</i> C1. (In [PATIENT'S] last week/While [PATIENT] was under care of hospice), did you talk with any of [PATIENT'S] doctors yourself?	yesno 1 Yes 0 No
230	confusing_info_dr_hospice	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?	yesno 1 Yes 0 No
231	dr_listen_concerns_hospice	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?	radio 1 YES 2 NO 3 HAD NO CONCERNS
232	amount_info_given_hospice	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?	radio 1 LESS THAN WAS NEEDED 2 JUST THE RIGHT AMOUNT 3 MORE THAN WAS NEEDED
233	dr_confusing_info_hospice	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?	radio 1 ALWAYS 2 USUALLY 3 SOMETIMES 4 NEVER
234	always_dr_incharge_hospice	C2. (In that last week/ While under care of hospice), was there always a doctor in charge of [PATIENT]'s care?	yesno 1 Yes 0 No
235	clear_dr_incharge_hospice	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?	yesno 1 Yes 0 No
236	hospice_patient_wish_care	D1. Did [PATIENT] have specific wishes or plans about the types of medical treatment (he/she) did or did not want while dying?	radio 1 YES 2 NO 3 DON'T KNOW
237	hospice_dr_know_pat_wish	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?	yesno 1 Yes 0 No
238	care_consist_wish_hospice	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?	yesno 1 Yes 0 No
239	hspice_care_inconsist_wish	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?	yesno 1 Yes 0 No
240	durable_power_decisions2	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?	radio 1 YES 2 NO 3 DON'T KNOW
241	signed_living_will_2	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?	radio 1 YES 2 NO 3 DON'T KNOW
242	in_hspice_discuss_wil_w_dr	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?	yesno 1 Yes 0 No

243	loss_of_consciousness	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?	radio <table border="1"> <tr><td>2</td><td>LOST CONSCIOUSNESS FOR A CERTAIN NUMBER OF DAYS</td></tr> <tr><td>3</td><td>LOST CONSCIOUSNESS FOR A CERTAIN NUMBER OF WEEKS</td></tr> <tr><td>4</td><td>NEVER LOST CONSCIOUSNESS</td></tr> </table> Custom alignment: LV	2	LOST CONSCIOUSNESS FOR A CERTAIN NUMBER OF DAYS	3	LOST CONSCIOUSNESS FOR A CERTAIN NUMBER OF WEEKS	4	NEVER LOST CONSCIOUSNESS		
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3	LOST CONSCIOUSNESS FOR A CERTAIN NUMBER OF WEEKS										
4	NEVER LOST CONSCIOUSNESS										
244	days_loss_consciousness	A8 i. For how many days did the patient lose consciousness?	text								
245	weeks_loss_consciousness	A8 ii. For how many weeks did the patient lose consciousness	text								
246	patient_pain_med_hospice	D12. (In that last week/ While under care of hospice), was [PATIENT] on medicines to treat (his/her) pain?	radio <table border="1"> <tr><td>1</td><td>YES</td></tr> <tr><td>2</td><td>NO</td></tr> <tr><td>3</td><td>DON'T KNOW</td></tr> </table>	1	YES	2	NO	3	DON'T KNOW		
1	YES										
2	NO										
3	DON'T KNOW										
247	hospice_dr_explain_med	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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No				
1	Yes										
0	No										
248	amount_pain_med_in_hospice	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?	radio <table border="1"> <tr><td>1</td><td>TOO MUCH</td></tr> <tr><td>2</td><td>TOO LITTLE</td></tr> <tr><td>3</td><td>RIGHT AMOUNT</td></tr> </table>	1	TOO MUCH	2	TOO LITTLE	3	RIGHT AMOUNT		
1	TOO MUCH										
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3	RIGHT AMOUNT										
249	hospice_care_discrepancies	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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No				
1	Yes										
0	No										
250	trouble_breath_in_hospice	D16. (In that last week/ While under care of hospice), did (he/she) have trouble breathing?	radio <table border="1"> <tr><td>1</td><td>YES</td></tr> <tr><td>2</td><td>NO</td></tr> <tr><td>3</td><td>DON'T KNOW</td></tr> </table>	1	YES	2	NO	3	DON'T KNOW		
1	YES										
2	NO										
3	DON'T KNOW										
251	help_trouble_breath_hspice	D16b. How much help in dealing with (his/her) breathing did [PATIENT] receive - less than was needed, or about the right amount?	radio <table border="1"> <tr><td>1</td><td>LESS THAN WAS NEEDED</td></tr> <tr><td>2</td><td>RIGHT AMOUNT</td></tr> </table>	1	LESS THAN WAS NEEDED	2	RIGHT AMOUNT				
1	LESS THAN WAS NEEDED										
2	RIGHT AMOUNT										
252	patient_feel_sad_hospice	D17. (In that last week/ While under care of hospice), did (he/she) have any feelings of anxiety or sadness?	radio <table border="1"> <tr><td>1</td><td>YES</td></tr> <tr><td>2</td><td>NO</td></tr> <tr><td>3</td><td>DON'T KNOW</td></tr> </table>	1	YES	2	NO	3	DON'T KNOW		
1	YES										
2	NO										
3	DON'T KNOW										
253	amount_aid_sad_patient	D17b. How much help in dealing with these feelings did [PATIENT] receive - less than was needed or about the right amount?	radio <table border="1"> <tr><td>1</td><td>LESS THAN WAS NEEDED</td></tr> <tr><td>2</td><td>RIGHT AMOUNT</td></tr> </table>	1	LESS THAN WAS NEEDED	2	RIGHT AMOUNT				
1	LESS THAN WAS NEEDED										
2	RIGHT AMOUNT										
254	hspice_dr_unaware_med_hist	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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No				
1	Yes										
0	No										
255	care_w_o_fam_input_hospice	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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No				
1	Yes										
0	No										
256	in_hospice_prsl_needs_met	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?	radio <table border="1"> <tr><td>1</td><td>ALWAYS</td></tr> <tr><td>2</td><td>USUALLY</td></tr> <tr><td>3</td><td>SOMETIMES</td></tr> <tr><td>4</td><td>NEVER</td></tr> </table>	1	ALWAYS	2	USUALLY	3	SOMETIMES	4	NEVER
1	ALWAYS										
2	USUALLY										
3	SOMETIMES										
4	NEVER										
257	hspice_pat_treat_w_respect	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?	radio <table border="1"> <tr><td>1</td><td>ALWAYS</td></tr> <tr><td>2</td><td>USUALLY</td></tr> <tr><td>3</td><td>SOMETIMES</td></tr> <tr><td>4</td><td>NEVER</td></tr> </table>	1	ALWAYS	2	USUALLY	3	SOMETIMES	4	NEVER
1	ALWAYS										
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3	SOMETIMES										
4	NEVER										

258	hospice_pat_treat_w_kind	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?	radio <table border="1"> <tr><td>1</td><td>ALWAYS</td></tr> <tr><td>2</td><td>USUALLY</td></tr> <tr><td>3</td><td>SOMETIMES</td></tr> <tr><td>4</td><td>NEVER</td></tr> </table>	1	ALWAYS	2	USUALLY	3	SOMETIMES	4	NEVER
1	ALWAYS										
2	USUALLY										
3	SOMETIMES										
4	NEVER										
259	hspice_help_met_prsnl_need	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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No				
1	Yes										
0	No										
260	hospice_help_med_dressing	D25. (In that last week/ While under care of hospice), was there enough help with medications and getting dressings changed?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No				
1	Yes										
0	No										
261	info_what_expct_die_hspice	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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No				
1	Yes										
0	No										
262	more_info_what_expct_die	D26a. Would you have wanted (some/more) information about that?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No				
1	Yes										
0	No										
263	knew_what_expct_dying	D26b. How confident were you that you knew what to expect while [PATIENT] was dying - very confident, fairly confident, or not confident?	radio <table border="1"> <tr><td>1</td><td>VERY CONFIDENT</td></tr> <tr><td>2</td><td>FAIRLY CONFIDENT</td></tr> <tr><td>3</td><td>NOT CONFIDENT</td></tr> </table>	1	VERY CONFIDENT	2	FAIRLY CONFIDENT	3	NOT CONFIDENT		
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264	info_wht_do_wnh_die_hspice	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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No				
1	Yes										
0	No										
265	more_info_what_do_when_die	D27a. Would you have wanted (some/more) information about that?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No				
1	Yes										
0	No										
266	knew_what_do_time_die	D27b. How confident were you that you knew what to do at the time of death - very confident, fairly confident, or not confident?	radio <table border="1"> <tr><td>1</td><td>VERY CONFIDENT</td></tr> <tr><td>2</td><td>FAIRLY CONFIDENT</td></tr> <tr><td>3</td><td>NOT CONFIDENT</td></tr> </table>	1	VERY CONFIDENT	2	FAIRLY CONFIDENT	3	NOT CONFIDENT		
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267	info_symptom_med_hospice	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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No				
1	Yes										
0	No										
268	want_more_info_sympt_med	D28a. Would you have wanted (some/more) information about the medicines?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No				
1	Yes										
0	No										
269	knew_meds_for_pt	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?	radio <table border="1"> <tr><td>1</td><td>VERY CONFIDENT</td></tr> <tr><td>2</td><td>FAIRLY CONFIDENT</td></tr> <tr><td>3</td><td>NOT CONFIDENT</td></tr> </table>	1	VERY CONFIDENT	2	FAIRLY CONFIDENT	3	NOT CONFIDENT		
1	VERY CONFIDENT										
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3	NOT CONFIDENT										
270	confidence_care_pat_home	D29b. How confident did you feel about taking care of [PATIENT] at home - very confident, fairly confident, or not confident? <i>If patient did not die at home or someone else's home then skip D29b and go to E1</i>	radio <table border="1"> <tr><td>1</td><td>VERY CONFIDENT</td></tr> <tr><td>2</td><td>FAIRLY CONFIDENT</td></tr> <tr><td>3</td><td>NOT CONFIDENT</td></tr> </table>	1	VERY CONFIDENT	2	FAIRLY CONFIDENT	3	NOT CONFIDENT		
1	VERY CONFIDENT										
2	FAIRLY CONFIDENT										
3	NOT CONFIDENT										
271	fam_informed_pat_hospice	These next questions are about YOUR experience during [PATIENT'S] last week/while under care of hospice). 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?	radio <table border="1"> <tr><td>1</td><td>ALWAYS</td></tr> <tr><td>2</td><td>USUALLY</td></tr> <tr><td>3</td><td>SOMETIMES</td></tr> <tr><td>4</td><td>NEVER</td></tr> </table>	1	ALWAYS	2	USUALLY	3	SOMETIMES	4	NEVER
1	ALWAYS										
2	USUALLY										
3	SOMETIMES										
4	NEVER										

272	concern_pat_needs_hospice	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	radio <table border="1"> <tr><td>1</td><td>ALWAYS</td></tr> <tr><td>2</td><td>USUALLY</td></tr> <tr><td>3</td><td>SOMETIMES</td></tr> <tr><td>4</td><td>NEVER</td></tr> </table>	1	ALWAYS	2	USUALLY	3	SOMETIMES	4	NEVER														
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3	SOMETIMES																								
4	NEVER																								
273	spiritual_belief_discussed	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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No																		
1	Yes																								
0	No																								
274	belief_discuss_sensatively	E5a. Was this done in a sensitive manner?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No																		
1	Yes																								
0	No																								
275	enough_talk_beliefs_hspice	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)?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No																		
1	Yes																								
0	No																								
276	supt_when_pat_die_hospice	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?	radio <table border="1"> <tr><td>1</td><td>LESS THAN WAS NEEDED</td></tr> <tr><td>2</td><td>RIGHT AMOUNT</td></tr> </table>	1	LESS THAN WAS NEEDED	2	RIGHT AMOUNT																		
1	LESS THAN WAS NEEDED																								
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277	discuss_feel_once_pat_die	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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No																		
1	Yes																								
0	No																								
278	sensitive_about_feelings	E7 i. Was it done in a sensitive manner?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No																		
1	Yes																								
0	No																								
279	wnt_talk_feel_once_pat_die	E7 ii. Would you have wanted them to?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No																		
1	Yes																								
0	No																								
280	suggest_prsn_help_w_stress	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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No																		
1	Yes																								
0	No																								
281	com_hspice_staff_and_fam	Section Header: <i>RATINGS</i> 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?	radio <table border="1"> <tr><td>0</td><td>0</td></tr> <tr><td>1</td><td>1</td></tr> <tr><td>2</td><td>2</td></tr> <tr><td>3</td><td>3</td></tr> <tr><td>4</td><td>4</td></tr> <tr><td>5</td><td>5</td></tr> <tr><td>6</td><td>6</td></tr> <tr><td>7</td><td>7</td></tr> <tr><td>8</td><td>8</td></tr> <tr><td>9</td><td>9</td></tr> <tr><td>10</td><td>10</td></tr> </table> Custom alignment: LH	0	0	1	1	2	2	3	3	4	4	5	5	6	6	7	7	8	8	9	9	10	10
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282	hspice_care_consist_w_wish	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?	radio <table><tr><td>0</td><td>0</td></tr><tr><td>1</td><td>1</td></tr><tr><td>2</td><td>2</td></tr><tr><td>3</td><td>3</td></tr><tr><td>4</td><td>4</td></tr><tr><td>5</td><td>5</td></tr><tr><td>6</td><td>6</td></tr><tr><td>7</td><td>7</td></tr><tr><td>8</td><td>8</td></tr><tr><td>9</td><td>9</td></tr><tr><td>10</td><td>10</td></tr></table> Custom alignment: LH	0	0	1	1	2	2	3	3	4	4	5	5	6	6	7	7	8	8	9	9	10	10
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283	hospice_control_symptoms	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)?	radio <table><tr><td>0</td><td>0</td></tr><tr><td>1</td><td>1</td></tr><tr><td>2</td><td>2</td></tr><tr><td>3</td><td>3</td></tr><tr><td>4</td><td>4</td></tr><tr><td>5</td><td>5</td></tr><tr><td>6</td><td>6</td></tr><tr><td>7</td><td>7</td></tr><tr><td>8</td><td>8</td></tr><tr><td>9</td><td>9</td></tr><tr><td>10</td><td>10</td></tr></table> Custom alignment: LH	0	0	1	1	2	2	3	3	4	4	5	5	6	6	7	7	8	8	9	9	10	10
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284	hospice_pt_die_w_dignity	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?	radio <table><tr><td>0</td><td>0</td></tr><tr><td>1</td><td>1</td></tr><tr><td>2</td><td>2</td></tr><tr><td>3</td><td>3</td></tr><tr><td>4</td><td>4</td></tr><tr><td>5</td><td>5</td></tr><tr><td>6</td><td>6</td></tr><tr><td>7</td><td>7</td></tr><tr><td>8</td><td>8</td></tr><tr><td>9</td><td>9</td></tr><tr><td>10</td><td>10</td></tr></table> Custom alignment: LH	0	0	1	1	2	2	3	3	4	4	5	5	6	6	7	7	8	8	9	9	10	10
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285	hospice_provide_emo_supt	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?	radio <table><tr><td>0</td><td>0</td></tr><tr><td>1</td><td>1</td></tr><tr><td>2</td><td>2</td></tr><tr><td>3</td><td>3</td></tr><tr><td>4</td><td>4</td></tr><tr><td>5</td><td>5</td></tr><tr><td>6</td><td>6</td></tr><tr><td>7</td><td>7</td></tr><tr><td>8</td><td>8</td></tr><tr><td>9</td><td>9</td></tr><tr><td>10</td><td>10</td></tr></table> Custom alignment: LH	0	0	1	1	2	2	3	3	4	4	5	5	6	6	7	7	8	8	9	9	10	10
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286	overall_care_pt_in_hospice	<p>And now an overall rating...</p> <p>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?</p>	<p>radio</p> <table border="1"> <tr><td>0</td><td>0</td></tr> <tr><td>1</td><td>1</td></tr> <tr><td>2</td><td>2</td></tr> <tr><td>3</td><td>3</td></tr> <tr><td>4</td><td>4</td></tr> <tr><td>5</td><td>5</td></tr> <tr><td>6</td><td>6</td></tr> <tr><td>7</td><td>7</td></tr> <tr><td>8</td><td>8</td></tr> <tr><td>9</td><td>9</td></tr> <tr><td>10</td><td>10</td></tr> </table> <p>Custom alignment: LH</p>	0	0	1	1	2	2	3	3	4	4	5	5	6	6	7	7	8	8	9	9	10	10
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287	patient_marital_status3	<p>Section Header: <i>SOCIAL BACKGROUND</i></p> <p>H1. At the time of (his/her) death, was [PATIENT] married, widowed, divorced, separated, or had he/she never been married?</p>	<p>radio</p> <table border="1"> <tr><td>1</td><td>MARRIED</td></tr> <tr><td>2</td><td>WIDOWED</td></tr> <tr><td>3</td><td>DIVORCED</td></tr> <tr><td>4</td><td>SEPARATED</td></tr> <tr><td>5</td><td>NEVER MARRIED</td></tr> <tr><td>6</td><td>DON'T KNOW</td></tr> </table> <p>Custom alignment: LV</p>	1	MARRIED	2	WIDOWED	3	DIVORCED	4	SEPARATED	5	NEVER MARRIED	6	DON'T KNOW										
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288	patient_living_alone2	H2. Was (he/she) living alone?	<p>radio</p> <table border="1"> <tr><td>1</td><td>YES</td></tr> <tr><td>2</td><td>NO</td></tr> <tr><td>3</td><td>DON'T KNOW</td></tr> </table>	1	YES	2	NO	3	DON'T KNOW																
1	YES																								
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3	DON'T KNOW																								
289	patient_highest_education	H3. What was the highest level of schooling [PATIENT] completed?	<p>radio</p> <table border="1"> <tr><td>1</td><td>LESS THAN HIGH SCHOOL</td></tr> <tr><td>2</td><td>HIGH SCHOOL GRADUATE</td></tr> <tr><td>3</td><td>TECHNICAL SCHOOL OR AA DEGREE</td></tr> <tr><td>4</td><td>COLLEGE GRADUATE</td></tr> <tr><td>5</td><td>ADVANCED DEGREE</td></tr> <tr><td>6</td><td>DON'T KNOW</td></tr> </table> <p>Custom alignment: LV</p>	1	LESS THAN HIGH SCHOOL	2	HIGH SCHOOL GRADUATE	3	TECHNICAL SCHOOL OR AA DEGREE	4	COLLEGE GRADUATE	5	ADVANCED DEGREE	6	DON'T KNOW										
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6	DON'T KNOW																								
290	patient_religion2	H4. What was [PATIENT'S] religious preference - Protestant, Catholic, Jewish, none/Atheist, something else or don't know?	<p>radio</p> <table border="1"> <tr><td>1</td><td>PROTESTANT</td></tr> <tr><td>2</td><td>CATHOLIC</td></tr> <tr><td>3</td><td>JEWISH</td></tr> <tr><td>5</td><td>NONE/ATHEIST</td></tr> <tr><td>4</td><td>SOMETHING ELSE</td></tr> <tr><td>6</td><td>DON'T KNOW</td></tr> </table> <p>Custom alignment: LV</p>	1	PROTESTANT	2	CATHOLIC	3	JEWISH	5	NONE/ATHEIST	4	SOMETHING ELSE	6	DON'T KNOW										
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6	DON'T KNOW																								
291	denomination_protestant	H4 i. If Protestant, what denomination if that?	text																						
292	jewish_denomination2	H4 ii. If Jewish, what denomination?	<p>radio</p> <table border="1"> <tr><td>1</td><td>ORTHODOX</td></tr> <tr><td>2</td><td>REFORM</td></tr> <tr><td>3</td><td>CONSERVATIVE</td></tr> <tr><td>4</td><td>OTHER</td></tr> </table> <p>Custom alignment: LV</p>	1	ORTHODOX	2	REFORM	3	CONSERVATIVE	4	OTHER														
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4	OTHER																								
293	specify_other_religion	H4 iii. If something else, specify	text																						
294	patient_latino_hispanic	H5. Was [PATIENT] Hispanic or Latino?	<p>yesno</p> <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No																		
1	Yes																								
0	No																								

295	patient_race2	H6. (In addition to being Hispanic or Latino), Was [PATIENT] White, Black, Asian, or something else?	radio 1 WHITE 2 BLACK 3 ASIAN 4 SOMETHING ELSE 5 DON'T KNOW Custom alignment: LV
296	specify_other_race	H6 i. If something else, specify	text
297	pat_pain_last_month_life	Section Header: <i>MODULE: Last Month of Life Questions Now I was to ask about the care [PATIENT] received during (his/her) last month of life.</i> B1. During the last month of [PATIENT'S] life, were there times when (he/she) experienced pain?	radio 1 YES 2 NO 3 DON'T KNOW
298	patient_had_help_with_pain	B1a. Did (he/she) get any help in dealing with (his/her) pain?	yesno 1 Yes 0 No
299	amount_help_patient_pain	B1b. How much help in dealing with (his/her) pain did [PATIENT] receive - less than was needed or about the right amount?	radio 1 LESS THAN WAS NEEDED 2 RIGHT AMOUNT
300	patient_trouble_breathing	B2. During the last month of [PATIENT'S] life, were there times when (he/she) had trouble breathing?	radio 1 YES 2 NO 3 DON'T KNOW
301	help_pat_w_trouble_breath	B2a. Did (he/she) get any help in dealing with (his/her) trouble breathing?	yesno 1 Yes 0 No
302	amount_aid_trouble_breath	B2b. How much help in dealing with (his/her) breathing did [PATIENT] receive - less than was needed or about the right amount?	radio 1 LESS THAN WAS NEEDED 2 RIGHT AMOUNT
303	patient_feel_sad_anxious	B3. During the last month of life, did [PATIENT] have any feelings of anxiety or sadness?	radio 1 YES 2 NO 3 DON'T KNOW
304	help_w_feeling_sad	B3a. Did (he/she) get any help in dealing with (his/her) feelings of anxiety or sadness?	yesno 1 Yes 0 No
305	amount_help_w_feeling_sad	B3b. How much help in dealing with these feelings did [PATIENT] receive - less than was needed or about the right amount?	radio 1 LESS THAN WAS NEEDED 2 RIGHT AMOUNT
306	decision_without_fam_input	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?	yesno 1 Yes 0 No
307	decision_patient_not_want2	B5. During the last month of life, was there any decision made about care or treatment that [PATIENT] would not have wanted?	yesno 1 Yes 0 No
308	patient_prsnl_needs_met	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	radio 1 ALWAYS 2 USUALLY 3 SOMETIMES 4 NEVER

309	patient_treated_w_respect2	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?	radio <table border="1"> <tr><td>1</td><td>ALWAYS</td></tr> <tr><td>2</td><td>USUALLY</td></tr> <tr><td>3</td><td>SOMETIMES</td></tr> <tr><td>4</td><td>NEVER</td></tr> </table>	1	ALWAYS	2	USUALLY	3	SOMETIMES	4	NEVER														
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4	NEVER																								
310	family_kept_informed	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?	radio <table border="1"> <tr><td>1</td><td>ALWAYS</td></tr> <tr><td>2</td><td>USUALLY</td></tr> <tr><td>3</td><td>SOMETIMES</td></tr> <tr><td>4</td><td>NEVER</td></tr> </table>	1	ALWAYS	2	USUALLY	3	SOMETIMES	4	NEVER														
1	ALWAYS																								
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3	SOMETIMES																								
4	NEVER																								
311	always_dr_incharge	B9. During the last month of life, was there always a doctor in charge of [PATIENT]'s care?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No																		
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312	clear_dr_incharge	B9a. During the last month of life, was it always clear to you which doctor was in charge of [PATIENT]'s care?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No																		
1	Yes																								
0	No																								
313	interest_talk_w_relig_prsn	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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No																		
1	Yes																								
0	No																								
314	pt_enough_time_relig_prsn	B10a. During the last month of life, do you think (he/she) had as much contact of this kind as (he/she) wanted?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No																		
1	Yes																								
0	No																								
315	pt_experience_last_month	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?	radio <table border="1"> <tr><td>0</td><td>0</td></tr> <tr><td>1</td><td>1</td></tr> <tr><td>2</td><td>2</td></tr> <tr><td>3</td><td>3</td></tr> <tr><td>4</td><td>4</td></tr> <tr><td>5</td><td>5</td></tr> <tr><td>6</td><td>6</td></tr> <tr><td>7</td><td>7</td></tr> <tr><td>8</td><td>8</td></tr> <tr><td>9</td><td>9</td></tr> <tr><td>10</td><td>10</td></tr> </table> Custom alignment: LH	0	0	1	1	2	2	3	3	4	4	5	5	6	6	7	7	8	8	9	9	10	10
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316	did_you_talk_dr_nurse_home	Section Header: <i>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).</i> 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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No																		
1	Yes																								
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317	hard_to_understand_dr	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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No																		
1	Yes																								
0	No																								
318	dr_listened_to_concerns	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?	radio <table border="1"> <tr><td>1</td><td>YES</td></tr> <tr><td>2</td><td>NO</td></tr> <tr><td>3</td><td>HAD NO CONCERNS</td></tr> </table>	1	YES	2	NO	3	HAD NO CONCERNS																
1	YES																								
2	NO																								
3	HAD NO CONCERNS																								
319	info_pat_med_condition	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?	radio <table border="1"> <tr><td>1</td><td>LESS THAN WAS NEEDED</td></tr> <tr><td>2</td><td>JUST THE RIGHT AMOUNT</td></tr> <tr><td>3</td><td>MORE THAN WAS NEEDED</td></tr> </table>	1	LESS THAN WAS NEEDED	2	JUST THE RIGHT AMOUNT	3	MORE THAN WAS NEEDED																
1	LESS THAN WAS NEEDED																								
2	JUST THE RIGHT AMOUNT																								
3	MORE THAN WAS NEEDED																								

320	confusing_info_about_care	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?	radio <table border="1"> <tr><td>1</td><td>ALWAYS</td></tr> <tr><td>2</td><td>USUALLY</td></tr> <tr><td>3</td><td>SOMETIMES</td></tr> <tr><td>4</td><td>NEVER</td></tr> </table>	1	ALWAYS	2	USUALLY	3	SOMETIMES	4	NEVER
1	ALWAYS										
2	USUALLY										
3	SOMETIMES										
4	NEVER										
321	alway_nurs_home_dr_incharg	C2. (In that last week/ While under care of the nursing home), was there always a doctor in charge of [PATIENT]'s care?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No				
1	Yes										
0	No										
322	nurshome_clear_dr_incharge	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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No				
1	Yes										
0	No										
323	pat_specific_care_wishes	D1. Did [PATIENT] have specific wishes or plans about the types of medical treatment (he/she) did or did not want while dying?	radio <table border="1"> <tr><td>1</td><td>YES</td></tr> <tr><td>2</td><td>NO</td></tr> <tr><td>3</td><td>DON'T KNOW</td></tr> </table>	1	YES	2	NO	3	DON'T KNOW		
1	YES										
2	NO										
3	DON'T KNOW										
324	dr_talk_w_pat_about_wishes	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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No				
1	Yes										
0	No										
325	ensure_care_consist_w_wish	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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No				
1	Yes										
0	No										
326	care_inconsistent_w_wish	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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No				
1	Yes										
0	No										
327	signed_durable_power	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?	radio <table border="1"> <tr><td>1</td><td>YES</td></tr> <tr><td>2</td><td>NO</td></tr> <tr><td>3</td><td>DON'T KNOW</td></tr> </table>	1	YES	2	NO	3	DON'T KNOW		
1	YES										
2	NO										
3	DON'T KNOW										
328	signed_living_will2	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?	radio <table border="1"> <tr><td>1</td><td>YES</td></tr> <tr><td>2</td><td>NO</td></tr> <tr><td>3</td><td>DON'T KNOW</td></tr> </table>	1	YES	2	NO	3	DON'T KNOW		
1	YES										
2	NO										
3	DON'T KNOW										
329	discussed_will_w_dr	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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No				
1	Yes										
0	No										
330	loss_of_consciousness2	A8. Did the patient lose consciousness for any number of days or any number of weeks? <i>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</i>	radio <table border="1"> <tr><td>2</td><td>LOST CONSCIOUSNESS FOR A CERTAIN NUMBER OF DAYS</td></tr> <tr><td>3</td><td>LOST CONSCIOUSNESS FOR A CERTAIN NUMBER OF WEEKS</td></tr> <tr><td>4</td><td>NEVER LOST CONSCIOUSNESS</td></tr> </table>	2	LOST CONSCIOUSNESS FOR A CERTAIN NUMBER OF DAYS	3	LOST CONSCIOUSNESS FOR A CERTAIN NUMBER OF WEEKS	4	NEVER LOST CONSCIOUSNESS		
2	LOST CONSCIOUSNESS FOR A CERTAIN NUMBER OF DAYS										
3	LOST CONSCIOUSNESS FOR A CERTAIN NUMBER OF WEEKS										
4	NEVER LOST CONSCIOUSNESS										
331	days_loss_consciousness2	A8 i. For how many days did the patient lose consciousness?	text								
332	week_loss_consciousness2	A8 ii. For how many weeks did the patient lose consciousness?	text								
333	patient_on_pain_meds	D12. (In that last week/ While under care of the nursing home), was [PATIENT] on medicines to treat (his/her) pain?	radio <table border="1"> <tr><td>1</td><td>YES</td></tr> <tr><td>2</td><td>NO</td></tr> <tr><td>3</td><td>DONT' KNOW</td></tr> </table>	1	YES	2	NO	3	DONT' KNOW		
1	YES										
2	NO										
3	DONT' KNOW										
334	dr_explain_pain_meds	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?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No				
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0	No										
335	amount_pain_med_received	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?	radio <table border="1"> <tr><td>1</td><td>TOO MUCH</td></tr> <tr><td>2</td><td>TOO LITTLE</td></tr> <tr><td>3</td><td>RIGHT AMOUNT</td></tr> </table>	1	TOO MUCH	2	TOO LITTLE	3	RIGHT AMOUNT		
1	TOO MUCH										
2	TOO LITTLE										
3	RIGHT AMOUNT										

	336	nursehome_discrepancies	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?	yesno 1 Yes 0 No
	337	trouble_breath_nursehome	D16. (In that last week/ While under care of the nursing home), did (he/she) have trouble breathing?	radio 1 YES 2 NO 3 DON'T KNOW
	338	help_w_trouble_breathing2	D16b. How much help in dealing with (his/her) breathing did [PATIENT] receive - less than was needed, or about the right amount?	radio 1 LESS THAN WAS NEEDED 2 RIGHT AMOUNT
	339	patient_feel_sad_nursehome	D17. (In that last week/ While under care of the nursing home), did (he/she) have any feelings of anxiety or sadness?	radio 1 YES 2 NO 3 DON'T KNOW
	340	help_w_sadness_nursehome	D17b. How much help in dealing with these feelings did [PATIENT] receive - less than was needed or about the right amount?	radio 1 LESS THAN WAS NEEDED 2 RIGHT AMOUNT
	341	dr_not_know_all_med_hist	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?	yesno 1 Yes 0 No
	342	decision_without_fam_input2	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?	yesno 1 Yes 0 No
	343	prsnl_need_met_nurshome	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?	radio 1 ALWAYS 2 USUALLY 3 SOMETIMES 4 NEVER
	344	pat_treat_w_rspct_nurshome	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?	radio 1 ALWAYS 2 USUALLY 3 SOMETIMES 4 NEVER
	345	pat_treat_w_kind_nurshome	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?	radio 1 ALWAYS 2 USUALLY 3 SOMETIMES 4 NEVER
	346	prsnl_need_met_nurshome2	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?	yesno 1 Yes 0 No
	347	help_med_in_nursinghome	D25. (In that last week/ While under care of the nursing home), was there enough help with medications and getting dressings changed?	yesno 1 Yes 0 No
	348	info_wht_expct_die_nurshom	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?	yesno 1 Yes 0 No
	349	more_info_wht_to_expct_die	D26a. Would you have wanted (some/more) information about that?	yesno 1 Yes 0 No

350	surenes_knew_wht_expct_die	D26b. How confident were you that you knew what to expect while [PATIENT] was dying - very confident, fairly confident, or not confident?	radio 1 VERY CONFIDENT 2 FAIRLY CONFIDENT 3 NOT CONFIDENT
351	info_what_do_after_death	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?	yesno 1 Yes 0 No
352	more_info_wht_do_after_die	D27a. Would you have wanted (some/more) information about that?	yesno 1 Yes 0 No
353	condfident_wht_do_time_die	D27b. How confident were you that you knew what to do at the time of death - very confident, fairly confident, or not confident?	radio 1 VERY CONFIDENT 2 FAIRLY CONFIDENT 3 NOT CONFIDENT
354	info_symptom_med_nurshome	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?	yesno 1 Yes 0 No
355	more_info_symptom_med	D28a. Would you have wanted (some/more) information about the medicines?	yesno 1 Yes 0 No
356	understood_symptom_med	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?	radio 1 VERY CONFIDENT 2 FAIRLY CONFIDENT 3 NOT CONFIDENT
357	fam_kept_informed_nurshome	These next questions are about YOUR experience during [PATIENT]'s last week/while [PATIENT] was under the care of nursing home. 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?	radio 1 ALWAYS 2 USUALLY 3 SOMETIMES 4 NEVER
358	prsnl_needs_met_nurshome	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?	radio 1 ALWAYS 2 USUALLY 3 SOMETIMES 4 NEVER
359	discuss_spiritual_belief	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?	yesno 1 Yes 0 No
360	nurshome_sensitive_beliefs	E4a. Was this done in a sensitive manner?	yesno 1 Yes 0 No
361	pat_talk_beliefs_enough	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)?	yesno 1 Yes 0 No
362	supt_w_feel_after_pat_die	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?	radio 1 LESS THAN WAS NEEDED 2 RIGHT AMOUNT
363	talk_feel_after_pat_die	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?	yesno 1 Yes 0 No
364	sensitive_talk_after_die	E7 i. Was this done in a sensitive manner?	yesno 1 Yes 0 No

365	want_to_talk_after_pat_die	E7 ii. Would you have wanted them to?	yesno 1 Yes 0 No																						
366	suggest_prsn_help_w_stress2	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?	yesno 1 Yes 0 No																						
367	nurshome_communicate_w_fam	Section Header: <i>RATINGS</i> 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?	radio <table border="1"> <tr><td>0</td><td>0</td></tr> <tr><td>1</td><td>1</td></tr> <tr><td>2</td><td>2</td></tr> <tr><td>3</td><td>3</td></tr> <tr><td>4</td><td>4</td></tr> <tr><td>5</td><td>5</td></tr> <tr><td>6</td><td>6</td></tr> <tr><td>7</td><td>7</td></tr> <tr><td>8</td><td>8</td></tr> <tr><td>9</td><td>9</td></tr> <tr><td>10</td><td>10</td></tr> </table> Custom alignment: LH	0	0	1	1	2	2	3	3	4	4	5	5	6	6	7	7	8	8	9	9	10	10
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368	nurshome_respected_wishes	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?	radio <table border="1"> <tr><td>0</td><td>0</td></tr> <tr><td>1</td><td>1</td></tr> <tr><td>2</td><td>2</td></tr> <tr><td>3</td><td>3</td></tr> <tr><td>4</td><td>4</td></tr> <tr><td>5</td><td>5</td></tr> <tr><td>6</td><td>6</td></tr> <tr><td>7</td><td>7</td></tr> <tr><td>8</td><td>8</td></tr> <tr><td>9</td><td>9</td></tr> <tr><td>10</td><td>10</td></tr> </table> Custom alignment: LH	0	0	1	1	2	2	3	3	4	4	5	5	6	6	7	7	8	8	9	9	10	10
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369	nurshome_control_symptoms	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)?	radio <table border="1"> <tr><td>0</td><td>0</td></tr> <tr><td>1</td><td>1</td></tr> <tr><td>2</td><td>2</td></tr> <tr><td>3</td><td>3</td></tr> <tr><td>4</td><td>4</td></tr> <tr><td>5</td><td>5</td></tr> <tr><td>6</td><td>6</td></tr> <tr><td>7</td><td>7</td></tr> <tr><td>8</td><td>8</td></tr> <tr><td>9</td><td>9</td></tr> <tr><td>10</td><td>10</td></tr> </table> Custom alignment: LH	0	0	1	1	2	2	3	3	4	4	5	5	6	6	7	7	8	8	9	9	10	10
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370	pat_die_w_dignity_nurshome	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?	<p>radio</p> <table border="1"> <tr><td>0</td><td>0</td></tr> <tr><td>1</td><td>1</td></tr> <tr><td>2</td><td>2</td></tr> <tr><td>3</td><td>3</td></tr> <tr><td>4</td><td>4</td></tr> <tr><td>5</td><td>5</td></tr> <tr><td>6</td><td>6</td></tr> <tr><td>7</td><td>7</td></tr> <tr><td>8</td><td>8</td></tr> <tr><td>9</td><td>9</td></tr> <tr><td>10</td><td>10</td></tr> </table> <p>Custom alignment: LH</p>	0	0	1	1	2	2	3	3	4	4	5	5	6	6	7	7	8	8	9	9	10	10
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371	nurshome_provide_emo_supt	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	<p>radio</p> <table border="1"> <tr><td>0</td><td>0</td></tr> <tr><td>1</td><td>1</td></tr> <tr><td>2</td><td>2</td></tr> <tr><td>3</td><td>3</td></tr> <tr><td>4</td><td>4</td></tr> <tr><td>5</td><td>5</td></tr> <tr><td>6</td><td>6</td></tr> <tr><td>7</td><td>7</td></tr> <tr><td>8</td><td>8</td></tr> <tr><td>9</td><td>9</td></tr> <tr><td>10</td><td>10</td></tr> </table> <p>Custom alignment: LH</p>	0	0	1	1	2	2	3	3	4	4	5	5	6	6	7	7	8	8	9	9	10	10
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372	overall_care_in_nurshome	<p>And now an overall rating...</p> <p>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)?</p>	<p>radio</p> <table border="1"> <tr><td>0</td><td>0</td></tr> <tr><td>1</td><td>1</td></tr> <tr><td>2</td><td>2</td></tr> <tr><td>3</td><td>3</td></tr> <tr><td>4</td><td>4</td></tr> <tr><td>5</td><td>5</td></tr> <tr><td>6</td><td>6</td></tr> <tr><td>7</td><td>7</td></tr> <tr><td>8</td><td>8</td></tr> <tr><td>9</td><td>9</td></tr> <tr><td>10</td><td>10</td></tr> </table> <p>Custom alignment: LH</p>	0	0	1	1	2	2	3	3	4	4	5	5	6	6	7	7	8	8	9	9	10	10
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373	patient_marital_status4	<p>Section Header: <i>SOCIAL BACKGROUND</i> Now I have a few background questions about [PATIENT].</p> <p>H1. At the time of (his/her) death, was [PATIENT] married, widowed, divorced, separated, or had he/she never been married?</p>	<p>radio</p> <table border="1"> <tr><td>1</td><td>MARRIED</td></tr> <tr><td>2</td><td>WIDOWED</td></tr> <tr><td>3</td><td>DIVORCED</td></tr> <tr><td>4</td><td>SEPARATED</td></tr> <tr><td>5</td><td>NEVER MARRIED</td></tr> <tr><td>6</td><td>DON'T KNOW</td></tr> </table> <p>Custom alignment: LV</p>	1	MARRIED	2	WIDOWED	3	DIVORCED	4	SEPARATED	5	NEVER MARRIED	6	DON'T KNOW										
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374	patient_living_alone3	H2. Was (he/she) living alone?	<p>radio</p> <table border="1"> <tr><td>1</td><td>YES</td></tr> <tr><td>2</td><td>NO</td></tr> <tr><td>3</td><td>DON'T KNOW</td></tr> </table>	1	YES	2	NO	3	DON'T KNOW																
1	YES																								
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375	patient_highest_education2	H3. What was the highest level of schooling [PATIENT] completed?	radio <table border="1"> <tr><td>1</td><td>LESS THAN HIGH SCHOOL</td></tr> <tr><td>2</td><td>HIGH SCHOOL GRADUATE</td></tr> <tr><td>3</td><td>TECHNICAL SCHOOL OR AA DEGREE</td></tr> <tr><td>4</td><td>COLLEGE GRADUATE</td></tr> <tr><td>5</td><td>ADVANCED DEGREE</td></tr> <tr><td>6</td><td>DON'T KNOW</td></tr> </table> Custom alignment: LV	1	LESS THAN HIGH SCHOOL	2	HIGH SCHOOL GRADUATE	3	TECHNICAL SCHOOL OR AA DEGREE	4	COLLEGE GRADUATE	5	ADVANCED DEGREE	6	DON'T KNOW
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3	TECHNICAL SCHOOL OR AA DEGREE														
4	COLLEGE GRADUATE														
5	ADVANCED DEGREE														
6	DON'T KNOW														
376	patient_religion3	H4. What was [PATIENT'S] religious preference - Protestant, Catholic, Jewish, none/Atheist, something else or don't know	radio <table border="1"> <tr><td>1</td><td>PROTESTANT</td></tr> <tr><td>2</td><td>CATHOLIC</td></tr> <tr><td>3</td><td>JEWISH</td></tr> <tr><td>5</td><td>NONE/ATHEIST</td></tr> <tr><td>4</td><td>SOMETHING ELSE</td></tr> <tr><td>6</td><td>DON'T KNOW</td></tr> </table> Custom alignment: LV	1	PROTESTANT	2	CATHOLIC	3	JEWISH	5	NONE/ATHEIST	4	SOMETHING ELSE	6	DON'T KNOW
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377	protestant_denomination2	H4 i. If Protestant, what denomination?	text												
378	jewish_denomination3	H4 ii. If Jewish, is that Orthodox, Conservative, Reformed, or something else	radio <table border="1"> <tr><td>1</td><td>ORTHODOX</td></tr> <tr><td>2</td><td>REFORM</td></tr> <tr><td>3</td><td>CONSERVATIVE</td></tr> <tr><td>4</td><td>OTHER</td></tr> </table> Custom alignment: LV	1	ORTHODOX	2	REFORM	3	CONSERVATIVE	4	OTHER				
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4	OTHER														
379	specify_other_religion2	H4 iii. If something else, specify	text												
380	patient_hispanic_latino	H5. Was [PATIENT] Hispanic or Latino?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No								
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381	patient_race3	H6. (In addition to being Hispanic or Latino), Was [PATIENT] White, Black, Asian, or something else?	radio <table border="1"> <tr><td>1</td><td>WHITE</td></tr> <tr><td>2</td><td>BLACK</td></tr> <tr><td>3</td><td>ASIAN</td></tr> <tr><td>4</td><td>SOMETHING ELSE</td></tr> <tr><td>5</td><td>DON'T KNOW</td></tr> </table> Custom alignment: LV	1	WHITE	2	BLACK	3	ASIAN	4	SOMETHING ELSE	5	DON'T KNOW		
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382	pt_race_something_else	If something else, please specify.	text Custom alignment: RH												
383	pat_pain_last_month_life2	Section Header: <i>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)</i> B1. During the last month of [PATIENT'S] life, were there times when (he/she) experienced pain?	radio <table border="1"> <tr><td>1</td><td>YES</td></tr> <tr><td>2</td><td>NO</td></tr> <tr><td>3</td><td>DON'T KNOW</td></tr> </table>	1	YES	2	NO	3	DON'T KNOW						
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384	patient_had_help_w_pain2	B1a. Did (he/she) get any help in dealing with (his/her) pain?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No								
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385	amount_help_patient_pain2	B1b. How much help in dealing with (his/her) pain did [PATIENT] receive - less than was needed or about the right amount?	radio <table border="1"> <tr><td>1</td><td>LESS THAN WAS NEEDED</td></tr> <tr><td>2</td><td>RIGHT AMOUNT</td></tr> </table>	1	LESS THAN WAS NEEDED	2	RIGHT AMOUNT								
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386	patient_trouble_breathing2	B2. During the last month of [PATIENT'S] life, were there times when (he/she) had trouble breathing?	radio <table border="1"> <tr><td>1</td><td>YES</td></tr> <tr><td>2</td><td>NO</td></tr> <tr><td>3</td><td>DON'T KNOW</td></tr> </table>	1	YES	2	NO	3	DON'T KNOW						
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387	pat_help_w_trouble_breath2	B2a. Did (he/she) get any help in dealing with (his/her) trouble breathing?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No								
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388	amount_aid_trouble_breath2	B2b. How much help in dealing with (his/her) breathing did [PATIENT] receive - less than was needed or about the right amount?	radio 1 LESS THAN WAS NEEDED 2 RIGHT AMOUNT
389	patient_sad_last_month2	B3. During the last month of life, did [PATIENT] have any feelings of anxiety or sadness?	radio 1 YES 2 NO 3 DON'T KNOW
390	help_patient_w_sad_feeling	B3a. Did (he/she) get any help in dealing with (his/her) feelings of anxiety or sadness?	yesno 1 Yes 0 No
391	amount_help_sad_patient2	B3b. How much help in dealing with these feelings did [PATIENT] receive - less than was needed or about the right amount?	radio 1 LESS THAN WAS NEEDED 2 RIGHT AMOUNT
392	decision_w_o_fam_input2	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?	yesno 1 Yes 0 No
393	decision_patient_not_want3	B5. During the last month of life, was there any decision made about care or treatment that [PATIENT] would not have wanted?	yesno 1 Yes 0 No
394	frequency_prsnl_needs_met	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?	radio 1 ALWAYS 2 USUALLY 3 SOMETIMES 4 NEVER
395	patient_treated_w_respect3	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?	radio 1 ALWAYS 2 USUALLY 3 SOMETIMES 4 NEVER
396	frequency_fam_informed2	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?	radio 1 ALWAYS 2 USUALLY 3 SOMETIMES 4 NEVER
397	always_dr_incharge_pat	B9. During the last month of life, was there always a doctor in charge of [PATIENT]'s care?	yesno 1 Yes 0 No
398	clear_which_dr_incharge2	B9a. During the last month of life, was it always clear to you which doctor was in charge of [PATIENT'S] care?	yesno 1 Yes 0 No
399	patient_want_relig_prsn2	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? <i>Skip B10 if ans to A8 is greater than or equal to 1 month.</i>	yesno 1 Yes 0 No
400	enough_time_w_relig_prsn	B10a. During the last month of life, do you think (he/she) had as much contact of this kind as (he/she) wanted?	yesno 1 Yes 0 No

401	pt_life_in_last_month	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?	<div>radio</div> <table border="1"> <tr><td>0</td><td>0</td></tr> <tr><td>1</td><td>1</td></tr> <tr><td>2</td><td>2</td></tr> <tr><td>3</td><td>3</td></tr> <tr><td>4</td><td>4</td></tr> <tr><td>5</td><td>5</td></tr> <tr><td>6</td><td>6</td></tr> <tr><td>7</td><td>7</td></tr> <tr><td>8</td><td>8</td></tr> <tr><td>9</td><td>9</td></tr> <tr><td>10</td><td>10</td></tr> </table> <div>Custom alignment: LH</div>	0	0	1	1	2	2	3	3	4	4	5	5	6	6	7	7	8	8	9	9	10	10
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402	patient_pain_relief	<p>Section Header: 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.</p> <p>1. The patient's pain relief</p>	<div>radio (Matrix)</div> <table border="1"> <tr><td>1</td><td>very satisfied</td></tr> <tr><td>2</td><td>satisfied</td></tr> <tr><td>3</td><td>undecided</td></tr> <tr><td>4</td><td>dissatisfied</td></tr> <tr><td>5</td><td>very dissatisfied</td></tr> </table>	1	very satisfied	2	satisfied	3	undecided	4	dissatisfied	5	very dissatisfied												
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403	info_provided_on_prognosis	2. Information provided about the patient's prognosis	<div>radio (Matrix)</div> <table border="1"> <tr><td>1</td><td>very satisfied</td></tr> <tr><td>2</td><td>satisfied</td></tr> <tr><td>3</td><td>undecided</td></tr> <tr><td>4</td><td>dissatisfied</td></tr> <tr><td>5</td><td>very dissatisfied</td></tr> </table>	1	very satisfied	2	satisfied	3	undecided	4	dissatisfied	5	very dissatisfied												
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404	answers_from_professionals	3. Answers from health professionals	<div>radio (Matrix)</div> <table border="1"> <tr><td>1</td><td>very satisfied</td></tr> <tr><td>2</td><td>satisfied</td></tr> <tr><td>3</td><td>undecided</td></tr> <tr><td>4</td><td>dissatisfied</td></tr> <tr><td>5</td><td>very dissatisfied</td></tr> </table>	1	very satisfied	2	satisfied	3	undecided	4	dissatisfied	5	very dissatisfied												
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405	info_given_about_sd	4. Information given about side effects	<div>radio (Matrix)</div> <table border="1"> <tr><td>1</td><td>very satisfied</td></tr> <tr><td>2</td><td>satisfied</td></tr> <tr><td>3</td><td>undecided</td></tr> <tr><td>4</td><td>dissatisfied</td></tr> <tr><td>5</td><td>very dissatisfied</td></tr> </table>	1	very satisfied	2	satisfied	3	undecided	4	dissatisfied	5	very dissatisfied												
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406	referrals_to_specialists	5. Referrals to specialists	<div>radio (Matrix)</div> <table border="1"> <tr><td>1</td><td>very satisfied</td></tr> <tr><td>2</td><td>satisfied</td></tr> <tr><td>3</td><td>undecided</td></tr> <tr><td>4</td><td>dissatisfied</td></tr> <tr><td>5</td><td>very dissatisfied</td></tr> </table>	1	very satisfied	2	satisfied	3	undecided	4	dissatisfied	5	very dissatisfied												
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407	availability_hospital_bed	6. Availability of a hospital bed	<div>radio (Matrix)</div> <table border="1"> <tr><td>1</td><td>very satisfied</td></tr> <tr><td>2</td><td>satisfied</td></tr> <tr><td>3</td><td>undecided</td></tr> <tr><td>4</td><td>dissatisfied</td></tr> <tr><td>5</td><td>very dissatisfied</td></tr> </table>	1	very satisfied	2	satisfied	3	undecided	4	dissatisfied	5	very dissatisfied												
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	408	fam_conference_for_illness	7. Family conferences held to discuss the patient's illness	radio (Matrix) 1 very satisfied 2 satisfied 3 undecided 4 dissatisfied 5 very dissatisfied
	409	symptom_treatment_speed	8. Speed with which symptoms are treated	radio (Matrix) 1 very satisfied 2 satisfied 3 undecided 4 dissatisfied 5 very dissatisfied
	410	dr_attention_to_symptoms	9. Doctor's attention to patient's description of symptoms	radio (Matrix) 1 very satisfied 2 satisfied 3 undecided 4 dissatisfied 5 very dissatisfied
	411	performance_test_treatment	10. The way tests and treatments are performed	radio (Matrix) 1 very satisfied 2 satisfied 3 undecided 4 dissatisfied 5 very dissatisfied
	412	availability_dr_to_family	11. Availability of doctors to the family	radio (Matrix) 1 very satisfied 2 satisfied 3 undecided 4 dissatisfied 5 very dissatisfied
	413	availability_nurse_to_fam	12. Availability of nurses to the family	radio (Matrix) 1 very satisfied 2 satisfied 3 undecided 4 dissatisfied 5 very dissatisfied
	414	coordination_of_care	13. Coordination of care	radio (Matrix) 1 very satisfied 2 satisfied 3 undecided 4 dissatisfied 5 very dissatisfied
	415	time_required_diagnosis	14. Time required to make a diagnosis	radio (Matrix) 1 very satisfied 2 satisfied 3 undecided 4 dissatisfied 5 very dissatisfied
	416	care_decisions_include_fam	15. The way the family is included in treatment and care decisions	radio (Matrix) 1 very satisfied 2 satisfied 3 undecided 4 dissatisfied 5 very dissatisfied

417	info_pain_management	16. Information given about how to manage the patient's pain	radio (Matrix) <table><tr><td>1</td><td>very satisfied</td></tr><tr><td>2</td><td>satisfied</td></tr><tr><td>3</td><td>undecided</td></tr><tr><td>4</td><td>dissatisfied</td></tr><tr><td>5</td><td>very dissatisfied</td></tr></table>	1	very satisfied	2	satisfied	3	undecided	4	dissatisfied	5	very dissatisfied				
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418	info_about_patient_tests	17. Information given about the patient's tests	radio (Matrix) <table><tr><td>1</td><td>very satisfied</td></tr><tr><td>2</td><td>satisfied</td></tr><tr><td>3</td><td>undecided</td></tr><tr><td>4</td><td>dissatisfied</td></tr><tr><td>5</td><td>very dissatisfied</td></tr></table>	1	very satisfied	2	satisfied	3	undecided	4	dissatisfied	5	very dissatisfied				
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419	thoroughness_assess_sympt	18. How thoroughly the doctor assess the patient's symptoms	radio (Matrix) <table><tr><td>1</td><td>very satisfied</td></tr><tr><td>2</td><td>satisfied</td></tr><tr><td>3</td><td>undecided</td></tr><tr><td>4</td><td>dissatisfied</td></tr><tr><td>5</td><td>very dissatisfied</td></tr></table>	1	very satisfied	2	satisfied	3	undecided	4	dissatisfied	5	very dissatisfied				
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420	dr_follow_up_tests	19. The way tests and treatments are followed up by the doctor	radio (Matrix) <table><tr><td>1</td><td>very satisfied</td></tr><tr><td>2</td><td>satisfied</td></tr><tr><td>3</td><td>undecided</td></tr><tr><td>4</td><td>dissatisfied</td></tr><tr><td>5</td><td>very dissatisfied</td></tr></table>	1	very satisfied	2	satisfied	3	undecided	4	dissatisfied	5	very dissatisfied				
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421	availability_dr_to_patient	20. Availability of the doctor to the patient	radio (Matrix) <table><tr><td>1</td><td>very satisfied</td></tr><tr><td>2</td><td>satisfied</td></tr><tr><td>3</td><td>undecided</td></tr><tr><td>4</td><td>dissatisfied</td></tr><tr><td>5</td><td>very dissatisfied</td></tr></table>	1	very satisfied	2	satisfied	3	undecided	4	dissatisfied	5	very dissatisfied				
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422	self_esteem	Section Header: <i>Mack Items #1-23</i> 1. <i>Life Changes</i> 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. My self-esteem	radio (Matrix) <table><tr><td>-3</td><td>-3</td></tr><tr><td>-2</td><td>-2</td></tr><tr><td>-1</td><td>-1</td></tr><tr><td>0</td><td>0</td></tr><tr><td>1</td><td>+1</td></tr><tr><td>2</td><td>+2</td></tr><tr><td>3</td><td>+3</td></tr></table>	-3	-3	-2	-2	-1	-1	0	0	1	+1	2	+2	3	+3
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423	physical_health	My physical health	radio (Matrix) <table><tr><td>-3</td><td>-3</td></tr><tr><td>-2</td><td>-2</td></tr><tr><td>-1</td><td>-1</td></tr><tr><td>0</td><td>0</td></tr><tr><td>1</td><td>+1</td></tr><tr><td>2</td><td>+2</td></tr><tr><td>3</td><td>+3</td></tr></table>	-3	-3	-2	-2	-1	-1	0	0	1	+1	2	+2	3	+3
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424	family_activities_time	My time for family activities	radio (Matrix) <table><tr><td>-3</td><td>-3</td></tr><tr><td>-2</td><td>-2</td></tr><tr><td>-1</td><td>-1</td></tr><tr><td>0</td><td>0</td></tr><tr><td>1</td><td>+1</td></tr><tr><td>2</td><td>+2</td></tr><tr><td>3</td><td>+3</td></tr></table>	-3	-3	-2	-2	-1	-1	0	0	1	+1	2	+2	3	+3
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	425	ability_to_cope_w_stress	My ability to cope with stress	<div>radio (Matrix)</div> <table><tr><td>-3</td><td>-3</td></tr><tr><td>-2</td><td>-2</td></tr><tr><td>-1</td><td>-1</td></tr><tr><td>0</td><td>0</td></tr><tr><td>1</td><td>+1</td></tr><tr><td>2</td><td>+2</td></tr><tr><td>3</td><td>+3</td></tr></table>	-3	-3	-2	-2	-1	-1	0	0	1	+1	2	+2	3	+3
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	426	relationship_w_friends	My relationship with friends	<div>radio (Matrix)</div> <table><tr><td>-3</td><td>-3</td></tr><tr><td>-2</td><td>-2</td></tr><tr><td>-1</td><td>-1</td></tr><tr><td>0</td><td>0</td></tr><tr><td>1</td><td>+1</td></tr><tr><td>2</td><td>+2</td></tr><tr><td>3</td><td>+3</td></tr></table>	-3	-3	-2	-2	-1	-1	0	0	1	+1	2	+2	3	+3
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	427	future_outlook	My future outlook	<div>radio (Matrix)</div> <table><tr><td>-3</td><td>-3</td></tr><tr><td>-2</td><td>-2</td></tr><tr><td>-1</td><td>-1</td></tr><tr><td>0</td><td>0</td></tr><tr><td>1</td><td>+1</td></tr><tr><td>2</td><td>+2</td></tr><tr><td>3</td><td>+3</td></tr></table>	-3	-3	-2	-2	-1	-1	0	0	1	+1	2	+2	3	+3
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	428	emotional_well_being	My emotional well-being	<div>radio (Matrix)</div> <table><tr><td>-3</td><td>-3</td></tr><tr><td>-2</td><td>-2</td></tr><tr><td>-1</td><td>-1</td></tr><tr><td>0</td><td>0</td></tr><tr><td>1</td><td>+1</td></tr><tr><td>2</td><td>+2</td></tr><tr><td>3</td><td>+3</td></tr></table>	-3	-3	-2	-2	-1	-1	0	0	1	+1	2	+2	3	+3
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	429	time_for_social_activities	My time for social activities	<div>radio (Matrix)</div> <table><tr><td>-3</td><td>-3</td></tr><tr><td>-2</td><td>-2</td></tr><tr><td>-1</td><td>-1</td></tr><tr><td>0</td><td>0</td></tr><tr><td>1</td><td>+1</td></tr><tr><td>2</td><td>+2</td></tr><tr><td>3</td><td>+3</td></tr></table>	-3	-3	-2	-2	-1	-1	0	0	1	+1	2	+2	3	+3
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	430	relationship_w_family	My relationship with family	<div>radio (Matrix)</div> <table><tr><td>-3</td><td>-3</td></tr><tr><td>-2</td><td>-2</td></tr><tr><td>-1</td><td>-1</td></tr><tr><td>0</td><td>0</td></tr><tr><td>1</td><td>+1</td></tr><tr><td>2</td><td>+2</td></tr><tr><td>3</td><td>+3</td></tr></table>	-3	-3	-2	-2	-1	-1	0	0	1	+1	2	+2	3	+3
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431	relationship_with_patient	My relationship with [PATIENT]	radio (Matrix) <table border="1"> <tr><td>-3</td><td>-3</td></tr> <tr><td>-2</td><td>-2</td></tr> <tr><td>-1</td><td>-1</td></tr> <tr><td>0</td><td>0</td></tr> <tr><td>1</td><td>+1</td></tr> <tr><td>2</td><td>+2</td></tr> <tr><td>3</td><td>+3</td></tr> </table>	-3	-3	-2	-2	-1	-1	0	0	1	+1	2	+2	3	+3																						
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432	who_pt_live_w_last_6month	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]	checkbox <table border="1"> <tr> <td>1</td> <td>who_pt_live_w_last_6month__1</td> <td>I lived with the patient [lived with participant's relationship by also check appropriate box below]</td> </tr> <tr> <td>2</td> <td>who_pt_live_w_last_6month__2</td> <td>Patient's partner/spouse/boyfriend</td> </tr> <tr> <td>3</td> <td>who_pt_live_w_last_6month__3</td> <td>Patient's mother</td> </tr> <tr> <td>4</td> <td>who_pt_live_w_last_6month__4</td> <td>Patient's father</td> </tr> <tr> <td>5</td> <td>who_pt_live_w_last_6month__5</td> <td>Patient's brother</td> </tr> <tr> <td>6</td> <td>who_pt_live_w_last_6month__6</td> <td>Patient's sister</td> </tr> <tr> <td>7</td> <td>who_pt_live_w_last_6month__7</td> <td>Patient's grandparent</td> </tr> <tr> <td>8</td> <td>who_pt_live_w_last_6month__8</td> <td>Patient's child(ren)</td> </tr> <tr> <td>9</td> <td>who_pt_live_w_last_6month__9</td> <td>Patient's other relative [specify]</td> </tr> <tr> <td>10</td> <td>who_pt_live_w_last_6month__10</td> <td>Patient's friend</td> </tr> <tr> <td>11</td> <td>who_pt_live_w_last_6month__11</td> <td>Other [please specify]</td> </tr> <tr> <td>12</td> <td>who_pt_live_w_last_6month__12</td> <td>The patient lived alone</td> </tr> </table> Custom alignment: LV	1	who_pt_live_w_last_6month__1	I lived with the patient [lived with participant's relationship by also check appropriate box below]	2	who_pt_live_w_last_6month__2	Patient's partner/spouse/boyfriend	3	who_pt_live_w_last_6month__3	Patient's mother	4	who_pt_live_w_last_6month__4	Patient's father	5	who_pt_live_w_last_6month__5	Patient's brother	6	who_pt_live_w_last_6month__6	Patient's sister	7	who_pt_live_w_last_6month__7	Patient's grandparent	8	who_pt_live_w_last_6month__8	Patient's child(ren)	9	who_pt_live_w_last_6month__9	Patient's other relative [specify]	10	who_pt_live_w_last_6month__10	Patient's friend	11	who_pt_live_w_last_6month__11	Other [please specify]	12	who_pt_live_w_last_6month__12	The patient lived alone
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433	specify_other_relative	2 i. If patient lived with another relative, please specify	text																																				
434	specify_other_prsn_live_w	2 ii. If patient lived with other, please specify	text																																				
435	patient_employment	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.)	radio <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>2</td><td>No</td></tr> <tr><td>3</td><td>Refused</td></tr> <tr><td>4</td><td>Don't know</td></tr> </table> Custom alignment: LV	1	Yes	2	No	3	Refused	4	Don't know																												
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436	why_pt_was_not_working	4.[If No] What is the main reason [PATIENT] was not working at that time?	radio <table border="1"> <tr><td>1</td><td>Patient did not need to work because he/she was still young</td></tr> <tr><td>2</td><td>Unable to work because ill/disabled</td></tr> <tr><td>3</td><td>Going to school</td></tr> <tr><td>4</td><td>Could not find work</td></tr> <tr><td>5</td><td>Retired</td></tr> <tr><td>6</td><td>On temporary layoff</td></tr> <tr><td>7</td><td>Maternity/paternity leave</td></tr> <tr><td>8</td><td>Taking care of home or family</td></tr> <tr><td>9</td><td>Wanted some time off</td></tr> <tr><td>10</td><td>Waiting to find work</td></tr> <tr><td>11</td><td>Other</td></tr> <tr><td>12</td><td>Refused</td></tr> <tr><td>13</td><td>Don't know</td></tr> </table> Custom alignment: LV	1	Patient did not need to work because he/she was still young	2	Unable to work because ill/disabled	3	Going to school	4	Could not find work	5	Retired	6	On temporary layoff	7	Maternity/paternity leave	8	Taking care of home or family	9	Wanted some time off	10	Waiting to find work	11	Other	12	Refused	13	Don't know										
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437	patient_live_w_participant	5. Did [PATIENT] live in your household in [calendar year before death]?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No																																
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438	patient_annual_income	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...	radio <table border="1"> <tr><td>1</td><td>No income</td></tr> <tr><td>2</td><td>\$1-5,000</td></tr> <tr><td>3</td><td>\$5001-10,000</td></tr> <tr><td>4</td><td>\$10,001-15,000</td></tr> <tr><td>5</td><td>\$15,001-25,000</td></tr> <tr><td>6</td><td>\$25,001-50,000</td></tr> <tr><td>7</td><td>\$50,001-100,000</td></tr> <tr><td>8</td><td>\$100,001 or more</td></tr> <tr><td>9</td><td>Refused</td></tr> <tr><td>10</td><td>Don't know</td></tr> </table> Custom alignment: LV	1	No income	2	\$1-5,000	3	\$5001-10,000	4	\$10,001-15,000	5	\$15,001-25,000	6	\$25,001-50,000	7	\$50,001-100,000	8	\$100,001 or more	9	Refused	10	Don't know						
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439	pt_job_as_of_death_month	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)	radio <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>2</td><td>No</td></tr> <tr><td>3</td><td>Refused</td></tr> <tr><td>4</td><td>Don't know</td></tr> </table> Custom alignment: LV	1	Yes	2	No	3	Refused	4	Don't know																		
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441	participant_gender	9. What is your gender	radio <table border="1"> <tr><td>1</td><td>Male</td></tr> <tr><td>2</td><td>Female</td></tr> </table>	1	Male	2	Female																						
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442	participant_highest_school	10. What is the highest level of school you have completed? Please check one.	radio <table border="1"> <tr><td>1</td><td>Less than high school</td></tr> <tr><td>2</td><td>High school graduate</td></tr> <tr><td>3</td><td>Technical school or AA (associate's) degree</td></tr> <tr><td>4</td><td>College graduate</td></tr> <tr><td>5</td><td>Advanced degree</td></tr> </table> Custom alignment: LV	1	Less than high school	2	High school graduate	3	Technical school or AA (associate's) degree	4	College graduate	5	Advanced degree																
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443	year_death_participant_job	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)	radio <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>2</td><td>No</td></tr> <tr><td>3</td><td>Refused</td></tr> <tr><td>4</td><td>Don't Know</td></tr> </table> Custom alignment: LV	1	Yes	2	No	3	Refused	4	Don't Know																		
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444	why_participant_no_work	12. [If no] What is the main reason you were not working at the time?	<div>radio</div> <table border="1"> <tr><td>1</td><td>Could not find work</td></tr> <tr><td>2</td><td>Retired</td></tr> <tr><td>3</td><td>Unable to work because ill/disabled</td></tr> <tr><td>4</td><td>Taking care of patient</td></tr> <tr><td>5</td><td>On temporary layoff</td></tr> <tr><td>6</td><td>Maternity/paternity leave</td></tr> <tr><td>7</td><td>Going to school</td></tr> <tr><td>8</td><td>Taking care of home or family, other than patient</td></tr> <tr><td>9</td><td>Wanted some time off</td></tr> <tr><td>10</td><td>Other</td></tr> <tr><td>11</td><td>Refused</td></tr> <tr><td>12</td><td>Don't Know</td></tr> </table> <div>Custom alignment: LV</div>	1	Could not find work	2	Retired	3	Unable to work because ill/disabled	4	Taking care of patient	5	On temporary layoff	6	Maternity/paternity leave	7	Going to school	8	Taking care of home or family, other than patient	9	Wanted some time off	10	Other	11	Refused	12	Don't Know
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445	participant_annual_income	13. What is your best guess of your total household income in [calendar year before death] from all sources before taxes were taken out?	<div>radio</div> <table border="1"> <tr><td>1</td><td>No income</td></tr> <tr><td>2</td><td>\$1-5,000</td></tr> <tr><td>3</td><td>\$5,001-10,000</td></tr> <tr><td>4</td><td>\$10,001-15,000</td></tr> <tr><td>5</td><td>\$15,001-25,000</td></tr> <tr><td>6</td><td>\$25,001-50,000</td></tr> <tr><td>7</td><td>\$50,001-100,000</td></tr> <tr><td>8</td><td>\$100,001 or more</td></tr> <tr><td>9</td><td>Refused</td></tr> <tr><td>10</td><td>Don't know</td></tr> </table> <div>Custom alignment: LV</div>	1	No income	2	\$1-5,000	3	\$5,001-10,000	4	\$10,001-15,000	5	\$15,001-25,000	6	\$25,001-50,000	7	\$50,001-100,000	8	\$100,001 or more	9	Refused	10	Don't know				
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446	month_die_participant_job	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)	<div>radio</div> <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>2</td><td>No</td></tr> <tr><td>3</td><td>Refused</td></tr> <tr><td>4</td><td>Don't Know</td></tr> </table> <div>Custom alignment: LV</div>	1	Yes	2	No	3	Refused	4	Don't Know																
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447	particip_no_work_month_die	15. [If No] What is the main reason you were not working at that time?	<div>radio</div> <table border="1"> <tr><td>1</td><td>Could not find work</td></tr> <tr><td>2</td><td>Retired</td></tr> <tr><td>3</td><td>Unable to work because ill/disabled</td></tr> <tr><td>4</td><td>Taking care of patient</td></tr> <tr><td>5</td><td>On temporary layoff</td></tr> <tr><td>6</td><td>Maternity/paternity leave</td></tr> <tr><td>7</td><td>Going to school</td></tr> <tr><td>8</td><td>Taking care of home or family, other than patient</td></tr> <tr><td>9</td><td>Wanted some time off</td></tr> <tr><td>10</td><td>Other</td></tr> <tr><td>11</td><td>Refused</td></tr> <tr><td>12</td><td>Don't Know</td></tr> </table> <div>Custom alignment: LV</div>	1	Could not find work	2	Retired	3	Unable to work because ill/disabled	4	Taking care of patient	5	On temporary layoff	6	Maternity/paternity leave	7	Going to school	8	Taking care of home or family, other than patient	9	Wanted some time off	10	Other	11	Refused	12	Don't Know
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448	how_long_savings_last	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?	radio <table border="1"> <tr><td>1</td><td>LESS THAN 1 MONTH</td></tr> <tr><td>2</td><td>1-2 MONTHS</td></tr> <tr><td>3</td><td>3-6 MONTHS</td></tr> <tr><td>4</td><td>7-12 MONTHS</td></tr> <tr><td>5</td><td>MORE THAN 1 YEAR</td></tr> <tr><td>6</td><td>DON'T KNOW</td></tr> <tr><td>7</td><td>REFUSED</td></tr> </table> Custom alignment: LV	1	LESS THAN 1 MONTH	2	1-2 MONTHS	3	3-6 MONTHS	4	7-12 MONTHS	5	MORE THAN 1 YEAR	6	DON'T KNOW	7	REFUSED
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449	people_supt_by_income	17 i. Including yourself, how many people living in your household are supported by your total household income?	text														
450	people_supt_by_income2	17 ii. Including yourself, how many people living in your household are supported by your total household income?	radio <table border="1"> <tr><td>1</td><td>DON'T KNOW</td></tr> <tr><td>2</td><td>REFUSE</td></tr> </table>	1	DON'T KNOW	2	REFUSE										
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2	REFUSE																
451	ppl_under_18_in_household	18 i. How many of these people are under the age of 18?	text														
452	ppl_under_18_in_household2	18 ii. How many of these people are children under 18?	radio <table border="1"> <tr><td>1</td><td>DON'T KNOW</td></tr> <tr><td>2</td><td>REFUSED</td></tr> </table>	1	DON'T KNOW	2	REFUSED										
1	DON'T KNOW																
2	REFUSED																
453	participant_marital_status	19. Are you currently married, widowed, divorced, separated, or never married?	radio <table border="1"> <tr><td>1</td><td>Never married</td></tr> <tr><td>2</td><td>Married/living as married</td></tr> <tr><td>3</td><td>Widowed</td></tr> <tr><td>4</td><td>Separated</td></tr> <tr><td>5</td><td>Divorced</td></tr> </table> Custom alignment: LV	1	Never married	2	Married/living as married	3	Widowed	4	Separated	5	Divorced				
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2	Married/living as married																
3	Widowed																
4	Separated																
5	Divorced																
454	particip_hispanic_latino	20. Do you consider yourself Hispanic/Latino?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No										
1	Yes																
0	No																
455	participant_race	21. What group best describes your racial background?	radio <table border="1"> <tr><td>1</td><td>White</td></tr> <tr><td>2</td><td>Black</td></tr> <tr><td>3</td><td>Asian/Pacific Islander</td></tr> <tr><td>4</td><td>Native American</td></tr> <tr><td>5</td><td>Other</td></tr> </table> Custom alignment: LV	1	White	2	Black	3	Asian/Pacific Islander	4	Native American	5	Other				
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5	Other																
456	participant_other_race	21 i. Please specify other race	text														
457	participant_language	22. What language do you speak at home?	radio <table border="1"> <tr><td>1</td><td>English</td></tr> <tr><td>2</td><td>Spanish</td></tr> <tr><td>3</td><td>Other</td></tr> </table>	1	English	2	Spanish	3	Other								
1	English																
2	Spanish																
3	Other																
458	participant_other_language	22 i. Please specify other language	text														
459	participant_religion	23. What is your religion?	radio <table border="1"> <tr><td>1</td><td>Catholic</td></tr> <tr><td>2</td><td>Protestant</td></tr> <tr><td>3</td><td>Jewish</td></tr> <tr><td>4</td><td>Other</td></tr> <tr><td>5</td><td>No religion</td></tr> </table> Custom alignment: LV	1	Catholic	2	Protestant	3	Jewish	4	Other	5	No religion				
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460	participant_other_religion	23 i. Please specify other religion	text														
461	interview_complete	Section Header: <i>Form Status</i> Complete?	dropdown <table border="1"> <tr><td>0</td><td>Incomplete</td></tr> <tr><td>1</td><td>Unverified</td></tr> <tr><td>2</td><td>Complete</td></tr> </table>	0	Incomplete	1	Unverified	2	Complete								
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