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Site Number					Enrollment Number			

**Audit of Communication, CarE Planning, and
DocumenTation:
A multicenter, prospective study**

The ACCEPT Study

Patient Questionnaire
Hospital or Acute Care Setting

Date of Interview

____-____-____
DD MMM YYYY

Interview Start Time: _____

Interview Stop Time: _____









Section 1: Patient Demographics

<p>Age: _____ years</p> <p>Sex (√) one: <input type="checkbox"/> Male <input type="checkbox"/> Female</p> <p>Current Marital Status (√) one:</p> <p><input type="checkbox"/> Married or living as married</p> <p><input type="checkbox"/> Widowed</p> <p><input type="checkbox"/> Never married</p> <p><input type="checkbox"/> Divorced or separated; not remarried</p> <p>Last location of living in last month (√) one: <i>(If in hospital, then month prior to hospitalization)</i></p> <p><input type="checkbox"/> Home</p> <p><input type="checkbox"/> Retirement Residence</p> <p><input type="checkbox"/> Long-Term Care or Nursing Home</p> <p><input type="checkbox"/> Rehabilitation Facility</p> <p><input type="checkbox"/> Ward in another hospital</p> <p><input type="checkbox"/> Other (specify): _____</p> <p>Do you live alone?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>Home Health Care</p> <p>Does a health care professional come to your home or residential setting to provide health care?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>Location of last residence (√) one: <i>(as noted above)</i></p> <p><input type="checkbox"/> Rural <input type="checkbox"/> Urban</p> <p>Postal Code: _____</p> <p><input type="checkbox"/> N/A (Non-Canadian)</p> <p>Health Insurance (√) all that apply:</p> <p><input type="checkbox"/> National, Provincial or other Government Health Insurance Plan</p> <p><input type="checkbox"/> Extended Health coverage (e.g. Blue Cross, Sun Life, etc.)</p> <p><input type="checkbox"/> Private Health Insurance</p> <p><input type="checkbox"/> Other (specify): _____</p> <p><input type="checkbox"/> None</p> <p>Health Literacy (REALM Score) (√) all correct</p> <table style="width: 100%; border: none;"> <tr> <td><input type="checkbox"/> Allergic</td> <td><input type="checkbox"/> Jaundice</td> </tr> <tr> <td><input type="checkbox"/> Anemia</td> <td><input type="checkbox"/> Directed</td> </tr> <tr> <td><input type="checkbox"/> Colitis</td> <td><input type="checkbox"/> Constipation</td> </tr> <tr> <td><input type="checkbox"/> Fatigue</td> <td><input type="checkbox"/> Osteoporosis</td> </tr> </table> <p style="text-align: right;">Total correct: ____ / 8</p>	<input type="checkbox"/> Allergic	<input type="checkbox"/> Jaundice	<input type="checkbox"/> Anemia	<input type="checkbox"/> Directed	<input type="checkbox"/> Colitis	<input type="checkbox"/> Constipation	<input type="checkbox"/> Fatigue	<input type="checkbox"/> Osteoporosis	<p>Education – highest level achieved (√) one:</p> <p><input type="checkbox"/> Elementary school or less</p> <p><input type="checkbox"/> Some high school</p> <p><input type="checkbox"/> High school graduate</p> <p><input type="checkbox"/> Some college (including CEGEP)/ trade school</p> <p><input type="checkbox"/> College diploma (including DEC)/ trade school</p> <p><input type="checkbox"/> Some university</p> <p><input type="checkbox"/> University degree</p> <p><input type="checkbox"/> Post Graduate</p> <p>How important is spirituality or religion in your life? (√) one</p> <p><input type="checkbox"/> Extremely important</p> <p><input type="checkbox"/> Very important</p> <p><input type="checkbox"/> Somewhat important</p> <p><input type="checkbox"/> Not very important</p> <p><input type="checkbox"/> Not at all important</p> <p><input type="checkbox"/> Don't know</p> <p>Do you identify with a formal religious group or practice? (√) one</p> <p><input type="checkbox"/> Protestant (includes Anglican, Baptist, United, Methodist)</p> <p><input type="checkbox"/> Catholic</p> <p><input type="checkbox"/> Jewish</p> <p><input type="checkbox"/> Muslim</p> <p><input type="checkbox"/> Sikh</p> <p><input type="checkbox"/> Other (specify): _____</p> <p><input type="checkbox"/> None</p> <p>Ethnicity (interviewer assessment)</p> <p>Is the respondent Caucasian?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>Language</p> <p>Besides English (or French if live in Quebec) do you speak another language on a daily basis?</p> <p><input type="checkbox"/> Yes, specify: _____</p> <p><input type="checkbox"/> No</p>
<input type="checkbox"/> Allergic	<input type="checkbox"/> Jaundice								
<input type="checkbox"/> Anemia	<input type="checkbox"/> Directed								
<input type="checkbox"/> Colitis	<input type="checkbox"/> Constipation								
<input type="checkbox"/> Fatigue	<input type="checkbox"/> Osteoporosis								

Section 1: Frailty Scale

Please consider your overall condition 2 weeks *prior to this admission to hospital*.

How fit or frail were you at that time point? Check one response only. If you have trouble deciding between two options, choose the higher functioning level.

(✓)	Description	
<input type="checkbox"/>		<p align="center">Very Fit (category 1)</p> <p>People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.</p>
<input type="checkbox"/>		<p align="center">Well (category 2)</p> <p>No active disease symptoms but less fit than people in category 1. Often, they exercise or are very active occasionally, e.g. seasonally.</p> <p><i>Well</i> older adults share most attributes of the very fit, except for regular, vigorous exercise. Like them, some may complain of memory symptoms, but without objective deficits.</p>
<input type="checkbox"/>		<p align="center">Managing Well (category 3)</p> <p>Medical problems are well controlled, but people in this category are not regularly active beyond routine walking.</p> <p>Those with treated medical problems who exercise are classed in categories 1 or 2.</p>
<input type="checkbox"/>		<p align="center">Vulnerable (category 4)</p> <p>Not dependent on others for daily help, but often symptoms limit activities. A common complaint is being “slowed up” and/ or being tired during the day. Many people in this category rate their health as no better than “fair”.</p> <p>Memory problems, if present, can begin to affect function (e.g. having to look up familiar recipes, misplacing documents) but usually do not meet dementia criteria. Families often note some withdrawal – e.g. needing encouragement to go to social activities.</p>
<input type="checkbox"/>		<p align="center">Mildly Frail (category 5)</p> <p>More evident slowing and individuals help needed in “high” activities of daily living (finances, transportation, heavy housework, medications). Mildly frail people might have difficulty with shopping or walking outside alone, meal preparation, and housework. Often, they will have several illnesses and take multiple medications.</p> <p>This category includes people with mild dementia. Their common symptoms include forgetting the details of a recent event, even though they remember the event itself, asking the same question, or telling the same story several times a day and social withdrawal.</p>
<input type="checkbox"/>		<p align="center">Moderately Frail (category 6)</p> <p>Individuals need help with all outside activities and with keeping house. Inside, they often have problems with stairs and need help with bathing and might need minimal assistance (cuing, standby) with dressing.</p> <p>If a memory problem causes the dependency, often recent memory will be very impaired, even though they seemingly can remember their past life events well.</p>
<input type="checkbox"/>		<p align="center">Severely Frail (category 7)</p> <p>Completely dependent on others for all or most personal activities of daily living, such as dressing and feeding.</p>
<input type="checkbox"/>		<p align="center">Very Severely Frail (category 8)</p> <p>Completely dependent, approaching the end of life. Typically, people in this category could not recover from even a minor illness.</p>

Section 2: Determinants of Decision Making

Now I am going to ask you some questions that may influence your decision making when you are sick.

1. Have you had the experience of making medical decisions at the end of life for another person in any setting (ICU, hospital, palliative care unit, etc.)?

Yes No

2. In general, how would you rate your health?

Excellent Very Good Good Fair Poor

3. In general, how would you rate your overall quality of life?

Excellent Very Good Good Fair Poor

Interviewer, for the following questions, please hand this page to the respondent and ask them to mark the line to indicate their views on the question.

Some people find this a sensitive or difficult question but please try to answer it.

4. The line below represents a person's total lifetime from birth on the far left to death on the far right. Please make a mark on the line where you see yourself at this point in your life.

Birth | _____ | Death

Interviewer, please measure the distance from the left anchor (birth) to this mark, in centimeters (cm) after the interview and mark here:

_____ **cm.**

If the respondent was unable to place a mark on the life line above, please note an alternative response below:

- Respondent could not answer (was not able to verbalize a response)
- Respondent provided a verbal response: _____

Section 3: Decisions About Your Health Care Prior to Hospitalization

1a) Have you heard about Advance Care Planning?

- Yes No
 ↓

b) If Yes, from which source:

- TV or other media A health care provider A family member or friend
 Other, please specify: _____

Advance Care Planning is thinking about your future health care treatment decisions and what your wishes are for end of life care. It is also about talking with your close family, friends, and health care providers (like your doctor) so they know your thoughts and wishes if you are not able to speak and make decisions yourself. It also involves naming someone to make medical decisions for you if you are not able to speak for yourself.

2. Before being in the hospital, have you ever thought about what kinds of treatments you would want, or not want, if your health got worse? For example, have you thought about the use of cardiopulmonary resuscitation (CPR), breathing machines, dialysis, Intensive Care Unit (ICU) admission, etc.

- Yes No

3. At this point in time, if life supports were needed to keep you alive, which option would you prefer for your care? Please check (√) one.

Interviewer please give respondent CARD 3 which explains life sustaining treatments and options.

Please check (√) one.

- Use machines and all possible measures including resuscitation (CPR) with a focus on keeping me alive at all costs.
- Use machines and all possible measures with a focus on keeping me alive but if my heart stops, no resuscitation.
- Use machines only in the short term to see if I will get better but if my illness is prolonged, change focus to comfort measures only. If my heart stops, no resuscitation (CPR).
- Use full medical care to prolong my life but if my heart or my breathing stops, no resuscitation (CPR) or breathing machines.
- Use comfort measures only with a focus on improving my quality of life and comfort. Allow natural death and no artificial prolongation of life and no resuscitation.
- Unsure

4. How comfortable are you with *thinking* about medical treatment options at the end of your life?

- Very Uncomfortable
- Quite Uncomfortable
- Neutral (neither uncomfortable nor comfortable)
- Quite Comfortable
- Very Comfortable

5. Please rate the importance of each one in your thinking about the use of life sustaining medical treatments as a part of your care.

Please circle one answer for each question on a scale of 1 to 10 where 1 is 'not at all important' and 10 is 'very important.'				
a) How important is it that I be comfortable and suffer as little as possible?	Not at all important	1 2 3 4 5 6 7 8 9 10	Very important	Unsure or Undecided
b) How important is it that I have more time in the future with my family?	Not at all important	1 2 3 4 5 6 7 8 9 10	Very important	Unsure or Undecided
c) How important is it that I live as long as possible?	Not at all important	1 2 3 4 5 6 7 8 9 10	Very important	Unsure or Undecided
d) How important is it that I avoid being attached to machines and tubes?	Not at all important	1 2 3 4 5 6 7 8 9 10	Very important	Unsure or Undecided
e) How important is it that my dying is not prolonged?	Not at all important	1 2 3 4 5 6 7 8 9 10	Very important	Unsure or Undecided
f) How important is a belief that nature should be allowed to take its course?	Not at all important	1 2 3 4 5 6 7 8 9 10	Very important	Unsure or Undecided
g) How important is the belief that life should be preserved?	Not at all important	1 2 3 4 5 6 7 8 9 10	Very important	Unsure or Undecided
h) How important is it that I respect the wishes of other family members regarding my care?	Not at all important	1 2 3 4 5 6 7 8 9 10	Very important	Unsure or Undecided

6. Prior to hospital, has a member of the health care team ever offered to arrange a time when you and your family can meet with the doctor to discuss the use of life-sustaining treatments you would want, or not want, in the event your physical health deteriorated?

- Yes No

7. Prior to hospital, have you discussed your preferences for using or not using life sustaining treatments with anyone?

Yes No
 ↓

If yes please complete table below.

	Have you had a discussion?	If Yes, how often?	If Yes, When was the last time you discussed these preferences with your _____	Do you remember what was the trigger or what precipitated the conversation? (circle all that apply)	Location of conversation
		1. Once 2. A few times 3. Regularly	1. More than a year ago 2. Within the last year 3. Within the last 6 months 4. Within the last month 5. Within the last week	1. Previous personal health crisis or deterioration in health 2. Previous experience with EOL treatment involving someone you cared about 3. Doctor brought it up 4. Getting older 5. Other (specify)	1. Home 2. Hospital 3. ER 4. Doctor office or clinic 5. Lawyer office 6. Don't remember/don't know 7. Other (specify)
i. Family doctor	Y N	1 2 3	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5 6 7
ii. Other doctor	Y N	1 2 3	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5 6 7
iii. Nurse	Y N	1 2 3	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5 6 7
iv. Social worker	Y N	1 2 3	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5 6 7
v. Spiritual care	Y N	1 2 3	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5 6 7
vi. Family member(s)	Y N	1 2 3	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5 6 7
vii. Surrogate Decision Maker	Y N	1 2 3	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5 6 7
viii. Lawyer	Y N	1 2 3	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5 6 7
ix. Other specify _____	Y N	1 2 3	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5 6 7

8. Thinking about all the conversations you had with health care providers about ACP, was the timing of the conversations right for you?

- The conversation occurred far too late
- The conversation occurred a little too late
- The conversation occurred at the right time
- The conversation occurred a little too early
- The conversation occurred far too early

9. How comfortable are you talking to a family member about medical treatment options at the end of life?

- Very Uncomfortable
- Quite Uncomfortable
- Neutral (neither uncomfortable nor comfortable)
- Quite Comfortable
- Very Comfortable

Many people have gone to a lawyer and completed a power of attorney for financial and property matters or last will and testament. The following questions pertain to what planning you have done as it relates to your future health care only and not financial matters.

10. a) Have you written down your wishes about the medical treatments you would want (or not want) in the event that you are unable to speak for yourself? For example, do you have an advance care plan, advance directive or living will, or another written document

- Yes No Unsure



b) If Yes, which of the following were used?

Check (✓) all that apply (*Interviewer: Make sure they are not referring to a 'last will and testament' or 'power of attorney for finances documents' Do not accept these answers.*)

- Goals of Care designation/Level of Intervention/MOST
- DNR/DNAR/NO CPR form/options for care order/R3
- "My Voice" documents
- "Respecting Choice"
- "Let Me Decide" booklet
- Generic Living Will or Advance Directive
- Speak Up Campaign Workbook
- Other, Please specify: _____

11. Have you named someone, in writing, to be your substitute decision maker for medical treatment decisions? (eg. Power of Attorney for Person Care, Personal Directive, Representation Agreement, Mandate in Case of Incapacity)

- Yes No

12. Prior to hospital, did the doctor ever talk to you about a poor prognosis or indicate in some way that you had a limited time left to live?

- Yes No

Section 4: Goals of Care during Current Hospitalization

The following questions concern the treatments you would, or would not want, the doctors to perform should your condition deteriorate to the point of being life threatening during THIS HOSPITALIZATION.

For example, some patients may have life-sustaining treatments used in the course of illness whereas others may not. By life sustaining treatments, we are referring to the use of cardiopulmonary resuscitation (CPR), breathing machines, dialysis, Intensive Care Unit (ICU) admission, etc. **Please note that some of these questions may not be applicable to you because we are interviewing many people who may have problems that are more life-threatening than yours.**

Interviewer please give CARD 4 to respondent.

		How important is this care issue to you?					If YES, how satisfied were you with the way this was done?				
		Not at all Important	Not Very Important	Somewhat Important	Very Important	Extremely Important	Not at all Satisfied	Not Very Satisfied	Somewhat Satisfied	Very satisfied	Completely Satisfied
Since your admission, has a member of the health care team...											
1. asked you if you had prior discussions or written documents about the use of life-sustaining treatments.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. offered to arrange a time when you and/or your family can meet with the doctor to discuss the treatment options and plans.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. provided you with printed information about goals of care discussions to read before you meet with the doctor.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. asked you what is important to you as you consider health care decisions at this stage of your life (i.e., values, spiritual beliefs, other practices).	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
5. asked you if you had any questions or needed things clarified about your overall goals of care.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
6. asked you what treatments you prefer to have or not have if you develop a life-threatening illness.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
7. offered you an opportunity to discuss with members of the health care team what would happen if you lost your ability to consent to care.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
8. informed you that you may change your mind about your decisions about goals of care.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

		How important is this care issue to you?					If YES, how satisfied were you with the way this was done?				
		Not at all Important	Not Very Important	Somewhat Important	Very Important	Extremely Important	Not at all Satisfied	Not Very Satisfied	Somewhat Satisfied	Very satisfied	Completely Satisfied
Since your admission, has a member of the health care team...											
9. talked to you about a prognosis or indicated in some way that you have limited time left to live.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
10. talked to you about the outcomes, benefits, and burdens (or risks) of life-sustaining medical treatments.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
11. given you the opportunity to express your fears or discuss what concerns you.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
12. offered you support from members of the health care team (e.g. spiritual care, social work, clinical nurse specialist) as needed.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
13. talked to you about outcomes, benefits, and burdens of focusing on quality of life and comfort care as the goal of your treatment (e.g. treating symptoms like pain without trying to cure or control the underlying illness).	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
14. helped you and/or your family access legal documents to communicate your Advanced Care Plans.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Section 5: CANHELP Lite

The following questions include items that are considered important in terms of quality of care for people with serious, life threatening illnesses. Please think about the health care that you have received **during the past month (this includes your time prior to and during this hospital visit)** from doctors, nurses and other health care professionals. For each question you will be asked to choose a number between 1 and 5 to indicate how satisfied you are with that particular aspect of your care -- the higher the number, the more satisfied you are. If you choose option #1 **“Not at all Satisfied”**, for example, you will be indicating that this aspect of the care you received did not meet any of your expectations of high quality care. At the other end of the scale, your choice of option #5 **“Completely Satisfied”** will indicate that this aspect of the care you received met or exceeded your expectations of quality care.

All answers are confidential and will not be shown to doctors or other health care professionals who are responsible for your care. There are no right or wrong answers. Completely honest answers are most helpful! Please note that some questions may not be relevant to your situation, as we are interviewing people who may have more serious health issues than yours.

Interviewer, please give CARD 5 to respondent. If the respondent attempts to convey that the question is “not applicable or not relevant”, then confirm with them they are ‘satisfied’ with the event and get their rating of satisfaction.

	1 Not At All	2 Not Very	3 Somewhat	4 Very	5 Completely
Global Questions of Patient Satisfaction					
A. <u>In general</u> , how satisfied are you with the quality of care you received <i>during the past month</i> ?					
Relationship with the Doctors					
1. How satisfied are you that your doctor(s) took a personal interest in you <i>during the past month</i> ?					
2. How satisfied are you that your doctor(s) were available when you needed them (by phone or in person) <i>during the past month</i> ?					
3. How satisfied are you with the level of trust and confidence you had in the doctor(s) who looked after you <i>during the past month</i> ?					
Illness Management					
4. How satisfied are you that the <u>doctors and nurses</u> who looked after you <i>during the past month</i> knew enough about your health problems to give you the best possible care?					
5. How satisfied are you that you were treated by those <u>doctors and nurses</u> in a manner that preserved your sense of dignity <i>during the past month</i> ?					
6. How satisfied are you that physical symptoms you had <i>during the past month</i> (for example: pain, shortness of breath, nausea) were adequately assessed and controlled?					
7. How satisfied are you that emotional problems you had <i>during the past month</i> (for example: depression, anxiety) were adequately assessed and controlled?					
8. How satisfied are you with the help you received with personal care <i>during the past month</i> (for example: bathing, toileting, dressing, eating)?					

1	0			-			
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Site Number

Enrollment Number

	1 Not At All	2 Not Very	3 Somewhat	4 Very	5 Completely
9. How satisfied are you that, <i>during the past month</i> , you received good care when a family member or friend was not able to be with you?					
10. How satisfied are you that you were able to manage the financial costs associated with your illness <i>during the past month</i> ?					
11. How satisfied are you with the environment or the surroundings in which you were cared for <i>during the past month</i> ?					
12. How satisfied are you that the care and treatment you received <i>during the past month</i> was consistent with your wishes?					
Communication					
13. How satisfied are you that the doctor(s) explained things relating to your illness in a straightforward, <u>honest</u> manner <i>during the past month</i> ?					
14. How satisfied are you that you received <u>consistent</u> information about your condition from all doctors and nurses looking after you <i>during the past month</i> ?					
15. How satisfied are you that the doctor(s) <u>listened</u> to what you had to say <i>during the past month</i> ?					
Decision Making					
16. How satisfied are you with discussions <i>during the past month</i> with your doctor(s) about where you would be cared for (in hospital, at home, or elsewhere) if you were to get worse?					
17. How satisfied are you with discussions <i>during the past month</i> with your doctor(s) about the use of life sustaining technologies (for example: CPR or cardiopulmonary resuscitation, breathing machines, dialysis)?					
18. How satisfied are you with your role <i>during the past month</i> in decision making regarding your medical care?					
19. How satisfied are you with discussions <i>during the past month</i> , involving a <u>family member</u> or someone who would make decisions for you, about your wishes for future care in the event you yourself are unable to make those decisions?					
Feeling at Peace					
20. How satisfied are you that you were at peace <i>during the past month</i> ?					

Section 6: Barriers & Facilitators

1. What is the one thing that makes it very difficult for you to participate in discussions about medical treatments at the end of life?

2. What is the one thing that went really well for you in your experience with these prior discussions about the medical treatments at the end of life?

Interviewer, record the interview stop time on the front page.

Section 7: Documentation of ACP/AD In the Medical Record at the End of the Interview

1. **At the time of the interview, who is the most responsible person/service looking after the patient?**
 Primary Care Physician (i.e. patient's own GP) Hospitalist service
 Clinical Teaching Unit (CTU) Sub-specialty service
 Other: _____

2. **A) Does your hospital use a standardized folder or any other strategy to easily localize ACP/AD tools in the medical record?**
 Yes No
B) If yes, was the folder on the chart on the day of the interview?
 Yes No

3. **What was the ACP/GCD on the medical chart on the day of the interview? Specify below.**

Contents	Tool present in medical record?	Tool completed?	Completion Date YYYY-MM-DD	GoC Specified on Document (use taxonomy on next page)
a) Goals of care designation/level of Intervention/MOST Form	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> NA	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Partially		
b) DNR/DNAR/No CPR form/Options for care order/R3	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> NA	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Partially		
c) Representation agreement/Personal Directive	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> NA	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Partially		
d) ACP Tracking Record	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> NA	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Partially		
e) Advance Directive	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> NA	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Partially		
f) Generic Living Will	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> NA	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Partially		
g) "My Voice"/Respecting Choice/"Let Me Decide" documents	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> NA	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Partially		
h) Other, please specify _____	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> NA	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Partially		

4. Is there evidence in the chart that some member of the health care team attempted to reach the family physician or a community care worker (e.g. nursing home worker) about this patient's prior expressed wishes?

Yes No

Goals of Care Designation Taxonomy

Alberta: R1 R2 R3 M1 M2 C1 C2

Refer to the Alberta Health Services Goals of Care Designation Order for a description of each designation.

British Columbia:

St Paul's: DNAR DNAR1 DNAR2 DNAR3 DNAR4 Full Code

Refer to Providence Healthcare DNAR orders for descriptions of each goals of care designation)

Fraser Health: MOST DNR M1 DNR M2 DNR M3 DNR C1 DNR C2 CPR C2

Refer to Fraser Health Medical Orders for Scope of Treatment form for descriptions of each goals of care designation

All other regions: 1 2 3 4 5 6 7 8

- 1 Use machines and all possible measures including resuscitation (CPR) with a focus on keeping me alive at all costs.
- 2 Use machines and all possible measures with a focus on keeping me alive but if my heart stops, no resuscitation.
- 3 Use machines only in the short term to see if I will get better but if my illness is prolonged, change focus to comfort measures only. If my heart stops, no resuscitation (CPR).
- 4 Use full medical care to prolong my life but if my heart or my breathing stops, no resuscitation (CPR) or breathing machines.
- 5 Use comfort measures only with a focus on improving my quality of life and comfort. Allow natural death and no artificial prolongation of life and no resuscitation.
- 6 Unsure, documentation unclear
- 7 No documentation
- 8 Other, specify: _____