APPENDIX A

AFTER-DEATH BEREADED FAMILY MEMBER INTERVIEW

This draft is based on the August 2000 edition from the Toolkit of Instruments to Measure End of Life Care

* The first series of questions determine where the decedent had spent the majority of their last month and last days of life. The location of care referred to is the place identified as where the decedent spent the majority of their time during a) the last 30 days or month of life and b) the very last days of life (i.e. hospital, home, or nursing home).

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COVERSHEET
(THIS INFORMATION IS KNOWN FROM THE DEATH CERTIFICATE AND FROM INITIAL CONTACT WITH THE INFORMANT AND IS TO BE COMPLETED PRIOR TO CONDUCTING THE INTERVIEW)

_________    ___________    ___________
Date of Interview    Interviewer ID    INFORMANT ID

_____/_____/______    _____/_____/______
Month   Day   Year    Month   Day   Year

DECEDEDNT Date of Birth    DECEDEDNT Date of Death

DECEDEDNT’s FIRST NAME:
__________________________________________________

DECEDEDNT Sex:    M    F

INFORMANT Name (First Last):
__________________________________________________

INFORMANT Sex    M    F
**INTRODUCTION & SCREENING - REMEMBER PUT A SMILE IN YOUR VOICE!**

For this project, informants will have been contacted via mail and they will have returned a positive response to indicate they would consider participation.

Hello, may I speak to Mr / Mrs / Ms [INFORMANT'S LAST NAME]?  *(address them as such unless they ask you to use their first name only)*

Hi Mr / Mrs / Ms [INFORMANT'S LAST NAME – see above] my name is [interviewer's first name]. I'm calling on behalf of Dalhousie University in Halifax in regard to a research study on care during the end of life. We sent you some material by mail recently that came from the office of Nova Scotia Vital Statistics, do you remember that?

We really appreciate you getting back to us and allowing us to contact you about [start with formal address [Mr. / Mrs. / Ms decedent's LAST name] and his/her experience of care during their final days. Is this a good time to call?

<table>
<thead>
<tr>
<th></th>
<th>YES → (CONTINUE)</th>
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<tbody>
<tr>
<td></td>
<td>NO → We will call you another time. When is usually a good time for you to talk? Can we set up a time for me to call again?</td>
</tr>
<tr>
<td></td>
<td>Day ___________________</td>
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<tr>
<td></td>
<td>Time ___________________</td>
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<tr>
<td></td>
<td>Great, so I will call you again [day] at [time].</td>
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<td></td>
<td>Thanks so much.</td>
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<tr>
<td></td>
<td>[CONFIRM THAT INFORMANT WILL BE CALLED AGAIN, AND TERMINATE INTERVIEW]</td>
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</table>

Thank-you. We're doing this research to identify ways to improve the care people receive during their last days of life. We've spoken to many people so far and the feedback has been extremely helpful. I realize this has might be a difficult time for you but I was wondering if you are able to answer some questions at this time?
[ ] YES ➔ (CONTINUE WITH INTRO)

[ ] NO ➔ I'll call you another time. What would be a good time for you to talk?

   ___________________________
   Day ________________
   Time ________________

Great, so I will call you again [day] at [time]

Thanks.

[CONFIRM THAT INFORMANT WILL BE CALLED AGAIN, AND TERMINATE INTERVIEW]

Thank you so much. It usually takes us about 30 (or 45) minutes [estimated duration of interview] to complete the interview.

Only if they hesitate or question the time … If this is too much time right now we could do it over 2 calls or at another time when you have 30 minutes. If this is the case, set up a time which would work best.

Are there any questions you'd like to ask before we begin? Are you ready to start? OK, let’s begin.
Informed Consent - Make Friendly, Warm ... Smile!

Most of the questions I'm going to ask you are about the care [Decedent's Name] received during their last month or so of life. I'll also be asking some questions about you and how you felt about the care [Decedents Name] received from others.

First, I want you to know that answering any questions that I ask is voluntary – it is up to you. You can say no at any time if you don't wish to continue, and it will not affect you in any way.

Your answers will be completely confidential. That means no one else will be able to know how you answered each question. All the information people give us will be combined so that nobody can be identified.

Please take your time when answering. If you're not sure what a question means or what kind of answer is wanted, please ask. To give us a good picture of the care provided to [Decedent's Name] it is important that you answer as honestly and as accurately as you can.

If you don't want to answer a question, no problem, let me know and we'll skip it. We can also stop any time you want. If you would like, we could always start where we left off at another time.

Okay, we're ready - Do you have any questions before we start?

No? Great, let's start ....
First of all …

How would you like me to refer to [DECEDENT NAME]? *(this may require suggestions …)*

As … Mr _____?
Mrs _____?
1st name ____?

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

   **Was he/she your … ?**
   *(DO NOT NEED TO READ LIST UNLESS PROMPTING IS REQUIRED)*

   [ ] SPOUSE [HUSBAND / WIFE]
   [ ] PARTNER
   [ ] CHILD
   [ ] DAUGHTER-IN-LAW/SON-IN-LAW
   [ ] MOTHER
   [ ] FATHER
   [ ] BROTHER OR SISTER
   [ ] OTHER RELATIVE (SPECIFY: ____________________________)
   [ ] FRIEND
   [ ] OTHER (SPECIFY: ____________________________)

2. Would you say that you know a lot about how [DECEDENT] was doing and (his/her) care during the last few weeks of life?

   [ ] YES (SKIP TO CHECKING THE FACTS A1)
   [ ] NO

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

   ____________________________ (ALTERNATIVE PERSON)

3b. What is her/his relationship to [DECEDENT NAME]?

   **Was he/she his/her …**
   *(DO NOT NEED TO READ LIST UNLESS PROMPTING IS REQUIRED)*

   [ ] SPOUSE [HUSBAND / WIFE]
   [ ] PARTNER
   [ ] CHILD
   [ ] DAUGHTER/SON-IN-LAW
[ ] MOTHER  
[ ] FATHER  
[ ] BROTHER OR SISTER  
[ ] OTHER RELATIVE  
[ ] FRIEND  
[ ] OTHER (SPECIFY: ___________________)

3c. We would like to interview [ALTERNATIVE PERSON], do you happen to have (his/her) full name and address nearby. We will only contact them by mail and it will be their choice to participate or not.

NAME: _____________________________________  
ADDRESS: ___________________________________

CITY: ___________________ PROVINCE ____________  
POSTAL CODE: ____________

INTERVIEWER: CONFIRM THAT THE REFERRAL PERSON KNOWS MORE THAN THE RESPONDENT ABOUT THE DECEDENT’S LAST MONTH.

3d. If [ALTERNATIVE PERSON] is unable to help, may we contact you again? We realize that you would only be able to answer the questions to the best of your ability.

[ ] YES  
[ ] NO

4. COMMENTS

********** THANK RESPONDENT AND TERMINATE INTERVIEW **********
REMEMBER, IN MOST CASES, DO NOT READ THE RESPONSE OPTIONS UNLESS THE INFORMANT REQUIRES PROMPTING

Checking the Facts, Location of death, Location of care

First of all …


[ ] At home Note: assisted living is ‘home’ (SKIP TO A1a.)
[ ] In a hospital (SKIP TO A1b.)
[ ] Nursing home or other long-term care facility (SKIP TO A1c.)
[ ] In transit to a medical facility (SKIP TO A2.)
(For example in the emergency department or on the way in an ambulance?)

[ ] Somewhere else (a hospice?)
   A1_other: Please specify _____________________ (SKIP TO A2.)
[ ] Don’t know (SKIP TO A2.)

A1a. Was that in …

[ ] [DECEDENT’s] own home (SKIP TO A2.)
[ ] In your HOME (SKIP TO A2.) (i.e. decedent didn’t normally live with them before the EOL)
[ ] or in someone else’s home?
   A1a_spec. Who’s home was that? ____________________________ (SKIP TO A2.)

A1b. Was that in the INTENSIVE CARE UNIT?

[ ] YES (SKIP TO A2.)
[ ] NO

A1c. Was that in a PALLIATIVE CARE UNIT?
(Definition if required: A palliative care unit is a special ‘department’ in a hospital with staff, physicians and beds dedicated to palliative care. Palliative care is the type of care that’s given to people with chronic, often life-threatening illnesses. Treatment is aimed at relieving symptoms and pain. It is not about looking for a cure.)

[ ] YES
[ ] NO
A2. During [DECENDENT]'s last 30 days or so, did he/she know they didn’t have long to live?

[ ] YES  
[ ] NO  
[ ] NOT SURE

A3. Did he/she talk openly about the fact that he/she was dying?

[ ] YES  
[ ] NO  
[ ] NOT SURE

A4. Did [DECEDENT] ever say where they would prefer to die?

[ ] YES  
[ ] NO (SKIP TO A10)

A5. Where was the last place he/she said he/she’d prefer?

[ ] At home Note: assisted living is ‘home’ (SKIP TO A5a.)  
[ ] In a hospital (SKIP TO A5b.)  
[ ] Nursing home or other long-term care facility (SKIP TO A5c.)  
[ ] Somewhere else (a hospice?)  
   A5_other: Please specify ______________________ (SKIP TO A6.)  
[ ] Don’t know (SKIP TO A10.)

A5a. Was that in …

[ ] [DECEDENT’s] own home (SKIP TO A6.)  
[ ] In your HOME (SKIP TO A6.)  
[ ] or in someone else’s home?  
   A5a_spec. Who’s home was that? ______________________ (SKIP TO A6.)

A5b. Was that in a REGULAR hospital ROOM?

[ ] YES  (SKIP TO A6.)  
[ ] NO

A5c. Was that in a PALLIATIVE CARE UNIT?  
   (Definition if required: A palliative care unit is a special ‘department’ in a hospital with staff, physicians and beds dedicated to palliative care where treatment is aimed at relieving symptoms and pain. It is not about looking for a cure.)

[ ] YES  
[ ] NO
A6. **Was this always their wish?**

[ ] YES (SKIP TO A10)
[ ] NO
[ ] DK (SKIP TO A10)

A7. **So, he/she changed her mind before he/she died? About how many days (or weeks) was that before he/she did die? (# Days / WEEKS/ BEFORE DEATH)**

________________________________________________________________________

A8. **Where did [DECEDENT] say they wished to die before he/she changed their mind?**

[ ] At home Note: assisted living is ‘home’ (SKIP TO A8a.)
[ ] In a hospital (SKIP TO A8b.)
[ ] Nursing home or other long-term care facility (SKIP TO A8c.)
[ ] Somewhere else *(a hospice?)*
  A8_other: Please specify _____________________________ (SKIP TO A10.)
[ ] Don't know (SKIP TO A10.)

A8a. **Was that in …**

[ ] [DECEDENT’s] own home (SKIP TO A10.)
[ ] In your HOME (SKIP TO A10.)
[ ] or in someone else’s home?
  A8a_spec. Who's home was that? _____________________________ (SKIP TO A10.)

A8b. **Was that in a regular hospital room?**

[ ] YES (SKIP TO A10.)
[ ] NO

A8c. **Was that in a Palliative Care Unit?**
*(Definition if required: A palliative care unit is a special ‘department’ in a hospital with staff, physicians and beds dedicated to palliative care where treatment is aimed at relieving symptoms and pain. It is not about looking for a cure.)*

[ ] YES
[ ] NO

A9. COMMENTS
A10. And our information is that [DECEDEENT] died on [DATE OF DEATH]. Is this correct?

[ ] YES
[ ] NO

In what month and year did (he/she) die? ______ M / _______ Y

We’re interested in finding out where [DECEDEENT] spent the last month of (his/her) life. Let’s start with where (he/she) was located 30 days before (he/she) died.

A11a. About a month or 30 days before [DECEDEENT] died, where was (he/she) staying?

PLACE (30 DAYS BEFORE): ________________________

If say a nursing home, ask what type, assisting living?, a retirement residence? or in a long term care facility with full medical care and services, much like a hospital?

A11b. For how many days of the last 30 days was (he/she) there?

NUMBER OF DAYS: _______

A11c. If required … and where is that located?

[City/town/county]? ________________________ [Province] ______________________

A11d. While there, did [DECEDEENT] require any care or treatment related to their health such as any help from a health care worker such as a doctor, nurse, pharmacist, physiotherapist, psychologist, social worker etc… be it at home, in a clinic, office or hospital.

[ ] YES
[ ] NO
[ ] DK

**** [IF A11b IS >= 30 DAYS THEN SKIP TO A11n, to ensure this is the place they died]

[IF < 30 DAYS CONTINUE AS NEEDED UNTIL PLACE OF DEATH]

A11e. Did (he/she) go anywhere after that?

[ ] YES
[ ] NO (PLACE ABOVE SHOULD BE >=30, SKIP TO A13)
[ ] DK (SKIP TO A11n LAST PLACE)

A11f. Where was that?

PLACE: ________________________________
A11g. How long was (he/she) there?

NUMBER OF DAYS: _______

A11h. if required … and where is that located?

[City/town/county]? _______________________ [Province] _____________

A11i. While there, did [DECEDENT] require any care related to their health?

[ ] YES
[ ] NO
[ ] DK

[CONTINUE IF REQUIRED UNTIL DEATH]

And where did he/she go after that?

A11j. PLACE: ________________________________

A11k. NUMBER OF DAYS: _______

A11l. If required … and where is that located?

[City/town/county]? _______________________ [Province] _____________

A11m. While there, did [DECEDENT] require any care related to their health?

[ ] YES
[ ] NO
[ ] DK

A11n. Was this the last place? The place where they died?

IF YES, RECORD
IF NO, CONTINUE PROBING FOR WHERE THE INFORMANT WAS LOCATED UNTIL THEY DIED

LAST PLACE: ________________________________

A11o. NUMBER OF DAYS: _______

A11p. If required … and where is that located?

[City/town/county]? _______________________ [Province] ___________________
A11q. While there, did [DECEDENT] require any care related to their health?

[ ] YES  
[ ] NO  
[ ] DK

* A11r. ASK THE FOLLOWING ONLY FOR THE LAST LOCATION OF CARE and ONLY IF THE PERSON DID NOT SPEND THE FULL 30 DAYS IN THIS LAST LOCATION

(For most = location of death – the exception may be death on route to hospital or less than 24 hours in emergency)

And what was the reason [DECEDENT] moved to this location?

[Can state last location to ensure informant knows what place you are asking about …e.g. hospital, nursing home etc]. (Mark all that apply)

[ ] Breathing problems  
[ ] Abdominal pain  
[ ] Other pain  
[ ] Other medical emergency  
[ ] Caregiver burden too high  
[ ] Family preference  
[ ] [DECEDENT] wanted to go there  
[ ] Lives alone / needs 24 care / inadequate home support  
[ ] Care provider recommendation  
[ ] Lack of access to professional help after hours  
[ ] Community service supported environment, such as assisted living/group home with a policy that discourages dying in the environment  
[ ] Other: Please specify _______________________________

A12. COMMENTS

The table is not be part of the database. Use as required for your record keeping during the interview.

<table>
<thead>
<tr>
<th>Place (beginning with 30 days prior to death)</th>
<th>Days in that location</th>
<th>Received care related to their health?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
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<tr>
<td>2.</td>
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<td>3.</td>
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<td>4.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td></td>
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</tbody>
</table>
USE THE ABOVE TO DETERMINE WHICH LOCATION THE MAJORITY OF CARE WAS PROVIDED DURING THE LAST 30 DAYS OF LIFE AND LAST DAYS OF LIFE.

Decision rules:

IF NO CARE RELATED TO THEIR HEALTH WAS PROVIDED DURING THE LAST 30 DAYS AT ALL, THANK THE RESPONDENT AND GO DIRECTLY TO SOCIAL BACKGROUND (M1)

Last 30 days: Choose the location where THE MAJORITY OF CARE RELATED TO THEIR HEALTH was provided.

In the event of a ‘tie’ or if the split between 2 locations is within 1-2 days (31 day month possible), use the last location of care for subsequent questions.

Very last days: For the vast majority this will be the same location as the LOCATION OF DEATH.

IF DEATH WAS VERY SUDDEN AND CARE WAS PROVIDED ONLY DURING THE VERY LAST DAYS … CONTINUE WITH THE QUESTIONS BUT EXCLUDE THE ‘30 DAYS’ PHRASE. ALSO EXCLUDE REPEAT QUESTIONS THAT ARE FLAGGED AS ‘REPEAT (R)’ IN THE LAST DAYS OF LIFE QUESTIONS MODULE
To check:

A13  So, for [DECEDENT]'s last month (or 30 days), she/he spent most of the time GETTING CARE RELATED TO THEIR HEALTH at [LAST PLACE WITH 15+ DAYS]. Is that correct?

[ ] YES  
[ ] NO

A13a. Please record location where decedent spent the most time getting care related to their health in the last month.

[ ] Decedent's home  
[ ] Informant's home (IF differs from the decedent's home)  
[ ] Someone else's home  
[ ] Hospital – Palliative care unit  
[ ] Hospital – Intensive care unit  
[ ] Hospital – Other (e.g emergency, other acute care room)  
[ ] Nursing home / long-term care facility  
[ ] Other, please specify: ____________________

A14  … and, she/he spent the very last days of his/her list at [LAST LOCATION OF CARE]. Is that right?

[ ] YES  
[ ] NO

A14a. Please record location where decedent spent the most time getting care related to their health in the last days.

[ ] Decedent’s home  
[ ] Informant’s home (IF differs from the decedent’s home)  
[ ] Someone else’s home  
[ ] Hospital – Palliative care unit  
[ ] Hospital – Intensive care unit  
[ ] Hospital – Other (e.g emergency, other acute care room)  
[ ] Nursing home / long-term care facility  
[ ] Other, please specify: ____________________

A15. COMMENTS
OTHER SERVICES:

In this section we would like to discuss if [DECEDENT] received any palliative care services. In case you’re not sure what I mean, palliative care is the type of care that’s given to people with chronic, often life-threatening illnesses. It focuses on helping with symptoms, such as relieving pain or stopping nausea, bettering quality of life and emotional needs. It is not about looking for a cure.

B1. As far as you know, was palliative care presented as an option for [DECEDENT]’s care?

[ ] YES
[ ] NO (SKIP TO C1 IF TIME SPENT AT HOME; OTHERWISE D1)
[ ] DK (SKIP TO C1 IF TIME SPENT AT HOME; OTHERWISE D1)

What about a PALLIATIVE CARE PROGRAM? This is a program where a team of specialized health care workers such as doctors, nurses, therapists, and social workers work together to provide palliative care. This is in addition to the care provided by their regular family doctor or home care nurse (or VON) ....

B2. To your knowledge was [DECEDENT] provided care from a specialized palliative care program at any time during their last month?

[ ] YES
[ ] NO (SKIP TO C1 IF TIME SPENT AT HOME; OTHERWISE D1)
[ ] DK (SKIP TO C1 IF TIME SPENT AT HOME; OTHERWISE D1)

B3. For about how long were staff from palliative care involved with [DECEDENT]’s care?

__________ days ___________ months

B4. In what locations was specialized palliative care provided? (Mark all that apply)

[ ] Home
[ ] While in the hospital, as an inpatient
[ ] Outpatient clinic
[ ] Nursing home
[ ] Cancer clinic
[ ] Nursing home
[ ] Other: Please specify _______________________________

B5. COMMENTS
CARE IN THE HOME

ASK ONLY IF DECEDEENT SPENT AT LEAST SOME TIME AT HOME DURING THE LAST 30 DAYS … OTHERWISE GO TO D1 (home may be anyone’s home, assisted living, a retirement residence. It is not a hospital or long term care nursing home).

These next questions ask about the care [DECEDEENT] received while AT HOME during their last month …

C1. While [DECEDEENT] was at home, did family members or friends help with his/her care?

[ ] YES
[ ] NO
[ ] DK

C2. At any time during this last month did [DECEDEENT] get any services from a home care agency?

[ ] YES
[ ] NO (SKIP TO C6)
[ ] DK (SKIP TO C6)

C3. Was that the home care service offered by the province (Nova Scotia Continuing Care or Nova Scotia Home care)?

[ ] YES (SKIP TO C5)
[ ] NO
[ ] DK (SKIP TO C6)

C4. If it wasn’t offered by the province, what kind of service was it?

____________________

C5. And what type of care was provided by the home care service (e.g. nursing, housekeeping) [Mark all that apply]

[ ] Housekeeping
[ ] Nursing care
[ ] Palliative care
[ ] Respiratory care
[ ] Mental health care
[ ] Social work
[ ] Medication management
[ ] Speech therapy
[ ] Personal hygiene/grooming
[ ] Meals
[ ] Other, specify  _______________________________________________
C6. **At any time during the last month while at HOME did [DECEDENT]’s get any services from a visiting nurse (eg VON)?**

- [ ] YES
- [ ] NO
- [ ] DK (SKIP TO C9)

C8. **And how was this nurse found?** (e.g. private)

____________________________________

C9. **While at home during [DECEDENT]’s last 30 days, did she/he have a family doctor visit them in the home?**

- [ ] YES
- [ ] NO (SKIP TO C11)
- [ ] DK (SKIP TO C11)

C10. **About how many times during the last 30 days?**

___________(number only eg. ‘3’)

C11. **Did [DECEDENT] make any visits to a family doctor’s office during this time?**

- [ ] YES
- [ ] NO (SKIP TO D1)
- [ ] DK (SKIP TO D1)

C12. **About how many times during the last 30 days?**

___________

C13. **COMMENTS**
These next questions are about [DECEDENT’S] last 30 days/while being cared for at [LOCATION WITH MAJORITY OF CARE]. Check A13 for location of care


D1. During this time did you talk with any of his/her doctors or nurses yourself?
   [ ] YES
   [ ] NO (SKIP TO D6)
   [ ] I WAS NOT AT THE LOCATION OF CARE (SKIP TO D6)

D2. Was there ever a problem understanding what any doctor or nurse was saying to you about what to expect from treatment?
   [ ] YES
   [ ] NO
   [ ] NO TREATMENT

D3. Did you feel that the doctors or nurses you talked to listened to your concerns about [DECEDENT’S] medical treatment?
   [ ] YES
   [ ] NO
   [ ] HAD NO CONCERNS

D4. How much information did the doctors or nurses provide you about [DECEDENT’S] medical condition - would you say less information than was needed, just the right amount, or more than was needed?
   [ ] LESS THAN WAS NEEDED
   [ ] JUST THE RIGHT AMOUNT
   [ ] MORE THAN WAS NEEDED

D5. How often did any doctor or nurse give confusing or contradictory information about [DECEDENT’S] medical treatment? Was it always, usually, sometimes, or never?
   [ ] ALWAYS
   [ ] USUALLY
   [ ] SOMETIMES
   [ ] NEVER
D6. Again while at [LOCATION OF CARE] during the last month, was there always a **doctor in charge** of [DECEDEENT]'s care?

[ ] YES  
[ ] NO (SKIP TO D9)  
[ ] SOMEONE ELSE, WHO? (e.g. nurse) _________________________

D7. **Was it always clear to you** which doctor was in charge of (his/her) care?

[ ] YES  
[ ] NO

D8. COMMENTS

D9. **Did [DECEDEENT] have specific wishes or plans about the types of medical treatment (he/she) did or did not want while dying?**

[ ] YES  
[ ] NO (SKIP TO D13)  
[ ] DON'T KNOW (SKIP TO D13)

D10. **To the best of your knowledge, did [DECEDEENT]'s doctor or the medical staff who cared for (him/her) while at [LOCATION OF CARE] speak to (him/her) or you about (his/her) wishes about medical treatment?**

[ ] YES  
[ ] NO

D11. **Did (his/her) doctor or the medical staff speak to (him/her) or you about making sure the care (he/she) received was in keeping with their wishes?**

Or .... In the event clarification is needed …

**Were you or [DECEDEENT] ever asked, by the doctor or medical staff, if the care being given was what she/she wanted?**

[ ] YES  
[ ] NO
D12. Was there any medical procedure or treatment that happened to (him/her) that was not in keeping with (his/her) previously stated wishes?

[ ] YES
[ ] NO

D13. Did [DECEDENT] have a signed Enduring Power of Attorney for Health Care naming someone to make decisions about medical treatment if (he/she) could not speak for (him/her) self? (This is where [DECEDENT] would have named someone to make decisions on (his/her) behalf when he/she was no longer able to).

[ ] YES
[ ] NO
[ ] DON’T KNOW

D14. Did [DECEDENT] have a signed Living Will or Advanced Directive of some sort giving directions for the kind of medical treatment (he/she) would want if (he/she) could not speak for (him/her) self?

[ ] YES
[ ] NO
[ ] DON’T KNOW

D15. While cared for at [LOCATION OF CARE], did you or [DECEDENT] discuss with a doctor or nurse, (his/her) wishes or directions for Health Care, such as a Living Will or Enduring Power of Attorney.

[ ] YES
[ ] NO

D16. COMMENTS
Now I want to ask some specific questions about [DECEDENT]'s health and (his/her) symptoms during the last month (or their last days).

E1. Did [DECEDENT] lose consciousness before (he/she) died?

[ ] YES  
[ ] NO (SKIP TO E4)  
[ ] DON'T KNOW (SKIP TO E4)

E2. [If yes] … for about how many days or weeks before (he/she) died?

______ DAYS OR ______ WEEKS

INTERVIEWER CHECK: IS E1 (DAYS LOST CONSCIOUSNESS) GREATER THAN OR EQUAL TO 30 days …

[ ] YES (SKIP TO F1)  
[ ] NO

* Partial days are to be counted as a whole day.

E3. COMMENTS

You’re doing great.
(It will probably be dependent on the ‘type’ or attitude of participant to whether encouragement is needed or not).

Thank you so much. We are now about ½ way through the survey!

We’re still focusing on [DECEDENT’S] last 30 days while he/she was at [LOCATION OF CARE] …

E4. During that time did [DECEDENT] experience any pain?

[ ] YES  
[ ] NO  
[ ] DK

E5. Was he/she given any medicines or other help to treat pain?

[ ] YES  
[ ] NO (SKIP TO E10)  
[ ] DON'T KNOW (SKIP TO E10)
E6. Did (his/her) doctor or nurse or another medical person **tell you** how (his/her) pain would be treated, in a way you could understand?

[ ] YES
[ ] NO

E7. Did [DECEDEENT] receive too much, too little, or just the right amount of medication for (his/her) pain?

[ ] TOO MUCH
[ ] TOO LITTLE
[ ] RIGHT AMOUNT
[ ] DON'T KNOW

E8. Who provided this help with managing his/her pain? (Mark all that apply)

[ ] Family doctor
[ ] Other doctor
[ ] Palliative care nurse
[ ] Other nurse
[ ] Informal caregiver (family/friends)
[ ] Emergency staff (paramedics)
[ ] Other, specify ___________________

E9. Was there ever a time when one doctor or nurse said one thing about treatment of (his/her) pain and another said something else?

[ ] YES
[ ] NO

E10. (In that last 30 days / While being cared for at [LOCATION OF CARE]), did [DECEDEENT] have trouble breathing?

[ ] YES
[ ] NO (SKIP TO E14)
[ ] DON'T KNOW (SKIP TO E14)

E11. How much help did [he/she] receive to deal with these breathing problems - less than was needed, or about the right amount? (remember if no help was received, but the informant says they didn’t need or want help, then it was the right amount)

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT
[ ] DK
E12. **Who provided this help?** (Mark all that apply)

- [] Family doctor
- [] Other doctor
- [] Palliative care nurse
- [] Other nurse
- [] Informal caregiver (family/friends)
- [] Emergency staff (paramedics)
- [] Other, specify ___________________

E13. **COMMENTS**

E14. **Did (DECEDENT) have any feelings of anxiety or sadness?**

- [ ] YES
- [ ] NO (SKIP TO F1)
- [ ] DON’T KNOW (SKIP TO F1)

E15. **How much help in dealing with these feelings did he/she receive - less than was needed or about the right amount?** *(remember if no help was received, but the informant says they didn’t need or want help, then it was the right amount)*

- [ ] LESS THAN WAS NEEDED (SKIP TO F1)
- [ ] RIGHT AMOUNT
- [ ] DK

E16. **Who provided this help?** (Mark all that apply)

- [] Family doctor
- [] Other doctor
- [] Palliative care nurse
- [] Other nurse
- [] Informal caregiver (family/friends)
- [] Spiritual care person (such as a chaplain, minister, rabbi, priest …)
- [] Other, specify ___________________

E17. **COMMENTS**
F1. So during those last 30 days / While being cared for at [LOCATION OF CARE]), was there any problem with doctors or nurses not knowing enough about [DECEDENT’S] medical history to provide the best possible care?

[ ] YES
[ ] NO
[ ] DK

F2. Was there ever a decision made about (his/her) care without enough input from (him/her) or (his/her) family?

[ ] YES
[ ] NO
[ ] DK

F3. How often were [DECEDENT’S] personal care needs - such as bathing, dressing, and changing bedding - taken care of as well as they should have been - would you say always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER (SKIP TO F5)
[ ] DK (SKIP TO F5)

F4. Who provided this help? (Mark all that apply)

[ ] Family members
[ ] Friends
[ ] Palliative care nurse
[ ] Other nurse
[ ] Other medical staff
[ ] Personal care worker
[ ] Other, specify __________________

F5. During those last 30 days / While at [LOCATION OF CARE]), how often was (he/she) treated with respect by those who were taking care of (him/her) - always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER
[ ] DK
F6. How often was [DECEDEENT] treated with kindness by those who were taking care of (him/her) – always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER
[ ] DK

F7. Was there enough help available to meet (his/her) personal care needs, like bathing, dressing, feeding, and going to the bathroom?

[ ] YES
[ ] NO
[ ] DK

F8. Was there enough help with medications and things like getting dressings changed?

[ ] YES
[ ] NO
[ ] DK

F9. COMMENTS
Ratings

Now we would like you to RATE some aspects of the care [DECEDENT] received (in that last 30 days while (he/she) was being cared for at [LOCATION OF CARE]). 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.

H1. How well did the doctors, nurses, and other professional staff who cared for [DECEDENT] communicate with [him/her] and the family about the illness and the likely outcomes of care?

[ 0 1 2 3 4 5 6 7 8 9 10 ]

On a scale from 0 to 10, where 0 means the worst care possible and 10 means the best care possible.

H2. How would you rate how well those taking care of [DECEDENT] provided medical care that respected [his/her] wishes?

[ 0 1 2 3 4 5 6 7 8 9 10 ]

H3. How well did those taking care of [DECEDENT] make sure [his/her] symptoms were controlled to a degree that was acceptable to [him/her]?

[ 0 1 2 3 4 5 6 7 8 9 10 ]

On the same scale from 0 to 10, where 0 means the worst care possible and 10 means the best care possible.

H4. How well did those taking care of [DECEDENT] make sure that [he/she] died with dignity - that is, died on (his/her) own terms?

[ 0 1 2 3 4 5 6 7 8 9 10 ]

H5. How well did those taking care of [DECEDENT] do at providing emotional support for you and [his/her] family and friends?

[ 0 1 2 3 4 5 6 7 8 9 10 ]

And now an overall rating...

H6. 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 [DECEDENT] received during those last 30 days of life/ while [he/she] was being cared for at [LOCATION OF CARE]]?

[ 0 1 2 3 4 5 6 7 8 9 10 ]
H7. COMMENTS

In the next set of questions we ask about YOUR experience during the time around [DECEDENT’S] death.

G1. At any time did you or your family receive any information about what to expect while (he/she) was dying? (e.g. symptom relief (pain, breathing), emotions)

[ ] YES
[ ] NO (SKIP TO G3.)

G2. Who provided you with this information? (Mark all that apply)

[ ] Family doctor
[ ] Other doctor
[ ] Palliative care nurse
[ ] Other nurse
[ ] Informal caregiver (family/friends)
[ ] Spiritual care person (such as a chaplain, minister, rabbi, priest …)
[ ] Other, specify ___________________

G3. Would you have wanted (some if G1 = no; more if G1 = yes) information about that – about what to expect?

[ ] YES
[ ] NO

G4. How confident were you that you knew what to expect while [DECEDENT] was dying - very confident, fairly confident, or not confident?

[ ] VERY CONFIDENT
[ ] FAIRLY CONFIDENT
[ ] NOT CONFIDENT

G5. At any time did you or your family receive any information about what to do at the time of (his/her) death? (process of who to call, contact …)

[ ] YES
[ ] NO (SKIP TO G7.)

G6. Who provided you with this information? (Mark all that apply)

[ ] Family doctor
[ ] Other doctor
[ ] Palliative care nurse
G7. Would you have wanted (some if G5 = no; more if G5 = yes) information about that? – about what to do at the time of their death?

[ ] YES
[ ] NO

G8. How confident were you that you knew what to do at the time of death - very confident, fairly confident, or not confident?

[ ] VERY CONFIDENT
[ ] FAIRLY CONFIDENT
[ ] NOT CONFIDENT

G9. At any time during the time around [DECEDENT'S NAME] death, did you or your family receive any information about the medicines that would be used to manage (his/her) pain, shortness of breath, or other symptoms?

[ ] YES
[ ] NO (SKIP TO G11)
[ ] DK (SKIP TO G11)

G10. Who provided you with this information? (Mark all that apply)

[ ] Family doctor
[ ] Other doctor
[ ] Palliative care nurse
[ ] Other nurse
[ ] Informal caregiver (family/friends)
[ ] Spiritual care person (such as a chaplain, minister, rabbi, priest …)
[ ] Other, specify ___________________

G11. Would you have wanted (some if G9 = no; more if G9 = yes) information about the medicines?

[ ] YES
[ ] NO
G12. How confident were you that you understood about the medicines that would be used to manage (his/her) pain, shortness of breath, or other symptoms - very confident, fairly confident, or not confident?

[ ] VERY CONFIDENT
[ ] FAIRLY CONFIDENT
[ ] NOT CONFIDENT

G13. COMMENTS

MODULE: LAST DAYS OF LIFE QUESTIONS

Thank you so much for hanging in. We are more than 3/4s of the way through!

* Now I want to ask about the care [DECESENT] received during (his/her) last DAYS of life while at/in [LOCATION OF CARE A14].

You will notice many of these questions are the same as some you just answered. But, this time I need you to think of those very last days of [DECESENT’s] life.

* The above 2 statements are NOT necessary if all the previous questions were asked about the [DECESENT]’S last few days only (ie. a more sudden death with little or no care prior to death).

INTERVIEWER CHECK: IS E1 [WHETHER LOST CONSCIOUS OR NOT) IN DOMAIN QUESTIONS SECTION] GREATER THAN OR EQUAL TO THE TOTAL DAYS SPENT IN THEIR LAST LOCATION OF CARE?

[ ] YES (SKIP TO J14)
[ ] NO


J1. R During [DECESENT’S] last days of life while at/in [LOCATION OF CARE], were there times when (he/she) experienced pain?

[ ] YES
[ ] NO
[ ] DON’T KNOW
J2. R Did (he/she) get any help in dealing with pain?

[ ] YES
[ ] NO (SKIP TO J5)

J3. R Who provided this help? (Mark all that apply)

[ ] Family doctor
[ ] Other doctor
[ ] Palliative care nurse
[ ] Other nurse
[ ] Informal caregiver (family/friends)
[ ] Other, specify ___________________

J4. R How much help in dealing with (his/her) pain did [DECEDED] receive - less than was needed or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

J5. R During these last days were there times when (he/she) had trouble breathing?

[ ] YES
[ ] NO (SKIP TO J9)
[ ] DON'T KNOW (SKIP TO J9)

J6. R Did (he/she) get any help in dealing with (his/her) trouble breathing?

[ ] YES
[ ] NO (SKIP TO J9)

J7. R Who provided this help? (Mark all that apply)

[ ] Family doctor
[ ] Other doctor
[ ] Palliative care nurse
[ ] Other nurse
[ ] Informal caregiver (family/friends)
[ ] Other, specify ___________________

J8. R How much help in dealing with (his/her) breathing did [DECEDED] receive - less than was needed or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT
J9. R During these last days, did [DECEDEDNT] have any feelings of anxiety or sadness?

[ ] YES
[ ] NO (SKIP TO J14)
[ ] DON'T KNOW (SKIP TO J14)

J10. R Did (he/she) get any help in dealing with (his/her) feelings of anxiety or sadness?

[ ] YES
[ ] NO (SKIP TO J14)

J11. R Who provided this help? (Mark all that apply)

[ ] Family doctor
[ ] Other doctor
[ ] Palliative care nurse
[ ] Other nurse
[ ] Informal caregiver (family/friends)
[ ] Spiritual care person (such as a chaplain, minister, rabbi, priest …)
[ ] Other, specify ___________________

J12. R How much help in dealing with these feelings did [DECEDEDNT] receive - less than was needed or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

J13. COMMENTS

J14. R Was there ever a decision made about [DECEDEDNT’S] care or treatment without enough input from (him/her) or (his/her) family?

[ ] YES
[ ] NO

J15. During these last days was there any decision made about care or treatment that [DECEDEDNT] would not have wanted?

[ ] YES
[ ] NO
J16. R How often were (his/her) personal care needs - such as bathing, dressing, and changing bedding - taken care of as well as they should have been - always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

J17. R Who provided this care? (Mark all that apply)

[ ] Family members
[ ] Friends
[ ] Palliative care nurse
[ ] Other nurse
[ ] Other medical staff
[ ] Other, specify ___________________

J18. R How often was [DECEDENT] treated with respect by those who were taking care of (him/her) - always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

J19. During the these last days, how often were you or other family members kept informed about [DECEDENT’S] condition - always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

J20. R Was there always a doctor in charge of [DECEDENT]’s care?

[ ] YES
[ ] NO (SKIP TO J23)

J21. R And was it always clear to you which doctor was in charge of [DECEDENT’S] care?

[ ] YES
[ ] NO
J22. COMMENTS

INTERVIEWER CHECK: IS E1 [WHETHER LOST CONSCIOUS OR NOT] IN DOMAIN QUESTIONS SECTION GREATER THAN OR EQUAL TO THE TOTAL TIME THEY SPENT IN THEIR LAST LOCATION OF CARE?

[ ] YES (SKIP TO K1)
[ ] NO

J23. Do you think (he/she) had any interest in seeing or talking with a priest, rabbi, minister, or other religious or spiritual person?

[ ] YES
[ ] NO (SKIP to K1)

J24. Do you think (he/she) had as much contact of this kind as (he/she) wanted?

[ ] YES
[ ] NO

K1. Now, on a scale of 0 to 10, where 0 means the worse care possible and 10 means the best care possible, overall, how would you rate the OVERALL CARE for [DECEDEDNT] during those last days of life while at [LOCATION OF CARE]?

[ 0 1 2 3 4 5 6 7 8 9 10 ]

K2. COMMENTS
These next questions are about your experience during [DECEDEANT’S] last days /while [he/she] was being cared for at [LOCATION OF CARE]) Check P2 for location

L1. During this time, did someone talk with you about your religious or spiritual beliefs?

[ ] YES
[ ] NO (SKIP TO L3)

L2. Was this done in a sensitive manner?

[ ] YES
[ ] NO

L3. Did you have as much contact of that kind as you wanted? (if they didn’t want or require contact and received none then it was what they wanted)

[ ] YES
[ ] NO

L4. How much support in dealing with your feelings about [DECEDEANT’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? (Professional staff includes any person helping with the decedent’s care)(again, if they did not want or need support it was the right amount)

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

L5. Did a doctor, nurse, or other professional staff taking care of [DECEDEANT] talk about how you might feel after [DECEDEANT’S] death?

[ ] YES (SKIP TO L7.)
[ ] NO

L6. Would you have wanted them to?

[ ] YES (SKIP TO L8.)
[ ] NO (SKIP TO L8.)
[ ] Don’t know (SKIP TO L8.)
L7. **Was it done in a sensitive manner?**

[ ] YES  
[ ] NO

L8. **Did a doctor, nurse, or other professional staff taking care of [DECEDENT] suggest someone you could turn to for help if you were feeling stressed?**

[ ] YES  
[ ] NO

L9. **COMMENTS**
**SOCIAL BACKGROUND**

We’re almost done – just a few background questions left.

These questions are important so we can group people with similar answers when we analyze the information.

The first ones are about [DECEDEMENT] …

**M1.** At the time of (his/her) death, was [DECEDEMENT] married, widowed, divorced, separated, or had he/she never been married?

[ ] MARRIED  
[ ] WIDOWED  
[ ] DIVORCED  
[ ] SEPARATED  
[ ] NEVER MARRIED  
[ ] DON’T KNOW

**M2.** Was (he/she) living alone?

[ ] YES  
[ ] NO  
[ ] DON’T KNOW

**M3.** What was the highest level of schooling [DECEDEMENT] completed?

[ ] GRADE 8 OR LESS  
[ ] SOME HIGH SCHOOL  
[ ] HIGH SCHOOL GRADUATE  
[ ] SOME UNIVERSITY/TECHNICAL SCHOOL/ COLLEGE  
[ ] UNIVERSITY/COLLEGE/TECHNICAL SCHOOL GRADUATE  
[ ] GRADUATE DEGREE  
[ ] DON’T KNOW

**M4.** Did [DECEDEMENT] consider her/him self a visible minority?

[ ] YES  
[ ] NO  
[ ] DON’T KNOW

[ ] WHITE
[ ] BLACK
[ ] NORTH AMERICAN ABORIGINAL
[ ] SOUTH ASIAN (East Indian, Pakistani, Sri Lankan)
[ ] SOMETHING ELSE (SPECIFY: _____________________________)
[ ] DON’T KNOW

M5b. What language did [DECEDENT] usually use in [his/her] home?

[ ] English
[ ] French
[ ] Other

M6. What is your best guess of [DECEDENT’S] USUAL household income from all sources before taxes were taken out? Would you say it was …

Less than $40,000?
[ ] Yes
[ ] No
[ ] DK (Skip to M7)
[ ] Refused (Skip to M7)

If yes … Between $20,000 and $30,000 [ ]?
Less than $20,000 [ ]?

If no … More than $50,000 [ ]?

If yes …. Between $50,000 and $60,000 [ ]?
Between $60,000 and $70,000 [ ]?
Between $70,000 and $80,000 [ ]?
More than $80,000 [ ]?

M7. Did [DECEDENT] have health insurance coverage that offered more than what the province provided?

[ ] YES
[ ] NO (SKIP TO N1)
[ ] DON’T KNOW (SKIP TO N1)

M8. Was this a …

[ ] PRIVATE PLAN
[ ] EMPLOYER PAID PLAN
M9. Was this insurance plan used for ... (Mark all that apply)

[  ] MEDICATIONS? (DRUGS ETC)
[  ] HEALTH CARE SUPPLIES
[  ] PROFESSIONAL CARE TO COME TO THE HOME
[  ] OTHER, SPECIFY _____________________

M10. Was this insurance plan as helpful as you would have liked?

[  ] YES
[  ] NO
[  ] DON'T KNOW

M11. COMMENTS
Respondent Demographic Characteristics

Now I have a few last questions about you.

N1. In what year were you born?
   
   19 __________________

N2. What is the highest level of schooling you have completed?
   
   [ ] GRADE 8 OR LESS
   [ ] SOME HIGH SCHOOL
   [ ] HIGH SCHOOL GRADUATE
   [ ] SOME UNIVERSITY/TECHNICAL SCHOOL/ COLLEGE
   [ ] UNIVERSITY/COLLEGE/TECHNICAL SCHOOL GRADUATE
   [ ] GRADUATE DEGREE
   [ ] DON'T KNOW

N3. How would you rate your health? Would you say excellent, very good, good, fair, or poor?
   
   [ ] EXCELLENT
   [ ] VERY GOOD
   [ ] GOOD
   [ ] FAIR
   [ ] POOR

N4. We would like to link some of your answers about the care provided to [DECEDENT] to information collected by the province, such as how long [DECEDENT] was in hospital or how often they were seen by a doctor .... Numbers are used to do this so nobody would be able to identify you or [DECEDENT].

   (If asked … other information would include registration in a palliative care program, continuing care (home care), emergency department visits)

   Are you willing to allow us to link this information?
   
   [ ] YES
   [ ] NO
N5. Is there anything else you’d like to share about the health care [DECEDENT] received during his/her last 30 days of life?

___________________________________________________________________________

___________________________________________________________________________

___________________________________________________________________________

N6. Is there anything else that you would like to share about how that care could have been improved for [DECEDENT]?

___________________________________________________________________________

___________________________________________________________________________

___________________________________________________________________________

N7. Bereavement and grief information required? ONLY IF THE INFORMANT ASKS. Details ....

___________________________________________________________________________

___________________________________________________________________________

Thanks again for taking the time to answer these questions and helping us with this research.

This information is important in our efforts to improve care at the end of life. Locally, our findings will be brought to the attention of local palliative care programs, district health authorities and the Nova Scotia Department of Health.

If you have any questions or concerns about this survey, you can call Beverley Lawson, the co-ordinator of the study. Would you like her number?

If yes, provide number (1-877-251-0057) and thank again.
If no, thank again

* if interested in future results ask for their address so that they can be mailed to them when available.

********** THANK RESPONDENT AND TERMINATE INTERVIEW **********