Recommendation to the Nova Scotia Palliative Care Advisory Committee and the Decision Support Working Group:

An ongoing, province-wide patient-focused, family centred quality measurement strategy for the experience of end-of-life care from the perspective of the bereaved family member caregiver

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June 2015

Support was provided by the ‘Supportive care for women with advanced breast cancer (ABC-SC)’ project that was funded by a Breast Cancer Society of Canada / QEII Foundation Award for Breast Cancer Research through the Beatrice Hunter Cancer Research Institute.

Please cite as: Loney E, Lawson B (2015) An ongoing, province-wide patient-focused, family centred quality measurement strategy for the experience of end-of-life care from the perspective of the bereaved family member caregiver. Network for End of Life Studies, Dalhousie University, Halifax, Nova Scotia.

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Recommended Strategy: An Overview

Mortality Follow-back Survey of End–of-Life Care Quality
Family Member Caregiver Perspective

Method: Postal survey with an online option

Data source: Bereaved family members or other close persons identified as informants on Nova Scotia (NS) Vital Statistics death certificates of persons dying from non sudden causes

Time Period: Two-year data collection and reporting period

Procedures:

- Vital Statistics Roles: Extract eligible death certificates and relevant variables and identify and contact with informants to preserve confidentiality (including coding and mailing survey materials supplied by the DHW).
- Department of Health & Wellness Roles: Develop documents, ethics submission, coordinate the survey, receive and analyze surveys, and report outcomes

Data collection:

- 3 waves per year (6 waves total per survey reporting period)
- Mailing of survey to informants 3-7 months from bereavement.
- Two reminders

Instrument: A self-administered survey based on existing instruments adapted to the NS context.
Time Frames: Last 3 months of life, last 2 days of life, circumstances around death.
Content:

- Overall ratings of care by setting and time frame, & specific provider groups by setting
- Care provided to the dying person and their family in the home, hospital, & long term care home settings (including treatment with respect and dignity, symptom relief, emotional & spiritual support; responsiveness to care needs in the home; collaboration & other topics)
- Urgent care provided out of business hours
- Care from the family doctor or other doctor providing the most care in the last 3 months of life
- Use of palliative care & specialized palliative care services
- Topics concerning the circumstances around death, such a place of death, and expressed preferences; informational, emotional, and spiritual support provided to the caregiver; transfers between settings of care, coordination of care, cultural competence of providers, decision making involvement and goals of care
- Advance Care Planning
- Demographic characteristics of respondents and decedents
- Supplemental items for several areas of focus and additional optional modules that might be considered depending on interests & applicability [e.g. Visiting volunteers, Cancer Centre care, Care in the home—special equipment, Financial aspects, and (residential) Hospice care]

Project Objective

To prepare a recommendation regarding an ongoing, population-based, sustainable method to identify those who have died non-suddenly of advanced chronic disease and capture data to measure the experience of end-of-life (EOL) care from the perspective of their bereaved family member caregiver.

Background

Nova Scotia faces an increased demand for palliative care, given our aging population (one-third of Nova Scotians will be aged 65+ by 2038)(1), and that seven of the ten leading causes of death are from chronic disease (cancer, heart, stroke, respiratory, diabetes, Alzheimer's, kidney), accounting for approximately 70% of all deaths.(2)

Nova Scotia's 2014 Integrated Palliative Care Strategy is guided by the vision that all Nova Scotians can access integrated, culturally competent, quality palliative care in a setting of their choice.(3) The strategy recommends developing a provincial palliative care system report card for accountability purposes. This will require timely, systematically collected, population-based information that can be used to monitor and evaluate progress toward realizing the goal of patient-focused, family-centred, integrated palliative care. An important component of a provincial palliative care report card will be information on the experience of care at the end-of-life (EOL) from the perspective of the bereaved family member caregiver. [Note: The terms palliative care and end-of-life care are often used interchangeably. To avoid confusion with "specialized palliative care," which is a type of palliative care, references to "specialized palliative care" will be distinguished as such.]

Nationally, the Canadian Hospice and Palliative Care Association is promoting that governments establish quality indicators (including family satisfaction, among others) and monitoring systems.(4) Canada and Nova Scotia are not alone in seeking to monitor and improve end of life care. For example in England, the Office for National Statistics has employed an annual population-based postal/online survey of bereaved people (Voices instrument) for several years to examine quality of care in multiple settings, as part of the National Health Services Outcomes Framework.(5-9) This year, the U.S. Centers for Medicare and Medicaid will begin national implementation of a mailed/telephone survey of primary caregivers of deceased person receiving hospice care [palliative care], across multiple settings of care [Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospice Survey].(10)

Nova Scotia is uniquely positioned to implement sustainable, ongoing, population-based monitoring of family/caregiver perceptions concerning the end-of-life care their deceased relatives received. Our province benefits from a previous research study that collected baseline data on a range of EOL care outcomes from the next-of-kin perspective across settings of care(11-14) and accrued experience in using informants listed on death certificates as the primary data source. (15)

Methods

A review of the literature from 2009-2014 was conducted to identify methods and tools used to measure population-based end-of-life experiences and quality indicators in Canada and in other developed countries. Additional sources of information consulted included the Provincial Palliative Care Coordinator and members of the Advanced Breast Cancer-Supportive Care research team. We drew on the knowledge and experience of Beverley Lawson (Dalhouse University, Family Medicine) who was closely involved with the population-based research study that has established Nova Scotia population-based baseline data (11-15).

Outcomes

To measure the quality of patient-focused, family-centered end-of-life care in Nova Scotia from the family member caregiver perspective, three possible options for a mortality follow-back design and their advantages and disadvantages were considered (displayed in Table 1 and discussed below).

Recommended Option: Option 1

A self-administered postal/online survey of bereaved family members or other close persons who are listed as the informant on the Nova Scotia Vital Statistics death certificate

This is the preferred, recommended option, meeting the provincially population-based, feasible and sustainable criteria, with the added advantage of the existence of comparable baseline data.

- There is opportunity to build on Canadian Institute of Health Research funded work by Burge and his colleagues.(11) Using a *population based mortality follow-back survey design* they recently established Nova Scotia provincial baseline values for several indicators (i.e. location of care, place of death, care preferences, unmet needs for pain and other symptom relief, satisfaction with care, advance care planning, spiritual and emotional support, etc.).(11-14)
- To our knowledge, while there are efforts to monitor quality of care for programs and services (16-18), this was the first Canadian provincial *population-based* survey concerning end-of-life care in the home, hospital, and long term care settings, and/or from specialized palliative care programs. Using an adaptation of the comprehensive After Death Bereaved Family Member Interview (ADBFMI) (19, 20), researchers surveyed by telephone knowledgeable informants (typically next-of-kin) who were identified on Nova Scotia Vital Statistics death certificates.
- Experience dealing with the operational challenges prompted the investigators to recommend that a more cost effective, and thus more sustainable mailed, self-administered survey method be used in the future.(15)
- If a Nova Scotia survey could be implemented to commence data collection January 1, 2016, it would examine deaths from 2015-2017, and could report changes in care quality compared to the base line, 6 years prior. (The last population-based survey was conducted using deaths occurring June 1, 2009 to May 31, 2011.)

Table 1 Mortality Follow-Back Design: Survey Options

Option	Pros	Cons	Comments
1. Self-administered postal/online survey of bereaved family members or other close persons who are listed as the informant on Nova Scotia Vital Statistics' death certificates	• Population-based, province wide (increased validity & generalizability) • Includes those who did not receive care as well as those who did receive care • Informants are typically next-of-kin • Extraction of informant data is systematically uniform • Baseline data for NS was obtained using interview data from death certificate informants	• Confidentiality concerns re use of death certificate data requires involvement of Vital Statistics as intermediary to contact informants • Listed informants are occasionally institutional staff or funeral director. Although not eligible to respond, their association is usually not known. As such most are considered 'non-respondents' which will result in a lower 'response rate'.	Screening of respondents is feasible to eliminate informants who are not knowledgeable about the decedent's care; informants can pass along survey to a more informed caregiver.
2. Self-administered postal/online survey of bereaved family member caregivers (or other close persons) identified through records of programs or services (e.g. Continuing Care, hospitals, LTC homes) used by deceased person/family caregivers	• Permits focus on quality improvement in a specific program or institution • Permits comparisons among specific programs or settings of care if multiple programs and sites are involved • Possible pilot opportunity for survey instrument • Response rates may be higher given the established relationship • May be possible to assess non response bias since more demographic info may be available (21)	• Results maybe valid, but are not generalizable beyond the program(s) or service(s) studied • Does not meet criterion of a provincial population-based approach • Selection bias. Excludes those who, for whatever reason, did not receive services from the particular program, hospital, LTC home • May be difficult to achieve an adequate sample size for meaningful analysis • Involvement & coordination of multiple sites or organizations may be necessary • May be difficult to identify/locate caregiver at time of data collection. (21)	A guide for implementing VOICES at a local level is available. (21)

Option	Pros	Cons	Comments
3. Include an EOL module in the annual Canadian Community Health Survey of Nova Scotia residents	• Population-based	• Large oversampling of NS residents would be required to identify caregivers in sufficient numbers to yield sufficient numbers and variability for meaningful analysis. • No. of survey items that could be included in a large multicomponent survey is likely to be small, limiting the range and depth of information obtained. • Information on costs is required to assess feasibility.	Specific information on the NS sample size was not available. Nationally, 65,000 Canadians 12 years and older are sampled. A gross proportional estimate for NS might be 2.64% of this this based or 1716, based on a 2014 total NS pop. of 0.94M and a Canadian pop of 35.54M. (22) Of these, only a small number would likely have cared for or arranged care for a family member who died in the previous year. The baseline NS EOL data was obtained using a sample of more than 1200 adults known to be caregivers of or close to the deceased person.

Other Options

Option 2

A self-administered postal/online survey of bereaved family member caregivers (or other close persons) identified through records of programs and services used by the deceased person.

This is not the preferred option because it is not generalizable to the provincial population, as people who for whatever reason do not receive services from the organizations involved will be excluded. It may be difficult to obtain an adequate sample size for meaningful analysis of multiple variables for comparison among sites in the desired time frame. However, this approach could provide an opportunity to pilot the proposed survey before provincial implementation.

- The literature review found Canadian examples of mortality follow back methods with family member informants in Ontario homecare, (23) long term care (18) and hospital (17) settings and British Columbia long term care settings (16). All of these employed administrative program or institutional data to identify decedents and next-of-kin caregivers.
- Guidelines and instruction to administer a national survey on a program or institutional basis are available from the UK, offering advice on using either death registrations or program administrative data to identify participants. (21)
- It may be difficult to identify or locate caregivers at the time of data collection(21)

Option 3

Incorporating an EOL care experience of care module in the annual Canadian Community Health Survey of Nova Scotia residents.

This population-based approach also employs a mortality follow-back design wherein respondents to the larger survey are identified through a screening question. This option is not readily applicable to our context because to achieve an adequate sample size with enough variability to examine a range of outcomes for quality assurance would require large oversampling.

- This alternative population-based approach has been used in other jurisdictions by incorporating brief end of life care modules into large, multi-topic health surveys, e.g.) the South Australian Omnibus Health Survey (24) and a telephone survey based on the CDC Behavioral Risk Factor Surveillance Survey conducted in Allegheny County, Pennsylvania.(25, 26)
- The major ongoing population-based health survey, the annual Canadian Community Health Survey relies on a 65,000 person *national* sample to represent a target population of Canadians age 12 years and older (27). Oversampling Nova Scotia residents in large numbers would be required to provide meaningful detailed data for EOL provincial quality assurance. Specific information on the past NS sample size was not available. A very gross proportional estimate for NS might be 2.64% of 65,000 or 1716, based on a 2014 total NS pop. of 0.94M and a Canadian pop of 35.54M. (22) Of these, only a small number would likely have cared for or arranged care for a family member who died in the previous year (hence the need to oversample).
- One estimate of the number of caregivers in a health survey population comes from Pennsylvania. 5442 interviews were conducted with a general population sample of people aged 18 years and older, yielding a subsample of 461 adults (7.8%) who reported caring for or arranging care for a relative who died in the previous 12 months. (26) In contrast, Nova Scotia researchers determined data from almost three times as many (1200) known caregivers were required to effectively analyze and describe a range of outcomes according to age, sex, and location of care. (11)
- If this option were considered, only a small number of EOL items would be feasible to include in a multicomponent survey implemented for other purposes, limiting the range and depth of information that could be collected. For example, Australia embedded 18 items, (24) and Allegheny County, 8 items (25), compared to the 58 item stand-alone VOICES-SF survey (28).

Recommended Strategy: Research Design & Methods

Strategy

A regular postal self-administered survey (with an online option) of bereaved family member caregivers, who are knowledgeable about the care of their deceased adult relative is recommended to implement a retroactive mortality follow-back design.

Primary Data Source

Individuals listed as the informant (typically next-if-kin) on the Vital Statistics' death certificates that are selected using inclusion & exclusion criteria described below. Eligible informants are those who are a family member caregiver or other close person, who is knowledgeable about the decedent's care and is not a paid health professional or funeral director. Should the informant feel they are not able to take part or that they are not the best person to respond to the survey, they would be asked to pass the survey to another family member / close friend or informal caregiver for completion.

- Obtaining respondents listed on Nova Scotia Vital Statistics records meeting inclusion and exclusion criteria is congruent with a population-based method.
- Surveying bereaved, knowledgeable family members is an acceptable and reliable means of obtaining proxy data that is otherwise ethically unavailable from dying persons who are too ill or incapacitated to participate, and who cannot be reliably identified to participate in prospective, provincial population-based research.
- Bereaved family members provide first hand accounts of their own experience with EOL care to their relative provided in a family-centred context.

Population of Interest: Inclusion and Exclusion Criteria Applied to Death Certificates

The following recommended inclusion and exclusion criteria are consistent with the survey that produced the baseline data.(11)

Inclusion criteria: all available death certificates for adults (age18 and over) in Nova Scotia whose cause of death was non-sudden (to capture death from advanced chronic disease).

Exclusion criteria: deaths by external causes, including pregnancy and childbirth, medical and surgical complications, injury, motor vehicle accidents, intentional harm, etc. as identified by the associated International Classification of Disease codes and unconfirmed cause of death. See Appendix A for a complete list of recommended exclusions.

- If the Province wishes to focus on EOL care related to advanced chronic disease, it would be advisable to exclude those who experienced sudden, unexpected deaths because they would not necessarily have received end of life care services and could bias the results by underestimating the outcomes.
- It is very difficult to distinguish deaths that were very sudden, unexpected and where no medical care was provided using the cause listed on the death certificate (e.g. circulatory causes).
- This information may need to be collected on the survey, or similar to Burge et al.(11), potential participants might be asked to self-select and answer the survey if least 2 days of care was received prior to the death. With a mailed survey, participants also could be asked to complete the refusal slip, indicating this as the reason for nonparticipation.
- Alternatively, sudden deaths can be included if a skip pattern is used as VOICES-SF employs.(28)The first survey question determines if death was sudden, asking the respondent to skip to the section "Circumstances Around Death" that asks about insight

about dying, place of death, preferences, decision making support to family around the time of death and bereavement services.

- The recommended focus is on adults because of the smaller numbers of annual deaths <18 years of age from non sudden causes. (For example, the mortality rate for Nova Scotia male and female children age 5-9 years is 0.2/1,000 and 0.1 /1,000 pop. respectively, compared to the all-ages male and female rates of 9.0/1,000 and 8.5/1,000 pop. respectively.) Provision of care to this vulnerable population differs from adults. Instruments validated for use in examining pediatric EOL care would need to be identified. Children requiring EOL care are likely known to the IWK, permitting direct follow-up for quality assurance purposes.

Sample Size & Power

The information needs of the province will need to be considered when determining an appropriate sample for monitoring purposes. A minimum sample of 1200 completed interviews was required for the baseline research project to examine differences by three variables: gender, age and location of care, and to have the capacity to use logistic regression to examine the relationships between location of care, perceived unmet needs and overall satisfaction with adjustment for several covariates. Covariates included: decedent age, gender, cause of death, marital status, education, income, living alone, minority status, relationship of informant and informant's perception of decedent's awareness of approaching death.(11) Burge et al. (11) required a two-year period to obtain a usable sample of 1316 interviews (25.4% response rate of 5343 eligible informants).

Biennial Reporting

A biennial reporting period is recommended.

- This allows a two-year period of data collection to get a large enough sample to yield useful information if a minimum response rate of approx. 25% is achieved. To obtain a similar number of usable responses as Burge et al. achieved on an *annual* basis would require about a 49% response rate[1] This may not be immediately achievable in Nova Scotia as it exceeds the approximate 45% rate achieved by the established, nationally supported UK VOICES survey.

- A biennial reporting period is also supported by the VOICES finding that in 3 annual surveys, the overall quality of care did not change significantly, although some specific aspects showed variation over one and two year periods (e.g. lower perceived quality of coordination of care for those dying at home, increased dignity and respect shown by hospital nurses, respectively).(29)

Expected Response Rate

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[1] Calculation: 1316 completed surveys divided by [5343 eligible informants obtained by Burge et al. in 2 years/2] yields 49.2%. A minimum number of 1200 completed surveys will require a 44.9% response rate annually.

A response rate between 25-45% is feasible with a mailed survey. A higher response rate would be expected to a mailed survey procedure modeled on the VOICES approach [which achieves approximately 45% (30)], compared to that obtained in the research study interview study [25.4% of 5343 potentially eligible informants listed on the certificates (11)]. Participants in the proposed survey would not be required to separately "opt-in" (i.e. indicate their willingness to participate before receiving the survey) and the overall response burden would be less compared to the opt-in telephone interview process used previously.

- Mailing the survey directly to potential participants in a trial resulted in a better response rate (48%), compared to an opt-in approach where potential participants had to actively respond in order to then receive a survey (37%).(9)
- In the US, a 53.6% response rate among eligible family caregivers was obtained using a mailed mortality follow back survey on hospice care[2], with one reminder and telephone follow-up of non respondents.(31) Telephone follow-up is not an option in NS as the informants' telephone numbers are not collected on the death certificates and direct contact is not possible for ethical considerations.
- The research study found that the information in the informant field sometimes was not in fact a family member (e.g. a funeral director, or other person) and this may contribute to a lower response rate. (15)

Bereaved Family Members as a Source of information

Bereaved family members are recognized as a primary source for information about EOL care.(9, 20, 32-37) The family member perspective provides proxy information for the deceased person that is otherwise unobtainable and a first hand account of the family's experience of patient-focused, family-centred end-of-life care. Bereaved family member caregivers remain the most practicable and closest source of information even with the inherent limitations of proxy reporting. Several arguments support the use of data from bereaved family member caregivers:

- From a practical standpoint, is very difficult to gather information about quality of care at EOL prospectively from patients as they are too ill to participate. We are unable to systematically identify people close to end of life at a point where they can participate longitudinally in quality of care research that is population-based.
- Prospective identification may miss people who are not recognized by their health care providers or by themselves to be in a terminal phase, and it may be biased toward people with certain types of life-limiting diagnoses or who are receiving certain types of health care services at EOL. A retrospective, population-based approach including all adult, non sudden deaths reduces these biases while necessitating as the primary data source, the use of the bereaved family members or other close, nonprofessional caregivers who are knowledgeable about the decedent and their care.

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[2] Hospice care in the US context is generally (but not always) delivered in the home, relying on family caregiver and visiting nurses and is overseen by team of hospice professionals. Hospice eligibility is based on expected death within 6 months; comfort is the main goal, extensive life-extending treatment is not. Hospice care is always palliative but palliative care is not always hospice care because it can be provided at any stage of the disease trajectory not just the last 6 months and is often delivered in institutions by an interprofessional team.. Sources: http://www.caregiverslibrary.org/caregivers-resources/grp-end-of-life-issues/hsgrp-hospice/hospice-vs-palliative-care-article.aspx ; http://www.nhpco.org/about-hospice-and-palliative-care/hospice-faqs

- Perceptions of care around the time of death can only be ethically and operationally obtained from proxy informants.
- Evidence suggests that bereaved next-of-kin (proxies) can provide reliable reports on the quality of service and observable symptoms when compared to patients' reports.(38)
- There has been conflicting evidence of proxy reliability at various intervals in the bereavement period, making consistency in the timing of survey administration important to enhance comparability.(37) Recent work demonstrated that when a mailed survey was used similar to the approach recommended in this report, bereaved family members' responses were stable 3-9 months after the death even with fluctuating grief and across different settings of EOL care.(39)
- Family-centred EOL includes not only support and symptom management for the patient, but also support to the family as they cope with the patient's illness and their own bereavement. The family member caregiver perspective is important in assessing the quality of EOL care as it affects both the patient and caregiver. For example, bereavement outcomes are associated with adequacy of informational and psychological support to the caregiver (40), and place of death (41). Better patient quality of death and advance care planning indicated by DNR order completion predicts improved caregiver bereavement adjustment (re cancer deaths).(42)

Identification and Contact of Bereaved Family Members

To identify eligible informants, Vital Statistics would apply the inclusion/exclusion criteria to identify eligible death certificates and extract the necessary information from the death certificates, including the informant name and address.

Ideally, if the Department of Health and Wellness (DHW) was able to obtain the necessary information from the death certificates directly from Vital Statistics, the entire survey could be managed through DHW from that point forward, including initial and reminder contacts with potential survey respondents.

However, if similar restrictions to protect privacy and confidentiality apply as they did during the baseline research study, it would be necessary to request that Vital Statistics function as a third party and make the initial and reminder contacts with potential respondents. In this event Vital Statistics would be asked to apply the exclusion criteria, identify eligible participants using the informant/next-of-kin field on the death certificate, and mail the DHW prepared survey packages and reminders to them.

Sensitivity to the Bereavement Period, Timing of Survey Administration and Minimizing Distress

The period of bereavement is recognized as a sensitive time. A respectful interval of time must be allowed before approaching the bereaved family members to participate in the survey.

- Most after death surveys published up to June 2012 were administered within 1-6 months after death.(37) The US PROMISE survey for veterans' care,(43, 44) and its precursor(45) were administered 1 month after the death. The shorter interval may be more acceptable in this setting because of the established relationship between the organization, and the deceased client and their family that is not present in a population-based study that requires indirect contact of potential respondents. However, this has not been tested in Nova Scotia.

- Burge et al.(11) contacted potential participants indirectly through Vital Statistics 3-7 months from the time of death to capture from as many deaths as possible given the lag time from registration to death certificate availability, while trying to ensure completion of a telephone interview within 10 months of the relative's death. The response rate was 25.4% of potentially eligible informants and the average time between death and the interview was 9.7 months (SD 2.3 months). A mailed survey using three data collection waves per year, with two reminders at one-month intervals from first mailing would require a similar 10 month time frame as the interview study.
- The large VOICES (Views of Informal Carers –Evaluation of Services) mailed survey, which also uses death registrations, contacts informants within 4-11 months of bereavement, achieving a 45% response rate with two reminders, the first spaced three weeks after the initial mailing and the second, four months later.(30)

Grief is one known reason for refusing to participate in a cancer mortality follow back survey.(46) Risks to bereaved respondents include bringing back strong memories, emotional upset or distress. Despite this, widespread use of the design has not produced evidence that it is harmful and benefits appear to outweigh the risks.

- The validation study of the tool (20) later adapted to Nova Scotia found most participants had a positive experience with the ADBFMI , and a small number (7/156 or 4.5%) had a negative experience.

- Recent cognitive interviewing work from the UK described how participation in follow-back surveys can be distressing, bringing back painful memories and feelings of failure related to patient symptom relief.(47) The authors also found survey participation can be perceived as a therapeutic and/or an altruistic experience, affirming to them the approach is acceptable if conducted in a sensitive manner.

Strategies to acknowledge and mitigate potential distress can be employed for a written, self-administered survey, as was the case with the Nova Scotia baseline interview study.(11, 15) It is recommended that participants be informed through the survey materials about the potential to evoke distress or uncomfortable feelings, and that they can stop answering the survey at any time. The information accompanying the survey should also provide information as to how to contact bereavement services. Survey personnel responding to questions about the study need to be prepared to provide this information. More information about strategies to address potential distress is given below.

- The invitation to participate accompanying the VOICES mail survey includes: an acknowledgement that it is a difficult time for the person (the informant) who registered the death, an apology if the enquiry has caused any distress, and a reply slip to indicate refusal to participate so as to prevent receipt of reminder letters.(5) See Appendix B.
- The cover page of the survey also acknowledges the possibility that the survey may evoke strong memories and reminds respondents that they do not have to continue with the survey and can stop at any time.(9)
- The VOICES information sheet sent to potential respondents includes telephone and internet contact information for enquiries about the survey and bereavement services. (See Appendix B)

- The Nova Scotia research team took care to avoid mailing research materials around emotionally sensitive events such as Christmas and Valentine's Day. (Personal communication, Beverley Lawson.)

Research Ethics Approval

Although the data will be collected for quality improvement purposes, it is likely researchers will want access to the data to answer other questions and explore associations. It is recommended that research ethics approval be pursued before administration of the survey in order to facilitate research use of the data. The materials accompanying the survey may need to include a statement seeking the participant's consent to use this information for research purposes together with an assurance that no identifying info would be provided in those circumstances.

Data Collection

Three data collection waves per year (6 waves for the two-year reporting period) are recommended. The decision as to the frequency of the data collection wave has to balance resources with data reliability and facilitating as high a response rate as possible while minimizing the emotional burden to bereaved family members. The three or four wave per year data collection approaches offer the best opportunities for obtaining the most reliable data. Appendix C displays the interval between death and initial contacts for 2, 3, and 4 waves of data collection per year; their implications are discussed below.

- As previously employed by Burge et al.(11) three data collection waves per year with the goal of obtaining responses closer to death are preferable for the proposed survey to enhance comparability with the baseline data. In this approach, the mailing of the survey (i.e. contact with participants) will occur between 3-7 months after the death of their family member. Assuming two reminder notices are used, the first within 1 month of initial contact, most surveys would be returned between 4-10 months after the death, which is close the 3-9 month period in which participants' responses are known to be stable despite fluctuating grief. (39)
- Research suggests response rates drop with an increasing interval from the time of death in both interview (48) and mailed (31) mortality follow back surveys.
- Surveys closer to 3 months after death are recommended to reduce bias from relocation of bereaved family members caused by physical disability or socioeconomic disadvantage.(39)
- The most recent evidence using a mailed survey indicates bereaved family members' perceptions of care quality remain stable 3-9 months after death, and furthermore appear stable even with fluctuating grief.(39) Similarly, the test-retest reliability for the original survey later adapted by Burge et al. showed stable responses 3-6 months after the death.(20) DiBiasio et al.(39) found pain items focused on whether adequate care was received showed moderate to high stability. This is reassuring in light of previous evidence that proxies tend to assess pain as less severe (and depression as less frequent) 7-9 months after death compared to 3-5 months after death(49).
- A *minimum* of two data collection waves a year might be acceptable because it would decrease the demands on Vital Statistics. However, diligent care must be taken with this approach not to contact potential participants close to the first anniversary of the death.

Information derived from a two-wave approach would not be as reliable because the interval from death would exceed the known reliability time frame of 3-9 months.(39)

- If resources permit, four data collection waves a year might be advantageous in terms of obtaining responses 3-6 months after death, when response rates might be higher and ratings are provided closer to the event, increasing their reliability. This approach would have to be weighed against the reduced pool of available death certificates since only about half were available as ‘cleared’ death certificates at the beginning of each wave in the first study (personal communication, Beverley Lawson, February 18, 2015).

Mailed, Self-Administered Survey: Advantages & Disadvantages

A mailed EOL survey is recommended because it is less costly, more sustainable, and poses a lower burden of response on participants than a telephone interview. Overall, a mailed survey provides valid data, and may be better for eliciting answers to sensitive questions.

- A telephone interview required 2-4 contacts in the previous study: replying by phone or mail to actively opt-in to participate, contact by the interviewer to schedule an interview time, administration of the survey interview and possibly, an additional contact at a scheduled time to continue an uncompleted interview. The Nova Scotia telephone interviews required 35-90 minutes.(11) In contrast, the VOICES –Short Form (SF) survey requires approximately 30 minutes to complete and is mailed with the invitation to participate,(28) and the Ontario Caregiver Voice adaptation of VOICES-SF that also incorporates FAMCARE-2 requires 45 minutes of participant’s time.(50) The survey proposed in this report is estimated to take 45-52 minutes to complete.
- One advantage encountered in the interview is that the interviewer could explain or define terminology in the survey (Beverley Lawson, personal communication, Feb. 23, 2015). However, the development of the VOICES-SF survey was informed by cognitive interviewing, a research technique that explores how respondents interpret items and response options.(9) Cognitive interviewing would be advisable for items adapted to Nova Scotia. This should minimize the need for additional clarification during the survey.
- There is the possibility of increased missing data with self-administered surveys that can be addressed to some extent through improved survey layout and wording, but the loss of data must be balanced against the cost savings of a mailed vs. interview approach.(34)
- Research suggests mailed surveys are better for obtaining information on dissatisfaction and sensitive issues. (34, 51-54) More positive responses were found in an EOL telephone survey compared to a mailed survey.(34) This is similar to other health surveys.(52, 53). Better validity and willingness to answer sensitive questions has also been found in mailed health (non palliative care) surveys.(51-54).

Online Option

A mailed survey is recommended together with an online option available to participants through the use of a unique login ID number that would be sent with the invitation and survey.

- Provision of an online option in the VOICES redesign trial did not appreciably affect response rates in the single mailing group as more of those in the opt-in group completed the survey online than used the paper version, signifying this was a convenient and acceptable option to those must opt-in to participate.(9)

- Ontario's Caregiver Voice survey, a very recent adaptation of the VOICES survey is offering an online option. https://sccru.mcmaster.ca/index.php/39595/lang-en
- Online data collection permits collection of data on all respondents who start a survey rather than only those who return by mail their completed survey.(21)
- An online option is likely to become even more acceptable in the future as the population of the bereaved is generally aged, and the use of computers in older age groups is likely to only increase as today's computer users become older.

Survey Procedures

It is proposed that the NS DHW coordinate the mailed and online survey. The following description of the survey procedure is based on the assumption that the same ethical restrictions on access to death certificate data will be required as in the first study to protect privacy and confidentiality. Briefly, this means that in addition to being asked to supply the death certificate data, Vital Statistics also would be asked to identify potential participants, assigning a non identifying ID number to each survey, and as the third party, contact potential participants during the data collection waves. This would include the initial mailing of the survey and two reminders. Subject to a Privacy Assessment, DHW would directly receive completed coded surveys from the participants by business reply mail, thus preserving participant anonymity. DHW would be responsible for survey promotion, analysis and reporting of the data. More detail on proposed roles and responsibilities is found below.

DHW Roles & Responsibilities

- Make arrangements with Vital Statistics to ensure completion of the specified data collection waves each year. This includes communicating to Vital Statistics the respondents' ID numbers (located on completed surveys and refusal reply slips) in a timely fashion so Vital Statistics can process the reminder mail outs and extract death certificate data needed for analysis.
- Prepare and supply the survey and reminder packages
- Create and maintain an online survey option
- Receiving survey responses (that are coded with an non identifying number) and manage the collected data
- Data analysis
- Report the outcomes
- Throughout the process, the DHW would only receive coded data that would not identify the decedent or the informant, provided that free text response options were avoided. Avoiding free text survey response options reduces the possibility that participants would intentionally or unintentionally divulge information that threatens their anonymity. If free text response options were desired, a cautionary statement should be included on the survey instruction page to discourage respondents from revealing identifying information. For example, the Caregiver Voice survey states: "Choosing to name a provider can have an affect your anonymity. All efforts will be made to maintain the highest level of anonymity and information security."

Vital Statistics Roles & Responsibilities

- Identify the eligible death certificates and extract and provide the information for the variables specified by the DHW that are necessary for descriptive, stratified analysis [e.g. age, sex, place of death(11)].
- Identification of the eligible death certificates would involve applying the inclusion/exclusion criteria in each of three data collection waves, creating and maintaining a file with an ID number for each eligible death certificate, and extracting the informant's name and contact information for contact purposes.
- Contact the potential respondents at all stages of data collection (initial mailing, two reminders).
- Prepare the mailing labels, apply the specific ID number to each survey and mail the initial survey package (supplied by DHW). In this way, potential participants' identities are kept confidential within Vital Statistics.
- Determine the mailing list for reminder notices by comparing the lists of ID numbers for returned surveys provided by DHW, would mail the two reminder notices 3 weeks after the initial mailing and 1 month after the first reminder.
- Supply the DHW on an annual basis, ID number coded information previously extracted from the death certificates for which survey responses were obtained, in addition to the information on the total number of potentially eligible death certificates and the number of informants to whom surveys were mailed in each data collection wave.

What is important to measure?

Time Frame

It is recommended that the survey time frame cover three time periods: care received in the last three months of life, in the last two days of life and circumstances around death. The time frame encompassing the period around death (circumstances around death) is not as discretely defined, and in the proposed survey described below also contains items pertaining to the family experience around the actual death and concepts that may not have discrete time periods attached (e.g. communication, decision-making, goals of care, bereavement).

- These periods would facilitate comparison with the baseline data (11) (especially for the last few days of life) and with a regular, international population-based survey.(7)
- The last three months is a longer period than the last month of life period examined in the baseline survey(11) but it aligns with the timeframe employed by the VOICES survey,(28) and its recent Ontario adaptation.(50) This period provides more information on end-of-life care.
- Patients are often transferred to another setting of care, especially hospital in the last week of life.(55, 56) It is important to capture information about the last few days as it reflects the last setting of care.
- Setting the time frame as the last two days of life relieves the respondent of having to identify the one setting of most care toward the end of life in the last week as requested by the Caregiver Voice survey (Item 58) caregiver (50) .

Content Areas

The proposed survey is based on existing instruments and would contain between 81 (69 content and 12 demographic) and 95 items (82 content, 13 demographic), depending on the number of optional items included. [This does not include optional *modules* of content areas.] See Table 2.

The content is primarily based on the VOICES-SF (28) with additional areas of focus and/or individual items from/adapted from the following instruments: the ADBFMI-NS interview (19) and the Caregiver Voice (CV) (50), Family Evaluation of Palliative Care (FEPC) (57) and CAHPS ®-Hospice (58) surveys. Note: References to the specific surveys are provided only in the text of this report and are not provided in the tables to improve readability.

- Content areas address the dying person's comfort and experiences and family/caregiver experiences concerning the EOL care in different settings, at different times (the last 3 months of life, the last 2 days of life, and around death).
- The content areas include:
    - Palliative Care & Specialized Palliative Care
    - Care in the Home
    - Urgent Care Provided Out of Hours
    - Care from Family Doctor or Other Doctor (providing most care in the last three months of life)
    - Long Term care
    - Hospital care (last admission)
    - Experiences in the Last Two Days of Life
    - Circumstances Around Death
    - Advance Care Planning.
- Overall satisfaction ratings are included for the last 3 months of life, the last 2 days of life, care in different settings and from providers (doctors providing most care, doctors, nurses and personal care workers in last 2 days of life; doctors and nurses in hospital and homecare providers).
- Several of the content areas contain possible optional items that could be included to assess particular aspects of care in more depth (one example, specifically detailing the last urgent care contact and outcomes).
- The proposed survey collects information on several demographic variables for both the decedent and the respondent. All but one of the variables was collected in the ADBMI-NS interview, providing comparability and scope for research use of the data.

- Five optional modules were identified. Some might be of interest to particular stakeholders or applicable if service delivery changes, for example the availability of residential hospice care. Optional models:
    - Visiting Volunteers
    - Care in the Home—Special Equipment
    - Cancer Centre care
    - Financial
    - Hospice (residential, last admission)
- The proposed survey combines the general order of the VOICES-SF with additional adaptations from other instruments, in similar relative positioning where possible.

The administration time for the proposed survey is likely between 45-52 minutes, since it is comparable to the CV survey in the number of items (Table 2). The full proposed survey has 12 more items than the CV survey, and of these, half are demographic items that can be answered rapidly, and six are additional content questions that would likely require 5-6 minutes. As well, free text options are avoided in the proposed survey and that will reduce completion time.

Table 2 Comparison of Proposed Survey, VOICES-SF and Caregiver Voice Surveys: Number of Content and Demographic Items

Survey (Approximate Administration Time)	Total items	Number Recommended Content Items	Number Optional Content Items §	Number Recommended Demographic Items	Number Optional Demographic Items
Proposed NS (unknown; estimated 45-52 min.)	81-95	69*	13	12	1
VOICES-SF (30 min.)	60	53**¶		7	
Caregiver Voice (45 min.)	83	76***¶		7	

§ Items are displayed in Table 3 categorized according to area of focus.
* Includes section on palliative care and specialized palliative care services not present in the other two surveys.
** Includes a section on District & Community Nurses not present in the proposed NS survey or in Caregiver Voices.
***Includes Cancer Centre section that is not present in VOICES-SF and is proposed as an optional module for the proposed NS survey. Incorporates the 17 item FAMCARE-2 scale that is not in either Voices or the proposed NS Survey.
¶ VOICES-SF and Caregiver Voice each contain a 4 item Hospice Care section; one of these items in the Caregiver Voice survey contains 4 parts. The Hospice Care section is not yet applicable to NS context and is proposed as an optional module.

Table 3 provides a summary of the proposed survey content and optional modules.

Appendix D contains detailed information showing the original item and response options, possible adaptations to the Nova Scotia context, the extent the proposed items align with existing baseline data, and other comments.

Table 3 Summary of Proposed Survey Content Areas of Focus & Items Summary

1	**Length of Illness Prior to Death**
2	**Participant Eligibility—Caregiving**
Palliative Care Services	
3	Offered as option
Specialized palliative care services	
4	Use of Service
5	Intensity
Care in the Home	
6	Setting of care
7	Services Used
8	Collaboration / Services working together
9	Responsiveness / To needs
10	Responsiveness / Timeliness
11	Homecare / Intensity
12	Homecare / Communication *[Optional suppl. Item]*
13	Homecare / Dignity & Respect
14	Homecare / Symptom Relief & Support [pain & other symptoms relief, spiritual & emotional support]
15-17	Caregiver Support / Information / Pain [2-6 items; presence of pain, enough help, received pain medication, side effects discussion, info on side effects to watch for, info on if & when to give more pain medication.]
18	Caregiver Support / Information / Shortness of breath
19	Caregiver Support / Information / Restlessness & agitation *[Optional suppl. Item]*
20	Caregiver Support / Information / Safe transfers, position changes *[Optional suppl. Item]*
21	Homecare / Overall rating homecare providers care
Urgent Care Provided Out of Hours	
22	Use
23	Availability / Contacting health professional/ Know who to call
24	Availability / Contacting Health professional / Needed to *[Optional suppl. Item]*
25	Availability / Last urgent care contact / Professional contacted *[Optional suppl. Item]*
26	Last urgent care contact / Outcome *[Optional suppl. Item]*
27	Last urgent care contact / Outcome / Caregiver assessment *[Optional suppl. Item]*
28	Overall rating of care
Care from Family Doctor or Other Doctor (providing most care, last 3 months of life)	
29	Type of doctor
30	Respect & dignity
31	Communication
32	Home visits
33	Availability *[Optional suppl. Item]*
34	Symptom relief & support [pain & other symptoms relief, spiritual & emotional support]
35	Overall rating of care
Long term care	
36	Use
37	Respect & Dignity
38	Symptom Relief & Support [pain & other symptoms relief, spiritual & emotional support]
39	Overall rating care

Hospital / Last admission	
40	Occurrence of
41	Respect & Dignity [doctors, nurses separately rated]
42	Symptom relief & support [pain & other symptoms relief, spiritual & emotional support]
43	Collaboration / hospital services working well with family physician and services outside hospital
44	Overall rating care from doctors and nurses
Experiences in the last 2 days of life	
45	Setting of care
46	Respect & dignity [separate ratings of doctors, nurses, personal support workers]
47	Availability of help / personal care, nursing care
48	Privacy *[Optional suppl. Item]*
49	Symptom Relief & Support [pain & other symptoms relief, spiritual & emotional support; support to be where he/she wanted to be]
50	Overall Rating of care
Circumstances surrounding His / Her Death	
51	Insight
52	Breaking the news in a sensitive manner
53	Communication with caregiver
54	Place of Death / Setting
55	Place of Death / Preference / Setting
56	Place of Death / Preference / Amount of Choice
57	Place of Death /Setting / Caregiver's view
58	Caregiver Support / Information / Dying process
59	Caregiver Support / Emotional
60	Caregiver Support / Spiritual
61	Caregiver Support / Time of Death / amount of help & support
62	Caregiver Support / Time of Death / sensitivity to family
63	Transfers between settings of care / smoothness
64	Transfers between settings of care / reason for transfer
65	Decision making / Decedent involvement
66	Decision making / Caregiver involvement
67	Coordination of Care / Communication among professionals
68	Coordination of Care / Doctor
69	Caregiver Support / Information / condition
70	Caregiver Support / Information / consistency
71	Cultural competency
72	Goals of Care / Preferences
73	Goals of Care / Discussion
74	Goals of Care / Care consistency with wishes
75	Goals of Care / Care consistency with wishes / Caregiver satisfaction *[Optional suppl. Item]*
76	Overall rating of care (last 3 months of life]
77	Caregiver Support / Bereavement
Advance Care Planning	
78	Discussion Opportunity
79	Discussion timing
80	Signed Enduring Power of Attorney Health Care *[Optional suppl. Item]*
81	Signed Living Will or Advance Directive *[Optional suppl. Item]*

Demographic Variables Collected from Respondent	
82-88	**Re: Decedent** Marital status Living alone Education Visible minority status Ethnic/racial background Language Religion
89-93 **94**	**Re: Respondent** Relationship to decedent Gender Age Education *Optional suppl. item* Self-rated health status (ADBFMI-NS)
95	**Comments /** Good & bad care received **[***Optional suppl. free text item;* not currently recommended.]
OPTIONAL MODULES	
Visiting Palliative Care or Hospice Volunteers	
Vol-1	Help from
Vol-2	Intensity
Vol-3	Improving quality of life, avoiding unnecessary ED visits or hospitalizations
Care in the Home / Special Equipment	
Equip-1	Need for
Equip-2	Timely receipt
Equip-3	Timely pick up
Cancer Centre	
CC-1	Care from
CC-2	Respect & dignity
CC-3	Symptom Relief & Support [pain & other symptoms relief, spiritual & emotional support]
CC-4	Caregiver Support / Communication
CC-5	Collaboration / Family doctor
CC-6	Collaboration / Community service providers
CC-7	Overall rating of care
Financial	
Fin-1	Supplemental insurance / coverage
Fin-2	Supplemental insurance / type
Fin-3	Supplemental insurance / benefits used
Fin-4	Supplemental insurance / helpfulness
Fin-5	Burden
Last Hospice Admission (not yet applicable to Nova Scotia)	
Hspc-1	**Last Hospice Admission /** occurrence of
Hspc-2	**Last hospice admission** / Respect & Dignity
Hspc-3	**Last hospice admission** / Symptom relief & support [pain & other symptoms relief, spiritual & emotional support]
Hspc-4	**Last hospice admission** / Overall rating of care

While the prominent instruments have exhibited the ability to detect variation among settings for key variables (11, 21, 30, 31), there is potential for ceiling effects in certain categories in the proposed survey. The NS research study found this to be true for patient comfort pain-related items (personal communication, Beverley Lawson, March 25, 2015). The CAHPS ® Hospice Experience of Care field trial found ceiling effects (90% of responses were in the highest category) for a dozen items (some examples are the items concerning privacy, treatment with respect and dignity, medical equipment, support for religious and spiritual beliefs, and emotional support to the caregiver. (31) Nonetheless content related to these areas are important stakeholder interests or concerns, and some were retained in the final survey. As well, any drops in ratings over time might signal problem areas.

Qualitative items are not recommended at this time to preserve anonymity if there are privacy concerns, and because resources will be required to perform qualitative analysis on the large amount of data that could be collected. The baseline study collected some qualitative data that has not been analyzed to date. Analysis of this data could inform adaptation of response options, increasing their relevancy. It might also determine whether the kinds of issues raised are already detected in the fixed response items. The CAHPS field trial revealed that most of the issues raised by respondents in their qualitative responses were covered by fixed response items thus the qualitative questions were dropped from the final survey. (31)

The content recommendations are based on:

1) Review of nine instruments that measure the quality of end of life care.

    - These instruments reflect years of development and careful consideration of what is important to measure in assessing quality EOL from the family member perspective.
    - Most of the instruments selected for review were prominent in the literature and were easily available. The Nova Scotia adaptation of the ADBFM Interview (originally developed in the US) (19), and the VOICES-SF (UK) (28, 30)self-administered survey have both been used in population-based research. Other self-administered surveys reviewed included: Family Evaluation of Palliative Care (57), Family Evaluation of Hospice Care (59), and the CAHPS ® (Consumer Assessment of Healthcare Providers and Services)-Hospice Experience of Care Survey [all from the US]; and Canadian surveys FAMCARE-2 (60), Caregiver Voice (an adaptation of VOICES-SF and FAMCARE-2) (50)and the CANHELP Bereavement Questionnaire (full and Lite versions) (61, 62).

    - In reviewing the instruments, the following aspects were considered: their comprehensiveness, evolution to address salient issues, response burden, successful implementation in a population-based design and congruence with the Nova Scotia Integrated Palliative Care Strategy

    - An overview of the surveys/instruments that were reviewed:
        - The VOICES-SF (V) survey is used for population-based initiatives in the UK (30). The longer VOICES interview format was used for population-based study in Italy.(63). The VOICES surveys have a long history of development by Addington-Hall and her associates (24, 33, 34, 64, 65). VOICES-SF was deemed appropriate for the national survey of EOL care in England because it is sensitive

    enough to detect differences between primary care trusts (administrative bodies commissioning services for geographical areas), care settings, cause of death and place of death. (9, 30)
    - The Caregiver Voice survey (CV) is an adaption of VOICES-SF to Ontario (50) that also includes the FAMCARE-2 survey and additional items. The CV survey is currently being piloted in home care and hospices. (Personal email communication from Erin O'Leary to Beverley Lawson, Feb. 5, 2015). To the best of our knowledge, the CV survey is not in use in Ontario as a population-based survey.
    - The After Death Bereaved Family Member Interview Nova Scotia adaptation (ADBFMI-NS)(11), the original Toolkit ADBFMI Interview (20) and self-administered survey derivations of the original interview, the Family Evaluation of Palliative Care (FEPC) (57) and Family Evaluation of Hospice Care (FEHC) (59) surveys, have been used in North America. The ADBFMI-NS has been administered in a population-based design.(11)
    - The FEPC and FEHC surveys are performance measures for a voluntary quality assessment program offered by the US National Hospice and Palliative Care Organization (NHPCO). The FEHC is being replaced by the Consumer Assessment of Healthcare Providers and Services (CAHPS ®) Hospice survey (10, 58), mandated by the Centers for Medicare and Medicaid Services (CMS) for hospices/ programs receiving CMS funding (personal phone communication, Carol Spence, NHPCO with Elaine Loney, March 13, 2015) The CAHPS survey underwent a rigorous field trial prior to its national implementation this year. (31)
    - Of note are two Canadian instruments that have been used in to measure palliative care services or program based care: 1) The 17 item FAMCARE-2 (66-68) instrument inquires about family member caregiver satisfaction and has been used for EOL care evaluation in Canada and Australia; and 2) the Canadian Health Care Evaluation Project CANHELP Bereavement Questionnaire (17, 61) and its "lite" version (62). Published reports about the original CANHELP caregiver satisfaction instrument include literature pertaining to its development (69-71) with hospital inpatients and outpatients; there is a recent report of a hospital-based survey of next-of-kin of deceased inpatients using the Bereavement questionnaire.(17)

2) Alignment with the Nova Scotia Integrated Palliative Care Strategy (3) and Other Indicators

- Appendix E summarizes how the proposed survey might contribute to the provincial Palliative Care Strategy. The Provincial Palliative Care Coordinator was consulted to better understand some specific provincial interests related to the Strategy. Alignment with the proposed provincial survey and the other reviewed surveys can be found in Appendix F.
    - Most surveys contained items relevant to the specific interests expressed by the Provincial Coordinator, with the most comprehensive coverage provided by the VOICES-SF, Caregiver Voice survey and the ADBFMI-NS interview.
    - Cultural competency items are rare; one is present in the Caregiver Voice survey. An extensive set of items on cultural competency (not specific to EOL care) is available for the Clinical and Group Surveys, US Consumer Assessment of Healthcare and Providers (CAHPS ®) surveys.(72)

- In March 2015 Cancer Care Nova Scotia initiated a Delphi process to determine Nova Scotia quality indicators for EOL care (personal communication to Beverley Lawson from Cancer Care Nova Scotia, Mach 2015). The potential indicators under consideration are organized according to eight domains defined by the [U.S.] National Consensus Project for Quality Palliative Care.(73) An experience of care survey from the family member caregiver perspective as recommended is congruent with the potential quality indicator of patient and family satisfaction with EOL care within the Social Aspects of Care Domain. The content areas in the proposed survey would augment the administrative and patient record data for other indicators.

3) Comparison of survey content areas

- No single survey reviewed addressed all perceived areas of interest. Some surveys are stronger in some areas compared to others. See Appendix F.
- Instruments vary greatly in their structure and coverage of specific areas (e.g. VOICES-SF scaffolds 50 items under settings of care and specified time frames while the CANHELP Bereavement questionnaire presents the respondent with 40 items groups under six conceptual components (e.g. relationships, communication & decision making, etc.).
- Comparison of surveys can be difficult as they are not standardized in their approach to evaluating EOL care and can lack congruence on what general topics or what aspects of the topic are included. Often the stated domains of surveys were not directly comparable.
- Surveys often emphasize different aspects of one construct. As one example, VOICES-SF does not directly inquire about provision of information and caregiver education about disease processes and management, while the ADBFMI-NS and the related FEHC survey include items on information given and received pertaining to symptom management and caregiver confidence as to understanding or knowing what to do (self-efficacy). The CAHPS ® -Hospice Experience of Care survey which replaces the FEHC survey focuses on whether or not caregivers perceived they received enough training regarding medication (when and if to give more pain medication and their side effects; safe mobility transfers of the dying person, and dealing with restlessness and agitation).

4) Comparison of survey content area

- A recent systematic review found fourteen (14) different content area categories among 51 unique surveys, with information and care planning, provider care, symptom management, and overall experience most often addressed.(37) Elements of all these categories are found in the proposed survey.
- Reviews have highlighted that various surveys are not completely comprehensive of the numerous areas of interest in research and evaluation of quality of care (37, 74, 75). This was also demonstrated when several surveys were examined for inclusivity with respect to the areas of interest in Nova Scotia (Appendix F).
- There are several instruments attempting to measure family satisfaction with care, promoting one review to suggest the development of new instruments is not warranted.(74) This supports adaptation of existing instruments.

5) Existing baseline data from the previous research (11-14)

- Appendix D indicates whether or not there is comparable Nova Scotia baseline data for specific content areas and items.
- Over 65% of the 65 recommended content items had been captured in the baseline data. Content areas not captured in the baseline included urgent care provided out of hours, responsiveness to need for help in the home, training provided to caregivers, perception of care provided by specific providers, collaborative care and several circumstances surrounding the death.

Adaptation of Surveys / Survey Items

The proposed survey requires incorporation and adaptation of existing instruments as described in Appendix D to answer the specific questions of interest in Nova Scotia and to provide survey question wording and response options that align with the Nova Scotia context. This would include adaptation of the terminology used to refer to providers of care and existing services, to reflect how care is provided, and to express concepts in language used by Nova Scotians.

It is recommended that the resulting survey be subjected to an assessment of its face validity and literacy level. If possible, it is also recommended that cognitive testing (76) be performed with a sample of potential participants to determine the acceptability of the instrument and identity problems with interpretation of the adapted questions and response options. A pilot is also recommended.

Permissions: Survey Use or Adaptation

Information on how to obtain permissions to use or adapt other surveys/items is provided below.

VOICES-SF: “The VOICES-SF used in the national survey is freely available on the DH website.” (30) The survey plus the accompanying letter of invitation, information leaflet, and reply slip are available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216896/VOICES-Survey-Appendix-B.pdf

FAMCARE-2: While not recommended for the proposed survey, this survey is brief and depending on stakeholder’s interests, some items may have application. They are all satisfaction items. This survey and its guidelines for use are available on the Edmonton Zone Palliative Care Program Website. http://www.palliative.org/NewPC/_pdfs/tools/FAMCARE%20Guidelines_v2%200_12Dec2012%20(2).pdf

A search of the website for FAMCARE-2 revealed a notice on a webpage updated March 24, 2014 that states: "If you wish to use FAMCARE-2, please contact Professor Samar Aoun (s.aoun@curtain.edu.au) directly regarding your request."
An undated pdf request for permission form was also retrieved in the same search.

ADBFMI: This is the original instrument adapted for use in Nova Scotia. The required registration form for use is available from:
http://www.chcr.brown.edu/pcoc/linkstoinstrumhtm.htm
The registration form (http://www.chcr.brown.edu/pcoc/registration.htm) states:

> “The Toolkit of Instruments to Measure End-of-Life Care (T.I.M.E.) is copyrighted material. However, you are free to use it, in full or as individual items, adapt it to your local circumstances, or reproduce it without charge providing that you complete the following registration form and agree to the following conditions.”

FEPC and FEHC: These are copyrighted by the (US) National Palliative and Hospice Care Organization (NHPCO), 1731 King Street, Alexandria, VA 22314; (703) 837-1500; website. www.nhpco.org).
FEPC:
http://www.nhpco.org/performance-measures/family-evaluation-palliative-care-fepc
FEHC:
http://www.nhpco.org/performance-measures/family-evaluation-hospice-care-fehc

The FEHC will be used through the first quarter of 2015 after which hospices will transition to the **CAHPS® Hospice Survey.** The NHPCO will not be the vendor for the CAHPS survey. [Personal telephone communication Carol Spence, NHPCO and Elaine Loney, March 13, 2015]

CAHPS® Hospice Survey

Use of this survey will be required by all US Medicaid and Medicare funded hospices, commencing in 2015. The vendor is US Health Care Research (website: http://ushcrc.com/cahpshospicesurvey).
The survey is available for use and modification. Consult the CAHPS website for more information:
https://cahps.ahrq.gov/surveys-guidance/helpful-resources/modifying/index.html

Caregiver Voice Survey (CV): This is an adaptation of two available surveys (Voices-SF and Famcare-2) and is under the direction of Principal Investigator Dr. Hsein Seow, McMaster University. The Caregiver Voice Survey was piloted through the Community Care Access Centres (homecare) although a population-based method to identify participants was not used; hospices, using their own administrative data to identify decedents and their caregivers are now using the survey (personal email communication from Erin O’Leary to Beverley Lawson, February 5, 2015). The survey tool and contact information are available at: https://sccru.mcmaster.ca/index.php/39595/lang-en

Costs

A complete costing of options was beyond the scope of this recommendation. Recognizing he higher costs of a labour intensive interview study, Lawson et al.(15) suggested a more cost effective mail strategy. Associated costs for recommended option include, but are not limited to the following:

- Costs for Vital Statistics services were $15,212 (data professional services and temporary clerical assistance during the 2010-2011 data collection period, 3 waves per year). Estimated costs for 2015 would be $16,353.96 based on a 7.5% cost of living increase from 2010-2014.
- Postal services are estimated to cost $30,623 over two years assuming an initial mailing of a 90 gram, large envelope at regular postal rate to 5900 potential participants, a 40% overall response rate (n=2360) with 1/3 responding after the initial mail out and 1/3 after each of 2 reminder notices, and use of business reply for returned surveys and reply slips (and assuming no rate increases).
- Survey coordination
- Survey adaptation and formatting
- Set-up and maintenance of an online version,
- Printing surveys, invitation letters, information sheets, reminders, envelopes
- Promotion of the survey
- Data entry, data management
- Analysis
- Report production
- Dissemination

Conclusion

In summary, given Nova Scotia’s aging population and high mortality from chronic disease, provision of high quality, effective palliative care is required.(3) Nova Scotia is advantageously positioned to implement sustainable, ongoing population-based monitoring of family members’ views on quality of care to assess the progress of our provincial strategy. In particular, we have previously established population-based, baseline values of family satisfaction measures that can be immediately used for comparison purposes, together with operational knowledge *that is specific* to the Nova Scotia context to meet the challenges of implementing an ongoing mortality follow-up back survey design that is valid, reliable and sustainable.

List of Appendices

Appendix A Death Certificate Inclusion & Exclusion Criteria

Death Certificate Inclusion Criteria

- Informant subjects will be selected from the death certificates of all Nova Scotians who died in the province between three and seven months prior to each study sampling date.

Death Certificate Exclusion Criteria

- Death certificates of decedents less than 18 years of age
- Decedents with the following underlying external causes of death

Cause of death	**ICD-10**
Certain conditions originating in the perinatal period	P00-P96
Pregnancy, childbirth and the puerperium	O00-O99
Injury, poisoning and certain other consequences of external causes	S00-T98
Accidents (unintentional injuries)	V01-X59, Y85-Y86
External causes of morbidity and mortality	V01-Y98

- Death certificates of decedents for whom the contact information of the informant (next of kin or caregiver) is missing or incomplete.
- Death certificates with an unconfirmed cause of death (not cleared by the Canadian Institute of Health information).

Informant Inclusion Criteria

- Adults (18 years and older) listed on the death certificate as the informant with complete contact information, and who are knowledgeable about the care the decedent received. next-of-kin or informal caregivers . This includes family member, friend or someone else close enough to be knowledgeable about the decedent’s last days and their care.
- Potential respondents will be asked to self-assess as to whether or not they are the best person to answer the survey and if not, to indicate this on a refusal reply slip <u>and</u> if appropriate pass the survey to someone they deem as more knowledgeable.

Informant Exclusion Criteria:

- All professional caregiver or funeral director informants

Appendix B VOICES Invitation Letter and Information Leaflet

Source: Office for National Statistics. Appendix B: Survey questionnaire. 2012. In: National Bereavement Survey (VOICES), 2011 [Internet]. Office for National Statistics, Government of the United Kingdom; [Appendix B]. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216896/VOICES-Survey-Appendix-B.pdf.

Office for
National Statistics

[Name]
[Address Line 1]
[Address Line 2]
[Address Line 3]
[Address Line 4]
[Address Line 5]
[Address Line 6]

VOICES

VIEWS OF INFORMAL CARERS -
EVALUATION OF SERVICES

Dear [title] [surname]

Invitation to help with the VOICES survey of experiences of care in the last months of life.

If you would like to receive this information in large print please call our Survey Enquiry Line on 0800 298 5313

We are writing to you because you registered the death of [TITLE] [FIRST NAME AND SURNAME OF DECEASED].
We appreciate that this may be a very difficult time but we would like to invite you to take part in the VOICES survey of experiences of care in the last months of life. The results will be used to improve care and services for people and their families at the end of life. The Department of Health is funding this survey which the Office for National Statistics (ONS) is undertaking on their behalf. ONS will not release your personal details to anyone else. Your responses to the survey will be shared with the Department of Health and their approved researchers using only your Study ID Number to ensure that total confidentiality is maintained.

Taking part in the VOICES survey involves completing a questionnaire which asks about experiences in the last months of life, care received from health and social services and whether care needs were fully met. This takes about 30 minutes. If you do not think you are the best person to complete the questionnaire, please pass it on to whoever you feel would be the best person to complete it. If you do not wish to participate you can let us know by completing and returning the reply slip in the pre-paid envelope provided. This will ensure that you do not receive reminder letters.

If you do decide to take part we ask that you complete this questionnaire and return it in the pre-paid envelope to the Office for National Statistics. Alternatively, you can complete the questionnaire online on our secure website at: www.ons.gov.uk/VOICESonline. This facility is available until 31st January 2012. After clicking on 'Begin Survey Now', you will be asked to log in using your Study ID Number (see the box at the bottom of the page) and your unique password:
Password: [XXXXXXXXXX]

Your views are important and will help improve future care for patients and families in England. We apologise if this enquiry has caused you any distress and hope this letter does not bring back too many painful memories. We are aware that some local surveys of the bereaved have been undertaken and we apologise if this means you have been approached twice. Thank you for taking the time to read this letter and we very much hope that you feel able to take part in this study.

Yours sincerely

Myer Glickman, Head of Health Analysis, Office for National Statistics

StudyID
Number

VOICES Survey

Experiences of care in the last months of life INFORMATION LEAFLET

You are being invited to take part in a questionnaire-based research study called The VOICES Survey (Views Of Informal Carers – Evaluation of Services). Before you decide to participate, it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

If you would like more information or you have any questions, please phone our Survey Enquiry number on 0800 298 5313 (Monday to Thursday - 9 am to 9 pm; Friday - 9 am to 8 pm and Saturday – 9 am to 1 pm).

What is the purpose of the VOICES Survey?

VOICES is a survey of bereaved carers who provided support and care to a relative, partner or friend. It covers experiences in the last months of life and will be used nationally to monitor and improve services provided. Although participation in VOICES will not help you directly, we hope that the information you give us will enable us to improve people's experiences of care at the end of their lives and improve services provided to bereaved relatives and friends.

Why have I been chosen?

You have been chosen to take part because you registered a death in the past year. The Office for National Statistics will not share any personal information about you with anyone else. Your survey responses will be shared with the Department of Health but only identified by an anonymous ID number. This ensures that the information you provide is totally confidential, in accordance with the Data Protection Act.

What will taking part involve?

We would like you to fill in a questionnaire which will take around 30 minutes. It asks about the care and support both you and your relative / friend received in the last months of their life and whether your relative / friend's needs were fully met. Your experiences are very important, so please feel free to be completely open and honest. If you do not think that you are the best person to complete the questionnaire, please pass it on to whoever you feel would be the best person to complete it.

Most of the questions can be answered by simply ticking the most appropriate box. If you would prefer not to answer a question, please go on to the next one. We would be very grateful for any additional comments that you would like to make in the spaces provided.

To return the completed questionnaire, simply use the enclosed pre-paid envelope. You can request a replacement envelope by phoning the Survey Enquiry Line number 0800 298 5313.

If you prefer, you can complete the questionnaire online (until 31st January 2012) on our secure website at: www.ons.gov.uk/ons/index.html. Click on the 'About ONS' tab, then select 'A-Z of Surveys' and go to the letter N for 'National Bereavement Survey'. After clicking on 'Begin Survey Now', you will be asked to log in using your Study ID Number (see the box at the bottom of the questionnaire page) and your unique password:

Do I have to take part?

Taking part is completely voluntary. If you do decide to take part you may change your mind or choose not to continue in the research at any time, without having to give a reason for doing so. However, if you decide not to complete the questionnaire, please return the reply slip so that the Office for National Statistics does not contact you again about this survey.

What are the possible disadvantages of taking part?

Some people find it distressing to think about the care that their loved ones or close friends received during the last year of their lives. Answering questions about care at the end of life can bring back painful memories. If you find it distressing, you can stop completing the questionnaire at any time and choose not to continue.

We are working with Cruse Bereavement Care services, a charitable organisation that provides help and support to those who have lost loved ones. If you feel that you would like to talk about your feelings or discuss painful memories brought back by completing this questionnaire, please call Cruse Bereavement Care on 0844 477 9400 or by email at helpline@cruse.org.uk

How will the information I give be kept confidential?

The Office for National Statistics (ONS) will not give personal information which identifies you to anyone else. Your survey responses will only be identified by an anonymous ID number. All the information collected will be kept strictly confidential within the approved researchers and secured against unauthorised access. We would also like to make absolutely clear that no information that could identify you will be used in any reports or journal articles we write. If you add comments at the end of the questionnaire, you are asked for additional consent to share these comments in full with local care organisations and providers. You will not be asked to include your name (or the name of your relative, partner or friend) on the questionnaire.

The information collected will be retained and securely stored for 10 years and will then be disposed of securely.

Who is organising and funding the study?

The VOICES study is funded by the Department of Health and run by the Office for National Statistics.

What will happen to the results of the study?

Information obtained from the questionnaire will be entered into a database and analysed by the Office for National Statistics, the Department of Health and their approved researchers. At the end of the project, the findings will be written up into a report that will be submitted to the Department of Health. The results will be available to the public. The information we get from this project will help improve the quality of end of life care provided in England.

If you have further questions about the study, or if English is not your first language and you would like interpreter services, you can call our Survey Enquiry Line on 0800 298 5313 which is open Monday to Thursday - 9 am to 9 pm; Friday - 9 am to 8 pm and Saturday – 9 am to 1 pm.

We understand that coping with the loss of a loved one is not easy and we really appreciate you taking the time to read this information. We are confident that this study will make a difference to improving the way that care is delivered to people at the end of their lives.

Many thanks again.

National Bereavement Survey (VOICES), Office for National Statistics, Room 1364, Government Buildings, Cardiff Road, NEWPORT NP10 8XG

Appendix C Data Collection Waves

Table 1: Data Collection Wave Frequency Comparisons - death & collection period examples

Waves per year	Date of death period (example)	Start date of wave	Interval between death & start date (months)*
2 (6 month cycle)	April 1, 2015 - Sept 30, 2015	Jan 1, 2016	3 - 9
3 (4 month cycle)	June 1, 2015 – Sept 30, 2015	Jan 1, 2016	3 - 7
4 (3 month cycle)	July 1, 2015 – Sept 30, 2015	Jan 1, 2016	3 - 6

* It is likely that the time between the mailing of a survey to return will extend the interval by approximately 1-3 months depending on the response and reminders sent.

- Mailing of survey is assumed to occur within 1 week of start of wave.
- Reminders are sent only to those who have not yet responded.
- Two reminders are suggested, the first approx. 3 weeks after the initial mailing and the second, one month later.

Table 2: Two waves of data collection per year - death period and start date examples

Wave	Date of death period	Start date of wave	Reminder 1	Reminder 2
1	April 1 2015 – Sept 30, 2015	Jan 1, 2016	Feb 1. 2016	Mar 1, 2016
2	Oct 1, 2015 – March 31, 2016	July 1, 2016	Aug 1, 2016	Sept 1, 2016

Table 3: Three waves of data collection per year - death period and start date examples

Wave	Date of death period	Start date of wave	Reminder 1	Reminder 2
1	June 1 2015 – Sept 30, 2015	Jan 1, 2016	Feb 1, 2016	Mar 1, 2016
2	Oct 1, 2015 – Jan 31, 2016	May 1, 2016	June 1, 2016	July 1, 2016
3	Feb 1, 2016 – May 30, 2016	Sept 1, 2016	Oct 1, 2016	Nov 1, 2016

Table 4: Four waves of data collection per year - death period and start date examples

Wave	Date of death period	Start date of wave	Reminder 1	Reminder 2
1	July 1 2015 – Sept 30, 2015	Jan 1, 2016	Feb 1, 2016	Mar 1, 2016
2	Oct 1, 2015 – Dec 31, 2015	April 1, 2016	May 1, 2016	June 1, 2016
3	Jan 1, 2016 – Mar 31, 2016	July 1, 2016	Aug 1, 2016	Sept 1, 2016
4	April 1, 2016 – June 30, 2016	Oct 1, 2016	Nov 1, 2016	Dec 1, 2016*

*In order to avoid the Christmas season it is suggested that reminders be sent either mid-November or early Jan 1, 2017.

Appendix D Proposed Survey Content Areas of Focus and Items

Due to the length of the table, Notes and the Key to Abbreviations are offered below, immediately preceding the table rather than at the end as is customary.

Notes:
No. Column Refers to the proposed survey item number.
B Column “x” indicates presence of baseline data from Burge et al. 2014 research study; non sudden deaths two year period June 1, 2009 - May 31, 2011. Baseline information pertains to either the last month or days of life.
* The VOICES-SF survey has two gender specific versions. To simplify administration in NS, several VOICES-SF items will require adaptation to accommodate both genders; “he or she”, “him or her”.
** Adaptation of the term UK term “care home” is required. Suggest using “long term care home” instead.
*** All items under “Urgent Care” pertain to care out of normal business hours (evenings, weekends, holidays).

Time Frame

L3M	Last 3 months of life
L2D	Last 2 days of life (typically equates to last place of care)

Survey Name

ADBFMI-NS	After Death Bereaved Family Member Interview, NS adaptation of Toolkit to Measure End of Life Care
CAHPS	Consumer Assessment of Healthcare Providers and Services (CAHPS) Hospice Survey. Note: CAHPS items refer to the period the decedent was in hospice care, a program typically delivered in, but not restricted to the home. Includes home, residential hospice, long term care settings
CANHELP	CANHELP Bereavement Survey
CV	Caregiver Voice Survey
FEPC	Family Evaluation of Palliative Care
V	VOICES-SF

Baseline B

Y	Yes
N	No
S	Somewhat

Response Options

Y	Yes	O	Outstanding
N	No	E	Excellent
DK	Don’t know	G	Good
NA	Not applicable	F	Fair
		P	Poor

No.	B	Focus Area	Time Frame	**Survey Item (as written)** Survey name/survey item no.	Response Options	Recommended Adaptations & Comments
1	**N**	**Length of Illness Prior to Death**		V1 How long had he* been ill before he died? After response options are presented, respondent is instructed: If he* died suddenly or there was no time for care, please go to question 37. V37 starts "Circumstances Around Death Section.	Tick one only He was not ill – he died suddenly; Less than 24 hours; One day or more but less than one week; One week or more but less than one month; One month or more but less than six months; Six months or more but less than one year; One year or more.	Can possibly identify sudden deaths that may be missed using ICD coded cause of death listed on the death certificate. CV survey places V1 item later in survey, under "Circumstances around death." *Recommend retaining V1 as the first item* in a NS survey to screen for sudden death and reduce response burden.
2	**N**	**Participant Eligibility—Caregiving**	L3M	CAHPS/3 How often did you take part in or oversee care for him or her?	Never –skip to demographic questions; Sometimes, Usually, Always	No V or CV equivalent
3	**Y**	**Palliative care services /** Offered as option	Ever	ADBFMI-NS/B1 Palliative care is a type of care that is given to people who with chronic, often life-threatening illness. It focuses on helping with symptoms, such as relieving pain and 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 offered (presented as an option) for [Decedent's] care?	Y, No-skip; DK-skip	Determine time frame. If "Ever", change to read: "was palliative care ever offered" Consider adding item about when in illness trajectory palliative care was offered, (e.g. About long before he/she died was this type of care offered? Provide fixed response options.) Consider placing this module later in the survey, e.g. immediately before last 2 days of life section. The phone interview items will require adaptation to self-administered survey format at a lower literacy level than the verbal questions.
4	**Y**	**Palliative care services /** Specialized / Use of Service	L3M	ADBFMI-NS/B2, B3, B4 "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	B2-Yes, No-skip; DK-skip)	Adapt to written format. Remove "What about…" Suggest reworking definition and state "Specialized palliative care is a program…" B2: Modify time frame to read "during their last 3 months of life"

				doctor or homecare nurses or VON. B2-To your knowledge was [Decedent] provided care from a specialized palliative care program at anytime during their last month?	B2: Y, N-skip; DK-skip	
5	**Y**	**Palliative care services /** Specialized / Intensity	Ever	ADBFMI-NS/ B3, B4 B3: For about how long were staff from palliative care involved with [Decedent]'s care. B4: In what locations was specialized palliative care provided?	B3-____days____months B4-Home; While in the hospital as an inpatient; Outpatient clinic; Nursing home; Cancer clinic; Other: (please specify)	B3: Provide response options: 1 week or less; more than a week but less than a month; 1-3 months; 4-6 months, 6-9 months, 10 – 12 months; 1 year or more. B4: Review list of options for completeness. Qualitative date from baseline study may inform new response categories and avoid write-in option.
6	**Y**	**Care in the Home** / Setting of care	L3M	V/20. Did he* spend any time at home during the last 3 months of life?	Y, N- he was in a care home** for the whole 3 months–skip; N- he was in hospital–skip.	Replace "care home" with "long term care home".
7	**Y S**	**Care in the Home** / Services Used	L3M	V/13 When he* was at home in the last 3 months of life, did he* get any help from any of the services listed below? These may be provided by different organizations, a private agency or social services. Tick all that apply.	List of 15 options—12 services/providers; He* did not receive any care; DK; Something else (write in option).	Adapt similar to CV/14: Remove "These may be… services" sentence. Tailor response options to fit NS context. 1) Assess CV/14 response options for relevancy to NS: homecare nurse, private (paid) nurse, advanced practice or nurse practitioner; family or palliative care physician, specialist physician (oncologist, cardiologist), OT, CCAC [home care?] case manager, dietician, spiritual leader, volunteer, PT, massage therapist, meals, personal support worker. 2) Consider items from ADBFMI-NS (p.17) to include /C3 Home Care Service offered by province (Nova Scotia Continuing Care or Nova Scotia home care); /C4 Home care service not offered by province with write in option; /C5 all types of care provided by the home care service (housekeeping, nursing,

						respiratory care, mental health care, social work, palliative care, speech therapy, medication management). Avoid write in options. Qualitative data from baseline study may identify relevant options.
8	**N**	**Care in the Home** / Collaboration / Services working together	L3M	V/4 When he* was at home in the last 3 months of life, did all these services work well together?	Y, definitely; Y, to some extent; N, they did not work well together; He* did not receive any care; DK.	
9	**Y**	**Care in the Home** Responsiveness / To Needs	L3M	V/5 Overall, do you feel that you and your family got as much help and support from health and social services as you needed when caring for him*?	Y, we got as much support as we needed; Y, we got some support but not as much as we wanted: N, although we tried to get more help; N, but we did not ask for more help; We did not need help.	CV/16 modified V/5 by re-ordering the two “No” responses. Re: Baseline. Analogous to rating the setting of care where the majority of care was provided in the home. Recommend splitting this double-barreled question into two parts: … a) health services, b) social services. Adapt “social services” term to NS context.
10	**N**	**Care in the Home** / Responsiveness / Timeliness	L3M	CAHPS/7 While your family member was in hospice care, when you or your family member asked for help from the hospice team, how often did you get the help as soon as you needed it?	Never, Sometimes, Usually, Always	Adapt to NS: Remove “While your family member was in hospice care” and replace with “Overall”. Change “hospice team” to “health care providers”
11	**Y**	**Care in the Home** / Homecare / Intensity	L3M	CV/17 Did he/she have care from homecare providers contracted by CCAC (nurses, support workers, equipment, social workers, etc.) in the last 3 months of life? CV/18 How often did the homecare providers visit (at the most frequent time?)	CV/17 Y; No-skip CV/18: More than once a day; Everyday; 2-6 times a week; Once a week; 2-3 times a month; Less than 2-3 times a month; DK	Adapt to NS. Replace “contracted by CCAC”, with NS term, e.g. “from a provincial home care program”
12	**N**	*Opt. Suppl. Item* **Care in the Home** / Homecare / Communication	L3M	*Opt. Suppl. Item* CAHPS/6 When your family member was in hospice care, how often did the hospice team keep you informed about when they would arrive to care for your family member? Note: US hospice care is typically delivered at home.	Never, Sometimes, Usually, Always	Adapt to read: “When he/she received home care services, how often did the home care providers keep you informed about when they would arrive to care for him/her?

13	**Y**	**Care in the Home** / Homecare / Dignity & Respect	L3M	CV/19 How often was he/she treated with dignity and respect by the homecare providers?	Always; Most of the time; Some of the time; Never; DK	VOICES does not include an item on dignity and respect in the home setting.
14	**Y**	**Care in the Home** / Homecare / Symptom Relief & Support	L3M	CV/20. During the last 3 months of his/her life, while he/she was receiving homecare, what is your assessment of the overall level of support given in the following areas: a) Relief of physical pain b) Relief of other symptoms c) Spiritual support d) Emotional support	Presented for each part: E, G, F, P, DK	CV/20 is an adaptation of V/36 to the home setting. May wish to adapt to read "when receiving care at home". CAHPS field test eliminated proxy reports of spiritual support for greater face validity. <u>Constipation</u>: CAHPS /24, CAHPS/25 address presence of trouble with & enough help for this problem. Constipation is not specified singly in V or CV.
15-17	**Y S**	**Care in the Home / Caregiver Support / Information /** Pain		CAHPS/15 – 20. /15-if decedent had pain, /16-did they get as much help as needed; /17-did decedent receive any pain medicine; /18-were side effects discussed; /19 did hospice team give caregiver the training they needed about what side effects to watch for; /20 did hospice team give caregiver the training they needed about if & when to give more pain medicine	/15 Y, N-skip /16 Y, definitely; Y, somewhat; N. /17 Y, N /18 Y, definitely; Y, somewhat; N. /19 Y, definitely; Y, somewhat; N. /20 Y, definitely; Y, somewhat; N.	Items /15, /16, /17 are redundant of CV/20a. Suggest using /18 and /19 & /20 . The last two items, /19 & /20 would then replace the caregiver confidence question from ADBFMI-NS that is non specific to pain med management (e.g. /G12 confidence in understanding medicines used to manage pain, shortness of breath, other symptoms). Suggest adapting by replacing "hospice team" with "health care providers" and "your family member" with him/her. Suggest adding :"DNA-He/she did not need pain medication" to option for /19 with skip for "No".
18	**Y S**	**Care in the Home / Caregiver Support / Information /**	L3M	CAHPS/23 Did the hospice team give you the training you needed about how to help your family member if he or she had trouble breathing?	Y, definitely; Y, somewhat; N; I did not need to help my family member with trouble breathing.	Would replace "caregiver confidence " question from ADBFMI-NS (e.g. /G12 confidence in understanding medicines used to manage pain, shortness of breath,

		Shortness of breath				other symptoms). Note: CAHPS/21, /22 ascertain presence of trouble breathing & how often they received help that was needed. Suggest adapting by replacing “hospice team” with “health care providers”; “training” with information and “your family member” with him/her.
19	**N**	*Opt. Suppl. Item* **Care in the Home / Caregiver Support / Information /** restlessness & agitation	L3M	*Opt. Suppl. Item* CAHPS/23 Did the hospice team give you the training you needed about what to do if your family member became restless or agitated?	Y, definitely; Y, somewhat; N	Suggest adapting by replacing “hospice team” with “health care providers”; “training” with information and “your family member” with him/her. Note: CAHPS/28 ascertains presence of restlessness & agitation. Suggest adding to response options if not using CAHPS/28: “Does Not Apply-he/she did not become restless or agitated”
20	**N**	*Opt. Suppl. Item* **Care in the Home / Caregiver Support / Information /** Safe transfers, position changes	L3M	*Opt. Suppl. Item* CAHPS/30 Moving your family member includes things like helping him or her turn over in bed, or get in and out of bed or a wheelchair. Did the hospice team give you the training you needed about how to safely move your family member?	Y, definitely; Y, somewhat; N	
21	**Y**	**Care in the Home** / Homecare / Overall rating homecare providers care	L3M	CV/21 Overall, do you feel that the care he/she got from the homecare providers in the last 3 months was:	Tick one only. E, G, F, P, DK	Recommend including similar item. No equivalent item in V survey. When results are stratified by location of care, baseline data is available. May need modification to specify care from the homecare program is that is the primary interest to distinguish from all providers in the home, some of whom may not be associated with the homecare program.
22	**N**	**Urgent Care Provided Out of Hours /** Use	L3M	CV/7 In the last 3 months of life, did he/she have to go to the emergency Department?	Not at all, Once or twice, Three or four times, Five or more times, DK	

23	**N**	**Urgent Care*** /** Availability / Contacting health professional/ Know who to call	L3M	CV/23 Other than calling “911” or going to the emergency department, did he/she or you know who to contact any time assistance was needed with an urgent problem? This includes evenings and weekends.	Y, N, Not sure.	Consider modifying to include “holidays” (CAHPS).
24	**N**	*Opt. Suppl. Item* **Urgent Care ***/** Availability / Contacting health professional / Needed to	L3M	*Opt. Suppl. Item* V/7 In the last 3 months of life, when he* was at home, did he ever need to contact a health professional for something urgent in the evening or at the weekend?	Not at all-skip, Once or twice, Three or four times, Five or more times, DK	Consider modifying to read in the evening, during the weekend or on holidays. (From CV/24 & CAHPS/4)
25	**N**	*Opt. Suppl. Item* **Urgent Care ***/** Availability / Last urgent care contact / professional contacted	L3M	*Opt. Suppl. Item* V/8 The last time this happened, who did he contact, or who was contacted on his* behalf?	Lists contextually appropriate services and write-in option.	Provide NS options. CV/25 lists ON services incl. His/her family doctor or the doctor’s after-hours number; His/her palliative care doctor; Homecare; Both a doctor and homecare; Hospice; (911 or used lifeline pendant); Other (no write-in option). Avoid write-in option.
26	**N**	*Opt. Suppl. Item* **Urgent Care *** /** Last urgent care contact / Outcome	L3M	*Opt. Suppl. Item* V/9 What happened as a result? Was he*…	Tick one only. Lists several contextually appropriate choices and Something else--please write below.	CV/26 modifies choices to ON setting, incl. Visited by his/her family doctor at home; Visited by palliative care doctor or another doctor at home; Visited by a homecare provider at home; Visited by both a doctor and homecare; Visited by hospice volunteer at home; Given medical advice over the telephone; Given another number to call for medical advice; Advised to call 911; Advised to go to an Emergency Department at a hospital; Other (no write-in option)
27	**N**	*Opt. Suppl. Item* **Urgent Care *** /** Last urgent care contact / Outcome / Caregiver assessment	L3M	*Opt. Suppl. Item* V/10 In your opinion was this the right thing for them to do?	Y, N, Not sure	CV/287 modifies item to read “…the right thing to do or not”

28	N	**Urgent Care*** /** Rating of care	L3M	V/11 Overall, do you feel that the care he* got when he* needed care urgently in the evenings or weekends in the last 3 months of life was:	Tick one only. E, G, F, P, DK	Recommend adapting wording similar to CAHPS to read: “during evenings, weekends or holidays “
29	N	**Care from Family Doctor or Other Doctor /** Type of doctor providing most care	L3M	CV/32 In the last 3 months, which type of doctor provided the <u>most</u> of his/her care?	Tick one only. His/her family doctor; Palliative care doctor; Oncologist, Other doctor; He/she did not need to see a doctor-skip; He/she needed to see a doctor but did not see one – skip; DK-skip.	Interpretation of “He/she needed to see a doctor but did not see one” may be problematic. Considering adapting response options to qualify why doctor was not seen.
30	N	**Care from Family Doctor or Other Doctor /** Respect & dignity	L3M	CV/33 How often was he/she treated with respect and dignity by this doctor?	Always, Most of the time; Some of the time; Never; DK	Adapted from V/16 which refers to GP and uses “how much of the time”.
31	S	**Care from Family Doctor or Other Doctor /** Communication	L3M	V/17 Were you able to discuss any worries and fears you may have had about his*condition, treatment, or tests with the GP?	Tick one only. I had no worries or fears to discuss; Yes, I discussed them as much as I wanted; Yes, I discussed them but not as much as I wanted; No, although I tried to discuss them; No, but I did not try to discuss them.	Recommend changing “fears” to “concerns”. Recommend changing “fears” to “concerns” and “GP” to “this doctor” (referring to doctor providing most care identified in CV/32). Alternative item: CV/34 Did you have any worries or concerns that you were not able to discuss with that doctor? N, Y—if yes what were they? Recommend against using free text space to protect anonymity. Re Baseline. ADBFMI-NS has several items on communication & information giving (/D1, D2, D3, D4, D5, E6). These were directed towards doctors and nurses involved in care, not a specific physician provider. Some items are similar in meaning but not exact.
32	YS	**Care from Family Doctor or Other Doctor /** Home visits	L3M	V/18 Overall, if the GP visited him* at home in the last 3 months, how easy or difficult was it to get this doctor to visit?	Very easy; Fairly easy; Fairly difficult; Very difficult; He* wanted the GP to visit but they would not visit; Does not apply—	Considering adapting by replacing “GP” with “family doctor”. Re Baseline. ADBMFI-NS/C9, /C10 ask about family doctor home visits and frequency, not about difficulty

					the GP did not need to visit; DK	obtaining visits. Visits by other specialties are likely to be rare and once only in most cases.
33	**N**	*Opt. Suppl. Item* **Care from Family Doctor or Other Doctor /** Availability	L3M	*Opt. Suppl. Item* CANHELP/4 How satisfied were you that the doctor(s) were available when you or your relative needed them (by phone or in person) in the last month?	Not at all, Not very, Somewhat, Very, Completely.	Suggest adapting to a VOICES format and using "this doctor": How often was this doctor available (by phone or in person) when they were needed? Suggest using VOICES response options: Always, Most of the time; Some of the time; Never; DNA-doctor was not needed; DK
34	**Y**	**Care from Family Doctor or Other Doctor /** Symptom relief & support	L3M	CV/35. During the last 3 months of his/her life, while he/she was being cared for by the doctor indicated above, what is your assessment of the overall level of support given in the following areas: a) Relief of physical pain b) Relief of other symptoms c) Spiritual support d) Emotional support	Presented for each part: E, G, F, P, DK	CV/35 is an adaptation of V/36 to the care provided by the doctor. There are several ratings across settings. Could be an optional item depending on stakeholder interests. CAHPS field test eliminated proxy reports of spiritual support for greater face validity.
35	**N**	**Care from Family Doctor or Other Doctor /** Overall rating of care	L3M	CV/37 / [Care from the doctor providing the most care in the L3M] Overall, do you feel that the care he/she got from this doctor in the last 3 months was:	Tick one only. E, G, F, P, DK	Adapted from V/19. Possibly an optional item. Either this item or CV/35 (above) may be enough, depending on stakeholders' interests. Re: Baseline ADBFMI-NS does not ask overall ratings of specific care provider groups.
36	**Y**	**Long term care /** Use	L3M	V/20. Did he* live or stay in a care** home at any time during his last 3 months of life?	Y-write in name, location, N-skip, DK-skip	Adapt to read "long term care home". Recommend removing write in name & location.
37	**Y**	**Long term care /** Respect & Dignity	L3M	V/21 How much of the time was he* treated with dignity & respect by the staff at the care home**?	Always, Most of the time, Some of the time, Never, DK	CV/46 modified V/21 to read: "How often was he/she…"
38	**Y**	**Long term care /** Symptom Relief & Support	L3M	CV/47 During the last 3 months of his/her life, while he/she was in a long term care home, what is your assessment of the overall level of	Presented for each part:	CV/47 is an adaptation of V/36 to the long term care setting. V/22 asks about pain only.

				support given in the following areas: a) Relief of physical pain b) Relief of other symptoms c) Spiritual support d) Emotional support	E, G, F, P, DK	CAHPS field test eliminated proxy reports of spiritual support for greater face validity.
39	**Y**	**Long term care /** Overall rating care	L3M	V/23 Overall, do you feel that the care he* got from the care home** in the last 3 months of life was:	Tick one only. E, G, F, P, DK	Adapt to read “nursing home” or “long term care home” instead of “care home”
40	**Y S**	**Hospital /** Last admission / occurrence of	L3M	CV/24 Did he* stay in hospital at any time during his* last 3 months?	Y-please select main reason for admission: Treatment for disease (ex. chemo, surgery, tests, etc.); Pain issues; Other symptom issues (nausea, shortness of breath); Infection; Caregiver respite/unable to manage at home; Multiple issues; Other reason. N-skip, DK-skip	CV/24 is modification of V/24. Added main reason for admission and dropped identifying hospital name & location. Requires modification to Yes response option to specify ***last*** hospital admission Re: baseline. ADBFMI-NS data includes if time was spent in hospital but the reason for admission was only asked if it was the last location of care.
41	**Y**	**Hospital /** Last admission / Respect & Dignity	L3M	CV/50 During his/her last hospital admission, how often time was he/she treated with respect & dignity by the hospital doctors and nurses?	Answer individually for each [doctors, nurses] E, G, F, P, DK	Adapted from V/25
42	**Y S**	**Hospital /** Last Admission / Symptom relief & support	L3M	CV/51 During his/her last hospital admission, what is your assessment of the overall support given in the following areas: a) Relief of physical pain b) Relief of other symptoms c) Spiritual support d) Emotional support	Presented for each part E, G, F, P, DK	CV/51 is an adaptation of V/36 to the hospital setting. V/26 inquires *only* about pain relief. CAHPS field test eliminated proxy reports of spiritual support for greater face validity.
43	**N**	**Hospital /** Last admission / Collaboration	L3M	V/27 Did the hospital services work well together with his* GP and other services outside the hospital?	Y, definitely; Y, to some extent; No, they did not work well together; DK	Adapt similar to CV/52. Substitute “family doctor” for “GP”
44	**Y**	**Hospital / Last**	L3M	V/28 V/23	Please answer for both doctors	CV/53 modified V/28 response instructions

		admission / Overall rating care from doctors and nurses		Overall, do you feel that the care he* got from the staff at the hospital on that admission was…	& nurses E, G, F, P, DK [presented in two columns, doctors & nurses)	to read "Answer individually for each. Re: baseline. ADBFMI-NS data reports hospital experience if it was the setting of the majority of care in the month or few days.
45	**Y**	**Experiences in the last 2 days of life /** Setting of care	L2D	V/33 During his* last two days of life was he*…	Tick one only. At home all the time; In a care home** all the time; in a hospital all the time; In a hospice all the time: Other (write in the space below)	Adapt to read "long term care home". Omit write in option. Qualitative data from baseline study may identify relevant options. Baseline data for last few days of life.
46	**YS**	**Experiences in the last 2 day of life /** Respect & dignity	L2D	CV/59 How often was he/she treated with respect and dignity in the last 2 days of life by the doctors, nurses, and personal support workers?	Answer individually for each. Always, Most of the time; Some of the time; Never; DNA; DK	Adapted from V/34. Uses "how often" in place of "how much of the time" and added "Personal support workers." Recommend modifying "personal support workers" to suit NS context. Query depending on stakeholder interest, possible use of: "personal care workers," "continuing care support workers," or "others helping with their health care (more inclusive). " Re: Re: baseline. ADBFMI-NS data reports L2D separately only if this setting differed from the setting of the majority of care in the last month.
47	**Y a** **N b**	**Experiences in the last 2 days of life** / Availability of help / personal care, nursing care	L2D	V/35/a & b Please look at the following statements and tick the answer box that corresponds most with your opinion about the help he* received in the last 2 days of life. a) There was enough help available to meet his personal care needs (such as toileting) b) There was enough help with nursing care, such as giving medicine and helping him find a comfortable position in bed	Presented for each part: Strongly agree, Agree, Neither agree nor disagree, Disagree, Strongly disagree, DNA, DK	CV/60 adapted to read: "Indicate your opinion about the help he/she received …" Consider modifying V/35 by replacing "corresponds" with "agrees" to reduce literacy level.
48	**N**	*Opt. Suppl. Item* **Experiences in the last 2 days of**	L2D	*Opt. Suppl. Item* V/35/c c) The bed area and surrounding		Recommend as optional item or excluding. A privacy item on CAHPS survey was dropped after the field test due to a ceiling

		life / Privacy		environment had adequate privacy for him*		effect & inability to distinguish variation between hospices
49	**Y**	**Experiences in the last 2 days of life** / Symptom Relief & Support	L2D	V/36 During the last 2 days of life, how do you assess the overall level of support given in the following areas from those caring for him*? a) Relief of physical pain b) Relief of other symptoms c) Spiritual support d) Emotional support e) Support to stay where he* wanted to be	Presented for each part: E, G, F, P, DK	CV/61 adapted wording asks "During ….of life, what is your assessment of the overall level of support…"
50	**Y**	**Experiences in the last 2 days of life** / Overall Rating of care	L2D	*New item.* Overall, and taking all services into account, how would you rate his* care in the last 2 days of life?	Tick one only. O, E, G, F, P, DK	Uses V survey style (similar to V/51). No overall satisfaction question re last few days of life is included in either V or CV. Provides comparison to baseline ADBFMI-NS/K1. Consider if change to 0-10 rating scale is warranted for enhanced comparability. Recommend inserting as last item in the Last 2 Days of Life section for comparability with.
51	**Y**	**Circumstances surrounding His/Her Death** / Insight		V37 Did he* know he* was likely to die?	Tick one only. Y, certainly; Y, probably; Probably not; No, definitely; Not sure	
52	**N**	**Circumstances surrounding His/Her Death** / Breaking the news		V38 In your opinion, did the person who told him he was likely to die break the news to him in a sensitive and caring way?	Tick one only. Y, definitely; Y, to some extent; No, not at all; DK, DNA-they did not know he was dying; DNA-they did not tell him he was dying.	
53	**N**	**Circumstances surrounding His/Her Death** / Communication with caregiver		V39 Were you contacted soon enough to give you time to be with him before he died?	Y; N; I was already there; It was not clear that he was going to die soon; I couldn't have got there anyway.	
54	**Y**	**Circumstances**		V/40 Where did he* die?	Tick one only. [For each	Will require adaptation to NS context.

		surrounding His/Her Death / Place of Death / Setting			institution, name & location are requested] In his own home; In the home of another family member or friend; In a hospital ward; In a hospital Emergency Department; In a hospital intensive care unit; In a hospice; In a care home**; In an ambulance on the way to the hospital or hospice. Somewhere else, please write below.	CV/65 modified by dropping: in home of family or friend, and emergency department; modifying “hospital ward” and “intensive care unit” by combining both into “In a hospital acute or intensive care unit”, & including “In a hospital palliative care unit (PCU)” and “”In a hospital complex continuing care unit (CCCU)”. Included “Other” option without free text space.
55	**Y**	**Circumstances surrounding His/Her Death** / Place of Death / Preference / Setting		V41 Did he* ever say where he would like to die?	Y-skip; N-skip; Not sure-skip	
56	**N**	**Circumstances surrounding His/Her Death** / Place of Death Preference / Amount of Choice		CV/70 Do you think he had enough choice about where he* died?	Tick one only Y, N, Not sure, He died too suddenly to make a choice.	Added “to make a choice” to V/44 response option “He died too suddenly.”
57	**N**	**Circumstances surrounding His/Her Death** / Place of Death /Setting / Caregiver’s view		CV/71 Do you think he/she died in the right place?	Tick one only Y, N, Not sure	Adapted V/45 by removing the preface phrase “On balance,”
58	**Y**	**Circumstances surrounding His/Her Death** / Caregiver Support / Information / Dying process		CAHPS/31 Did the hospice team give you as much information as you wanted about what to expect while your family member was dying?	Y, definitely; Y, somewhat; N	Adapt by replacing “hospice team” with “health care providers”. Would replace non equivalent items: ADBFMI-NS/G4 (caregiver confidence knew what to expect) & ADBFMI-NS/G8 (confidence knew what to do at time of death)

59	**Y**	**Circumstances surrounding His/Her Death** / Caregiver Support / Emotional	L3M	CAHPS/37 How much emotional support did you get from the hospice team?	Too little, right amount, Too much.	Requires adaptation: Insert preface phrase: "In the last 3 months of his/her life… ." Replace "hospice team" with "their health care providers". Underline "<u>you</u>". Somewhat analogous to ADBFMI-NS/L4 Alternative item: FAMCARE-2/10 satisfaction with emotional support provided to family; requires adaptation of "palliative care team".
60	**Y**	**Circumstances surrounding His/Her Death** / Caregiver Support / Spiritual		New item. CAHPS/36 Support for religious or spiritual beliefs includes talking, praying, quiet time, or other ways of meeting your religious or spiritual needs. While your family member was in hospice care, how much support for your religious and spiritual beliefs do you get from the hospice team?	Too little, right amount, too much.	Requires adaptation: Replace phrase "While your member was in hospice care" with "In the last 3 months of his/her life… ." Replace "hospice team" with "their health care providers". Better version of ADBFMI-NS/L3. No equivalent item in V or CV surveys.
61	**N**	**Circumstances surrounding His/Her Death** / Caregiver Support / Time of Death / amount of help & support		V/46 Were you or his* family given enough help and support by the healthcare team at the actual time of his death?	Tick one only Y, definitely; Y, to some extent; N, not at all; DK	Appears to be an overall rating. Re: Baseline data. Does not ask for an overall rating of help & support received. Does ask if providers provided support in dealing with feelings (ADBFMI-NS/L4; /L5, /L6) & if providers suggested someone to turn to if feeling stressed (L8)
62	**Y S**	**Circumstances surrounding His/Her Death** / Caregiver Support / Time of Death / sensitivity to family		V/47 After he/she died, did staff deal with you or his family in a sensitive manner?	Tick one only Y; N; DK; DNA, I didn't have any contact with staff	Consider CV/74 adaptation: changed "staff" to health care providers. Re Baseline: With reference to ADBFMI-NS/L4 & /L5 described above, /L7 asks if this was done in a sensitive manner; however time frame is last few days of life.
63	**N**	**Circumstances surrounding His/Her Death** / Transfers	L3M	CV/73 Do you feel that he/she experienced smooth transitions between settings of care during the last 3 months of life?	Y, definitely; Y, to some extent; N, not at all; DK	The performance of CV/73 is unknown. Presupposes transfers took place. Add response option: NA—he/she stayed in one place the last 3 m of life. Placed in

		between settings of care/ smoothness				“Circumstances Around Death” section in CV survey. Consider using “transfers” instead of “transitions.” Item will not provide information on problems in transfers. The occurrence of transfers can be deduced from responses to settings of care items above, but no information on sequence or LOS will be available.
64	**Y**	**Circumstances surrounding His/Her Death** Transfers between settings of care / reason for transfer	L3M / L2D	ADBFMI-NS/11r What was the reason decedent moved to this setting of care? [Refers to last setting of care]	(Mark all that apply) Breathing problems; abdominal pain; other pain, medical emergency; caregiver burden too high; family preference; lived alone / needed 24 hour care / inadequate home support; care provider recommendation; lack of access to professional help after hours; assisted living or group home that discourages dying in that environment; other (please specify)	Requires adaptation. Options require literacy assessment. Consider insertion into “Last 2 Days of Life” section with an appropriate gatekeeper question.
65	**YS**	**Circumstances surrounding His/Her Death** / Decision making / Decedent involvement	L3M	V/48 Looking back over the last 3 months of his* life, was he* involved in decisions about his* care as much as he would have wanted?	Tick one only. He was involved as much as he wanted to be; He would have liked to be more involved; He would have liked to be less involved; DK	Re: Baseline. ADBFMI-NS has items about being involved or asked about wishes (e.g. /D10, /D11) but none cover satisfaction with the amount of involvement. /J14 is double barreled and does not separate out the decedent’s involvement from the caregiver/s involvement.
66	**N**	**Circumstances surrounding His/Her Death** / Decision making / Caregiver involvement	L3M	V/49 Looking back over the last 3 months of his* life, were you involved in decisions about his* care as much as you would have wanted?	Tick one only. I was involved as much as I wanted to be; I would have liked to be more involved; I would have liked to be less involved; DK	Re: Baseline. ADBFMI-NS/J14 inquires if there were ever decisions made about decedent’s care or treatment without enough input from him/her or his/her family. Does not differentiate decedent’s involvement from caregiver involvement.
67	**Y**	**Circumstances surrounding His/Her Death** /	L3M	FEPC/F3 Were there any problems with doctors or nurses not knowing enough about the	Y, N	Analogous to ADBFMI-NS/F1 Adapt by replacing patient’s with “his/her”

		Coordination of Care / Communication among professionals		patient's medical history to provide the best possible care?		
68	**Y**	**Circumstances surrounding His/Her Death /Coordination of Care** / Doctor	L3M	ADBFMI-NS/D7 Was it always clear to you which doctor was in charge of his/her care?	Y, N	Add "In the last 3 months of life" as preamble
69	**Y**	**Circumstances surrounding His/Her Death** / Caregiver Support / Information / condition	L3M	FEPC/D5 How often did the medical care team keep you or other family members informed about the patient's condition?	Always, Usually, Sometimes, Never.	Adapt. Consider if "medical care team" fits NS context. Replace "patient" with "his or her" Re: baseline ADBMFI-NS /D4 asks if doctors / nurses provided respondent with right amount of info about pt.'s medical condition.
70	**Y**	**Circumstances surrounding His/Her Death** Caregiver Support / Information / consistency	L3M	FEPC/F1 How often did someone from the medical care team give confusing or contradictory information about the patient's medical condition?	Always, Usually, Sometimes, Never.	Adapt. Consider if "medical care team" fits NS context. Suggest using "inconsistent" for "contradictory". Replace "patient" with "his or her" and drop "medical" so it reads "his/her condition"
71	**N**	**Circumstances surrounding His/Her Death** / Cultural competency	L3M	*New item.* In the last 3 months of life, how often did the health care providers respect his/her culture and customs?	Always, Most of the time; Some of the time; Never; DNA; DK	V type response options used for consistency. CV/12s uses Famcare-2 style to obtain satisfaction rating "Health care provided in a manner respectful of his/her culture, customs and faith. Spiritual/religious support would already be covered so faith would not be necessary in this item.
72	**Y**	**Circumstances surrounding His/Her Death** /Goals of Care / Preferences	L3M	ADBFMI-NS/D9 Did [Decedent] have specific wishes or plans about the types of medical treatment he/she did or did not want while dying?	Y, N-skip, DK-skip	Gatekeeper question to D10, D11, D12 Replace [Decedent] with he/she
73	**Y**	**Circumstances**	L3M	FEPC/A2 As far as you know, did any	Y, N	Analogous to ADBFMI-NS/D10

		surrounding His/Her Death /Goals of Care / Discussion		member of the medical care team speak to the patient or to a family member about the patient's wishes for medical treatment as he/she was dying. [Replace "patient" with "him/her"]		To the best of your knowledge, did [Decedent]'s doctor or the medical staff who cared for him [at location of care] speak to him/her about his/her wishes about medical treatment? Add DK response option. Replace "patient" with "him/her" Possibly replace medical care team with "doctor or medical staff". Omit ADBFMI-NS/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?
74	**Y**	**Circumstances surrounding His/Her Death** / Goals of Care / Care consistency with wishes		V/50 Were any decisions made about his* care that he* would not have wanted?	Tick one only. Y, N, DK	Partly analogous to verbal ADBFMI-N item D12 Was there any medical procedure or treatment that happened to him/her that was not in keeping with his/her previously stated wishes? Y, N C/77 adaption of Yes option—includes "please specify" and free text space. Qualitative data from baseline study may identify relevant options to avoid free text.
75	**Y**	*Opt. Suppl. Item* **Circumstances surrounding His/Her Death** / Goals of Care / Care consistency with wishes / Caregiver satisfaction	L1M	*Opt. Suppl. Item* CAN-HELP/21 How satisfied are you that the care and treatment your relative received in the <u>last month</u> of life was consistent with his or her wishes?	Not at all, Not very, Somewhat, Very, Completely	Item originally written for last month time frame. Consider preferred time frame. May be an alternative to using V/50 (any decisions made decedent would not have wanted)
76	**Y**	**Circumstances**	L3M	V/51 Overall, and taking all services into	Tick one only.	Could be adapted to use rating scale of 0

		surrounding His/Her Death / Overall rating of care		account, how would you rate his* care in the last 3 months of life?	O, E, G, F, P, DK	(worse possible) to 10 (best possible care) similar to ADBFMI-NS and CAHPS. This is the only item that includes the “Outstanding” option
77	**N**	**Circumstances surrounding His/Her Death** / Caregiver Support / Bereavement		CV/79 Since he/she died, have you talked to anyone from health and social services, or from a bereavement service, about your feelings about his/her illness and death?	Tick one only. Y; N, I was not aware of these services but I would have liked to use them; N, I was not aware of these services but I was <u>not interested</u> anyway; N, I was aware of these services but I was <u>not interested</u> anyway; Not sure.	Adapted from V/52. Changed response options to clarify awareness and interest.
78	**Y**	**Advance Care Planning** / Discussion Opportunity		CV. The following questions pertain to discussions surrounding Advance Care Planning. This is defined as planning for care in case your family member/friend is not able to make decisions about him/herself in the future. CV/80 Was he/she given the opportunity to discuss advance care planning with his/her health care providers?	Y, definitely; Y, to some extent; N he/she was not given the opportunity; DK-skip)	Analogous to verbal ADBFMI-NS item D15: While cared for at [location] did you or [decedent] discuss with a doctor or nurse (his/her) direction for health care, such as a Living will or Enduring Power of Attorney
79	**N**	**Advance Care Planning** / Discussion timing		CV/81 Did this discussion come:	Too early, Too late, At the right time; DK	
80	**Y**	*Opt. Suppl. Item* **Advance Care Planning** / Signed Enduring Power of Attorney Health Care		*Opt. Suppl. Item* ADBFMI-NS/D13 Did he/she 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?	Y, N, DK	Adapted from interview format. Recommend use ADBFMI-NS/D13 and ADBFMI-NS/D14 in place of V/43 “Did the health care staff have a record of this?” Face validity is questionable. Would respondent have knowledge of providers’ records? Knowledge of specific signed documents has more face validity.
81	**Y**	*Opt. Suppl. Item* **Advance Care Planning** / Signed Living Will or		*Opt. Suppl. Item* ADBFMI-NS/D14 Did he/she have a signed Living Will or Advanced Directive of some sort giving	Y, N, DK	Adapted from interview format.

		Advance Directive		directions for the kind of treatment he/she would want if he/she could not speak for him/her self?		
	Y	**Demographic /** Variables Collected from VS Death certificate		Date of death (VS Death Certificate) Age at death (VS Death Certificate) Gender (VS Death Certificate) Cause of death--ICD-10 code (VS Death Certificate) Location of death - (VS Death Certificate)		Note: Place (setting) of death obtained in Item V/40; proposed item 54.
82-88	Y	**Demographic /** Variables Collected from Respondent / Decedent		Marital status (ADBFMI-NS) Living alone (ADBFMI-NS) Education (ADBFMI-NS) Visible minority status (ADBFMI-NS) Ethnic/racial background (ADBFMI-NS) Language (ADBFMI-NS) Religion (V)		As noted, except no baseline data for religion.
89-94	Y	**Demographic /** Variables Collected from Respondent / Respondent (caregiver)		Relationship to decedent (ADBFMI-NS) Gender (ADBFMI-NS) Age (ADBFMI-NS) Education (ADBFMI-NS) *Optional suppl. item* Self-rated health status (ADBFMI-NS)		
95	Y	*Opt. Supple. Item* **Comments /** Good & bad care received		*Opt. Supple. Item* V/60 Please use space below if there is anything you would like to say about the care provided. What if anything was good about the care? What if anything was bad about the care? OR CV/83 What if anything was good about the care? (Tick boxes with free text space); Name up to 3 specific things you would keep about the care he/she received (free text); What if anything was bad about the care? (Tick boxes with free text space.) Name up to 3 specific things you would like to see changed about the care he/she received.	CV/83 Tick boxes: -Good aspects specified below; Nothing was good; Not sure. Followed by free text space. -Bad aspects specified below; Nothing was good; Not sure. Followed by free text space.	Or adapt to NS. Currently, the use of free text question(s) are not recommended. In the ADBMFI-NS, respondents were asked to share their experiences and suggest areas for improvement. However, this data, although collected has not been analyzed. Qualitative data from baseline study may identify whether or not free text will add value or if survey items will capture most of relevant data. The CAHPS field trial found most concerns raised in qualitative data were covered by the fixed response survey items. Additionally, the NS research study

						qualitative data, if analyzed has the potential to further inform adaptation of selected items to the NS context. Free text response options are not recommended to reduce risk to anonymity privacy concerns. Advise against collecting qualitative data unless resources are available for analysis.
		Optional Supplemental Items & Optional Modules				
		Optional Supplemental Items				
		Focus Area	**Time Frame**	**Survey Item (as written)** Survey name/survey item no.	**Response Options**	**Recommended Adaptations & Comments**
12	**N**	*Opt. Suppl. Item* **Care in the Home** / Homecare / Communication	L3M	*Opt. Suppl. Item* CAHPS/6 When your family member was in hospice care, how often did the hospice team keep you informed about when they would arrive to care for your family member? Note: US hospice care is typically delivered at home.	Never, Sometimes, Usually, Always	Adapt to read: "When he/she received home care services, how often did the home care providers keep you informed about when they would arrive to care for him/her?
19	**N**	*Opt. Suppl. Item* **Care in the Home / Caregiver Support / Information /** restlessness & agitation	L3M	*Opt. Suppl. Item* CAHPS/23 Did the hospice team give you the training you needed about what to do if your family member became restless or agitated?	Y, definitely; Y, somewhat; N	Suggest adapting by replacing "hospice team" with "health care providers"; "training" with information and "your family member" with him/her. Note: CAHPS/28 ascertains presence of restlessness & agitation. Suggest adding to response options if not using CAHPS/28: "Does Not Apply-he/she did not become restless or agitated"
20	**N**	*Opt. Suppl. Item* **Care in the Home / Caregiver Support /**	L3M	*Opt. Suppl. Item* CAHPS/30 Moving your family member includes things like helping him or her turn over in bed, or	Y, definitely; Y, somewhat; N	

		Information / Safe transfers, position changes		get in and out of bed or a wheelchair. Did the hospice team give you the training you needed about how to safely move your family member?		
24	**N**	*Opt. Suppl. Item* **Urgent Care** / Availability / Contacting Health professional	L3M	*Opt. Suppl. Item* V/7 In the last 3 months of life, when he* was at home, did he ever need to contact a health professional for something urgent in the evening or at the weekend?	Not at all-skip, Once or twice, Three or four times, Five or more times, DK	Consider modifying to read in the evening, during the weekend or on holidays. (From CV/24 & CAHPS/4)
25	**N**	*Opt. Suppl. Item* **Urgent Care ***/** Availability / Last urgent care contact / professional contacted	L3M	*Opt. Suppl. Item* V/8 The last time this happened, who did he contact, or who was contacted on his* behalf?	Lists contextually appropriate services and write-in option.	Provide NS options. CV/25 lists ON services incl. His/her family doctor or the doctor's after-hours number; His/her palliative care doctor; Homecare; Both a doctor and homecare; Hospice; (911 or used lifeline pendant); Other (no write-in option). Avoid write-in option.
26	**N**	*Opt. Suppl. Item* **Urgent Care** / Last urgent care contact / Outcome	L3M	*Opt. Suppl. Item* V/9 What happened as a result? Was he*…	Tick one only. Lists several contextually appropriate choices and Something else--please write below.	CV/26 modifies choices to ON setting, incl. Visited by his/her family doctor at home; Visited by palliative care doctor or another doctor at home; Visited by a homecare provider at home; Visited by both a doctor and homecare; Visited by hospice volunteer at home; Given medical advice over the telephone; Given another number to call for medical advice; Advised to call 911; Advised to go to an Emergency Department at a hospital; Other (no write-in option)
27	**N**	*Opt. Suppl. Item* **Urgent Care** / Outcome, last urgent care contact / Caregiver assessment	L3M	*Opt. Suppl. Item* V/10 In your opinion was this the right thing for them to do?	Y, N, Not sure	CV/287 modifies item to read "…the right thing to do or not"
33	**N**	*Opt. Suppl. Item* **Care from Family**	L3M	*Opt. Suppl. Item*	Not at all, Not very, Somewhat, Very, Completely.	Suggest adapting to a VOICES format and using "this doctor": How often was this

		Doctor or Other Doctor / Availability		CANHELP/4 How satisfied were you that the doctor(s) were available when you or your relative needed them (by phone or in person) in the last month?		doctor available (by phone or in person) when they were needed? Suggest using VOICES response options: Always, Most of the time; Some of the time; Never; DNA-doctor was not needed; DK
48	**N**	*Opt. Suppl. Item* **Experiences in the last 2 days of life** / Privacy	L2D	*Opt. Suppl. Item* V/35/c c) The bed area and surrounding environment had adequate privacy for him*		Recommend as optional item or excluding. A privacy item on CAHPS survey was dropped after the field test due to a ceiling effect & inability to distinguish variation between hospices
75	**Y**	*Opt. Suppl. Item* **Circumstances surrounding His/Her Death** / Goals of Care / Care consistency with wishes / Caregiver satisfaction	L1M	*Opt. Suppl. Item* CAN-HELP/21 How satisfied are you that the care and treatment your relative received in the last month of life was consistent with his or her wishes?	Not at all, Not very, Somewhat, Very, Completely	Item originally written for last month time frame. Consider preferred time frame. May be an alternative to using V/50 (any decisions made decedent would not have wanted)
80	**Y**	*Opt. Suppl. Item* **Advance Care Planning** / Signed Enduring Power of Attorney Health Care		*Opt. Suppl. Item* ADBFMI-NS/D13 Did he/she 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?	Y, N, DK	Adapted from interview format. Recommend use ADBFMI-NS/D13 and ADBFMI-NS/D14 in place of V/43 “Did the health care staff have a record of this?” Face validity is questionable. Would respondent have knowledge of providers’ records? Knowledge of specific signed documents has more face validity.
81	**Y**	*Opt. Suppl. Item* **Advance Care Planning** / Signed Living Will or Advance Directive		*Opt. Suppl. Item* ADBFMI-NS/D14 Did he/she have a signed Living Will or Advanced Directive of some sort giving directions for the kind of treatment he/she would want if he/she could not speak for him/her self?	Y, N, DK	Adapted from interview format.
94	**Y**	*Opt. Suppl. Item* Demographic / Respondent /		*Opt. Suppl. Item* ADBFMI-NS / N3 How would you rate your health? Would you	E, VG, G, F, P	Not used in other surveys.

		Self-rated health status		say it was …		
		Optional Modules				
		1. Visiting Palliative Care or Hospice Volunteers				
		Focus Area	**Time Frame**	**Survey Item (as written)** Survey name/survey item no.	**Response Options**	**Recommended Adaptations & Comments**
Vol-1	**N**	**Visiting Palliative Care or Hospice Volunteers /** Help from	L3M	CV/29 Did he/she get help from visiting hospice volunteer(s) in the home in the last 3 months of life?	Y, N-skip; DK	Modify to NS context to e.g.) "visiting palliative care volunteers". Place module in Care in Home section.
Vol-2	**N**	**Visiting Palliative Care or Hospice Volunteers /** Intensity	L3M	CV/30 How often did the visiting hospice volunteer(s) visit (at the most frequent time)?	More than once a day; Everyday, 2-6 times a week; Once a week; 2-3 times a month; Less than 2-3 times a month; DK	Modify to NS context to e.g.) "visiting palliative care volunteers"
Vol-3	**N**	**Visiting Palliative Care or Hospice Volunteers /** Improving quality of life, avoiding unnecessary ED visits or hospitalizations	L3M	CV/31 Indicate your opinion about the help he/she got from the visiting hospice volunteer(s) in the last 3 months of life as to the following: a) Helped improve his/her quality of life b) Helped him/her to avoid unnecessary emergency department visits or hospitalizations	For each part: Strongly agree; Agree; Neither; Disagree; Strongly Disagree; DNA; DK	Modify to NS context e.g.) "visiting palliative care volunteers". Consider if these impacts fit NS context.
		2. Care in the Home / Special Equipment				
		Focus Area	**Time Frame**	**Survey Item (as written)** Survey name/survey item no.	**Response Options**	**Recommended Adaptations & Comments**
Equip-1	**N**	**Care in the Home / Special Equipment /** need for	L3M	CAHPS Draft instrument home version / 48 Special equipment includes things like hospital beds, wheelchairs, or oxygen. While your family member was in hospice care, did your family member need special medical equipment?	Y, N-skip	Not included in CAHPS final version; deemed supplemental.
Equip-2	**N**	**Care in the Home / Special Equipment /**	L3M	CAHPS Draft instrument home version / 49 Did our family member get the equipment as soon as he or she needed it?	Y, N	Not included in CAHPS final version; deemed supplemental. Deemed little variation, ceiling effect; rarely occurring

		timely receipt				problem of great concern to families
Equip-3	**N**	**Care in the Home / Special Equipment** / timely pick up	L3M	CAHPS Draft instrument home version / 50 Was the equipment picked up in a timely manner when your family member no longer needed it?	Y, N	Not included in CAHPS final version; deemed supplemental. Deemed little variation; rarely occurring problem of great concern to families. Consider if pick up is relevant to NS.
		3. Cancer Centre				
		Focus Area	**Time Frame**	**Survey Item (as written)** Survey name/survey item no.	**Response Options**	**Recommended Adaptations & Comments**
CC-1	**N**	**Cancer Centre /** Care from	L3M	CV/38 Did he/she receive care at a cancer centre during his/her last 3 months?	Y, No-skip, DK-skip	
CC-2	**N**	**Cancer Centre /** Respect & dignity	L3M	CV/39 How often was he/she treated with respect & dignity by the staff at the cancer centre?	Always, Most of the time, Some of the time, Never, DK	
CC-3	**N**	**Cancer Centre/** Symptom Relief & Support	L3M	CV40 During the last 3 months of his/her life, while he/she was being cared for by the cancer centre, what is your assessment of the overall level of support given in the following areas: a) Relief of physical pain b) Relief of other symptoms c) Spiritual support d) Emotional support	Presented for each part E, G, F, P, DK	CV/40 is an adaptation of V/36 to the cancer centre setting (unclear if it refers to inpatient or outpatient or both) CAHPS field test eliminated proxy reports of spiritual support for greater face validity.
CC-4	**N**	**Cancer Centre /** Caregiver Support / Communication	L3M	CV/41 Did you have any worries or concerns that you were not able to discuss with the cancer centre providers?	N; Y – If Yes what were they? (free text space)	CV/41 is an adaptation of V/17 (discussion of worries & fears with GP).
CC-5	**N**	**Cancer Centre /** Collaboration / Family doctor	L3M	CV/42 Did the health care team at the cancer centre work well together with his/her family doctor?	Y, definitely; Y, to some extent; N, they did not work well together; He/she did not a family doctor; DK.	Is an adaptation of V4 for cancer centre setting
CC-6	**N**	**Cancer Centre /** Collaboration / Community	L3M	CV/43 Did the health care team at the cancer centre work well together with his/her community	Y, definitely; Y, to some extent; N, they did not work well together; He/she did not a family	Is an adaptation of V4 for cancer centre setting

		service providers		service providers (e.g. CCAC, hospice volunteers)?	doctor; DK.	
CC -7	**N**	**Cancer Centre /** Overall rating of care	L3M	CV/44 Overall, do you feel that the care he* got from the staff from the cancer centre in the last 3 months of life was:	E, G, F, P, DK	Is an adaptation of V/11, V23, etc,
		4. Financial				
		Focus Area	**Time Frame**	**Survey Item (as written)** Survey name/survey item no.	**Response Options**	**Recommended Adaptations & Comments**
Fin -1	**Y**	**Financial /** Supplemental insurance / coverage	L3M	ADBRMI-NS M7 Did [Decedent] have health insurance coverage that offered more than what the province provided?	Y, N-skip; DK-skip	Adapt: Substitute "he or she" for "decedent"
Fin -2	**Y**	**Financial /** Supplemental insurance / type	L3M	ADBRMI-NS M8 Was this a …	Private plan Employer paid plan (includes Veteran's Insurance)	
Fin -3	**Y**	**Financial /** Supplemental insurance / benefits used	L3M	ADBRMI-NS M9 Was this insurance plan used for…(mark all that apply)	Medications (drugs, etc) Health care supplies Professional to come to the home Other, specify_________	Recommend reviewing & expanding options to eliminate write in option. Check baseline results.
Fin -4	**Y**	**Financial /** Supplemental insurance / helpfulness	L3M	ADBRMI-NS M9 Was this insurance plan as helpful as you would have liked?	Y, N, DK	Consider if this is worth keeping; check baseline results.
Fin -5	**N**	**Financial /** Burden	L3M	CANHELP/19 How satisfied were you that you were able to manage the financial costs associated with your relative's illness in the last month of life?	Not at all, Not very, Somewhat, Very, Completely	Consider interpretability before retaining. To adapt replace "relative" with "his or her"; change time frame to last three months of life. Consider adapting: How well were you able to manage the financial costs…
		5. Last Hospice Admission (not yet applicable to NS)				
		Focus Area	**Time Frame**	**Survey Item (as written)** Survey name/survey item no.	**Response Options**	**Recommended Adaptations & Comments**
Hs pc-1	**N**	**Last Hospice Admission /** occurrence of	L3M	V/29 Did he stay at a hospice at any time during the last 3 months of life?	Tick one only. Y- please write name & location); N-skip; DK-skip	

Hs pc-2	**N**	**Last hospice admission** / Respect & Dignity	L3M	V/54 How often was he* treated with respect & dignity by the hospice providers (doctors and nurses)?	Always, Most of the time, Some of the time, Never, DK	CV/54 adapted this item by replacing “How much of the time” with “How often”; replaces
Hs pc-3	**N**	**Last hospice admission** / Symptom relief & support	L3M	CV40 During the last 3 months of his/her life, while he/she was in hospice, what is your assessment of the overall level of support given in the following areas: a) Relief of physical pain b) Relief of other symptoms c) Spiritual support d) Emotional support	Presented for each part E, G, F, P, DK	Adapted from V/36; replaces V31 that asks only about pain relief. CAHPS field test eliminated proxy reports of spiritual support for greater face validity.
Hs pc-4	**N**	**Last hospice admission** / Overall rating of care	L3M	V/32 Overall, do you feel that the care he* got from the staff at the hospice of life was:	E, G, F, P, DK	

Appendix E Proposed Survey Alignment with Nova Scotia's 2014 Integrated Palliative Care Strategy

Integrated Palliative Care Strategy: Planning for Action in Nova Scotia	
Framework Pillar & Selected Components	**Proposed Mortality Follow-back Survey Alignment with & Contribution to Relevant Components**
1. Integrated Service Delivery	
Access to services 24/7	Urgent Care Provided Out of Hours section can assess: Reported use of services, knowledge of who to call for issues arising out of business hours, reports of last urgent care contact including outcome (optional supplementary items) contact, and overall rating. Indirect: home visits by doctor, satisfaction with physician availability phone or in person (an optional item)
Options for sites of care	Collects data on use of home, long term, hospital sites of care in the last 3 months and last 2 days of life, and limited info on transfers. Collects ratings of symptom management & emotional and spiritual support in these settings. Extensive section on home as a site of care and formal home care provision. Data on family physician involvement or other doctors providing most care includes ratings of symptom management & emotional and spiritual support provided, satisfaction with home visits, and other availability (an optional item). Survey asks if the decedent died in the place of their expressed wishes and for caregiver's view of the setting's appropriateness. Single item rating support to stay where decedent wanted to be. Optional hospice module available if that option becomes applicable to NS. Optional module on care from Cancer Centre.
Enhanced continuing care	Includes items on long term care use and satisfaction with symptom relief, emotional & spiritual support in last 3 months of life, last 2 days of life and at death (circumstances around death).
Streamlining services	Data on caregiver ratings would be useful for monitoring changes over time.
2. Accountability	
Establishing a working group to address requirements for standardization of data collection and management.	Family/caregiver perspectives are an accepted proxy for the deceased patient given the ethical considerations that preclude collection of data from dying people. Family/caregivers provide first hand perspectives, important to evaluate the family centred approach embraced by NS. Proposed survey can be tailored to stakeholder needs.
Developing a provincial palliative care system report card.	A patient and family centred approach to palliative care requires seeking family/caregiver views to help assess the quality of EOL care that would be reported in a provincial palliative care report card. Could highlight overall ratings of care in L3M & L2D; overall ratings by specific site; and consistency of care with expressed wishes and other selected variables.
3. Family and Caregivers	
Establish a consistent process to ensure patients/family members are involved in care planning & all	Provide monitoring data (e.g. items on goals of care; preference for place of death & amount of choice; decision making involvement, consistency of care with expressed wishes)

relevant decisions	
Examine how equitable access to bereavement supports & services can be established	Providing monitoring data. Single item specific to use of, knowledge about and interest in using bereavement services. Items on help & support provided around time of death.
Develop a caregiver assessment tool to assess the unique needs and capacity of each caregiver	Outcomes concerning care in the home and caregiver support could inform development of tool. Optional Financial module is relevant.
Develop an education & training program for caregivers	Monitoring data and informing development of training. e.g.) Items on whether caregiver had enough information to give pain medications, help with breathing problems, deal with restlessness & agitation, perform safe mobility transfers; enough info about the dying process.
4. Capacity Building & Practice Change	
Establish a working group to recommend standardized training modules for health care teams	Several items may identify areas for improvement that could be addressed through education & training. Survey outcomes would be useful for monitoring progress: e.g. perceived collaboration (How well services work together; information consistency and knowledge of medical history); ratings of respect and dignity shown by doctors, nurses, home care, personal care workers; communication re ratings of care in various settings, ratings of symptom management by doctors, care of family around the time of death; provision of information to caregiver to care for family member, about their condition & dying process,
Enhance volunteer coordination and support	Optional module on Visiting Palliative Care/Hospice Volunteers--intensity of service and perceived impact.
Examine educational requirements for family caregivers & optimal methods to provide access to information	Items on enough information to manage specific aspects of care at home provide monitoring data and could inform educational program development.
Create an education program for family/caregivers relating to the care required for a loved one at all stages of disease	Items on enough information to manage specific aspects of care at home, information about dying process given to caregivers, provide monitoring data and could inform educational program development.
Develop materials for public education to build awareness & understanding	Family member caregiver survey outcomes could be useful content in public awareness campaigns. Such campaigns may also help increase response rates in an ongoing survey.
Develop advance care planning resources for providers and the public	Provides monitoring data on advance care planning opportunity and use.
Continue to support cultural competency guidelines and provide cultural safety training.	One proposed item re respect of culture and customs. Limited information for monitoring purposes.

Appendix F Survey Content Relevant to NS Palliative Care Strategy

Survey Content Pertinent to NS Palliative Care Strategy and Previous NS Findings*	Proposed NS	VOICES-SF	FAMCARE 2**	Caregiver Voice Survey¶	ADBFI (NS) §	CAHPS Hospice Care	FEHC	FEPC	CANHELP Bereave-ment	CANHELP Bereave-ment Lite
	Item No.									
Transition of care between settings	63, 64	x		x	x					
Awareness of how to access support for unexpected issues 24/7 (daytime, weekday vs nighttime, weekend)	23			x (well worded)						
Primary care level of involvement (Family Physician, Nurse Practitioner, Continuing Care)	7, 11; 29-35	x		x	x					
Primary care ability to meet palliative care needs (availability, help caring for person in home)	9, 10, 47	x	x	x	x				x	
Palliative care team level of involvement /availability, intensity of involvement in care	3, 4, 5	x	x	x	x	x	x	x		
Access to interdisciplinary care team	7	x	x	x	x					
Collaboration of interdisciplinary care team	8, 43, 67	x		x	x	x	x	x	x	x
Care providers' cultural competency	71			x						
Education & info about disease & disease process (incl. management)	15-20; 69, 70		x	x	x	x	x	x	x	x
Access to the right equipment, medication, home support (nursing, home care) $	9, 10 plus opt. equip module	x	x	x		EQ				
Use of community supports	7	H		V, SL	H					
Access to emotional support	D: 14, 34, 38, 42, 49, 59. C: 59	D	D, C	D, C	D, C	D, C	D, C	D, C	D, C	D, C
Access to spiritual support/care	D: 14, 34, 38, 42, 49, 59. C: 59	D		D	D, C	C	C	C		
Awareness of / access to bereavement support	77	x		x (well worded)	partial	x				
Caregiver needs were assessed* **				B	E, S		S	E, S		
Access to the right amount of support for self (i.e. respite)w	9, 61	P, CH, ToD	E, P	P, CH, ToD, E				E, S		
Involvement in decision making	D: 65, C: 66	D, C	C	D, C	D, C	x		D	C	C
Discussion about goals of care, patient wishes, future planning	72-75	x	x	x	x		x	x	x	x
Decedent's preferred place of death	77, 78, 79	x		x	x				x	x
Decedent's place of death	54-56	x		x	x				x	x
Caregiver's preference for decedent's place of death	57 >	>		>					x	x

***** Identified in consultation with Palliative Care Coordinator. Surveys may have items related to the content area but may differ in the specific aspects and depth explored.

******FAMCARE-2 items refers to "palliative care team"

*******items that contain wording that suggest a possible indicator of direct assessment e.g."did someone talk to you about…"

¶ Combines adapations of VOICES and FAMCARE-2.

§ Adaptation of Toolkit After-Death Bereaved Family Member Interview

X contains item or items. Items may not be equivalent across surveys

$- Items found pertain to enough help &support to care for family member at home., or pratical assistance provided. Access to medication is not directly covered. THE US Medicare CAHPS Home version tested in the field trial included 3 items on special medical equipment that were dropped in final survey. These were: needed special equipment, got it as soon as they needed it; picked up in a timely manner when no longer needed.

H services used in care at home
EQ equipment
V volunteers
SL spiritual leader
D decedent
C caregiver
B bereavement
E emotional
S spiritual
w respite care was not separately identified in any of the surveys. Proposed survey item 9 asks if enough help & support
to care for family member at home; Item 61 asks if enough help & support at time of death
P practical assistance
CH care at home
ToD time of death
> contains a related but not the exact question. Asks caregivers assessment if place of death as the right place.

Appendix F Survey Content Relevant to NS Palliative Care Strategy—specific items

Instrument	**VOICES-SF**	**FAM-CARE 2**	**Caregiver Voice Survey**	**ADBFI (Nova Scotia)**	**CAHPS Hospice Care Survey**	**Family Evaluation of Hospice Care**	**Family Evaluation of Palliative Care**	**CANHELP Bereavement Questionnaire**	**CANHELP Bereavement Questionnaire Lite**
Transition of care between settings	location of last 2 days & death--items 33, 40;		Items 73 - patient's experience of smooth transitions between settings of care in last 3 m	Items A11 determine settings of care in last 30 days; Item 11r reasons for transition to last setting					
Awareness of how to access support for unexpected issues 24/7 (daytime, weekday vs nighttime, weekend)	Does not address awareness. Addresses frequency of contact in last 3 months for urgent care/issue; contact made; outcome (visit, phone advise, advise on where to go, 911), was it the right thing for them to do?		Item 23 Well worded :Other than calling 911 or going to the ED, did decedent or you know how to contact a health professional anytime assistance was needed for an urgent problem? Incl. evenings & weekends. (Y, N, Not sure.) *does not ask who they would have called.		Does not address awareness directly. Items 4, 5 ask if needed to contact hospice team evenings, weekends, holidays & how often got the help they needed.		Does not address awareness directly. Item G2-rating of way medical care team responded to needs on evenings & weekends		
Primary care level of involvement (Fam Phys, NP, Continuing care)	Item 3 -list of service providers for care at home; Distr/comm nurse care In last 3 months: Item 12-frequency of district & community nurse involvement; Care from GP items 15-frequency of seeing GP; Item 18 ease of obtaining GP home visit in last 3 months		frequency of home care visits (item 18), frequency of visiting hospice volunteers (item 30); type of doctor providing most of the care (item 32);(no available item on freq of visits) Item 36 (ease of obtaining doctor home visit); help from several services/ providers care at home (Item 14); 12 i availability of health care providers instead of pall care teams.	IF majority of care received in home in last 30 days (incl. private res., assisted living, retirement res.): C1-did family members assist with care; C2-C4 home care agency service, provincial or private), C5-types of care provided; C6-Visiting nurse service; C9 family doc home visit, C11-famiy doc office visits during care at home. G2-who provided info on dying process; G10-who provided info on meds to manage pain & other symptoms [G2, G10 choices incl. family doctor, other doctor, nurse (not specified), etc.]					
Primary care ability to meet palliative care needs	Item 5 enough help caring for patient at home. Item 6, relief of pain at home. Items 14 & 19 ratings of district/comm nurse & GP care; Item 35 (help in the last 2 days). Item 35 enough help in last 2 days; Item 36, last 2 days level of symptom relief and spiritual, emotional support, support to stay where decedent wanted to be.	Item 1 pain relief, Item 6 speed symptoms are treated, Item 7 palliative care teams' attention to patient's description of symptoms, Item 8 the way patient's physical comfort needs are met; item 11 practical assistance provided by the pall are team (e.g. bathing, home care, respite) Item 12 doctors' attention to symptoms	Level of support for relief of symptoms, spiritual & emotional support by care site including home, family or other doctor, cancer centre, LTC, last hospital admission, hospice admission, last week of life , (items 20, 35, 40, 47, 51, 56, 61). Item 61 (last week of life) includes support in lasts week to stay where decedent wanted to be. Item 12 parts a,f, g, h, k, l, o, q (Famcare items 1, 6, 7, 8, 11, 12, 15, 16); Item 60 enough help in the last week	Could be determined by analyzing satisf re patient outcomes (pain, symptom control) and location. Not directly asked by location as in Voices or Caregiver Voice surveys. Does not ask about enough help (Voices or Caregiver Voices)				Item 17- how satisfied with home care services	
Palliative care team level of involvement/intensity of involvement in care	Items in UK context might refer to pall care teams incl. Item 3 lists of services provided for care at home; Item 12 - frequency of district & comm involvement; care from GP, items 15, & 18--frequency and ease of obtaining GP visit; Last hospital admission (Items 24-28); Last Hospice admission (Item 29-32	Q's usually refer to services delivered by pall care teams, not doctors, nurses; Item 5 meetings with pall care team to discuss pt's condition & plan of care; **Item 9 availability of pall care teams to family.** Item 15 how effectively the pall care team manages the patient's symptoms, Item 16 the palliative care team's responses to change in the patient's care needs.	Item 12 is an adaption of Famcare item 19, wherein "palliative care teams" are replaced with health care providers. Items "i" corresponds to Famcare 9, and would be assumed to refer to specialized palliative care if the respondent indicated they were responding about hospital palliative care unit in item 11. Item 32 --"palliative care doctor" is an option for type of doctor providing most care	B1-palliative care offered as an option of care; B2-received care from pall care program; B3-length of pall care involvement; B4-locations of pall care provided [added by NS]; G2-who provided info on dying process; G10-who provided info on meds to manage pain & other symptoms [G2, G10 choices incl. family doctor, other doctor, nurse (not specified), etc.]	Item 7 - when you or family member asked for help, how often did you get help as soon as you needed it? Item 5-how often did you get the help you needed on evenings ,weekends, holidays	A2-length of time patient received hospice care	A1 length of time patient received palliative care		

Instrument	VOICES-SF	FAM-CARE 2	Caregiver Voice Survey	ADBFI (Nova Scotia)	CAHPS Hospice Care Survey	Family Evaluation of Hospice Care	Family Evaluation of Palliative Care	CANHELP Bereavement Questionnaire	CANHELP Bereavement Questionnaire Lite
Access to interdisciplinary care team	Care at home section-list of services used; Item 5 -- did family get as much help & support as needed for care at home.	Item 5 -meetings with pall care team to discuss pt's condition & plan of care; Item 9 -availability of pall care teams to family	Care at home: Item 14 -list of services used Item 16 -- did family get as much help & support as needed	Items B1-4 offer of & use of specialized pall care services; C5-home care services used;					
Collaboration of interdisciplinary care team	Services working well together: Item 3 Care at home; Item 27 Last hospital admission hospital working with GP and services outside hospital		Item 15 home care services working well together; Item 43 Cancer Centre team working with comm service providers; Item 52 hospital services work well together with fam doc and other service outside hospital; Item 12 r (not in original Famcare-2; validity, reliability?) providers knowing about problems that bothered him/her and had been previously discussed.	D5-doctor or nurse gave confusing or contradictory info about pt's medical tx; F1-any problem with doctor or nurses not knowing enough about decedent's med hx to provide best possible care;	re: nursing home resident only. #32 screens for nursing home; #33 asks how often did the nursing home staff & hospice care team work well together to care for your family member.; #34-info given by nursing home staff diff than hospice team #10-did anyone give you confusing or contradictory info about fam member's condition or care?	F2-was one nurse identified as being in charge of pt's overall care	Item F1-confusing or contradictory info about pt.'s medical treatment; F2-one doctor identified as in charge; F3-problems with doctors or nurses not knowing enough about pt.'s med history to provide best possible care.	9. Knew enough about decedent's health problems to give the best possible care; 18. that health care workers worked together as a team	13. that health care workers worked together as a team
Care providers' cultural competency			1 item "s" appended to Famcare-2 [? wording]						
Education & info about disease & disease process (includes management)	Item 38 breaking the news about likelihood of death . Response option of "they did not tell him" infers lack of info about prognosis.	Item 2 - way pt condition & likely progress explained, Item 3-info about tx side effects; Item 14 info about how to manage the patient's symptoms	Item 12 b; !2 c; 12 n (Famcare-2) Item 63 breaking the news about likelihood of death; Item 82 --advance care planning section--did providers help caregiver understand what to expect, how to prepare for death.	D4-did doctors / nurses provide respondent with right amount of info about pt's medical condition; E6-did doctor or nurse or other tell respondent how pain would be treated in understandable way; (D4, E6,). G1-information about what to expect dying process , G2-who provided the info; G3-would respondent have wanted more info; G5-did respondent or family receive info on what to do at time of death; G6-who provided the info; G7-would respondent have wanted more info; G8- how confident knew what to do at time of death; G9-did respondent or family receive info about meds used to manage symptoms; G10-who provided the info; G11-would respondent have wanted more info; G12 how confident understood about meds to manage pain, SOB, other symptoms	#18-were side effects of pain med discussed with any member of hospice team? #19-did hospice team give you training you needed about what side effects to watch for from pain medicine; #20-did hospice team give you the training you needed about if and when to give more pain medication to your family member: #23-did hospice team give you the training you needed about how to help your family member if they have trouble breathing; #29-did the hospice team give you the training you needed about what to do if family member became restless/agitated? #30-training to safely move your family member; #31-info about what to expect while fam member dying; #34-info given by nursing home staff diff than hospice team	Item B3, B4-info on pain mgmt & meds; B7, B8-info on dyspnea & mgmt; D2-instruction to caregiver on doing what was needed; D5-kept informed about condition, D6 & D7 what to expect while pt dying; F1 contradictory or confusing info about tx.	Item B3, B4-info on pain mgmt & meds; B7, B8-info on dyspnea & mgmt; D2-instruction to caregiver on doing what was needed; D5-kept informed about condition, D6 & D7 what to expect while pt dying; F1 contradictory or confusing info about tx, F5-illness & likely outcomes	22. doctors explained things in honest manner. 23. doctors explained things in understandable way; 24. received consistent info about relative's condition from all docs and nurses ; 25. received updates about relative's condition, tx, lab tests in timely manner; 30. understand what to expect in last month (symptoms, comfort measures),	17. doctors explained things in honest manner.; 18. received consistent info about relative's condition from all docs and nurses
Access to the right equipment, medication, home support (nursing, home care)	item 5-care at home--enough help & support for family to care for dying family member	Item 11 -the practical assistance provided by the pall care team (e.g. bathing, home care, respite)	*meds not directly addressed Item 16 enough help & support as needed when caring for dying person		Supplemental questions re: equipment; not on final survey--did they need it? Get it as soon as it was needed? Picked up in timely manner when no longer needed?				
Use of Community supports	Care at home section		Use of visiting hospice volunteers items 29-31; Item 14 incl spiritual leader.	home care					

Instrument	VOICES-SF	FAM-CARE 2	Caregiver Voice Survey	ADBFI (Nova Scotia)	CAHPS Hospice Care Survey	Family Evaluation of Hospice Care	Family Evaluation of Palliative Care	CANHELP Bereavement Questionnaire	CANHELP Bereavement Questionnaire Lite
Access to emotional support	Decedent: Item 36d level of support to decedent in last 2 days; Respondent: Item 46 asks if respondent or family given enough help & support at actual time of death [interpretation? include emotional support?] .Item 47--providers dealing with family in sensitive way post death	Decedent: Emotional support provided to patient (item 17) Family: Emotional support provided to family (Item 10)	Decedent: level of support to patient in last 3 months at home - Item 20; by doctor - item 35; Cancer treatment centre Item 40; LTC Item 47; Hospital Item 51; Hospice Item 56, & in last week Item 61. Respondent/family: Emotional support provided to family members Item 12j; provided to patient Item 12q Item 72 asks if respondent or family given enough help & support at actual time of death [interpretation? include emotional support?] . Item 74--providers dealing with family in sensitive way post death	Patient: E14-did decedent have feelings of anxiety / sadness; E15-how much help in dealing with feelings did decedent have (less than needed, right amount; E16-who provided this help. Respondent: H5 - how well providers provided emotional support to family; L4-how much support in dealing with respondent's feelings about decedent's death (less than needed, right amount); L5-did doctor, etc. talk with respondent about how they might feel after decedent's death; L6 if No, would respondent have wanted them to.; L7-done in sensitive manner? L8-did doctor etc. suggest someone respondent could turn to for help if feeling stressed. (Item L8 could be classified as caregiver well being item)	Decedent: item 26 Did family member show any feelings of anxiety or sadness? Item 27 did they get the help they needed from the hospice team for feelings of anxiety or sadness? Caregiver: Item 37 When family member was in hospice care, how much emotional support did you get from the hospice team? Item 38 in the weeks after your family member died, did you get as much emotional support as you wanted from the hospice team?	Patient. Item B9, B10-help for anxiety, sadness. Caregiver Item E1, E2 spiritual support; E3-emotional support prior to pt. death & E4 emotional support after death	Patient. Item B9, B10-help for anxiety, sadness. Caregiver Item E1, E2 spiritual support; E3-emotional support prior to pt. death & E4 emotional support after death; F8 emotional support to family while pt receiving pall care	Decedent: 9. Compassionate & supportive of decedent Caregiver: 10. Compassionate & supportive of respondent;	Decedent: 6. Compassionate & supportive of decedent Caregiver: 7. Compassionate & supportive of respondent
Access to spiritual support/ care	Decedent: Last 2 days of life: Item 36 c spiritual support,		Last 3 months: Spiritual support Item 20 c home care, Item 35 c-care from family doctor; Item 40 c cancer tx centre; Item 47 c LTC, Item 51 c last hospital admission, Item 56 c -last hospice admission Last 2 days of life: 36 c spiritual support	Decedent: J23-do you think decedent had any interest in seeing or talking with religious or spiritual person (e.g. priest, rabbi, etc.); J24-did decedent have as much contact of this kind as wanted. Caregiver: L1-did someone talk to respondent about respondent's religious / spiritual beliefs; L2-was it done sensitively; L3-did they have as much contact as wanted;	(no decedent Q) Caregiver: (defines support) how support for religious & spiritual beliefs did you get from hospice team.	E1, E2-spiritual care	E1, E2-spiritual care		
Awareness of / access to bereavement support	Item 52 Use of service & desire for this service		Item 79; use of services, awareness & interest in such services	L4 support in dealing with feelings about decedent's death. L5-talk to you about how you might feel after the death. L6 would you have wanted them to & L7 done in sensitive manner. Items are about period before death.	Item 38 in the weeks after your family member died, did you get as much emotional support as you wanted from the hospice team?				
Caregiver needs were assessed			indirectly: Item 79 awareness & use of bereavement services (modified Voices item 52)	Emotional/spiritual: L1-did someone talk to respondent about respondent's religious / spiritual beliefs; L5-did doctor, etc. talk with respondent about how they might feel after decedent's death.		Emotional/spiritual: E1-did member of the hospice team talk with you about your religious or spiritual beliefs?	Emotional/spiritual: E1-did member of the medical care team talk with you about your religious or spiritual beliefs?		
Access to the right amount of support for self (i.e. respite)	Item 5 - help, support to care for pt at home; Item 11 practical assistance provided (e.g. bathing, respite) Item 46 support at time of death	Item 10 - emotional support provided to family members Item 11 -the practical assistance provided by the pall care team (e.g. bathing, home care, respite). [Respite would not be specifically identified as such in responses.]	Item 12j emotional support provided to family members Item 1 k practical assistance provided (e.g. bathing, respite) Item 16 - help, support to care for pt at home; 77 support at time of death;				re: Caregiver Item E1, E2 spiritual support; E3-emotional support prior to pt. death & E4 emotional support after death; F8 emotional support to family while pt receiving pall care		

Instrument	VOICES-SF	FAM-CARE 2	Caregiver Voice Survey	ADBFI (Nova Scotia)	CAHPS Hospice Care Survey	Family Evaluation of Hospice Care	Family Evaluation of Palliative Care	CANHELP Bereavement Questionnaire	CANHELP Bereavement Questionnaire Lite
Involvement in decision making	Circumstances around death section: items 48-50, decedent & caregiver	Item 5 - meetings with the pall care team to discuss the patient's condition & plan of care; Item 13- way family included in treatment & care decisions	Items 75, 76 patient and respondent involvement in decisions about care; Item 77 - decisions about care made that decedent would not want with free text field to describe. Item 12e meetings with providers to discuss condition & plan of care; Item 12m - way family included in treatment & health care decisions	F2 -was there ever a decision made about decedent's care or tx without enough input from decedent or family			A2-pt wishes, A3-care inconsistent with previously stated wishes; F7 making sure pt. died on own terms	31. respondent's role in decision making re relative's care	22. respondent's role in decision making re relative's care
Discussion about goals of care, patient wishes, future planning	Item 36e--overall level of support to stay where he wanted to be; item 44: amount of choice in place of death; items 48 & 49--decedent's & caregiver decision making involvement in last 3 months; item 50--decisions about care that would be unwanted	Item 5 - meetings with pall care team to discuss patient's condition & plan of care	Item 61--overall level of support to stay where he wanted to be; item 70: amount of choice in place of death; items 75 & 76--decedent's & caregiver decision making involvement in last 3 months; item 77--decisions about care that would be unwanted; Item 12e meetings with providers to discuss condition & plan of care. Section on Advance Care Planning Items 80-82	D9-did decedent have specific wishes or plans about types of medical tx he/she did or didn't want while dying; D10-did doctor or medical staff speak to decedent about decedent's wishes for medical tx (not asked of all if no pos response to D9); D11-did doctor or medical staff speak to decedent about making sure the care received was in keeping with wishes; D12-were there any med procedures or tx that happened that was not in keeping with previously stated wishes? D13, D14-signed Enduring POA, Living Will or Advance Care Directive; D15-decedent or respondent discussed Living Will or Enduring POA with doctor or nurse		A3-did hospice team member speak to pt or family member about pt's wishes for medical treatment as he/she was dying; G2a-hospice team explained plan of care, G2b-frequency respondent agreed to changes in plan of care. [G2 item not in FEPC).	Items A2 pt wishes and A3-care inconsistent with previously stated wishes	26. doctors listened to what respondent had to say.; 27. discussions about where relative would be cared for.; 29. discussions with doctors about use of life sustaining technologies 32. discussions with relative (while still able) about preferences for care & tx ; 33. able to talk comfortably with relative about dying & death	19. doctors listened to what respondent had to say.; 20. discussions about where relative would be cared for when condition got worse; 23. discussions with relative (while still able) about preferences for care & tx
Decedent's preferred place of death	Items 41, 42, 43, 44; Item 46 caregiver's assessment if pt died in the right place.		Items 67, 68, 69, 70. Item 71-aregiver's assessment if pt died in the right place.	A2 decedent's & respondent's knowledge of likely death; AA5 decedent's preference for place of death; A6, A7, A8 changes in decedent's preferences				2A	Item 2
Decedent's place of death	Item 40		Item 65	A1-place of death & A10 date of death				1A	Item 1
Caregiver's preference for decedent's place of death	Item 46 caregiver's assessment if pt died in the right place. ; a related but not exact question		Item 71 caregiver's assessment if pt died in the right place; a related question but not exact.					3A	Item 3

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