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Listening to Stakeholders

# **Report of Consultation on “End of Life Care in Nova Scotia Surveillance Report”**

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Network for End of Life Studies (NELS)  
Interdisciplinary Capacity Enhancement (ICE)  
Dalhousie University



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With facilitation, synthesis, and report drafting by Research Power Inc.



Finding the solution is simple when you know how



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### BACKGROUND:

The Network for End of Life Studies (NELS) is a team of Nova Scotia based researchers working to enhance interdisciplinary research capacity through collaborations aimed at improving end of life care. The specific objectives of NELS ICE are to:

- Develop a system that will enhance identification and surveillance of populations that are vulnerable at end of life.
- Design and conduct pilot studies to facilitate the development of full research proposals to examine and address vulnerability and inequity in the provision of quality end of life care.
- Engage in knowledge translation to inform decision-makers, health professionals and researchers on the provision of end of life care in vulnerable populations.
- Further build an interdisciplinary team of researchers, trainees, health professionals and community partners.

The NELS ICE **End of Life Care in Nova Scotia Surveillance Report** was the first product from the first objective. This **Listening to Stakeholders Report** is the first product from the third objective. Both reports enable and provide input into objectives two and four.

The purpose of this **Listening to Stakeholders Report** is to describe the process and present the findings of a survey and consultation designed to obtain feedback from a broad base of stakeholders on the NELS ICE **End of Life Care in Nova Scotia Surveillance Report** including suggestions for moving forward with the recommendations.

### PROCESS:

The consultation process consisted of three components including an online survey, small group consultations, and the review of the findings in this report. The survey and small group consultations had three main objectives:

- To explore issues for further research to help improve publicly funded health care services for persons dying of chronic conditions;
- To explore surveillance and monitoring information required to support policy and program development to reduce inequities and improve end of life care; and
- To reflect upon and discuss next steps for the 17 recommendations contained within the NELS ICE **End of Life Care in Nova Scotia Surveillance Report**.

### OBSERVATIONS AND CONCLUSIONS:

Key observations and conclusions from the survey and small group consultations were:

- To improve publicly funded health care services for persons dying of chronic conditions there is a need to conduct more research and gather evidence to:
  - » Obtain the perspective of patients and families about their needs for end of life care including current capacities and gaps;
  - » Define what is meant by end of life and develop an accurate description of end of life;
  - » Explore the use of and access to end of life programs and services among patients and their families;

- » Assess the cost of quality end of life care and monitor resources to improve and sustain the health care system in providing effective end of life care services;
- » Explore strategies to improve communication around the topic of end of life care which many providers, patients and families are uncomfortable discussing;
- » Explore and test assumptions among providers about what constitutes quality end of life care;
- » Determine needs and capacities related to provider knowledge, skills and education; and
- » Develop more effective knowledge translation and exchange strategies.
- Surveillance and monitoring information to support policy and program development to reduce inequities and improve end of life care include the need for more data and information on:
  - » The demographics of patients receiving end of life care;
  - » Patient and families experiences with end of life care;
  - » Who is vulnerable and the conceptualization of inequality; and
  - » Providers' awareness and knowledge related to end of life care.
- Building infrastructure to support data collection, analysis and reporting on end of life care (both qualitative and quantitative methodologies) is critically important for surveillance and monitoring, research and evidence development and knowledge translation.
- The 17 recommendations contained within the **Surveillance Report** were validated by the findings from the survey and small group consultation process with valuable feedback provided in moving forward with implementation.
- This **Listening to Stakeholders Report** helps address the third objective of NELS ICE which is to engage in knowledge translation to inform decision-makers, health professionals and researchers on the provision of end of life in vulnerable populations. The actions identified by the participants of the small group consultations provide information to help inform the work of NELS ICE and its expanding set of partners, particularly ideas and insights into future planning related to end of life care research, policy development and practice.

The **Listening to Stakeholders** process provided the opportunity for a broad base of stakeholders including researchers, advocates for vulnerable populations, care providers, managers, and policy advisors to provide input into the **Surveillance Report** and ongoing work of NELS ICE. The process was deemed a success by the NELS ICE team, informal feedback from consultation participants, and small group facilitators from several vantage points including:

- The meeting participants and survey respondents were deeply committed to exploring ways to improve access to quality end of life care as evidenced by the time and thoughtful comments they provided during the process;
- The range of expertise represented in the process surpassed the expectations of the NELS ICE team. A number of persons who had much to contribute but were previously unknown to NELS ICE team members participated as a result of being identified by the “snowball” invitation process;
- Diversity and respect for difference was apparent at many levels including the mix of policy, program, provider, advocate, research and educator attendees with a range from senior management to trainees; and the diversity of ages, ethnicities, professions, knowledge and expertise that were able to voice perspectives and be heard.



## BACKGROUND

The last few months of a person's life are often associated with an increased need for and significant utilization of health services resulting in substantial health care costs. Ideally, the focus at this time is on quality of life and supportive care. Public opinion surveys conducted in 2002 and 2003 show that 80% of Nova Scotians believe that it is critically important to have access to palliative and supportive care close to home. Unfortunately, fewer than 20% are completely satisfied with current practice, and a 2007 oncology survey found that 26% of patients wanted but did not receive information on palliative care. Given an aging population, the provision of quality care at end of life is becoming an increasing concern, and mechanisms are needed to report on the quality of end of life care, and to identify groups who are not receiving adequate levels of quality care.

The Network for End of Life Studies (NELS) is a team of Nova Scotia based researchers working to enhance interdisciplinary research capacity through collaborations aimed at improving end of life care. In 2006, a group of researchers within NELS (based at Dalhousie University, Capital Health, Cancer Care Nova Scotia and the IWK Health Centre) received funding from the Canadian Institutes of Health Research (CIHR) through a five-year (2006-2011) Interdisciplinary Capacity Enhancement (ICE) grant to help build research capacity through a systematic focus on vulnerable populations. The specific objectives of NELS ICE are to:

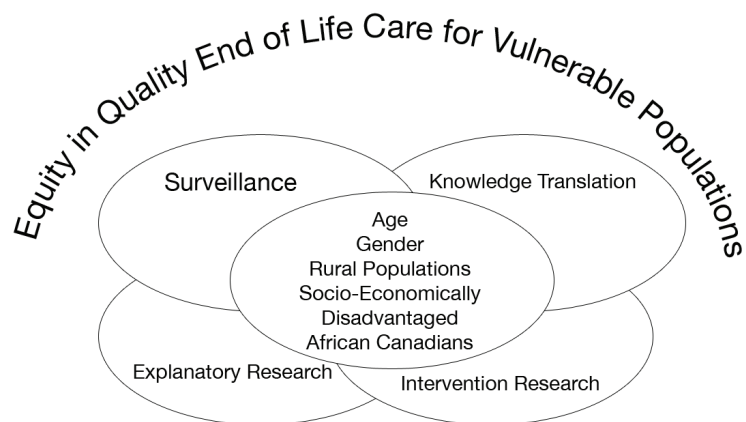
1. Develop a system that will enhance identification and surveillance of populations that are vulnerable at end of life.
2. Design and conduct pilot studies to facilitate the development of full research proposals to examine and address vulnerability and inequity in the provision of quality end of life care.
3. Engage in knowledge translation to inform decision-makers, health professionals and researchers on the provision of end of life in vulnerable populations.
4. Further build an interdisciplinary team of researchers, trainees, health professionals and community partners.

The NELS ICE **End of Life Care in Nova Scotia Surveillance Report** is the first product from the first objective. This **Listening to Stakeholders Report** is the first product from the third objective. Both reports enable and provide input into objectives two and four.

There are eight project streams within NELS ICE. NELS ICE studies are framed within four components of the research model of Baquet et al. (2002) and include surveillance, explanatory research, intervention or application research, and translation of evidence. The model is depicted in Figure 1.

The first NELS ICE project stream is to support the development of surveillance on access to quality care at end of life with a goal of working toward achieving equity for vulnerable populations. The **Surveillance**

Figure 1: Research Framework for the Network for End of Life Studies



Source: NELS ICE. (2008). End of Life Care in Nova Scotia Surveillance Report.

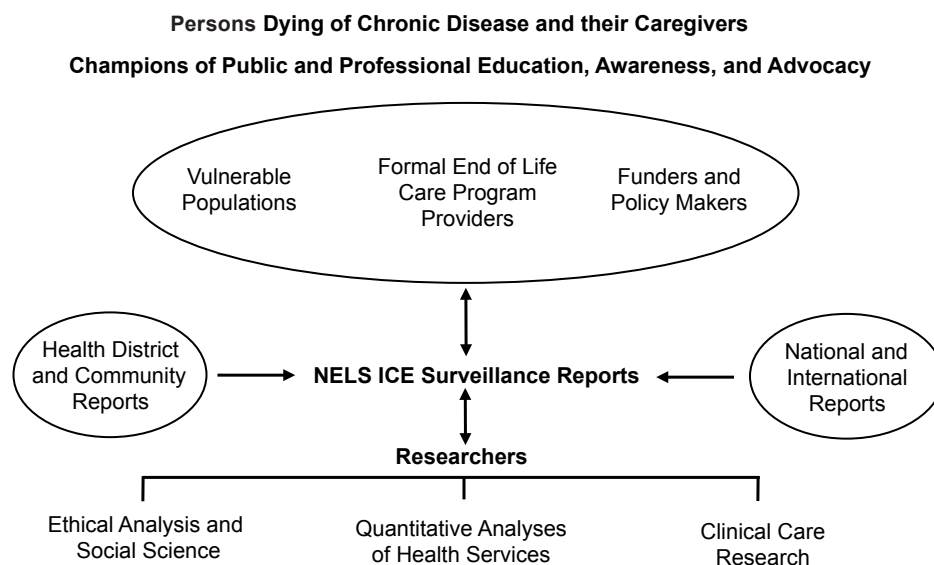
**Report** provides a template for consideration including background on end of life surveillance development with examples of indicators from extant population-based census, provincial health administrative databases, and ongoing research on retrospective measures of inequalities in care for cancer and congestive heart failure. NELS ICE surveillance objectives are to define vulnerable populations and to describe the disparities in health services use at end of life.

## OVERVIEW OF NELS ICE END OF LIFE CARE IN NOVA SCOTIA SURVEILLANCE REPORT

The NELS ICE **End of Life Care in Nova Scotia Surveillance Report** contains nine chapters and seventeen recommendations. A brief overview of each chapter is provided below.

Chapter One provides an introduction to the problem of end of life care as well as contextual information. The conceptual framework and approach of NELS ICE is presented. Figure 2 outlines the NELS ICE stakeholder consultation approach which forms a basis for this **Listening to Stakeholders Report**.

Figure 2: NELS ICE Surveillance Report in relation to its Contributors and Audience



Source: NELS ICE. (2008). End of Life Care in Nova Scotia Surveillance Report.

Chapter Two focuses on defining and describing vulnerable populations. Variables such as age, sex and gender; race, ethnicity, language and culture; and socio-economic status are explored.

Chapter Three provides data on the burden of death and dying for seven major chronic diseases – both current statistics as well as future projections. The importance of co-morbidities is also highlighted.

Chapter Four focuses on health service utilization noting potential inequities in access to care. Information on care available, utilization by persons dying of cancer including palliative care programs, utilization by persons dying of congestive heart failure, and costing are reviewed.

Chapter Five reviews indicators of quality care including variables such as location of death, family physician continuity of care and home visits, timing of palliative care program enrolment, and emergency visits.

Chapter Six provides a description of public policies to support care giving with a focus on the compassionate care benefit.

Chapter Seven describes current activities in building awareness among health care workers and the public about end of life care, and notes that there appears to be a lack of general awareness of end of life care issues within the wider community. A review of palliative care education in Nova Scotia universities and community colleges is provided. It is noted that there has been recent attention to educating health professionals, although continued efforts are needed.

Chapter Eight features the African Canadians in Nova Scotia by providing a more in-depth understanding of what is known and the research that is currently being undertaken. Although no specific recommendations are made, the development of cultural competence in end of life care is the theme.

Chapter Nine provides the conclusion and recommendations on developing research and surveillance to aid in understanding and improving access to end of life care. It is noted that more work is needed conceptualizing and defining end of life and vulnerable populations, and ongoing developmental work will help to further build surveillance and research capacity.

## PURPOSE OF THE LISTENING TO STAKEHOLDERS REPORT

The purpose of this **Listening to Stakeholders Report** is to describe the process and present the findings of a survey and consultation designed to obtain feedback from stakeholders on the NELS ICE **End of Life Care in Nova Scotia Surveillance Report**. In addition to an overview of the **Surveillance Report**, the current report describes the survey and consultation process, findings, and key observations and conclusions.

Numerous documents have been produced locally, nationally, and internationally on palliative and end of life care. Therefore, it is important to note the purposes and value of this report. Dimensions in the **Surveillance Report** that go beyond most other palliative and end of life care reports include the focus on: 1) identifying vulnerable populations (most at risk) for inadequate care, 2) exploring and conceptualizing end of life care surveillance methods using examples, and 3) making recommendations for building research to inform improvements in quality care. Since these are relatively new areas of consideration, it is quite important to carry out a stakeholder consultation process with a report documenting this step. Hence, the production of this **Listening to Stakeholders Report**.

This report does not directly advise on health care and system changes. Rather, this report documents the process of welcoming dialogue on the recommendations in the NELS ICE **Surveillance Report** and records the feedback received on further research and surveillance that should be considered. In other words, this report provides transparency into the NELS ICE knowledge exchange that occurred in mid 2008. Furthermore, the consultation process was a key means of informing and providing stakeholders with an opportunity for dialogue prior to the official media release of the **Surveillance Report** which is a key step in effective knowledge exchange so that all potential partners are provided with the open opportunity to work together.

This report process helps fulfill the NELS ICE objective of translating emerging end of life care research knowledge into practice. The **Listening to Stakeholders** process was developed to invite in and listen to feedback on building research and surveillance capacity to improve equity in access to quality end of life care for vulnerable populations. Spokespersons for vulnerable populations, formal care providers, researchers, educators, and decision makers who have fiduciary authority were engaged in focused dialogue around the **Surveillance Report** recommendations.

By having these diverse champions dialogue together, new opportunities for improving access to quality end of life care for all persons dying of chronic diseases have emerged since the consultation itself. For example, the fall of 2008 has seen growth in research development for end of life care in nursing homes, for children and youth, and among vulnerable population, as well as data and research development for a range of chronic diseases leading to death, and evolution and depth in the conceptualization of vulnerability. Furthermore, through enabling ongoing advocacy, the need for improved end of life care is kept in the spotlight, and provides momentum and direction for positive change in end of

life care across within Nova Scotia and elsewhere.

The goal of NELS ICE is to enhance the capacity for research, surveillance and the application of this new knowledge in order to reduce inequities and improve end of life care. Sustainability of this research and surveillance development is an important component. Thus, NELS ICE aims to ensure that the work being carried out is both relevant and useful. Formal mechanisms for interaction with others in Nova Scotia, such as this **Listening to Stakeholders** process, are critical.

Knowledge exchange is a key component of NELS ICE. The consultation process leading to this **Listening to Stakeholders Report** has been an important forum for building awareness and networking particularly within the Halifax area of Nova Scotia.

## OVERVIEW

A consultant, Stephanie Heath of Research Power Inc., was contracted to support a consultation process to obtain feedback from stakeholders on the NELS ICE **End of Life Care in Nova Scotia Surveillance Report**. The consultation process consisted of three components to raise awareness and invite dialogue: an online survey, small group consultations, and review of the report findings, which are described below.

## SURVEY

### *Survey Development*

A draft survey developed by Grace Johnston, the principal investigator (PI) of the NELS ICE initiative was reviewed and refined by the consultant and Fred Burge, NELS ICE co-PI. The survey consisted of three main objectives:

- To explore issues for **further research** to help improve publicly funded health care services for persons dying of chronic conditions (an open ended question);
- To explore **surveillance and monitoring** information required to support policy and program development to reduce inequities and improve end of life care (an open ended question); and
- To gain input on the 17 recommendations contained within the NELS ICE **End of Life Care in Nova Scotia Surveillance Report** (close ended rating and open ended comments).

Appendix 1 provides a copy of the survey.

### *Survey Administration*

The persons to whom the survey was sent were selected by the principal investigators of the NELS ICE initiative who developed a list of potential respondents based on involvement in NELS and end of life care. They represented a broad base of stakeholders including researchers, advocates for vulnerable populations, care providers, managers, and policy advisors. The survey was sent to 159 potential respondents. A snowball technique was used whereby these respondents were asked to send the survey to other potential respondents.

The survey was administered online through Survey Monkey. Potential respondents were sent a link to the survey with a cover letter explaining its purpose. Two weeks after the first email, a reminder email was sent out to complete the survey. At the June 13th consultation meeting, participants were reminded to complete the survey and access to the survey was left open until June 27th, 2008.

The timing of the survey turned out to be very unfortunate. The survey was launched just as the Nova Scotia Department of Health notified all health sector employees across the province to not participate in Survey Monkey questionnaires. The NELS ICE investigators and consultant had no prior knowledge that this was to occur. A number of persons informed the NELS ICE team that this was the reason that they could not participate in the survey.

### *Survey Analysis*

Frequencies and descriptive statistics were calculated for the responses to the close-ended questions, i.e., the ratings of the recommendations. The mean ratings are presented in the main body of this report with frequencies presented in table format in Appendix 2.

The responses to the open-ended questions on the survey were analyzed using content and thematic analysis. The survey findings were synthesized with the feedback received from the small group consultations with common themes identified. Verbatim quotations from survey respondents are used to illustrate the findings.

## GROUP CONSULTATION

### *Small Group Process and Participants*

The second strategy to obtain input into the **Surveillance Report** was consultation with key stakeholders. The individuals that were sent the survey were also invited to attend a half day meeting to provide input into the Report. Many attended this session rather than participate in the survey. Thirty-nine people registered for the meeting and 31 individuals attended including researchers, advocates for vulnerable populations, care providers, managers and policy advisors. Appendix 3 is a list of attendees. After a presentation that provided a review of the key findings of the **Surveillance Report**, meeting participants worked in four small groups to provide feedback on the recommendations for research and surveillance in the **Surveillance Report**.

Each group had a pre-determined facilitator and recorder to guide the discussion, ensure the group stayed focused on the task and included the range of perspectives of the attendees, and record the group discussion.

The consultant hired to support the design of the small group consultation met with the facilitators and recorders, prior to the meeting to review the process, provide direction and answer any questions. The consultant took notes during the opening presentation (prior to the small group consultation) and during the feedback session (when each facilitator provided highlights of their group discussion). Coffee and food were available at 8:30 AM and mid-morning, but otherwise no monetary or other incentives were provided to attendees.

### *Questions for the Small Group Consultations*

An interview guide was used to facilitate the small group discussion (see Appendix 4). The first two questions that were contained within the survey (i.e., What are the most critical issues and questions that you believe need further research evidence to help improve publicly funded health care services for persons dying of chronic conditions? What surveillance and monitoring information is needed to support policy and program development to reduce inequities and improve end of life care?) were asked during the small group discussions. Following a discussion of these two questions, each group reviewed four of the 17 recommendations and reflected upon the next steps in moving forward with the implementation of each recommendation (one group reviewed five recommendations). Meeting participants self selected into the four recommendation-based groups.

### *Large Group Report Back and Discussion*

Following the small group discussion, the facilitator from each group reported back to the larger group on the highlights of the feedback received about next steps in moving forward with each recommendation. This provided meeting participants with the opportunity to hear a synthesis of the feedback provided on all recommendations. In addition, after the report back of each facilitator, meeting participants were welcomed to comment, clarify or add to the feedback provided.

The meeting closed with a process where participants prioritized the recommendations. Each meeting participant was given three dots and asked to “vote” for what they felt were the top priority recommendations. Participants could vote for up to three recommendations, or they could place two or three dots on one recommendation if they preferred.

The consultant then met immediately after the meeting with the NELS ICE team to reflect on the process. All agreed that there was open, positive, and informed dialogue from a range of highly committed persons representing a wide spectrum of interests and expertise. The consultation process was deemed highly successful.

### *Synthesis of Discussion During Small Group Consultations*

The notes from the recorders of each small group as well as notes taken during the feedback session were reviewed and synthesized by the consultant. A synthesis was completed of the feedback for the first two questions. The findings from the survey were synthesized together with the findings from the small group discussions. Verbatim quotations from the notes from the recorders were used to help illustrate the findings. It is important to note that these are not verbatim quotations from participants but rather from the notes of the recorders who were recording the feedback. A synthesis of findings from the feedback for each recommendation in terms of next steps for moving forward was completed.

## **REVIEW OF THE LISTENING TO STAKEHOLDERS REPORT**

The consultant drafted the **Listening to Stakeholders Report** and sent the draft to the NELS ICE principal investigator for review and feedback on July 15th. In late July, the report was then circulated to all consultation meeting attendees for their review, as well as to the NELS ICE Management Committee of which four of the five members attended the consultation process. The eight facilitators and recorders were part of the group asked to review this report. Feedback was obtained from two individuals. In August and September, the consultant incorporated the feedback from these two individuals to finalize this report.

### *Process Limitations*

The survey and group consultation process provided feedback from a relatively small number, but influential group, of stakeholders. Enabling knowledge exchange among champions from different sectors was as or more important than attaining classic measures of rigor in qualitative and quantitative research. The NELS ICE team acknowledges that they are novices in the application of knowledge exchange processes, and are not as yet at the point of being experts in knowledge exchange research. Thus, this consultation and survey process should be viewed as pilot and feasibility testing of a knowledge exchange approach.

Only fifteen surveys were completed and returned from the over 150 being sent out. A snowball technique was used therefore the exact number distributed is not known. As with the survey, over 150 stakeholders were invited to participate in the consultation meeting with 31 attending. Since confidentiality of survey respondents was maintained, it is not known how many individuals who completed the survey also attended the consultation. Awareness of NELS ICE work was raised through the survey and consultation process among persons who did not complete the survey or attend the consultation. The full extent of this increased awareness is unknown.

The consultation process was not designed to rigidly follow a rigorous qualitative research process. Ideal research practice was balanced with participatory goals and adult learning processes. The facilitators guided but did not restrict or stringently limit the flow or boundaries of the small group dialogue. Relationship building and emergent knowledge exchange among participants were important components of the small group process. Therefore, tape recording and transcribing of the small group sessions were not incorporated in the consultation process. NELS ICE staff and research investigators were the recorders who took notes during the discussions. The notes provided for the synthesis in this report were in point form and lacked the detailed discussion on the points raised. While research ideals framed the development of the consultation, rigor in research design and process details was sacrificed as noted above to provide for more natural relationship building and knowledge sharing than typically occurs in a research project process.

### *Process Strengths*

This Listening to Stakeholders process is one aspect of longer term and more comprehensive NELS ICE knowledge exchange efforts. Reflection on an earlier stage of knowledge exchange (Surveillance Report development) has been carried out (Urquhart et al, 2008). A further forum for knowledge exchange will be at and after the official media launch of the Surveillance and Listening to Stakeholders reports. In addition, approximately six work-in-progress sessions are held in Halifax each year. A growing list of persons are invited to these sessions at which typically ten to twenty persons discuss a topic in more depth. Graduate students and clinical trainees along with researchers and others are continuously

being welcomed into ongoing developments. National and international connections are also occurring through Visiting Scholar events and presentations at a range of conferences most recently including the 17th International Congress on Palliative Care in Montreal in September 2008 (Johnston et al 2008a) and the Canadian Hospice Palliative Care Conference in Charlottetown in October 2008 (Johnston et al 2008b). Thus, the **Listening to Stakeholders Report** is only one snapshot in a larger process of engaging an expanding circle of stakeholders through a range of NELS ICE activities and projects.

This Listening to Stakeholders process tests the viability and value of approaches for knowledge exchange, networking and team building. It is also being used to scan for and welcome opportunities to enable longer term sustainability of the CIHR funded NELS ICE capacity development initiatives.



The findings from the survey and consultation process are grouped into areas where further research and evidence is required, surveillance and monitoring information needs, and feedback on the recommendations in the NELS ICE **Surveillance Report**. Within each of the areas, emerging themes are identified that relate to issues and questions that require further exploration. This chapter concludes with observations on the knowledge exchange process that go beyond the report of the survey and consultation findings.

## ISSUES AND QUESTIONS THAT REQUIRE FURTHER RESEARCH EVIDENCE

On the survey and during the small group consultations, participants were asked about the most critical issues and questions that require further research evidence to help improve publicly funded health care services for persons dying of chronic conditions. There was consistency between the findings from the survey and small group consultations in terms of critical issues and questions identified by participants. The major themes that emerged were:

- The perspective of patients and families;
- An accurate description of end of life;
- Use of and access to end of life programs and services;
- Funding for and the cost of quality end of life care;
- Communication issues; and
- Provider knowledge, skills and education.

Each of these themes is described in greater detail below.

### *The Perspective of Patients and Families*

A key theme that emerged on the survey and during the small group consultations was the need for more research to obtain the perspective of patients and families about what is needed to improve programs and services for those dying of chronic conditions. This research should include an exploration of what patients and their families need in terms of programs and services for end of life, what is currently available to meet these needs, and gaps in programs and services and the impact of these gaps.

*Is there adequate support in the community for someone to remain at home to die as assessed by those who have been through it? Where do they feel improvements should be made?*  
(Survey response)

*Follow back studies where you interview families after a loved one has died are particularly important [to obtain their perspective on programs and services].* (Small group response)

In one small group, participants discussed the importance of tailoring services to meet the unique needs of the individual and their families. Another group noted that program and service needs will vary based on diverse factors such as culture and the meaning of quality of life to individuals.

During another small group discussion, the importance of obtaining the public's view about end of life care was discussed. The participants in this group emphasized the importance of obtaining a better understanding about the public's understanding of end of life care and what they want to know about end of life care, expectations of end of life support and palliative care, and perceptions of a "good death".

*Knowledge on the public's perspective will be useful; what is their perspective on a "good" death.* (Small group response)

One of the small groups discussed the importance of obtaining the needs of children about end of life care and developing

measures to record children's wishes.

*We don't know what children want; where do they want to die. This might change over time; e.g., from childhood to adolescence. (Small group response)*

### *An Accurate Description of End of Life*

The importance of further research to help better define what is meant by end of life was a consistent theme revealed through the findings of the survey and discussed in three of the small groups. Questions and areas identified for further exploration include:

- What is the end of life period and how is it identified?
- When does an individual become terminal and what constitutes end of life?
- How do you identify when someone is dying of a chronic condition?
- What chronic conditions are individuals dying from?
- How do we identify the transition from a patient living with a chronic condition to a patient being at end of life?
- When is the beginning of end of life?

*There is virtually no research examining the patient's and family's perspectives on transitioning from being a person with a life threatening disease to a person dying of that disease. (Survey response)*

*Just because one cannot write a prescription, does not mean care giving ends. (Small group response)*

### *Use of and Access to End of Life Programs and Services*

Consistently discussed in three of the four small groups and on the survey was the importance of obtaining more data about individuals' and their families' use of programs and services such as what services are being utilized and what are not; when services need to shift as individuals reach end of life; who is referred to palliative care (and are children referred to palliative care); who are not accessing services and why; and what are the differences between rural and urban areas in terms of access and quality of services provided.

One small group focused on the importance of exploring inequities in end of life care including access to programs and services. Issues discussed included: coverage for medications; ability to obtain medications; availability of nursing care; access to home care; differences in the availability of programs and services by community including rural and urban settings e.g., in some communities patients receive intravenous therapy at home whereas in other communities they do not; emergency access to medications in rural settings can be challenging as they lack 24/7 coverage to pharmacy services; and access to care for certain populations such as children.

*Retrospectively assess those who don't access services [to determine why they are not accessed] – Do they want to? Do they know about them? Were they denied access or did they not need the service? What services has a person consumed [or used] (hospital, long term care, home)? Where and how? Is a palliative care facility available in the community? Are there barriers to access? Is there access to a pharmacy 24/7? (Small group response)*

Another group discussed the importance of developing a better understanding of who wants home based care at end of life and how best to provide these home based services.

### *Funding for and Cost of End of Life Programs and Services*

A finding from the survey was the importance of further researching the cost of end of life quality care and the need for funding to improve and sustain the health care system in providing effective end of life care services. Survey respondents noted the importance of determining a cost effective way to provide quality end of life care, and advocating for more funding so programs and services are offered equally and adequately for each patient at end of life.

*We need to record the negative impact that lack of supportive services (financial, practical and emotional) have on caregivers (family members and friends) giving care at home and in long term care or hospital settings. This information should then be used to push for funding for services that decrease negative outcomes for caregivers. (Survey response)*

*The most critical issue is the lack of surveillance of the need for, use of, and costs of palliative and end of life care services. (Survey response)*

### *Communication Issues*

All four of the small groups discussed challenges related to patient and provider assumptions about end of life. It was noted that patients and their families and providers are often uncomfortable discussing end of life care and communication about end of life care is complex. Many individuals such as providers and families refuse to make the transition from curative to palliative care as they do not want to appear to give up hope and prefer to focus on curative care. It was noted in a couple of the small groups that this may prevent the introduction of end of life and palliative care at the right time, i.e., earlier in a patient's care.

*We need markers of the shift to palliative care from curative care in children. (Small group response)*

*Professionals don't want to talk about end of life...they send junior doctors to get DNR [Do Not Resuscitate] information at the worst timing. (Small group response)*

One group noted that there are varying assumptions about end of life care among providers including what constitutes quality care.

*GPs [General Practitioners] have their assumptions on good care for patients, which are not necessarily shared with other care givers such as nurses, specialists, long term care facility workers, and family members. (Small group response)*

### *Provider Knowledge, Skills and Education*

One of the small groups discussed the fact that research is required to better understand both the capacities and needs of providers in end of life care. Participants of this group generally felt that there is a lack of expertise among providers in providing quality end of life care and a lack of education for providers in this aspect of health care, e.g., there is a lack of understanding of the distinctions in types of care at end of life such as home care versus palliative care. Concern was also expressed about a lack of expertise and practical knowledge and skills among educators about end of life and palliative care.

*Despite a long tradition of interest in end of life care, specific training in this field is largely inadequate. (Small group response)*

*Levels of education among educators are questionable and most health professionals are not well trained to provide proper end of life care. (Small group response)*

## SURVEILLANCE AND MONITORING INFORMATION NEEDS

On the survey and during the small group consultations, participants were asked what surveillance and monitoring information is needed to support policy and program development to reduce inequities and improve end of life care. There was consistency in the findings from the survey and small group consultations in terms of requirements for surveillance and monitoring. The major themes identified include:

- Patient demographics;
- Patient experiences with end of life care;
- The conceptualization of inequality;
- Data infrastructure; and
- Provider awareness and knowledge.

Each of these themes is described in greater detail below.

### *Patient Demographics*

A consistent theme on both the survey and during the consultations was the need for more information related to the demographics of patients receiving end of life care. Survey responses included the need for data on the type of diseases patients have at end of life including co-morbidities, causes of death, and place of death where patients receive care, i.e., what setting. A consistent theme during the small group consultations and also identified on the survey was the need for data about vulnerable populations including variables such as race, ethnicity, language, and culture.

*Review yearly the deaths in Nova Scotia and the percentage of cancer versus non cancer with a clear plan to partner with other specialists in chronic illnesses to assist in the understanding of our complimentary role in the patient care plan. (Survey response)*

*To what extent does the health system accommodate cultural difference – comprehensiveness of diversity is increasing in Canada – how far is the system willing to go? (Small Group response)*

One small group discussed the importance of obtaining more information on the needs of children including exploring the needs of various age groups, e.g., the very young to adolescence, and the transition stage when children are moving to adult care.

*Do we differentiate between the ages of children? People in this age group [children and youth] are a possible vulnerable group. At what point do children have the right to determine their care? (Small Group response)*

### *Patient Experiences with End of Life Care*

Patient and family experiences with end of life care was a consistent finding from both the survey and small group discussions. Information about symptom distress; grieving; challenges experienced by patients and their families; barriers and gaps in programs and services; and patient and family needs is required to support policy and program development to reduce inequities and improve end of life care.

*Need to assess the needs of elderly in their own home and the challenges/access burden that they have in providing their own care or that of a loved one. (Survey response)*

*Reports from individuals and their caregivers who are experiencing dying and palliative care services. First voice accounts of their experiences. This would need to be done through a reporting system that included all areas of the province and a population sample representative of those actually receiving care. (Survey response)*

### *The Conceptualization of Inequality*

During the small group discussions and on the survey it was consistently identified that information about who is vulnerable (or likely to be vulnerable) is required. One group indicated that this can be measured both quantitatively (identify predefined categories) and qualitatively (measure from the perspective of people who are in the categories identified as vulnerable). A couple of groups discussed the importance of ensuring a holistic approach when looking at who is vulnerable and issues related to inequity.

*There is a lack of a holistic look at what is happening. Research typically only examines one area or variable and forgets everything else. (Small Group response)*

*Determine what constitutes inequity in different contexts (for different populations, locations, services, etc.) and what can and should be done to rectify these. (Survey response)*

Related to inequities is the need for information on access to programs and services including why some people are not accessing services, who is utilizing programs and services. It was noted that “not assessed for services” is not equivalent to “no utilization”.

*How do population characteristics relate to inequitable access? What does “vulnerable population” mean? (Small Group response)*

*Just because something is there, people may not be able to access it. There may be systematic determinants for this that should be measured. Are there reasons within and across populations? (Small Group response)*

### *Data Infrastructure*

A consistent finding on the survey and during the small group discussions was the need to build data collection, analysis and reporting infrastructure. Specifics discussed include the need for: provincial databases; systems to enable linkages between care providers such as primary care, long term care facilities and emergency rooms, as well as linkages between jurisdictions, e.g., provincial, national and international; human resources to support data collection and monitoring; and a system or processes to review data and plan. The importance of operational definitions and common variables to support linkages and coordination was also discussed during the small groups.

*Better data capture for our population, i.e., integration with FP [family physician] office electronic health systems, long term care facilities electronic systems. (Survey response)*

*A dedicated research team who are able to report yearly to a Provincial Director for Palliative Care. (Survey response)*

Two of the small groups discussed challenges in developing data collection infrastructure and supporting more effective linkages including policies and guidelines related to data protection and privacy.

*Concern about the privacy of data – the new act restricts collection and use. (Small Group response)*

One small group identified the need to continue to build databases and expand information related to end of life care, e.g., symptoms and stage of illness.

### *Provider Awareness and Knowledge*

The survey findings and discussion from one group revealed the importance of obtaining more information about providers’ knowledge of end of life care and the system, e.g., the referral process.

*Family physicians do not necessarily know the system of end of life care. It is important to grasp*

*the state of family physicians' knowledge and also useful information is the variation of family physicians' practice on referrals to palliative care and other related end of life care. (Small Group response)*

*Need to look at the education needs for the end of life in the LTC [Long Term Care] facilities. (Survey response)*

### *Policy and Knowledge Exchange*

One respondent on the survey identified the need for policy research and information about the knowledge translation and exchange process to ensure data and evidence is effectively informing practice.

*We need to assess what policies exist and the congruence between policy and actual practice. Studies need to be performed to assess policy effectiveness and recommend strategies of knowledge translation to ensure optimum practice. (Survey response)*

## **FEEDBACK ON THE RECOMMENDATIONS**

During the small group consultations each group reviewed four recommendations (one group reviewed five) and provided feedback in terms of the next steps in moving forward with implementation. The recorders for each of the four groups summarized salient points in these discussions. In a separate process, the survey participants were provided the opportunity to give open ended comments on each recommendation. A synthesis of the feedback from the recorder notes and survey responses is provided below for each of the seventeen **Surveillance Report** recommendations.

The comments do not always show a direct connection to the recommendation itself. This is particularly true for recommendations that relate to the work of NELS ICE researchers that is new to or less easy for a general audience to fully understand. In depth explanations of these forms of research were not provided during the consultation process. Even though the consultation participants may not have fully appreciated the intent of the recommendation, their comments indicate that they remained involved in the review and consultation process and took the opportunity to share issues and ideas that were very important to them.

*Recommendation #1: In dialogue with others, continue to refine and develop comprehensive conceptual frameworks that help elucidate dimensions of vulnerability, disparities, and inequities in access to and receipt of quality end of life care.*

*Apply statistical analysis and mathematical models to explore issues such as dependent and independent variables, confounding variables, and controlling variables, e.g., is living in a rural area related to accessing palliative care through the hospital, home, etc.*

*Recommendation #2: Produce further reports that openly share and critique ideas and examples from research that challenge and extend the way we think about access to quality end of life care.*

*Once potential vulnerable groups are identified and if variability in access is found, dialogue with these groups to ensure the measures make sense to them (prescriptive indicators should not be used; it is better to determine which indicators are universal, which are specific/unique to certain populations and which ones need modification to fit with other groups; for example, a community with greater internal end of life care may not use palliative care services as often and may incorrectly appear to lack access through quantitative analysis).*

*In developing methodological reports ensure these are disseminated and shared; we need to communicate what is being done to ensure that we are building on and furthering work in this area.*



*Recommendation #3: Work with others so that worthwhile aspects of end of life care surveillance, quality indicator reporting, knowledge exchange, and improved access to quality end of life care for vulnerable populations become sustainable.*

Continue to support meetings where end of life care researchers, providers and decision-makers are sharing to build awareness and understanding about end of life care and key issues, e.g., dialoguing about key issues such as exploring needs within vulnerable populations, identifying indicators, exploring if various disease trajectories have different access to palliative care, and exploring issues within the pediatric population which is often ignored in terms of end of life care.

Develop and implement advocacy strategies to raise awareness and understanding among the public and providers about end of life care.

*Recommendation #4: Design and carry out population-based studies to better understand the needs of children and youth and the elderly as well as factors associated with sex and gender so that we can better discern where access to quality care may be sub-optimal and interventions can be designed to help improve care at end of life.*

Explore the identification of indicators and the creation of markers of transition from curative to palliative care to support more effective care planning - this is often a challenging area, particularly for children, as providers and patients often do not want to accept palliative care and also do not want to discuss end of life care.

*Recommendation #5: Improve our ability to identify factors associated with race, ethnicity, language, and culture that may adversely influence end of life care provision or, conversely, learn from these groups about ways and means to potentially improve care for all.*

Identify groups considered to be vulnerable and involve these diverse groups and communities in formulating the research questions, recognizing that supports are critical when using a participatory approach.

Conduct exploratory research using qualitative and mixed methods (exploratory research is needed before quantitative studies can begin) to identify the factors that may adversely influence end of life care provision and to also learn from groups about their experiences and ways to improve end of life care.

Build community capacity recognizing the unique context of diverse populations and communities, building on and sharing strengths.

Check assumptions around language and terminology, e.g., researchers may assume that a group is vulnerable but they may not perceive themselves as being vulnerable.

*Recommendation #6: Gain a better understanding of the costs associated with end of life care in rural and urban areas with particular attention to persons living in communities where household incomes may compromise access to quality care.*

There is a need to further define “costs” such as what costs (e.g., system costs, palliative care program costs, support care, provincial versus federal program costs, public versus private sector, etc.) and from whose perspective (e.g., Department of Health, volunteers, etc.).

Ensure an economist is on the team when exploring costing and economic analysis.

Explore costing inequities including disparities between those living in rural and urban areas, e.g., fewer options are available in rural areas and travel costs are greater.

Explore psychosocial and financial costs to family members providing care in the home, and there is also a need to assess if the care provided is adequate.

Explore the cost of end of life care to care givers versus the savings to the system.

Explore costs using a gender lens.

*Recommendation #7: Expand the clinical breadth of the research team so that we can gain a better understanding of end of life care issues for persons dying of chronic diseases other than cancer and including co-morbidities.*

There is a need to move to symptom based care rather than our current focus on disease, and a need to focus on treating the person not the disease, e.g. breathlessness is a major issue and needs to be addressed whether the disease is congestive heart failure or chronic obstructive pulmonary disease.

There is a need for greater clarity on co-morbidities (what are co-morbidities) and which combination of diseases need to be examined.

Explore who is disproportionately affected by chronic disease.

There are some major chronic diseases that affect many, e.g., heart disease, diabetes, and cancer, but it is also important to explore less common chronic conditions that impact certain populations, such as sickle cell anemia.

*Recommendation #8: In partnership with end of life providers, improve the classification of end of life care.*

The language issue needs to be addressed, clarified and resolved.

Synthesize what is known about end of life and palliative care classifications and definitions into discussion papers (begin work with the best classifications and test these).

*Recommendation #9: Provide a broader understanding of the role of the hospital for end of life care including delineating the in-patient services that are critical for symptom control and terminal care; the role of the emergency department, intensive care unit, and alternate care needs; and the relationships between the use of hospital services and alternative community care, e.g., substitution and available options.*

Explore the link between the emergency room (ER) and primary care system related to the provision of end of life care including more effective information sharing to improve quality care, and perceptions of end of life and palliative care among primary care and emergency room providers.

Explore the role of hospitals in the provision of palliative and end of life care including what programs and services hospitals should be providing.

*Recommendation #10: Continue to explore the use of the SEA (single entry access) MDS (minimum data set) home and long-term care data including an examination of its potential for recording palliative symptom assessment.*

Explore opportunities for collaboration on further end of life care MDS SEA data development



processes (e.g., documentation, data collection, quality indicators) to help reduce the burden of data collection and to help ensure consistent data collection across SEA, palliative care programs, long term care facilities, and other datasets, e.g., currently the SEA MDS database does not incorporate palliative care information and is not part of long term care facility documentation of client care over time.

Develop recommendations for end of life care MDS development across relevant datasets, share these with appropriate individuals and advocate for streamlining data collection processes.

Explore collaborations with the Canadian Institute for Health Information (CIHI) re: MDS for continuing care and explore work underway in British Columbia.

Explore opportunities to conduct a patient satisfaction survey for researching palliative symptom assessment.

*Recommendation #11: Encourage the development of palliative care service databases across the province with common data fields and definitions.*

The development of palliative care service databases across the province with common data fields and definitions is currently underway (through the Nova Scotia Hospice and Palliative Care Association); however, these are not standardized and the content and quality of data vary across district health authorities.

Support the continued development of palliative care service databases including the identification of a minimum standard for data collection as well as the identification of priorities.

Explore the use of databases to help ensure support and buy-in for data collection including how the data can be used for research purposes.

Explore issues related to bereavement (in end of life care in general) as well as the development of databases.

*Recommendation #12: Further examine the role of long-term care facilities in the provision of end of life care.*

Explore barriers to access to long term care facilities (e.g., why are some referred and others not?) including provider awareness and understanding of available services and programs, referral practices, etc.

In exploring the role of long term care facilities in the provision of end of life care, conduct ethnographic and qualitative studies to assess the care givers' role in the provision of care (versus studies that rely on documentation).

Provide education to build awareness of palliative care programs and services in long term care facilities, and build research capacity within long term care facilities.

*Recommendation #13: Carry out multivariate statistical analyses to test hypotheses and control for confounding and interaction among variables to provide a more rigorous understanding of resources used to provide end of life care.*

Identify key variables to be explored (what are the priorities in terms of indicators) and recognize the challenges with data, e.g., ecological data may be available; however, individual data is not available – and ecological data assumes that individuals are like their community.

Explore the supports provided for end of life care in First Nations communities (link with the Tui'kn Initiative in Cape Breton that has a common data base as well as the Native Council that has a project in Truro).

Explore what is happening in primary care to develop a better understanding of resources, programs and services used to provide end of life care, e.g., what is being done for symptom management, what are the available community services and programs.

Compile an inventory of end of life care programs and services (e.g., District Health Authority programs and services, provincial services, volunteer services, etc.) – a mapping of services in districts and communities. [These programs and services could be included in a database that can be used to enable surveillance and research as well as incorporated into multivariate analyses such as distance to services.]

*Recommendation #14: While gaining insights from other countries and Canadian provinces, continue to contribute to the further development of population-based surveillance of quality care at end of life.*

In contributing to the further development of population-based surveillance of quality care at end of life, explore work underway in First Nations Communities and other populations that have not traditionally been examined, e.g., military, RCMP.

Support the development of common definitions and issues to report on across provinces to enable the creation of a common structure for reporting across provinces, which will help to ensure comparable data.

Explore what is currently in place related to population-based surveillance of quality care at end of life and identify gaps.

*Recommendation #15: Use prospective study designs, as well as retrospective methods, to begin to examine the optimal sequences and combinations of end of life care provision given variations in needs and the timing of the identification of these needs to improve access to quality end of life care.*

While there is the need for further studies and the implementation of appropriate study designs, e.g., randomized control trials, there are currently many studies and applying the findings is required.

Explore the implementation of a survey with care providers to assess their experience with end of life care needs (including gaps in programs and services) and use a prospective study design to follow these individuals and their experiences over time.

A key issue in the provision of quality end of life care that meets the needs of patients and their families is communication, including communication between providers and their patients, and among providers.

*Recommendation 16: Promote the development of a sustainable province-wide end of life care surveillance system to plan how best to provide quality end of life care, evaluate programs, monitor care, and carry out research to enable the provision of cost-effective equity in care at end of life.*

Link with the [proposed] Health Policy Research Centre (HPRC) to help provide the development of a sustainable province-wide end of life care surveillance system.

Develop and implement advocacy strategies to ensure the development of a sustainable province-wide end of life care surveillance system (there is a need to build awareness of end of

*life care needs within the HPRC).*

*Involve provincial representatives who work in database development to ensure end of life variables are included in surveillance systems.*

*Recommendation #17: Assist providers of professional and public education to help ensure this research is accessible for translation into evidence-based practice.*

*Support the transfer and exchange of knowledge related to end of life care through educating providers of professional and public education about what evidence is available, creating a database of information that can be accessed online, creating a list serv, etc.*

*Develop strategies to ensure more effective coordination and linkages in the delivery of end of life education.*

## **RATINGS ON THE RECOMMENDATIONS**

To provide the Network for End of Life Studies (NELS) a sense of the priorities in terms of the 17 recommendations from the **Surveillance Report**, survey respondents were asked to rate the recommendations on a five point likert scale in terms of their importance (1 being low and 5 being high). In addition, at the consultation meeting, participants were provided with dots to “vote” on the recommendations that they felt were the highest priority (often called dotmocracy). Each participant was given three dots to “vote” and the process was very flexible, i.e., participants could put all three dots on one recommendation or choose their top three priorities by placing one dot on each priority.

The process of rating the recommendations was not to limit or constrain the future focus of NELS ICE research but rather to give the NELS ICE team and its expanding set of partners, information to help with future planning related to end of life care research, policy development and practice. For example, lower scores may indicate a need for greater clarity, discussion, and further explanation of the recommendation rather than implying that the recommendation is low priority. Higher scores may indicate perceived severity of a problem in the field.

Both the rating and voting processes have limitations including a relatively small sample size of survey and meeting participants, and in the case of the dotmocracy, ability for participants to place all dots on one recommendation.

Table 1 provides the mean rating of the recommendations from the survey and the results of the “dotmocracy”. Appendix 2 provides a more detailed summary of the findings from the survey including the frequencies for each category. The findings in Table 1 and Appendix 2 should not be generalized to imply meaning beyond a recording of the views expressed at a point in time using specific methods to raise awareness of issues and engage stakeholders in dialogue that can “snowball” into further knowledge exchange and actions led by the participants. They are a documentation of the process of sharing perspectives, rather than the quantitative scores being of broad interpretive importance.

All recommendations received relatively high support by the survey participants (rated 3.8 or higher out of 5). Three mean scores below 4.0 were related to: conceptualization, classification, and multivariate statistical analysis, which are often areas of importance to researchers advancing knowledge but not typically well understood beyond the research community. Dotmocracy “0” votes should not be interpreted that the recommendation is not important. Rather, the recommendation was not seen as a priority by the consultation attendees. Similarly, the higher scores reflect the perspectives of the attendees, not necessarily a wider audience that will be reviewing the **Surveillance Report** in the months and years ahead.

**TABLE 1: MEAN RATINGS AND “DOTMOCRACY” VOTES ON SURVEILLANCE REPORT RECOMMENDATIONS**

<b>Recommendation</b>	<b>Mean Rating (from survey)</b>	<b># of Votes (from dotmocracy)</b>
<b>Recommendation 1</b> In dialogue with others, continue to refine and develop comprehensive conceptual frameworks that help elucidate dimensions of vulnerability, disparities, and inequities in access to and receipt of quality end of life care.	3.9	0
<b>Recommendation 2</b> Produce further reports that openly share and critique ideas and examples from research that challenge and extend the way we think about access to quality end of life care.	4.3	1
<b>Recommendation 3</b> Work with others so that worthwhile aspects of end of life care surveillance, quality indicator reporting, knowledge exchange, and improved access to quality end of life care for vulnerable populations become sustainable.	4.5	3
<b>Recommendation 4</b> Design and carry out population-based studies to better understand the needs of children and youth and the elderly as well as factors associated with sex and gender so that we can better discern where access to quality care may be sub-optimal and interventions can be designed to help improve care at end of life.	4.3	3
<b>Recommendation 5</b> Improve our ability to identify factors associated with race, ethnicity, language, and culture that may adversely influence end of life care provision or, conversely, learn from these groups about ways and means to potentially improve care for all.	4.1	9
<b>Recommendation 6</b> Gain a better understanding of the costs associated with end of life care in rural and urban areas with particular attention to persons living in communities where household incomes may compromise access to quality care.	4.4	4
<b>Recommendation 7</b> Expand the clinical breadth of the research team so that we can gain a better understanding of end of life care issues for persons dying of chronic diseases other than cancer and including co-morbidities.	4.4	8
<b>Recommendation 8</b> In partnership with end of life care providers, improve the classification of end of life care.	3.9	5
<b>Recommendation 9</b> Provide a broader understanding of the role of the hospital for end of life care including delineating the in-patient services that are critical for symptom control and terminal care; the role of the emergency department, intensive care unit, and alternate care needs; and the relationships between the use of hospital services and alternative community care, e.g., substitution and available options.	4.5	5
<b>Recommendation 10</b> Continue to explore the use of the SEA (single entry access) MDS (minimum data set) home and long-term care data including an examination of its potential for recording palliative symptom assessment.	4.1	2

Recommendation	Mean Rating (from survey)	# of Votes (from dotmocracy)
<b>Recommendation 11</b> Encourage the development of palliative care service databases across the province with common data fields and definitions.	4.5	5
<b>Recommendation 12</b> Further examine the role of long-term care facilities in the provision of end of life care.	4.1	1
<b>Recommendation 13</b> Carry out multivariate statistical analyses to test hypotheses and control for confounding and interaction among variables to provide a more rigorous understanding of resources used to provide end of life care.	3.8	5
<b>Recommendation 14</b> While gaining insights from other countries and Canadian provinces, continue to contribute to the further development of population-based surveillance of quality care at end of life.	4.1	0
<b>Recommendation 15</b> Use prospective study designs, as well as retrospective methods, to begin to examine the optimal sequences and combinations of end of life care provision given variations in needs and the timing of the identification of these needs to improve access to quality end of life care.	4.1	2
<b>Recommendation 16</b> Promote the development of a sustainable province-wide end of life care surveillance system to plan how best to provide quality end of life care, evaluate programs, monitor care, and carry out research to enable the provision of cost-effective equity in care at end of life.	4.3	4
<b>Recommendation 17</b> Assist providers of professional and public education to help ensure this research is accessible for translation into evidence-based practice.	4.6	3

## ADDITIONAL OBSERVATIONS

Since the knowledge exchange process was more important than this report, rigor in the application of ideal research methodology was balanced against enabling a rich discourse amongst a range of strategic players who for the most part were placed in groups of persons who had limited or no previous knowledge of each other. At the end of the consultation process, many freely commented on how useful and rewarding the exchange had been. They indicated that the meeting itself was valuable and that time together shaped their thinking.

A number of one-to-one meetings occurred in the weeks and months after this consultation meeting. Common interests were identified amongst very committed people who had never met before. Although they were all located in the same geographic area, they operated primarily within different sectors: research, government, care delivery, advocacy, and education.

## 4 KEY OBSERVATIONS AND CONCLUSIONS

Key observations and conclusions from the survey findings and small group consultations were:

- To help improve publicly funded health care services for persons dying of chronic conditions there is a need to conduct more research and gather evidence to:
  - » Obtain the perspective of patients and families about their needs for end of life care including current capacities and gaps;
  - » Define what is meant by end of life and develop an accurate description of end of life;
  - » Explore the use of and access to end of life programs and services among patients and their families;
  - » Assess the cost of quality end of life care and monitor resources to improve and sustain the health care system in providing effective end of life care services;
  - » Explore strategies to improve communication around the topic of end of life care which many providers, patients and families are uncomfortable discussing;
  - » Explore and test assumptions among providers about what constitutes quality end of life care;
  - » Determine needs and capacities related to provider knowledge, skills and education; and
  - » Develop more effective knowledge translation and exchange strategies.
- Surveillance and monitoring information to support policy and program development to reduce inequities and improve end of life care include the need for more data and information on;
  - » The demographics of patients receiving end of life care;
  - » Patients' and families' experiences with end of life care;
  - » Who is vulnerable and the conceptualization of inequality; and
  - » Providers' awareness and knowledge related to end of life care.
- Building infrastructure to support data collection, analysis and reporting on end of life care (both qualitative and quantitative methodologies) is critically important for surveillance and monitoring, research and evidence development, and knowledge translation.
- The 17 recommendations contained within the **Surveillance Report** were validated by the findings from the survey and small group consultation process with valuable feedback provided in moving forward with implementation. This **Listening to Stakeholders Report** addresses the third objective of NELS ICE which is to engage in knowledge translation to inform decision-makers, health professionals and researchers on the provision of end of life in vulnerable populations. The actions identified by the participants of the small group consultations provide information to help inform the work of NELS ICE and its expanding set of partners, particularly ideas and insights into future planning related to end of life care research, policy development and practice.

The **Listening to Stakeholders** process provided the opportunity for a broad base of stakeholders including researchers, advocates for vulnerable populations, care providers, managers, and policy advisors to provide input into the **Surveillance Report** and ongoing work of NELS ICE. The process was deemed a success by the NELS ICE team, informal feedback from consultation participants, and small group facilitators from several vantage points including:

- The meeting participants and survey respondents were deeply committed to exploring ways to improve access to quality end of life care as evidenced by the time and thoughtful comments they provided during the process;
- The range of expertise represented in the process surpassed the expectations of the NELS ICE team. A number of persons who had much to contribute but were previously unknown to NELS ICE team members participated as a result of being identified by the "snowball" invitation process;

- Diversity and respect for difference were apparent at many levels including the mix of policy, program, provider, advocate, research and educator attendees with a range from senior management to trainees; and the diversity of ages, ethnicities, professions, knowledge and expertise that were able to voice perspectives and be heard.

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## APPENDIX 1: SURVEY

**1. Introduction**

Researchers associated with the Network for End of Life Studies (NELS) have been funded through an Interdisciplinary Capacity Enhancement (ICE) Vulnerable Populations grant provided by the Canadian Institutes for Health Research (CIHR) to help build research and surveillance capacity to reduce inequities and improve end of life care.

The NELS ICE research team received funding from CIHR in 2006, and is in the process of producing their first surveillance report entitled, "End of Life Care in Nova Scotia Surveillance Report". The pre-release version of the report is available at [www.nels.dal.ca](http://www.nels.dal.ca). While this report is Nova Scotia based, we are seeking input from informants in Nova Scotia as well as across Canada and other countries that are likely to be facing similar questions in the development of palliative and end-of-life care research and surveillance.

The NELS ICE research team is seeking the input of a broad base of stakeholders such as researchers, advocates for vulnerable populations, care providers, managers and policy advisors into a review of the Surveillance Report and its recommendations. As the NELS ICE research team continues its work in building capacity and infrastructure to support end of life care, input from stakeholders such as yourself is critical to help the team in their ongoing work.

Prior to completing this questionnaire, please review the NELS ICE "End of Life Care in Nova Scotia Surveillance Report" which is available at [www.nels.dal.ca](http://www.nels.dal.ca). The Executive Summary is on pages 3-5 and the 17 recommendations are listed on pages 51-53.

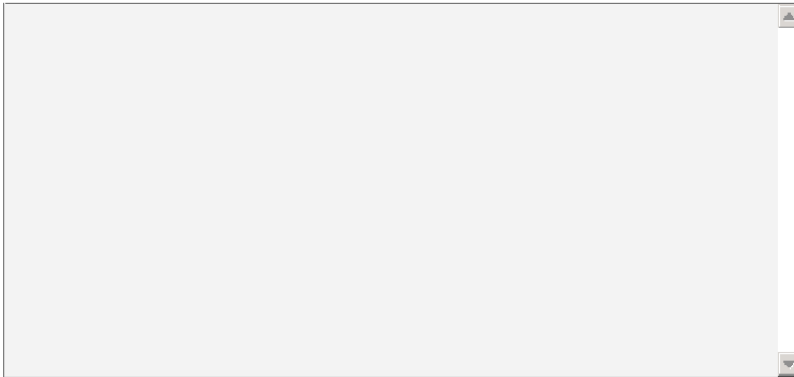
This questionnaire is designed to be completed anonymously. Please do not include any personal identifiers, such as your name, anywhere on this questionnaire. Please feel free to skip any questions that you do not want to answer or stop the questionnaire at any point. To ensure confidentiality, the results of the questionnaires will be reported in aggregate form. The questionnaire should take approximately 15 minutes to complete.

The questionnaires are being compiled and analyzed by an independent research and evaluation consulting firm.

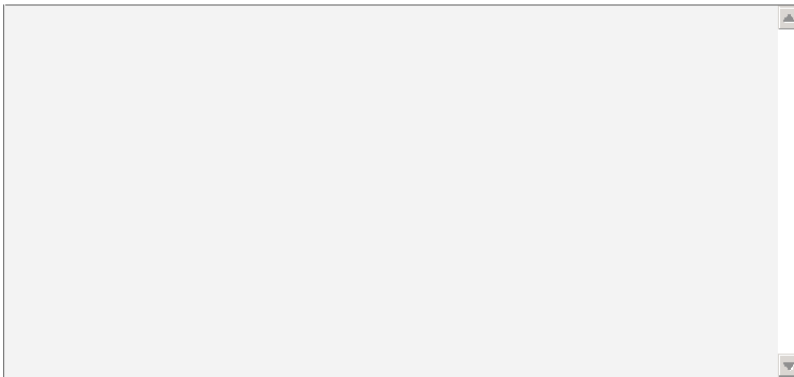
Thank you for taking the time to complete this questionnaire.

**2.**

**1. What are the most critical issues and questions that you believe need further research evidence to help improve publicly funded health care services for persons dying of chronic conditions?**



**2. What surveillance and monitoring information is needed to support policy and program development to reduce inequities and improve end of life care?**



### 3.

Please rate the importance of each the 17 recommendations in the NELS ICE Surveillance Report on a scale from 1 (low) to 5 (high), from your perspective. Add comments to help us understand the basis for your ranking.

Frameworks and Knowledge Exchange

**3. Recommendation 1: In dialogue with others, continue to refine and develop comprehensive conceptual frameworks that help elucidate dimensions of vulnerability, disparities, and inequities in access to and receipt of quality end-of-life care.**

☐ 1 (low)

☐ 2

☐ 3

☐ 4

☐ 5 (high)

Comments

**4. Recommendation 2: Produce further reports that openly share and critique ideas and examples from research that challenge and extend the way we think about access to quality end-of-life care.**

☐ 1 (low)

☐ 2

☐ 3

☐ 4

☐ 5 (high)

Comments

**5. Recommendation 3: Work with others so that worthwhile aspects of end-of-life care surveillance, quality indicator reporting, knowledge exchange, and improved access to quality end-of-life care for vulnerable populations become sustainable.**

☐ 1 (low)

☐ 2

☐ 3

☐ 4

☐ 5 (high)

Comments

Vulnerable Populations

**6. Recommendation 4: Design and carry out population-based studies to better understand the needs of children and youth and the elderly as well as factors associated with sex and gender so that we can better discern where access to quality care may be sub-optimal and interventions can be designed to help improve care at end-of-life.**

☐ 1 (low)

☐ 2

☐ 3

☐ 4

☐ 5 (high)

Comments

**7. Recommendation 5: Improve our ability to identify factors associated with race, ethnicity, language, and culture that may adversely influence end-of-life care provision or, conversely, learn from these groups about ways and means to potentially improve care for all.**

☐ 1 (low)      ☐ 2      ☐ 3      ☐ 4      ☐ 5 (high)

Comments

**8. Recommendation 6: Gain a better understanding of the costs associated with end-of-life care in rural and urban areas with particular attention to persons living in communities where household incomes may compromise access to quality care.**

☐ 1 (low)      ☐ 2      ☐ 3      ☐ 4      ☐ 5 (high)

Comments

Burden of the Death and Dying

**9. Recommendation 7: Expand the clinical breadth of the research team so that we can gain a better understanding of end-of-life care issues for persons dying of chronic diseases other than cancer and including co-morbidities.**

☐ 1 (low)      ☐ 2      ☐ 3      ☐ 4      ☐ 5 (high)

Comments

Health Service Utilization

**10. Recommendation 8: In partnership with end-of-life care providers, improve the classification of end-of-life and palliative care.**

☐ 1 (low)      ☐ 2      ☐ 3      ☐ 4      ☐ 5 (high)

Comments

**11. Recommendation 9: Provide a broader understanding of the role of the hospital for end-of-life care including delineating the in-patient services that are critical for symptom control and terminal care; the role of the emergency department, intensive care unit, and alternate care beds; and the relationships between the use of hospital services and alternative community care, e.g., substitution and available options.**

☐ 1 (low)      ☐ 2      ☐ 3      ☐ 4      ☐ 5 (high)

Comments

**12. Recommendation 10: Continue to explore the use of the SEA (single entry access) MDS (minimum data set) home and long-term care data including an examination of its potential for recording palliative symptom assessment.**

☐ 1 (low)

☐ 2

☐ 3

☐ 4

☐ 5 (high)

Comments

**13. Recommendation 11: Encourage the development of palliative care service databases across the province with common data fields and definitions.**

☐ 1 (low)

☐ 2

☐ 3

☐ 4

☐ 5 (high)

Comments

**14. Recommendation 12: Further examine the role of long-term care facilities in the provision of end-of-life care.**

☐ 1 (low)

☐ 2

☐ 3

☐ 4

☐ 5 (high)

Comments

**15. Recommendation 13: Carry out multivariate statistical analyses to test hypotheses and control for confounding and interaction among variables to provide a more rigorous understanding of resources used to provide end-of-life care.**

☐ 1 (low)

☐ 2

☐ 3

☐ 4

☐ 5 (high)

Comments

Indicators of Quality Care

**16. Recommendation 14: While gaining insights from other countries and Canadian provinces, continue to contribute to the further development of population-based surveillance of quality care at end-of-life.**

☐ 1 (low)

☐ 2

☐ 3

☐ 4

☐ 5 (high)

Comments

**17. Recommendation 15: Use prospective study designs, as well as retrospective methods, to begin to examine the optimal sequences and combinations of end-of-life care provision given variations in needs and the timing of the identification of these needs to improve access to quality end-of-life care.**

☐ 1 (low)

☐ 2

☐ 3

☐ 4

☐ 5 (high)

Comments

**18. Recommendation 16: Promote the development of a sustainable province-wide end-of-life care surveillance system to plan how best to provide quality end-of-life care, evaluate programs, monitor care, carry out research, and enable the provision of cost-effective equity in care at end-of-life.**

☐ 1 (low)

☐ 2

☐ 3

☐ 4

☐ 5 (high)

Comments

Education and Awareness

**19. Recommendation 17: Assist providers of professional and public education to help ensure equity in access to quality end-of-life care research is accessible and translates into evidence-based practice.**

☐ 1 (low)

☐ 2

☐ 3

☐ 4

☐ 5 (high)

Comments

**4.**

**20. What other recommendations should be included if we are to appropriately build surveillance and research capacity to produce the evidence needed to attain equity in the provision of quality end of life care for all persons dying of chronic conditions across Nova Scotia and beyond?**

**5.**

Please answer the following two questions to help us understand the perspective from which you answered the previous questions

**21. Please check off all of the following which apply to you:**

- ☐ Graduate student or other Trainee
- ☐ Researcher
- ☐ Advocate for vulnerable population(s)
- ☐ Provider of care to persons at end of life
- ☐ Manager or policy advisor associated with palliative care provision
- ☐ Other (please specify)

**22. What is the primary focus of your geographic area?**

- ☐ Halifax
- ☐ Nova Scotia, outside of Halifax
- ☐ Other Canadian province or other country

## APPENDIX 2: SURVEY RATINGS OF RECOMMENDATIONS

Recommendation	1 (low)	2	3	4	5 (high)	Average
<b>Recommendation 1:</b> In dialogue with others, continue to refine and develop comprehensive conceptual frameworks that help elucidate dimensions of vulnerability, disparities, and inequities in access to and receipt of quality end of life care. (n=15)	0% (n=0)	0% (n=0)	20.0% (n=3)	66.7% (n=10)	13.3% (n=2)	3.9
<b>Recommendation 2:</b> Produce further reports that openly share and critique ideas and examples from research that challenge and extend the way we think about access to quality end of life care. (n=15)	0% (n=0)	0% (n=0)	0% (n=0)	66.7% (n=10)	33.3% (n=5)	4.3
<b>Recommendation 3:</b> Work with others so that worthwhile aspects of end of life care surveillance, quality indicator reporting, knowledge exchange, and improved access to quality end of life care for vulnerable populations become sustainable. (n=15)	0% (n=0)	0% (n=0)	13.3% (n=2)	20.0% (n=3)	66.7% (n=10)	4.5
<b>Recommendation 4:</b> Design and carry out population-based studies to better understand the needs of children and youth and the elderly as well as factors associated with sex and gender so that we can better discern where access to quality care may be sub-optimal and interventions can be designed to help improve care at end of life. (n=14)	0% (n=0)	0% (n=0)	14.3% (n=2)	42.9% (n=6)	42.9% (n=6)	4.3
<b>Recommendation 5:</b> Improve our ability to identify factors associated with race, ethnicity, language, and culture that may adversely influence end of life care provision or, conversely, learn from these groups about ways and means to potentially improve care for all. (n=15)	0% (n=0)	0% (n=0)	13.3% (n=2)	66.7% (n=10)	20.0% (n=3)	4.1
<b>Recommendation 6:</b> Gain a better understanding of the costs associated with end of life care in rural and urban areas with particular attention to persons living in communities where household incomes may compromise access to quality care. (n=15)	0% (n=0)	13.3% (n=2)	0% (n=0)	20.0% (n=3)	66.7% (n=10)	4.4
<b>Recommendation 7:</b> Expand the clinical breadth of the research team so that we can gain a better understanding of end of life care issues for persons dying of chronic diseases other than cancer and including co-morbidities. (n=15)	0% (n=0)	0% (n=0)	6.7% (n=1)	46.7% (n=7)	46.7% (n=7)	4.4
<b>Recommendation 8:</b> In partnership with end of life care providers, improve the classification of end of life and palliative care. (n=15)	0% (n=0)	6.7% (n=1)	26.7% (n=4)	33.3% (n=5)	33.3% (n=5)	3.9



Recommendation	1 (low)	2	3	4	5 (high)	Average
<b>Recommendation 9:</b> Provide a broader understanding of the role of the hospital for end of life care including delineating the in-patient services that are critical for symptom control and terminal care; the role of the emergency department, intensive care unit, and alternate care beds; and the relationships between the use of hospital services and alternative community care, e.g., substitution and available options. (n=15)	0% (n=0)	6.7% (n=1)	6.7% (n=1)	20.0% (n=3)	66.7% (n=10)	4.5
<b>Recommendation 10:</b> Continue to explore the use of the SEA (single entry access) MDS (minimum data set) home and long-term care data including an examination of its potential for recording palliative symptom assessment. (n=15)	0% (n=0)	0% (n=0)	20.0% (n=3)	46.7% (n=7)	33.3% (n=5)	4.1
<b>Recommendation 11:</b> Encourage the development of palliative care service databases across the province with common data fields and definitions. (n=15)	0% (n=0)	0% (n=0)	6.7% (n=1)	40.0% (n=6)	53.3% (n=8)	4.5
<b>Recommendation 12:</b> Further examine the role of long-term care facilities in the provision of end of life care. (n=15)	0% (n=0)	6.7% (n=1)	13.3% (n=2)	46.7% (n=7)	33.3% (n=5)	4.1
<b>Recommendation 13:</b> Carry out multivariate statistical analyses to test hypotheses and control for confounding and interaction among variables to provide a more rigorous understanding of resources used to provide end of life care. (n=14)	0% (n=0)	0% (n=0)	35.7% (n=5)	50.0% (n=7)	14.3% (n=2)	3.8
<b>Recommendation 14:</b> While gaining insights from other countries and Canadian provinces, continue to contribute to the further development of population-based surveillance of quality care at end of life. (n=15)	0% (n=0)	0% (n=0)	20.0% (n=3)	46.7% (n=7)	33.3% (n=5)	4.1
<b>Recommendation 15:</b> Use prospective study designs, as well as retrospective methods, to begin to examine the optimal sequences and combinations of end of life care provision given variations in needs and the timing of the identification of these needs to improve access to quality end of life care. (n=14)	0% (n=0)	7.1% (n=1)	21.4% (n=3)	21.4% (n=3)	50.0% (n=7)	4.1
<b>Recommendation 16:</b> Promote the development of a sustainable province-wide end of life care surveillance system to plan how best to provide quality end of life care, evaluate programs, monitor care, carry out research, and enable the provision of cost-effective equity in care at end of life. (n=15)	0% (n=0)	0% (n=0)	13.3% (n=2)	40.0% (n=6)	46.7% (n=7)	4.3

Recommendation	1 (low)	2	3	4	5 (high)	Average
<b>Recommendation 17:</b> Assist providers of professional and public education to help ensure equity in access to quality end of life care research is accessible and translates into evidence-based practice. (n=14)	0% (n=0)	0% (n=0)	0% (n=0)	42.9% (n=6)	57.1% (n=8)	4.6

### APPENDIX 3: MEETING CONSULTATION PARTICIPANTS

Name	Position	Company/Organization
Michelle Baker	Manager	Department of Medicine, Capital Health
Fred Burge	Professor	Department of Family Medicine, Dalhousie University
Alyson Currie	Caregiver Support Coordinator	Caregivers Nova Scotia
Sharon Davis–Murdoch	Diversity & Social Inclusion Health Policy Advisor	Nova Scotia Department of Health
David Emmett	Research Coordinator	NELS ICE
Lorraine Etter	Health Policy Analyst	Atlantic Policy Congress of First Nations Chiefs Secretariat
Pamela Fancey	Associate Director and Research Associate	Nova Scotia Centre on Aging, Mount Saint Vincent University
Eva Grunfeld	Director	Cancer Outcomes Research Program, CCNS
David Henderson	Palliative Care Physician	Colchester East Hants Health Authority
Grace Johnston	Professor	School of Health Administration, Dalhousie University
Julie LaChance	Senior Policy Analyst	Health Policy Branch, Health Canada
Bev Lawson	Research Associate	Department of Family Medicine , Dalhousie University
Sara Limpert	Health Policy Analyst	Health Canada – Atlantic
Grace MacConnell	Clinical Nurse Specialist	Pediatric Palliative Care Service , IWK Health Centre
Peter MacDougall	Manager	Capital Health Integrated Palliative Care Service
Victor Maddalena	Assistant Professor	School of Health Administration, Dalhousie University
Suha Masalmeh	MHA Student	School of Health Administration, Dalhousie University
Paul McIntyre	Head of Palliative Medicine	Capital Health Integrated Palliative Care Service
Ann McKim	Board Director	N.S. and Canadian Hospice Palliative Care Association
Gael Page	Past President	Canadian Hospice Palliative Care Association
Patricia Randel	Research Associate	Pediatric Palliative Care Service, IWK Health Centre
Holly Richardson	Assistant Professor	School of Nursing, Dalhousie University
Graeme Rucker	Professor and Director	Respirology, Faculty of Medicine, Dalhousie University
Elsie Rolls	Director	Veterans Services, Capital Health
Sheila Scaravelli	Palliative Care Coordinator	Nova Scotia Department of Health
Grace Warner	Assistant Professor	School of Occupational Therapy, Dalhousie Univ
Yoko Yoshida	Research Associate	Department of Community Health and Epidemiology, Dalhousie University
Joanne Young	Respiratory Therapist, Research Coordinator	New Brunswick Extra Mural Program
Alison Zwaagstra	Health Information Analyst	NELS ICE
Michelle Harrison	Facilitator	Research Power Inc.
Stephanie Heath	Facilitator	Research Power Inc.

## APPENDIX 4: SMALL GROUP CONSULTATION GUIDE

### *Instructions for Facilitators and Recorders of the Focus Groups*

As a group facilitator you are responsible for:

- ☒ Creating a positive, open and comfortable environment
- ☒ Ensuring everyone has the opportunity to participate
- ☒ Helping the group stay focused on the task
- ☒ Clarifying any questions or comments made, e.g., probing for more detail if you are not clear about something
- ☒ Ensuring that you remain neutral and do not try to influence the group

As a group recorder, you are responsible for:

- ☒ Recording the key points of the group(s) discussion
- ☒ Taking clear and complete notes. You may want to review and add more details to the notes after the session is over to ensure that the notes are clear and detailed. In order for the consultants to compile and synthesize the findings from the focus group they require sufficient detail of the group discussion so the more you are able to provide, the better
- ☒ Writing your name on the recording sheet

### **Questions for Reflection:**

1. What are the most critical issues and questions that you believe need further research/evidence to help improve publicly funded health care services for persons dying of chronic conditions?
2. What surveillance and monitoring information is needed to support policy and program development to reduce inequities and improve end of life care?
3. Given this recommendation (facilitator to present the recommendation), what are the next steps in moving forward with its implementation? It will be acknowledged that it may not be the NELS project that addresses the recommendation, however participants can brain storm ideas about the supports and linkages needed to move this recommendation forward. Participants will be encouraged to build upon the work already done to date through the NELS project.

Thank you for agreeing to help us with this consultation process