

# End of Life Care in Nova Scotia: Surveillance Report



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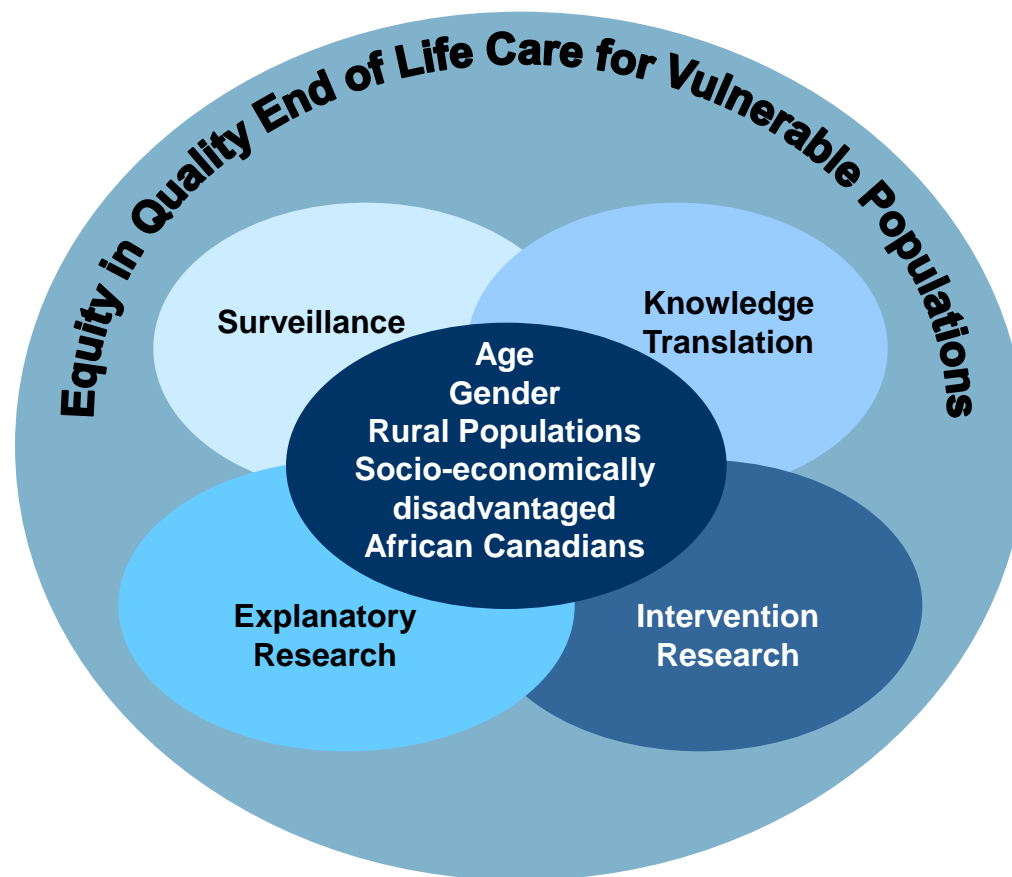
# What is the Network for End of Life Studies (NELS)?

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- ❑ Research group based at Dalhousie University, Capital Health, Cancer Care Nova Scotia and the IWK Health Centre
- ❑ Members have a range of research and clinical expertise.
- ❑ Goal: To improve end of life care for persons with terminal illness by enhancing interdisciplinary research capacity.

# NELS Research Framework

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# Interdisciplinary Capacity Enhancement (ICE) Grant

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- Canadian Institutes for Health Research (CIHR) strategic initiative grant: “Reducing Health Disparities and Promoting Equity for Vulnerable Populations” (2006-2011)
- Objectives of this research development grant:
  - Investigate factors associated with vulnerability at end of life
  - Identify inequities in end of life care.
- By building research capacity
- Six projects

# NELS ICE Project 1

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- Development of a surveillance report of indicators of *access* to quality care at end of life
- Purpose of surveillance report:
  - Offer recommendations to build surveillance and research capacity
  - Provide evidence needed by decision-makers to identify and address inequities in *access* to quality end of life care

# Chapter 1

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- ❑ The problem
- ❑ The Context
- ❑ Our Approach
- ❑ Our Conceptual Framework

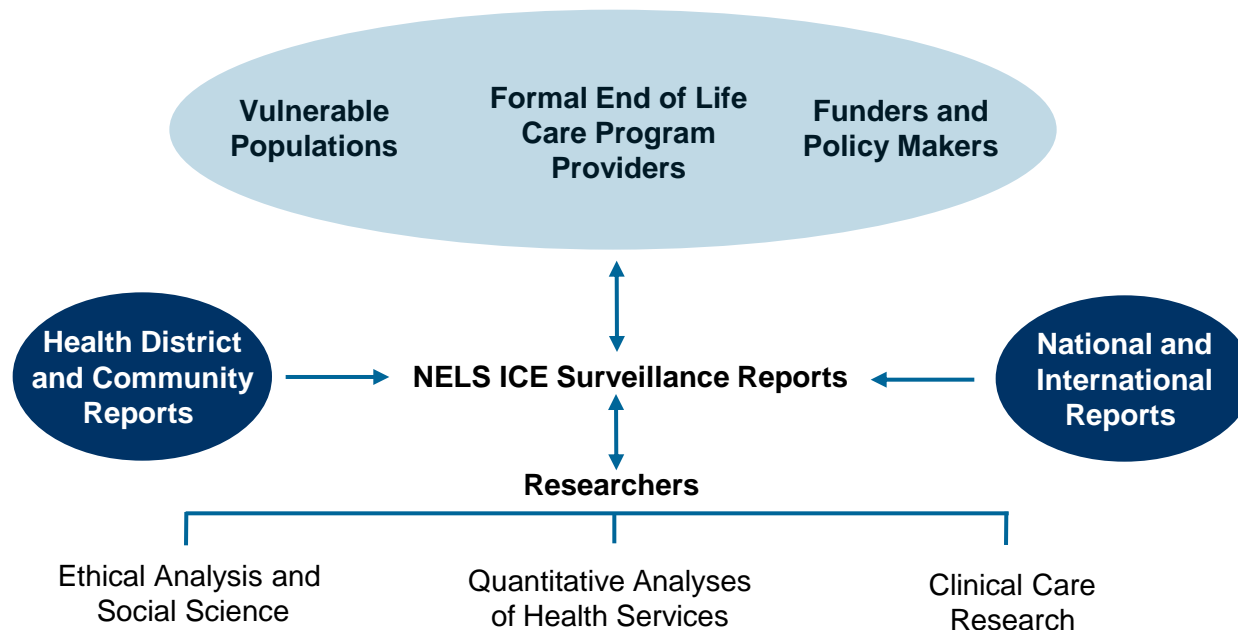
## End of life care

- Availability
  - Uptake
  - Quality
- (Hausman)

# Chapter 1: Introduction

## Surveillance Report in Relation to Contributors and Audiences:

- Persons dying of chronic disease and their caregivers
- Champions of public and professional education, awareness, and advocacy



# Chapter 1 Recommendations

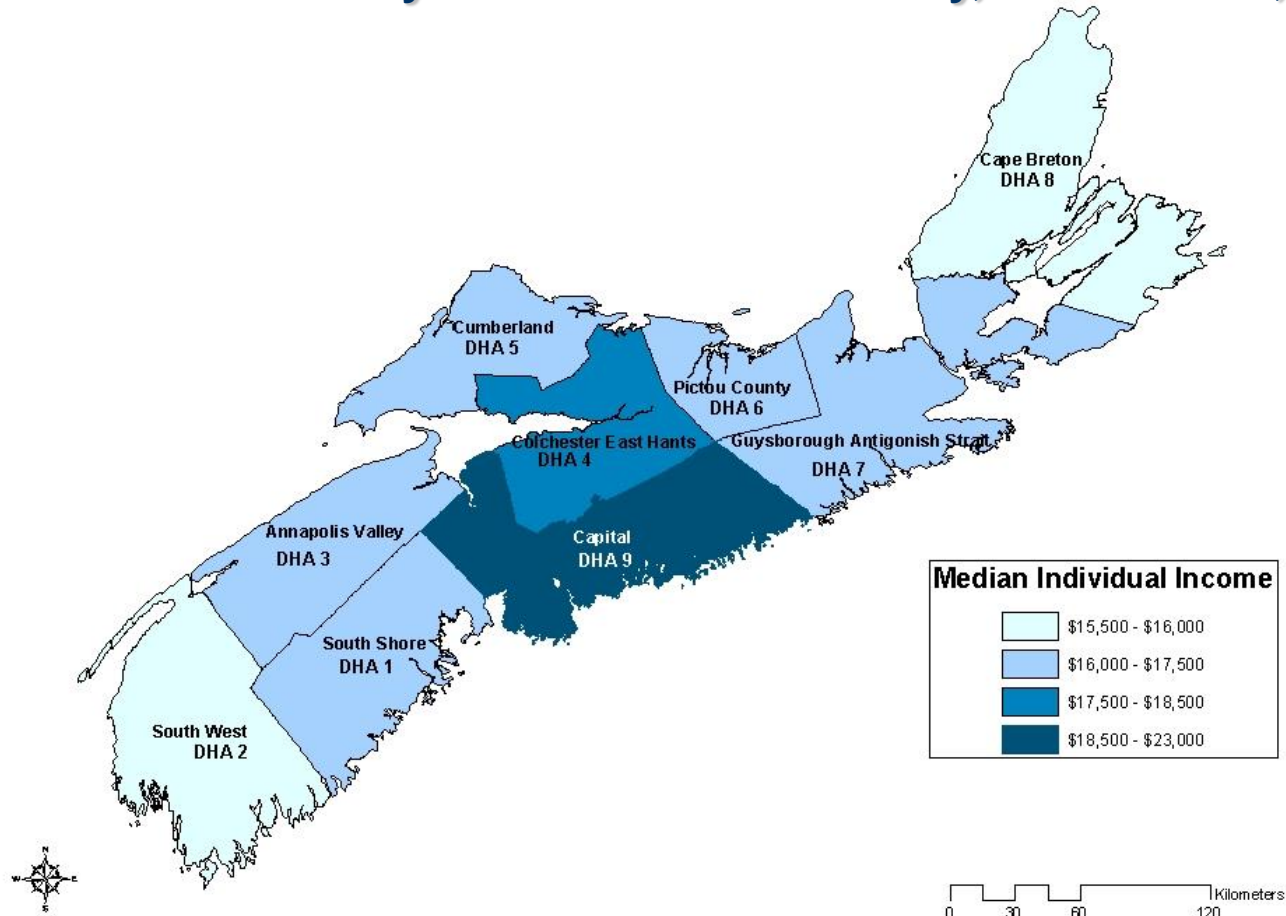
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- ❑ **Recommendation 1:** Refine and develop comprehensive conceptual frameworks that help elucidate dimensions of vulnerability, disparities, and inequities in access to end of life care.
- ❑ **Recommendation 2:** Produce further reports that openly share and critique ideas and examples from research.
- ❑ **Recommendation 3:** Work with others so that end of life care surveillance, quality indicator reporting, knowledge exchange, and improved access to quality end of life care for vulnerable populations become sustainable.



# Chapter 2: Vulnerable Populations

Distribution of income by district health authority, Nova Scotia, 2001



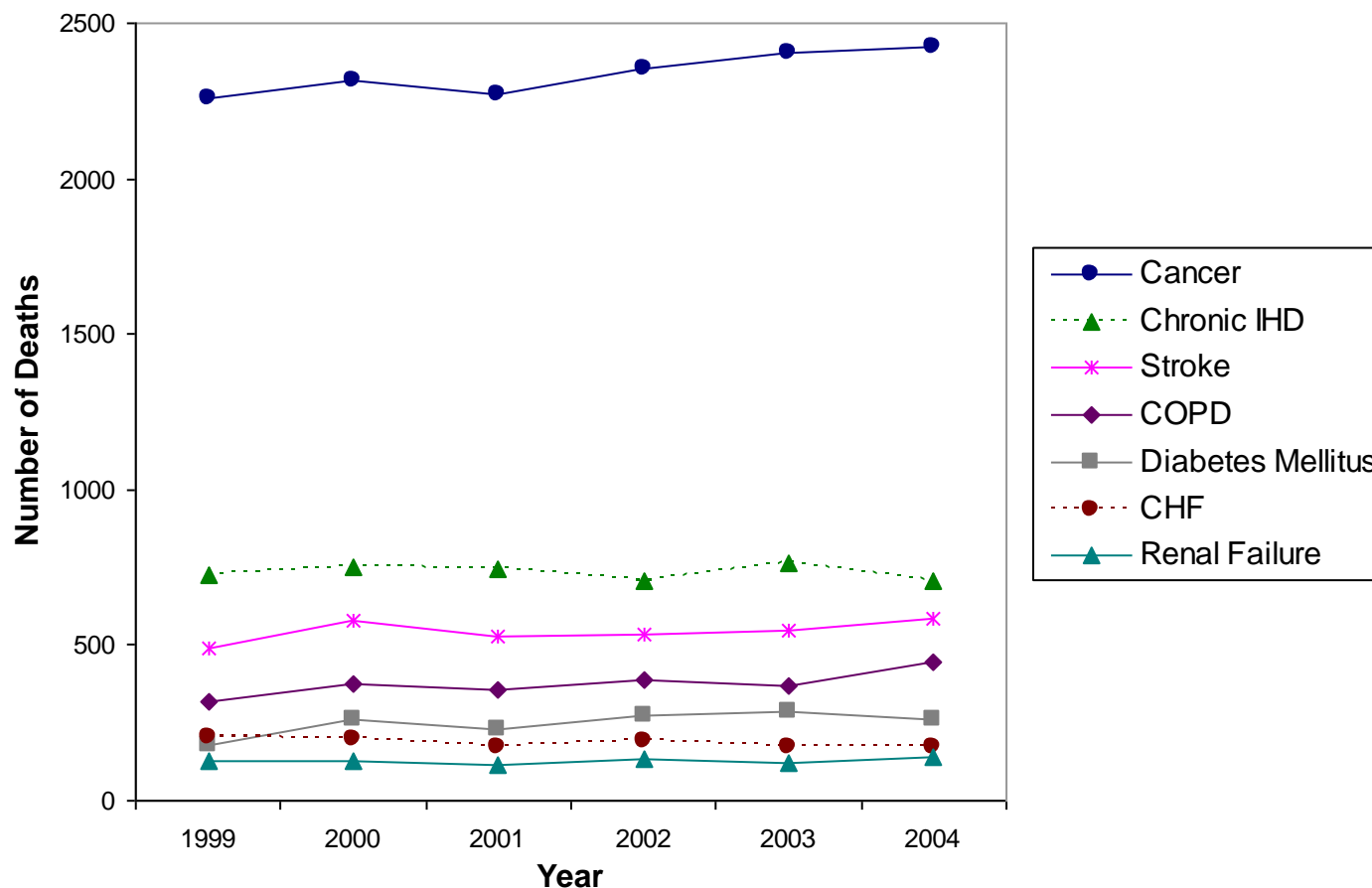
# Chapter 2 Recommendations

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- ❑ **Recommendation 4:** Conduct population-based studies to better understand the needs of children and youth and the elderly as well as factors associated with sex and gender.
- ❑ **Recommendation 5:** Improve our ability to identify factors associated with race, ethnicity, language, and culture that may adversely influence end of life care provision.
- ❑ **Recommendation 6:** Gain a better understanding of the costs associated with end of life care in rural and urban areas.

# Chapter 3: Burden of Death and Dying

Deaths from selected chronic diseases, by year, Nova Scotia, 1999-2004



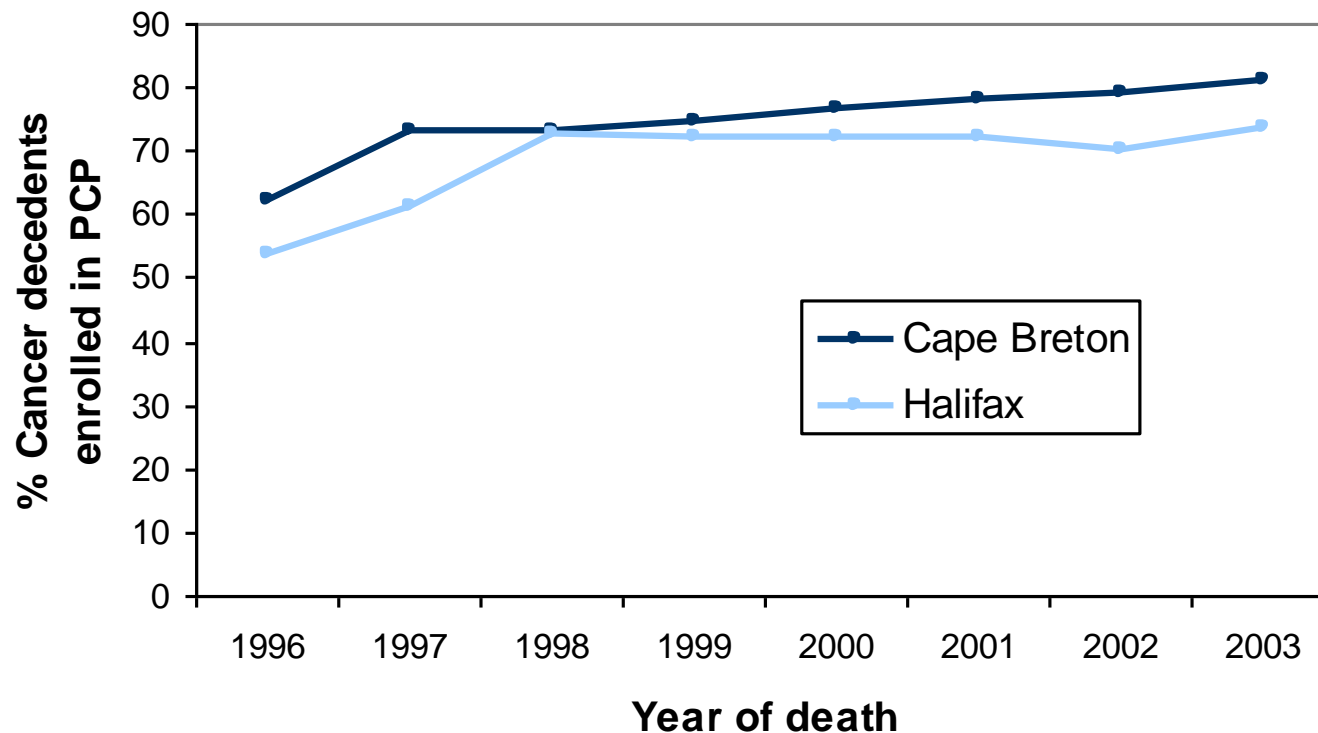
# Chapter 3 Recommendation

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- ▣ **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.

# Chapter 4: Health Service Utilization

Trends in palliative care program enrollment rates for adults dying of cancer,  
Halifax and Cape Breton counties, 1996-2005



# Chapter 4:

## Health Service Utilization

Mean number of family physician visits in the last 12 months of life for adults dying of congestive heart failure, Nova Scotia, 1998-2001

Location	Months Prior to Death			
	1	3	6	12
Hospital	11.8	4	2.3	1.3
Office	0.7	0.9	0.9	0.7
Home	0.7	0.3	0.3	0.2
Emergency	1	0.4	0.3	0.2
Long term care	1.7	0.8	0.6	0.4

# Chapter 4 Recommendations

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- ❑ **Recommendation 8:** In partnership with end-of life care providers, improve the classification of end of life and palliative care.
- ❑ **Recommendation 9:** Provide a broader understanding of the role of the hospital for end of life care.
- ❑ **Recommendation 10:** Continue to explore the use of the SEA (single entry access) MDS (minimum data set) for home and long-term care.

# Chapter 4 Recommendations

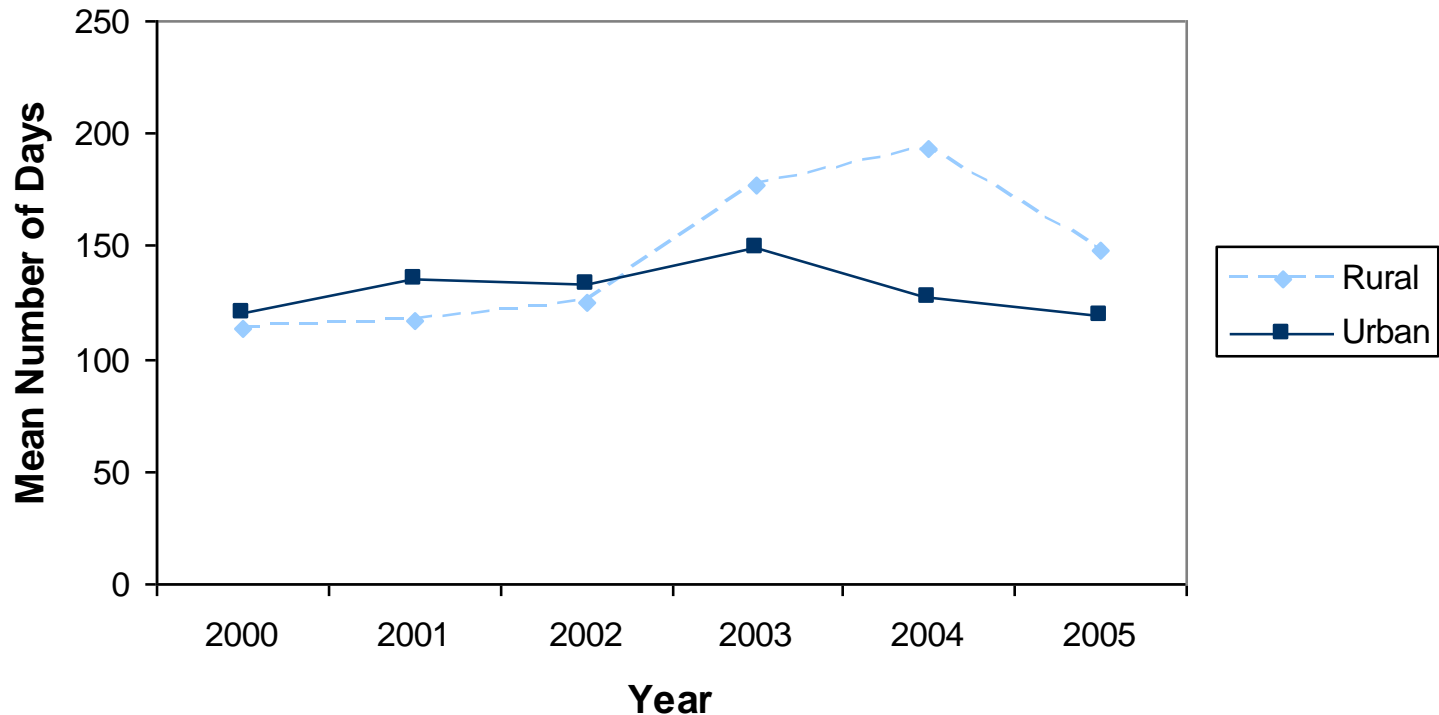
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- ❑ **Recommendation 11:** Encourage development of palliative care service databases across the province with common data fields and definitions.
- ❑ **Recommendation 12:** Further examine the role of long-term care facilities in the provision of end of life care.
- ❑ **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.



# Chapter 5: Indicators of Quality Care

Trend in the mean number of days between enrollment in a palliative care program and death for adults dying of cancer, Halifax and Cape Breton counties, 2000-2005



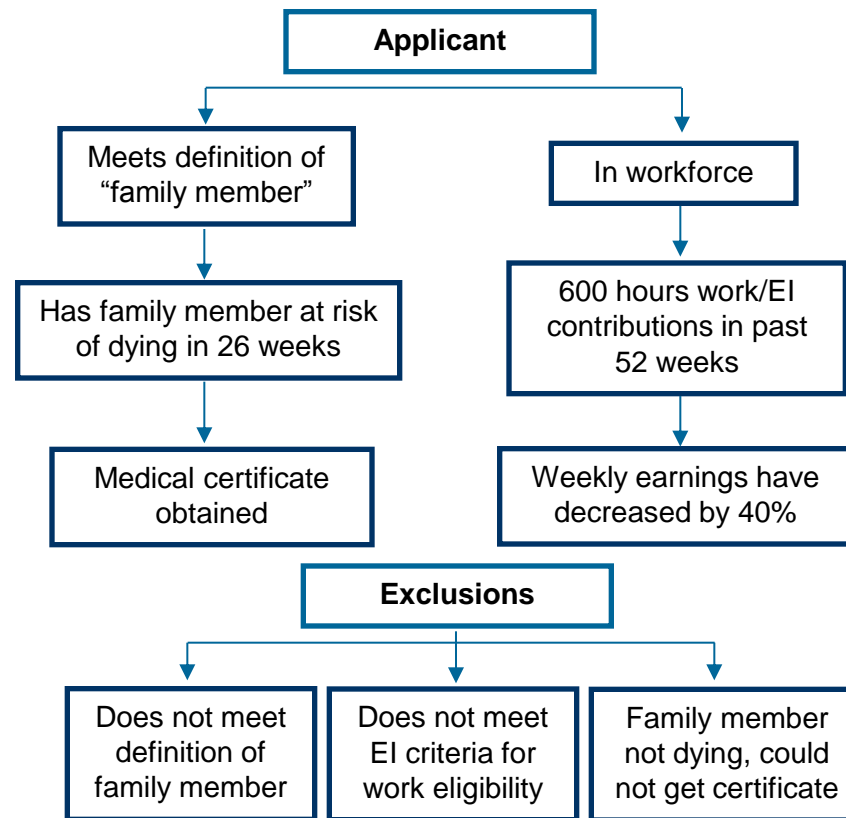
# Chapter 5 Recommendations

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- ❑ **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.
- ❑ **Recommendation 15:** Use both prospective and retrospective study designs to examine the optimal sequences and combinations of end of life care provision.
- ❑ **Recommendation 16:** Promote the development of a sustainable province-wide end of life care surveillance system

# Chapter 6: Public Policies to Support Caregiving

## Human Resources and Social Development Canada Employment Insurance Compassionate Care Benefits Eligibility Criteria



# Chapter 7: Education and Awareness

## Inclusion of palliative care education at Nova Scotia universities and community colleges

Institution	Profession	Undergraduate	Graduate
<b>St. Francis Xavier University</b>	Nursing		RN Certificate in Continuing Care via distance delivery
<b>Cape Breton University</b>	Nursing	Information unavailable at this time	
<b>Nova Scotia Community College</b>	Licensed Practical Nursing	Oncology Nursing/ Palliative Care is a required course	
	Continuing Care Worker	Continuing care is a required course	

# Chapter 7: Education and Awareness

Institution	Profession	Undergraduate	Graduate
Dalhousie University	Medicine	Four week medicine subspecialty clinical rotation in palliative medicine	<ul style="list-style-type: none"> <li>▣ Palliative Care in first 2 yrs Family Medicine curriculum</li> <li>▣ Other palliative care education available (e.g. videoconference, refresher courses)</li> </ul>
	Nursing	<ul style="list-style-type: none"> <li>▣ Palliative care elective</li> <li>▣ May elect mandatory community placement at a site offering end of life care</li> </ul>	Elective course on death and dying/palliative care and oncology nursing for Master of Nursing students
	Pharmacy	<ul style="list-style-type: none"> <li>▣ Senior seminar deals with cancer and addresses some end of life care issues</li> <li>▣ May opt for compulsory Community Experience Program at a site offering end of life care</li> </ul>	
	Social Work	Palliative Care education integrated in course on Aging	Palliative Care education integrated in course on Aging plus and elective on HIV/AIDS for Master of Social Work students
	All health care professions	Students from 22 independent health care profession programs participate in 2-hour inter-professional learning module on Palliative Care	

# Chapter 7 Recommendation

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- ▣ **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.

# Chapter 8:

## African Canadian Population

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- ❑ A potentially specific “vulnerable” population
- ❑ Highlight in each report
- ❑ Although no specific recommendation made, development of cultural competence in end of life care is the theme under development

# Conclusion

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- ❑ Remind ourselves that surveillance report is to be a “tool” to aid our understanding of *access* to end-of-life care
- ❑ We have more conceptual and definitional work to do
- ❑ We have more data development work to do



# Thank you

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