

## The ICE Team

The Network for End of Life Studies (NELS) based at Dalhousie University in Halifax was awarded \$820,000 over five years through a Canadian Institutes for Health Research (CIHR) strategic initiative grant “Interdisciplinary Capacity Enhancement (ICE) Reducing Health Disparities and Promoting Equity for Vulnerable Populations.”

NELS ICE is an interdisciplinary team of researchers and collaborators including clinicians from the Capital Health District Authority and IWK Health Centre who investigate factors associated with vulnerability at end of life and inequities in end of life care. The objective of NELS ICE research development grant is to build capacity to conduct research that will engage decision-makers and assist in overcoming inadequacies in end of life care for individuals and families living with terminal disease. Our key disciplinary strengths are ethics, epidemiology, and clinical care including palliative medicine, family medicine, oncology, respirology, and nursing.

CHIR funding for NELS ICE began in May 2006. This first newsletter focuses on the release of our Surveillance Report. Future issues of NELS News will feature other aspects of our work.



Inaugural meeting in May 2006.  
Back row: Sharon Davis Murdoch, Donna Smith, Beverley Lawson, Victor Maddalena, Graeme Rocker;  
Front row: Gael Page, Grace Johnston, Yukiko Asada

### NELS ICE PRINCIPAL INVESTIGATORS

Grace Johnston, MHSA PhD  
Frederick Burge, MD FCFP MSc

### CO-INVESTIGATORS

Yukiko Asada, MSc PhD  
Trevor Dummer, PhD  
Gerri Frager, MD, FRCPC  
Eva Grunfeld, MD DPhil CCFP FCFP  
Beverley Lawson, MSc  
Paul McIntyre, MD FCFP  
Victor Maddalena, BN MHSA PhD  
Graeme Rocker, MHSc DM FRCP FRCPC

### POST DOCTORAL FELLOW

Judith Fisher, BScPhm, MA, PhD

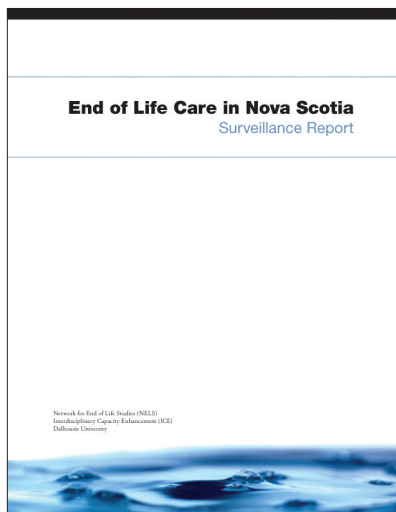
### HEALTH INFORMATION ANALYST

Alison Zwaagstra, BHIM, MHI, CHIM

### COLLABORATORS

Gael Page (05-08), Canadian/Nova Scotia Hospice Palliative Care Associations (CHPHA, NSHPCA)  
Ann McKim (08-11), CHPHA and NSHPCA  
Julie Lachance, Health Canada  
Craig Earle, Dana-Farber Cancer Institute  
Dan Hausman, Univ of Wisconsin-Madison  
Health Association of African Canadian

## End of Life Care in Nova Scotia Surveillance Report



The *End of Life Care in Nova Scotia Surveillance Report* provides an overview of ten years of Nova Scotia-based end of life care research with recommendations for future development. It raises awareness regarding the expected increase in the number of deaths from chronic conditions due to the aging population. This information will assist in making evidence-based decisions for end of life care.

The last few months of a person's life are often associated with an increased need and utilization of health services. Ideally, the focus is on quality of life and supportive care. NELS aims to enhance the capacity for end of life research to reduce inequities and improve care.

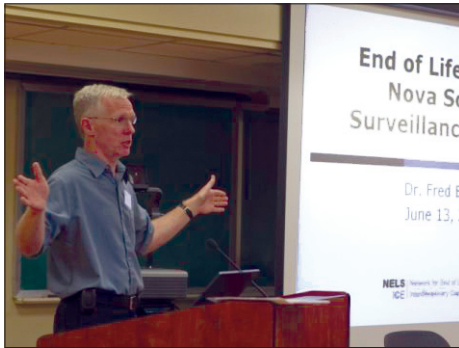
This Surveillance Report is the first population-based report on health system care for those dying of chronic terminal conditions in Nova Scotia, and is one of only a few reports of this type in the world.

This report includes recommendations to build surveillance and research capacity. Generating new knowledge will help answer both current and future questions. By working with district, provincial, national, and international expertise, NELS ICE researchers intend to further develop methods, insights, and information for public and professional dialogue on health system and service review.

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## End of Life Care in Nova Scotia Surveillance Report...

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Fred Burge, Co-Principal Investigator of NELS ICE presenting the Surveillance Report to Stakeholders in June 2008.

### Some Key Observations:

1. In 2006, there were 8166 deaths in Nova Scotia. Fifty-eight percent of these deaths were due to major chronic diseases with a potential need for end of life care: cancer, chronic ischemic heart disease, stroke, chronic obstructive pulmonary disease (COPD), diabetes mellitus, congestive heart failure (CHF) and renal failure. On average, nearly 13 of the approximate 22 deaths each day in Nova Scotia in 2004 were attributed to these diseases.

2. Nova Scotia has an aging population. Therefore the numbers of persons dying of chronic diseases will increase. In 2001, 14% of the population was 65 years or older. By the year 2020, the percentage of older persons is expected to increase to approximately 21.6% of the population. Correspondingly, the percentage of younger persons, who will be caregivers of the dying elderly, will decline.

3. The use of palliative care programs in Halifax and Sydney for persons dying of cancer is high (70-80%) compared to norms reported elsewhere. Comparative data are unavailable as yet for other palliative care programs in Nova Scotia.

4. Older persons appear less likely to receive specialized palliative services at end of life. Urban-rural differences exist. Associations between care received and average neighbourhood household income and community culture were observed.

5. Historically, most persons referred to palliative care were dying of cancer.

6. Challenges facing individuals dying of diseases other than cancer, including COPD and CHF, need attention.

7. Deaths from COPD are expected to increase rapidly, with Nova Scotia COPD deaths increasing to 770 per year in 2020, up from 447 in 2004.

8. The family physician and long-term care facilities have a more extensive role for persons dying of CHF, in comparison to cancer.

9. While differences exist among people of African descent in terms of cultural beliefs regarding death and dying, and gender roles in caregiving, there is a general expectation that family members will assume the primary caregiving role for chronic and terminal illness, and that this care will be in the home setting.

10. End of life issues in children require separate attention as their needs differ due to their range of diseases and changing developmental requirements.

11. End of life care research methods pioneered in Nova Scotia continue to expand with numerous new methodological developments including quality care indicators, ecological measures of deprivation, community culture, travel time, population-based methods, database development projects, more chronic diseases, prospective studies, surveillance indicators, costing, resource allocation, medication use and measures of equity.

12. There is a lack of consensus on:

- what is quality care at End of life?
- what outcome measures indicate a good death experience?
- what are cost effective options to provide quality care at End of life?
- how to overcome inequities, i.e., unjustifiable inequalities?

This Surveillance Report provides measures of inequality related to physician, hospital and other care accessed in the last months of life to persons dying of cancer and congestive heart failure. Over the coming years the NELS team proposes to:

- move from measures of inequality to measures of inequity by incorporating considerations of justice,
- move beyond indicators of care received to measures of quality of care;
- extend research to chronic conditions beyond cancer, which to date has been the primary focus of palliative care programs, and
- enhance understanding of the roles and services of long-term care facilities, home care, emergency departments, and intensive care, across all ages by developing interdisciplinary research capacity.



Grace Johnston, Principal Investigator of NELS ICE and Graeme Rucker, Co-Investigator discussing methods to include chronic obstructive pulmonary disease.

# Listening to Stakeholders Report

In June 2008, the NELS ICE team presented a preliminary version of the Surveillance Report to stakeholders for their review. A synopsis of this stakeholder consultation is provided in the *Listening to Stakeholders Report*. This report describes the process and presents the findings of a survey and consultation designed to obtain feedback from a broad base of stakeholders on the *End of Life Care in Nova Scotia Surveillance Report* including suggestions for moving forward with the recommendations. The consultation objectives were:

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

Valuable feedback was provided for moving forward with further NELS surveillance and research development.

## Observations and Conclusions:

1. To improve publicly funded health services for persons dying of chronic conditions there is a need to conduct research and gather evidence to:

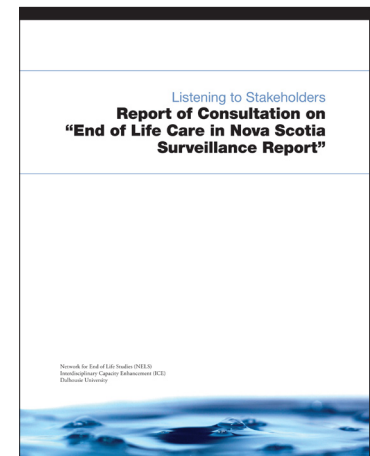
- Obtain the perspective of patients and families about their needs for end of life care including capacities and gaps,
- Define what is meant by end of life and develop an accurate description of end of life,

- 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 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.

2. 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.

3. 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, and knowledge translation.



4. The 17 recommendations contained within the Surveillance Report were validated by the findings from the survey and small group consultation process.

The Stakeholders Report provides input into the NELS ICE goal of producing evidence to improve the provision of end of life care to vulnerable populations. The Listening to Stakeholders process was an opportunity for a broad base of stakeholders including researchers, advocates for vulnerable populations, care providers, managers and policy advisors to share perspectives and interests. The participants 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 expectations. A number of persons who had much to contribute but were previously unknown to others 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 who ranged from senior management to trainees, and the diversity of ages, ethnicities, professions, knowledge, and expertise that were able to voice perspectives and be heard.



## Other Research

The goal of NELS ICE is to improve end of life care for persons with terminal illness by enhancing interdisciplinary research capacity. Specific objectives of the NELS ICE are to:

- Develop a system to 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 that 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 in vulnerable populations.
- Further build an interdisciplinary team of researchers, trainees, health professionals and community partners.

Future issues of NELS News will feature other research developments including measurement of inequity in accessing end of life care, vulnerable populations at end of life, children and youth end of life care, improving care for the elderly, especially those in long term care facilities, community based care for persons experiencing breathlessness with a focus on chronic obstructive pulmonary disease (COPD), surveillance and research on a range of terminal chronic conditions including congestive heart failure, stroke, Parkinson's disease, multiple sclerosis, renal disease, diabetes, and Alzheimer's disease.

The NELS ICE team members have been successful for many years in publishing, presenting at national and international conference, and receiving grants for their work. In future editions of NELS News will share this work with you.

## UPDATES

Congratulations to **Dr Eva Grunfeld** for her recent appointments as the Giblon Professor and Research Director in the Department of Family and Community Medicine at the University of Toronto, and Senior Clinician Scientist and Director of Knowledge Translation for Health Services Research Network with Cancer Care Ontario and the Ontario Institute of Cancer Research. Dr Grunfeld will continue as a NELS ICE co-investigator focusing on primary care knowledge translation.

Congratulations to **Dr Victor Maddalena** for his appointment in August 2009 as Associate Professor of Health Policy and Health Service Delivery in the Division of Community Health and Humanities at Memorial University of Newfoundland. Dr Maddalena will continue as a NELS ICE co-investigator focusing on the unique needs for end of life care among vulnerable populations by commencing with new work with the Pick's disease and deaf community in Newfoundland. During his time as a NELS ICE Post Doctoral Fellow in Nova Scotia, he carried out qualitative research in collaboration with the Health Association of African Canadians, and through a Metropolis grant with the East Asian immigrant community.

Congratulations to **Dr Craig Earle** for his new appointment this past summer. Dr Earle has now moved from the Dana-Farber Cancer Institute in Boston to become Program Leader for Health Services Research at the Ontario Institute for Cancer Research, and Scientist at Sunnybrook Research Institute and the Institute for Clinical and Evaluative Sciences. His research focuses on using administrative data to evaluate the access, quality, costs and outcomes of care delivered to cancer patients. He will continue as a NELS ICE collaborator contributing to cancer outcomes and quality indicators research development.

## RESEARCH TRAINEES & PROJECTS WANTED

Limited funding has become available from NELS ICE for graduate students, post doctoral fellows, and other research project development. Trainee and project application forms are available at [www.nels.dal.ca](http://www.nels.dal.ca). Review of new NELS ICE interdisciplinary research proposals will begin February 15, 2009. Priority for funding will be given to proposals that build on and extend NELS ICE interdisciplinary research capacity development.

## EVENTS

**Dr Judith Fisher** will join the NELS ICE team on January 5th, 2009, as a **Post Doctoral Fellow** for 2 years to develop research on medication use at end of life using population based administrative medication databases. Dr Fisher will also help the NELS ICE team investigate associations among chronic disease co-morbidities and dying in and out hospital. Judith successfully defended her PhD thesis, "Profiles and Patterns of Medication Use among Older Adults with Osteoarthritis," at the University of Toronto in Pharmaceutical Sciences on November 26th. She has 20 years of experience as a community pharmacist in Ontario and British Columbia and an MA in Gerontology.

Given their contributions over the last year, and plans for new research, **Dr. Gerri Frager** and **Dr. Trevor Dummer** were invited to formally join as NELS ICE co-investigators.

**Dr Sean Morrison** will be our **NELS ICE Visiting Scholar** in Halifax from **February 2 - 6, 2009**. Dr Morrison will be presenting at the Capital Health Medical Rounds on Tuesday February 3 at 8 AM and at Gerontology Rounds on Wednesday February 4 at 8 AM as well as be participating in other events. Dr. Morrison's research focuses on decision making at the end of life, pain and symptom management in high-risk and medically underserved populations, and quality measures in palliative care. He has received numerous awards for his research in geriatrics and palliative care. He is an active clinician who cares for healthy older adults and those with serious illness. He is the of the National Palliative Care Research Center, Vice-Chair for Research at the Brookdale Department of Geriatrics and Adult Development, Director of Research at the Hertzberg Palliative Care Institute and Hermann Merkin Professor of Palliative Care at the Mount Sinai School of Medicine, New York.

## MAILING LIST

If you'd like to receive future issues of NELS News and emails of upcoming events, email [NELS@dal.ca](mailto:NELS@dal.ca). Events will also be posted on our NELS website at [www.nels.dal.ca](http://www.nels.dal.ca)

## ACKNOWLEDGEMENT

NELS ICE research development is supported by funding from the Canadian **Institutes for Health Research through a strategic initiative grant (# HOA-80067) for "Interdisciplinary Capacity Enhancement (ICE) Reducing Health Disparities and Promoting Equity for Vulnerable Populations"**.