

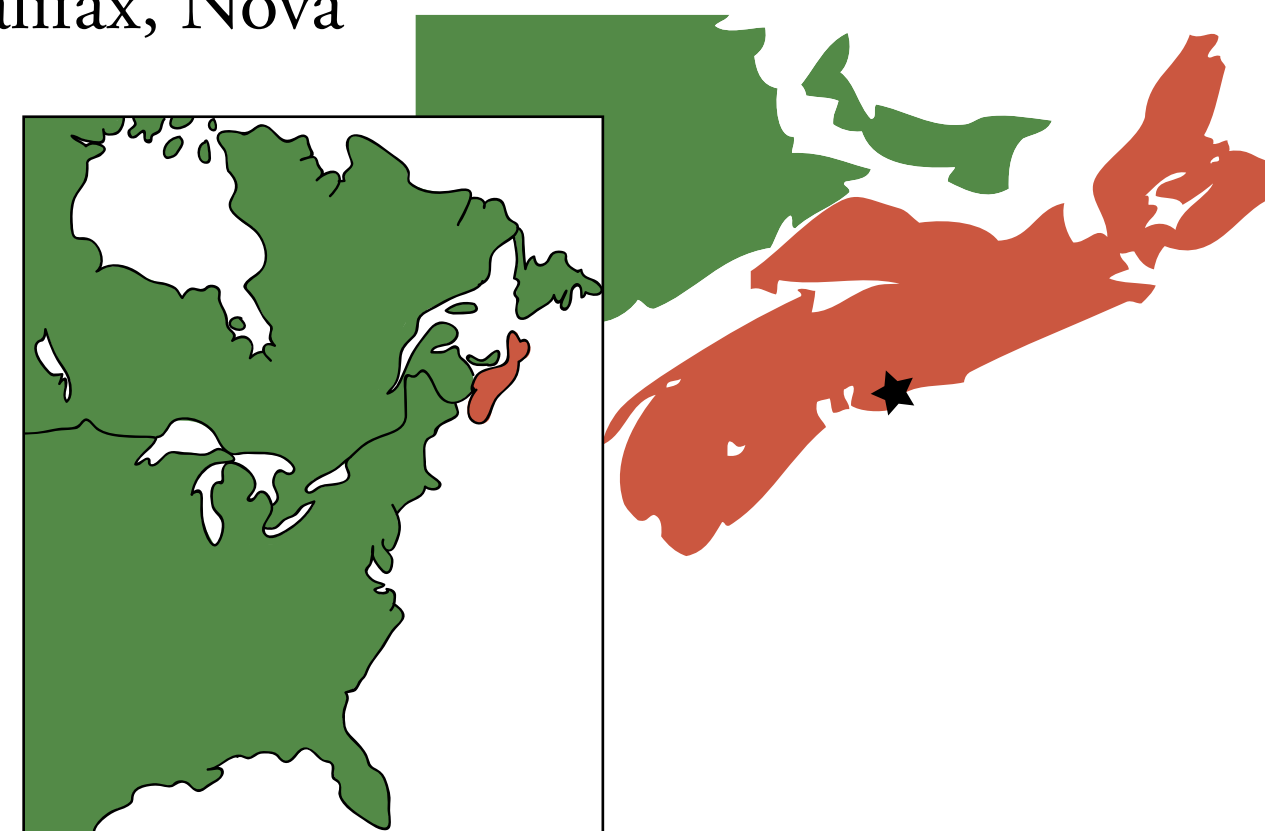
Building a palliative and end of life research program: Recent experiences of NELS ICE in Nova Scotia, Canada

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The Network for End of Life Studies (NELS) is an interdisciplinary team of researchers and clinicians from Dalhousie University, Capital Health District and IWK Health Centre in Halifax, Nova Scotia (NS). Canadian Institutes for Health Research (CIHR) funded a 5-year Interdisciplinary Capacity Enhancement (ICE) grant (2006-2011, \$820,000) to build research to address the needs of vulnerable populations.



Vision

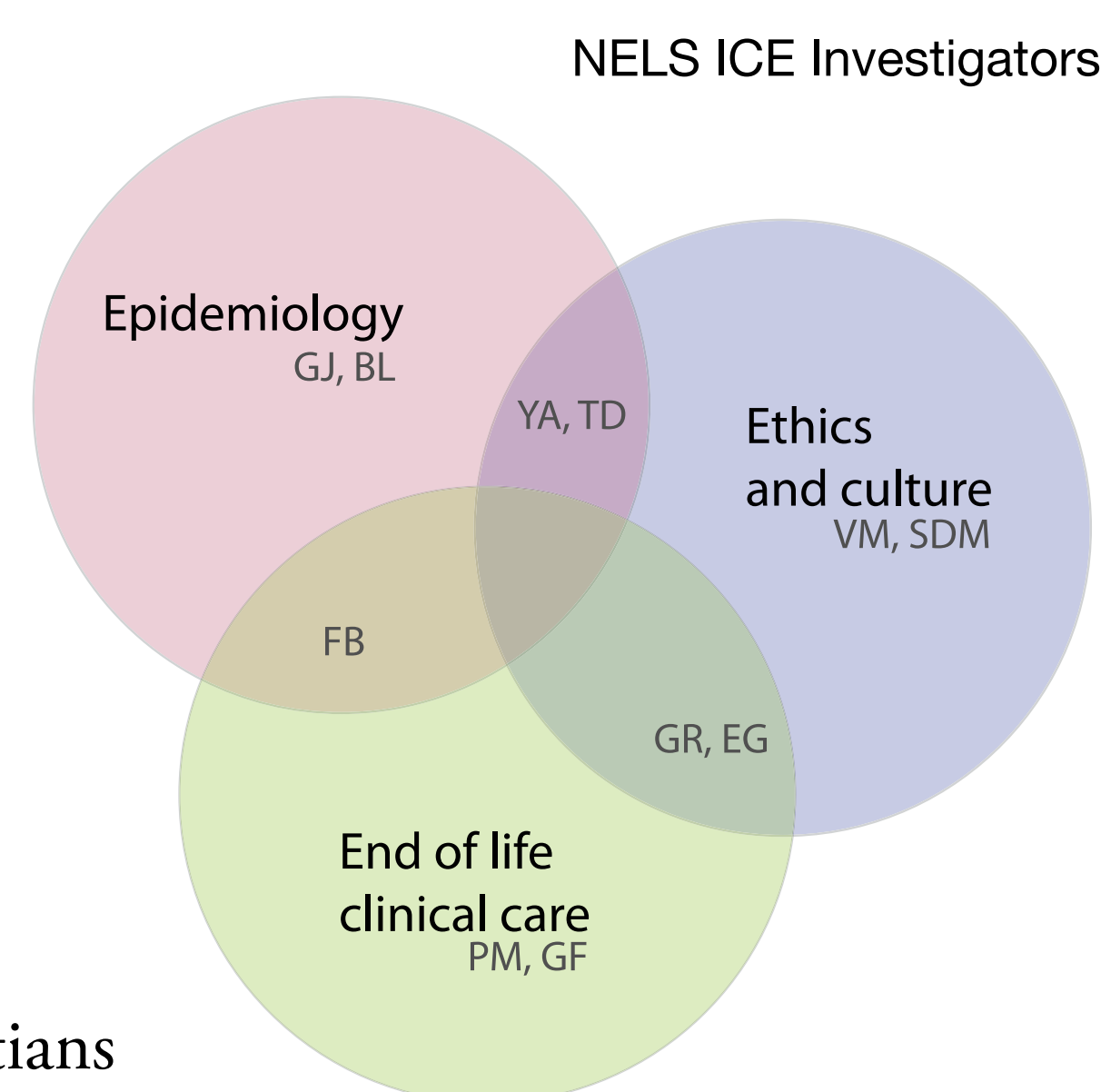
To enhance interdisciplinary research capacity through collaborations aimed to identify disparities and inequities in quality end of life care; explicate end of life care vulnerabilities; and develop and test ways to overcome inadequacies in publicly funded end of life care for persons at end of life with chronic disease.

Expanding interdisciplinary team

Primary strengths were in medicine, epidemiology and ethics. Interdisciplinary links are continually expanding. See nels.dal.ca for 35+ list of trainees.

New Co-Investigators

- Gerri Frager: pediatric palliative physician whose work resulted in the play, *Ed's Story: The Dragon Chronicles*
- Trevor Dummer: geographer who helped develop aggregate measures of deprivation and travel time to linked database analysis



Post Doctoral Fellows

- Victor Maddalena: African Nova Scotians and Newfoundland deaf community
- Judith Fisher: Prescription Monitoring Program, Pharmcare data and linking with College of Pharmacy

New Investigators

- Christine Beck: quality of end of life care in nursing homes
- Heather Castleden: Aboriginal communities
- Alix Carter: Emergency medicine
- and others

Other trainees

- André Maddison, Masters student: Equity
- Cathy Simpson, PhD student: Spiritual care
- Elsie Rolls, Health Administrator: Pain assessment and management
- Jennifer Williams, Masters Student: Pediatrics and nursing
- Rebecca Earle, PhD student: Pediatrics, nursing and emergency care
- and others

Collaborators

- Ann McKim (08-), Gael Page (05-08), Canadian and Nova Scotia Hospice Palliative Care Associations (CHPCA, NSHPCA)
- Julie Lachance, Health Canada
- Health Association of African Canadians

Research streams

1. Surveillance
2. Equity
3. Children and Youth
4. Vulnerable Populations
5. Age and Sex
6. Elderly
7. Beyond Cancer
8. Caregiving
9. Medications

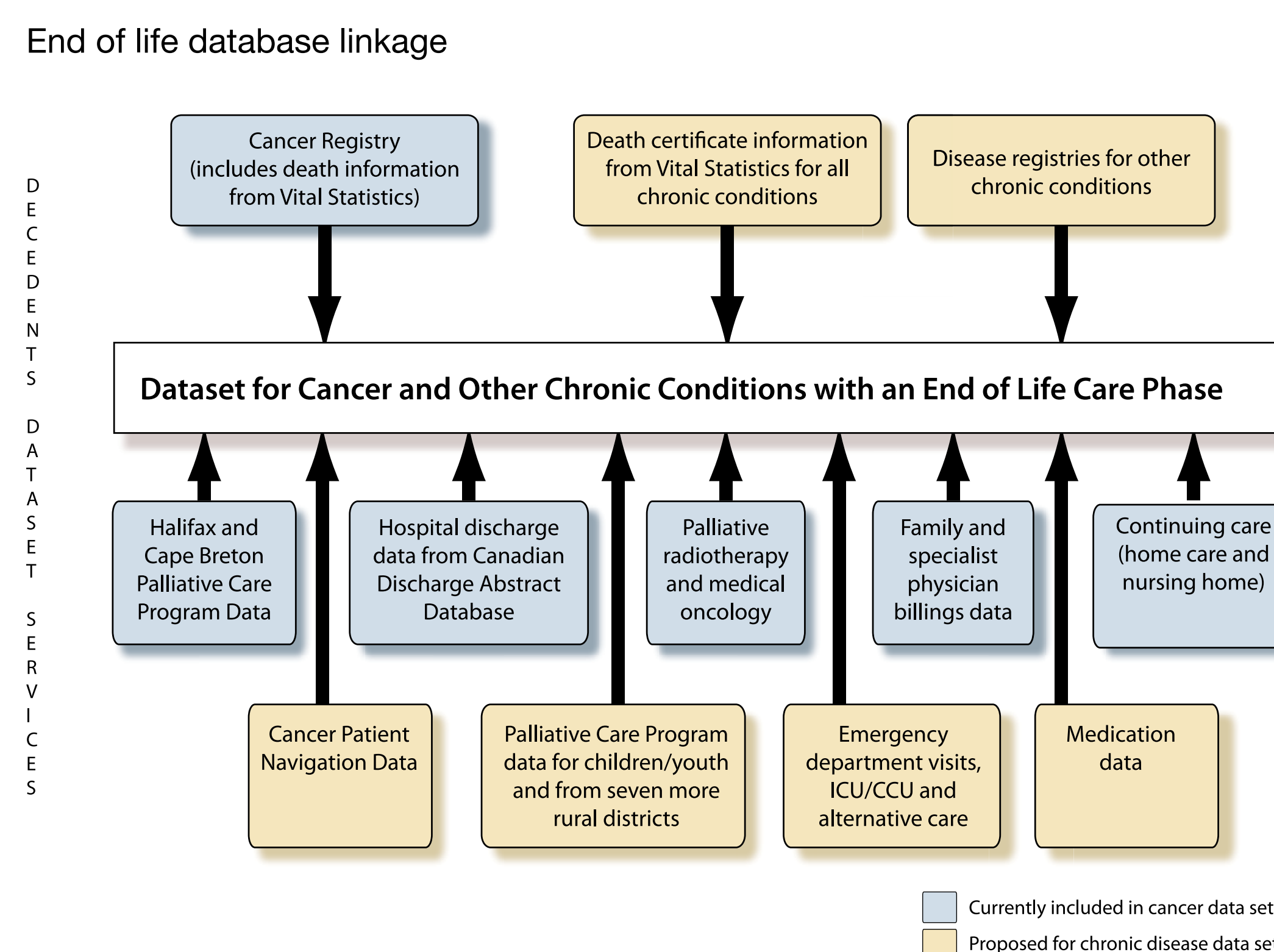
New grants

Since 2005 NELS Investigators have been involved in 20+ new grants totalling over \$9,000,000 including:

PI	Award (years)	Amount
Yukiko Asada	CIHR New Investigator Award (2008)	\$300,000
Fred Burge and Bev Lawson	Mortality Follow Back Study CIHR Operating Grant (2008-12)	\$432,188
Eva Grunfeld	Towards measuring and improving access to quality cancer services in Nova Scotia CIHR NET Grant (2007-12)	\$598,660
Graeme Rocker	Palliation of dyspnea in advanced COPD: Patient and caregiver experiences of opioid therapy CIHR Regional Partnership Grant (2009-10)	\$130,000

Beyond cancer database linkage

Early focus of NELS was on cancer. Collaboration has since extended to other chronic disease programs.



Moving beyond Halifax

Across Nova Scotia

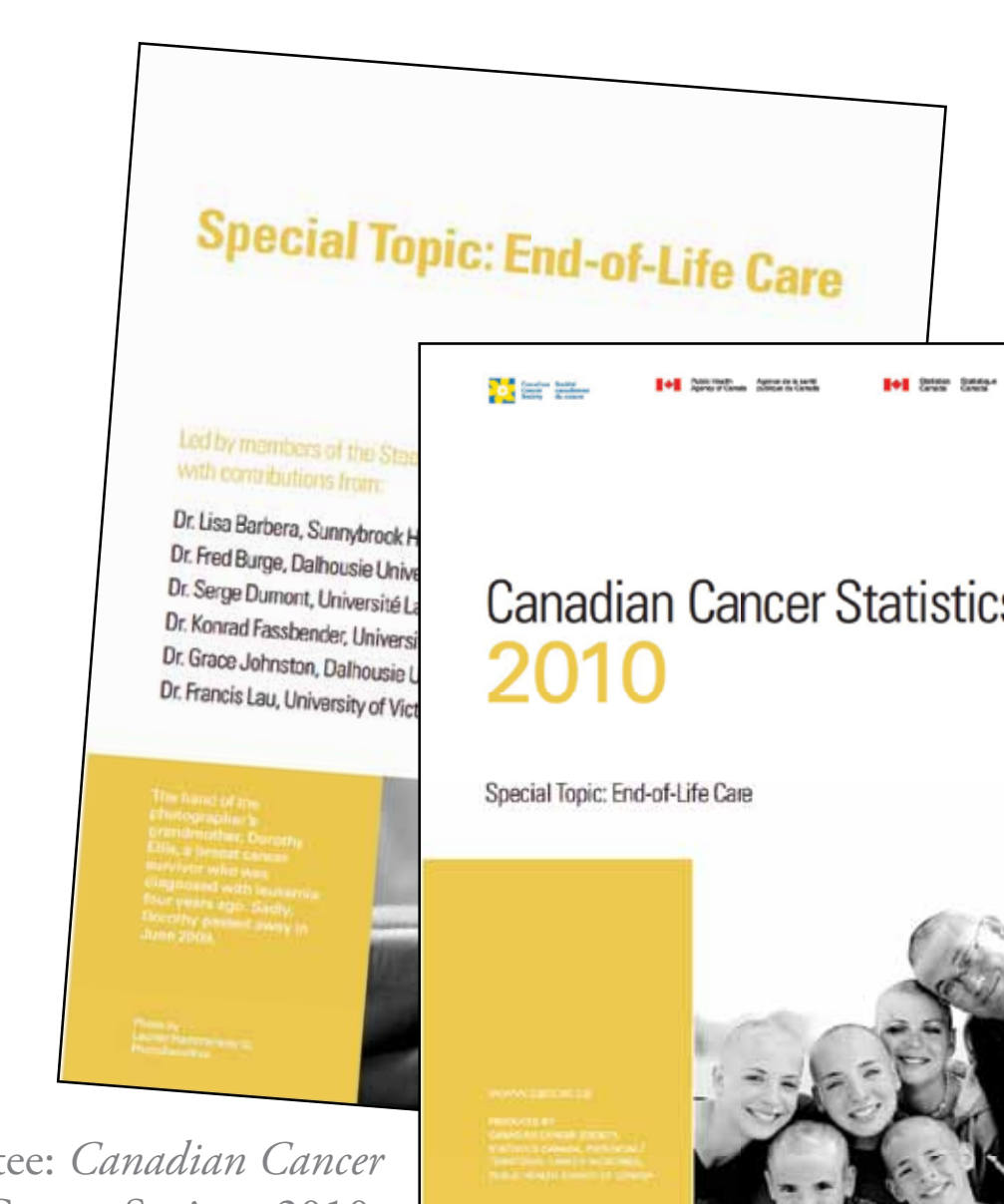
- Serge Dumont led cost study and David Henderson led needs study in Colchester East Hants
- NELS ICE presentation in Antigonish
- Collaboration with a Yarmouth nephrologist, Ahmad A. Tarakji
- Sue Korol and Anne Frances D'Intino caregiver study in Cape Breton

Atlantic Canada

- Graeme Rocker and Joanne Young's studies on chronic obstructive pulmonary disease in Saint John, New Brunswick
- Delores Mullings and Gail Wideman's Newfoundland research into the role of social work supporting informal caregivers
- Victor Maddalena's research with the deaf community in Newfoundland

Nationally

- Eva Grunfeld, relocated to Toronto, lead nationally the special topic, *end of life with cancer*, in the Canadian Cancer Statistics 2010 by the Canadian Cancer Research Institute. NELS ICE Principal Investigators, Grace Johnston and Fred Burge contributed to the end of life feature in this report.



Canadian Cancer Society's Steering Committee: *Canadian Cancer Statistics 2010*. Toronto: Canadian Cancer Society, 2010.

Knowledge translation

NELS News

- Issues highlight events and features completed and ongoing studies by ICE project streams.



Events

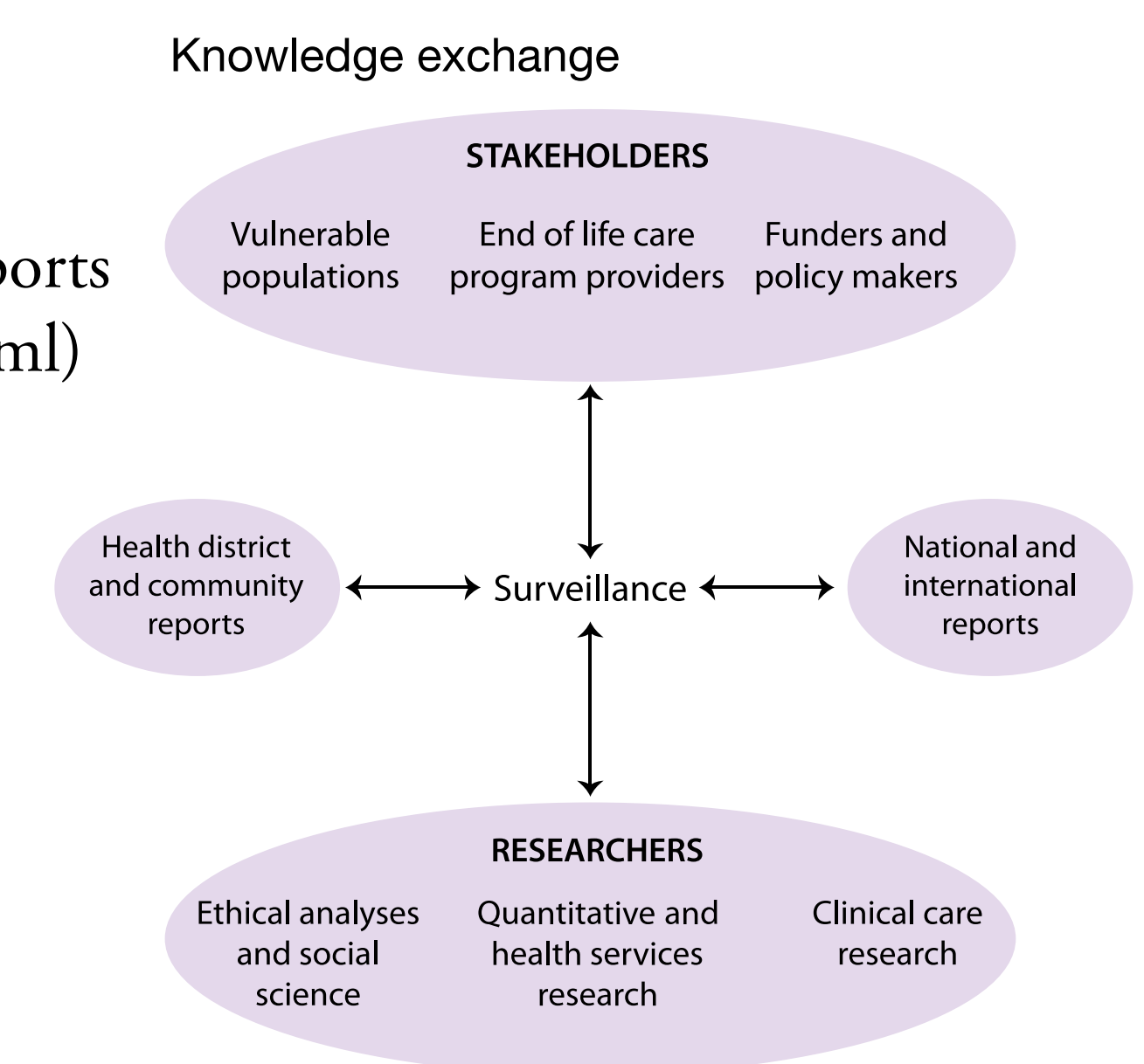
- Work-in-Progress Sessions
- Management Meetings
- 2009 Local Poster Event
- 2010 NELS Reception at the 18th International Congress on Palliative Care

Visiting Scholars

- 2011 - Mary Lou Kelley, Maxine Hancock
- 2010 - Vickie Baracos, Allan Kellehear, Kevin Brazil
- 2009 - David Kuhl, R. Sean Morrison
- 2008 - Scott Murray, Serge Dumont, Konrad Fassbender
- 2007 - Harvey Chochinov, Craig Earle, Dan Hausman

Reports

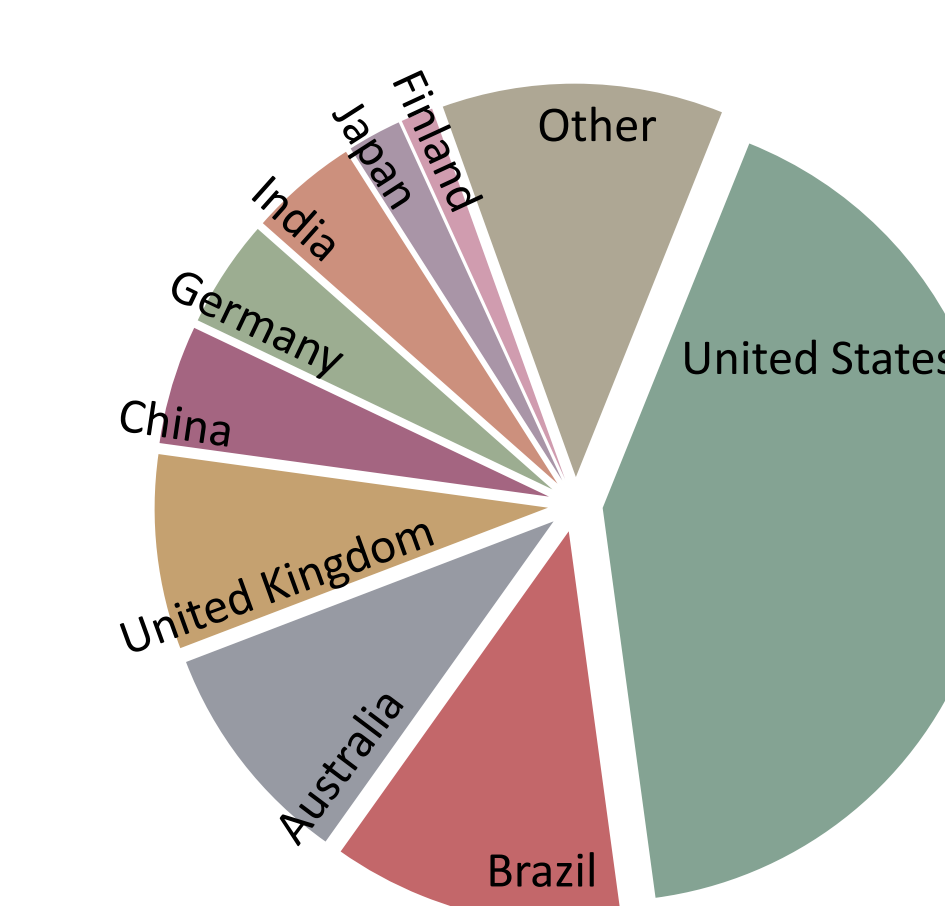
- Surveillance and Stakeholder Reports
- Project reports (nels.dal.ca/ice.html)
- Department of Health adapting NELS ICE report for district palliative care programs
- Media coverage of reports and research initiatives



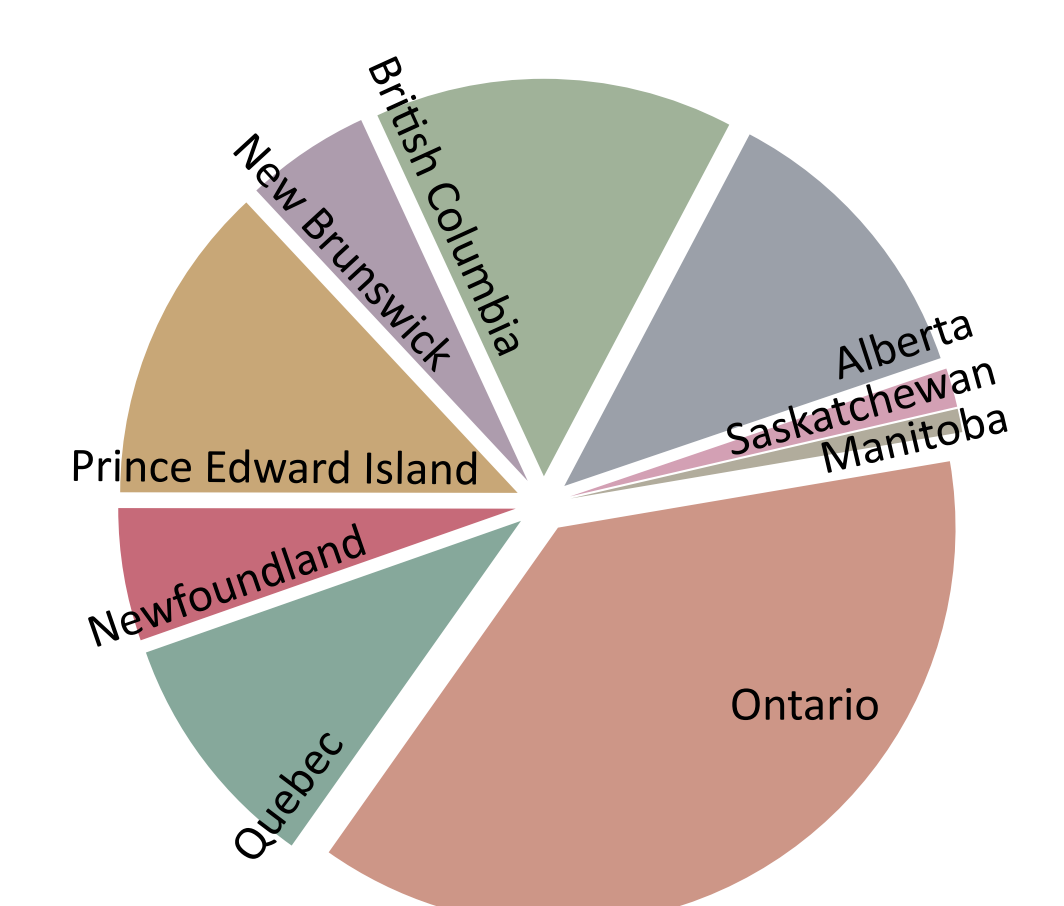
Website - nels.dal.ca

- NELS website traffic has been monitored since March 2009.
- 90% of visitors have been from Canada: others represented below.
- 85% of National visitors have been from NS: others represented below.

International web visits



National web visits



Conclusion

Good interpersonal relationships, flexibility and acceptance of new researchers, disciplinary areas and methods have been critical success factors. Struggles included protecting research time for clinician researchers and faculty with teaching and administrative responsibilities. New research grant funding, peer review publishing, supporting strong trainees, financial transparency and sustaining NELS after ICE ends remain priorities.

More information

NELS website features: ICE research streams; NELS studies; NELS News; upcoming events including visiting scholars, work-in-progress sessions and meetings; NELS reports; presentations with audio; and other resources. Contact Nicole McQuinn, ICE Coordinator, at nels@dal.ca for more info.