

# Ten Years of Research on Access to and Predictors of End of Life Cancer Care, Nova Scotia, Canada



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## Purposes

This poster provides an overview of the development of End of Life Studies in Nova Scotia, Canada, that have identified:  
- health care received in the last months of life by adults dying of cancer, and  
- demographic, clinical, community, and other service predictors of their care.

## Poster Design

The left side of the poster provides an overview of methods. The evolution of the population based administrative database linkage is presented horizontally through the middle of this poster from the initial work in the early 1990's at the cancer registry to the right side of the poster which indicates major university associated research grants received 10 years later. Examples of findings with associated publications are grouped by type of care examined over time.

## Study Subjects

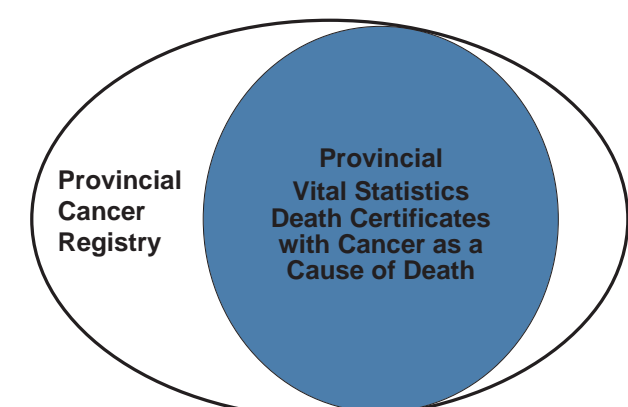
24,000 adults who died of cancer between 1994 and 2003 were identified from provincial death certificates. Initial publications were limited to early time periods. In parallel separate analyses, there are 3000 study subjects who died of congestive heart failure from 1998 to 2001.

## Study Design

Study subjects were individually linked to their health services recorded in provincial health services administrative data. Linkage begins with identification and validation of study subjects from death certificates using information from the provincial cancer registry. Services from the provincial oncology patient information system and urban palliative care program databases (Halifax, Sydney) are identified for each study subject. At the university, hospital days and physician billings were added for 1992 to 1998; these data are currently being updated to 2003, and homecare data is being included for the first time.

Descriptive statistics were used to report care received by the study subjects in the last months of life. In a series of retrospective studies, multivariate regression analyses were used to identify associations with predictors of care. Logistic regression was used when the dependent variable was dichotomous.

**Probabilistic Record Linkage began early 1990's; Thereafter Linked Annually**



Death Clearance of Cancer Registry shows that 50% of persons diagnosed with cancer die of cancer

## Data Quality Framework to Assess Administrative Databases Being Linked

- Value**
- Provide checklist for data quality monitoring
- Identify time periods and data fields of sufficient quality for reporting
- Assist in reconciling data quality problems
- Provide a structure for data quality reports
- Aid in establishing data quality standards

### Concepts

coding constancy	data fields complete
accuracy, reliability	includes all persons
validity, interpreting	includes all services
timely data transfer	reporting constancy

Johnston G, Burge F, Boyd C, MacIntyre M (2001) End-of-Life Population Study Methods. *Canadian Journal of Public Health* 92(5):385-386

## Expertise

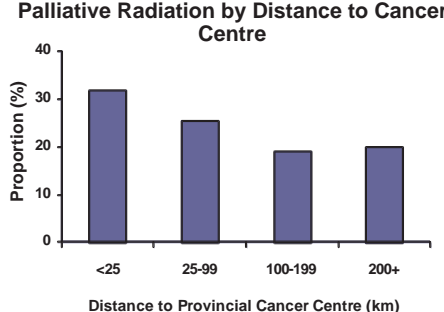
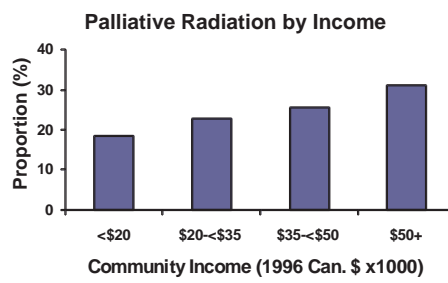
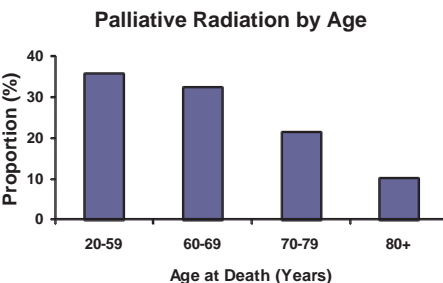
A variety of expertise is required to support end of life work:

•For Design, Record Linkage, Data Quality Assessment, Statistical Analysis, and Ongoing Database Updating

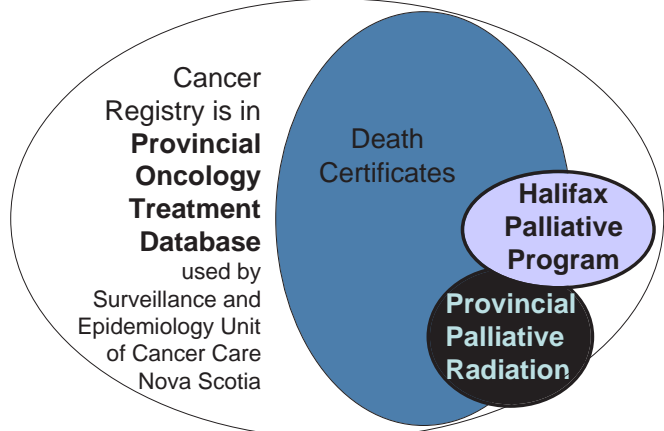
•For Application and Knowledge Translation: Clinicians from Family Medicine, Palliative Care, Palliative Radiation, Medical Oncology, and Pharmacy

## Radiotherapy Treatment in Last Nine Months of Life, 1994-1998

Radiotherapy Use	No	%
# consultation or Radiotherapy	6,313	63.3
Consultation	3,665	36.7
Palliative Radiotherapy	2,395	24.0
Non-Palliative Radiation	237	2.4
Consultation Only	1,033	10.4
Total	9,978	100.0



### Link to Major Urban Palliative Care Database



Develop indicator of Palliative Radiation from Provincial Oncology Treatment Data

## Family Physician Visits in the Last Six Months of Life

93% of Nova Scotian adults who died of cancer in 1995 received at least one visit from a FP during last six months of life

Total family physician visits: 20,759 (n = 2151)

Range per person dying of cancer: 0 - 56

Mean: 10.4 (SD 7.3) Median: 9.0

Johnston G, Burge F. (2002) Analytic Framework for Clinician Provision of End-of-Life Care. *Journal of Palliative Care* 18(3):141-149

## Family Physician Continuity Scores

14,037 died of cancer from 1992-1997

9,795 had at least 3 family physician visits

Continuity of care scores if 3+ visits (0-1):

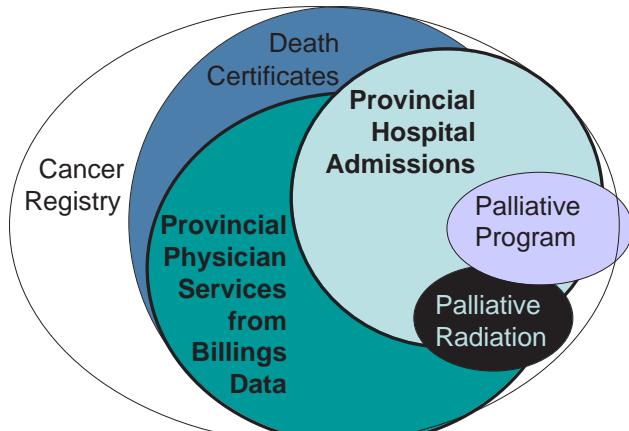
Mean 0.78; SD 0.22; Median 0.83

Categorized: Low (<0.5)

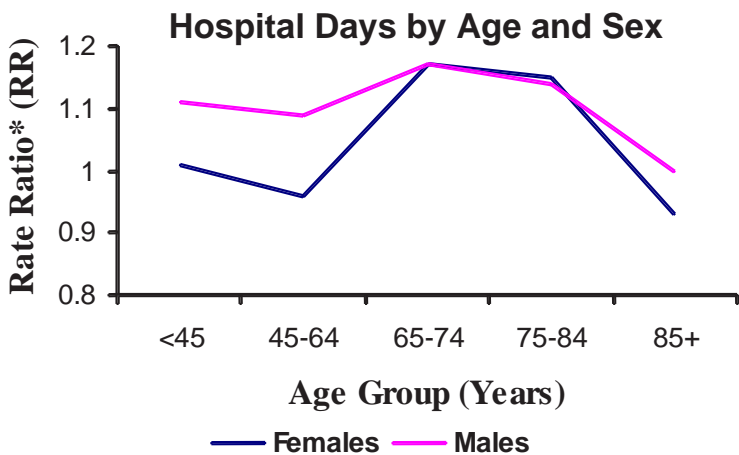
Moderate (0.5 - 0.8) High (> 0.8)

Burge F, Lawson B, Johnston G. Primary Care Continuity and Location of Death for those with Cancer. *Journal of Palliative Medicine*. 2003 6(6):911-917  
Burge F, Lawson B, Johnston G, Flowerdew G, Cummings I. (2005) Health care restructuring and family physician care for those who died of cancer. *BioMedCentral - Family Practice* 6:1-6  
Burge F, Lawson B, Johnston G. (2005) Home visits by family physician during the end-of-life: Does income or residency play a role? *BioMedCentral - Palliative Care* 4:1-9  
Burge F, Lawson B, Johnston G. (2005) Where a patient dies: The effect of rural residency. *Journal of Rural Health* 21(3):233-238

### Link to Provincial Physician Billings and Hospital Admissions, 1994-1998

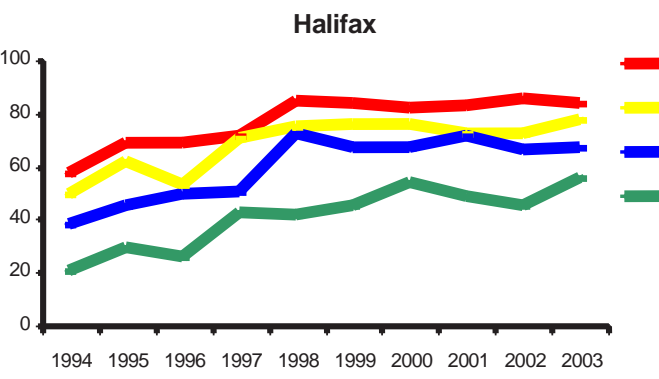


Created End of Life Research Dataset at Dalhousie University

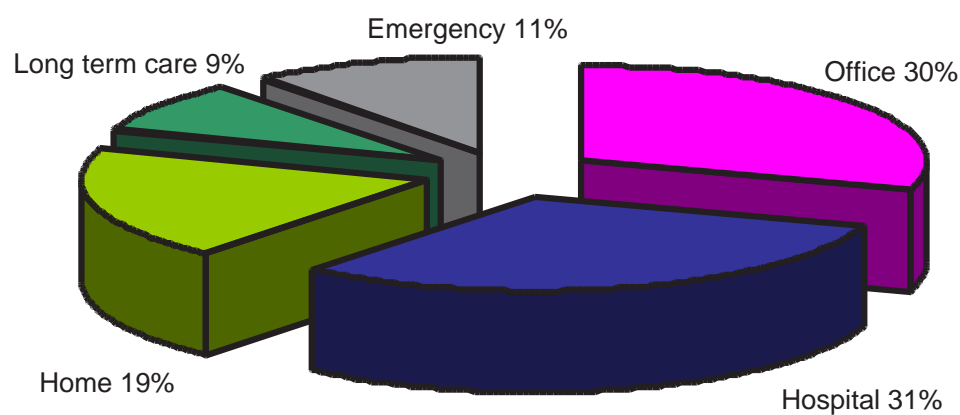


*Note:* Age (categorical) dropped out of the multivariate model (p<.01). Sex was retained in the multivariate model: RR(e\*)=1.08, 95% CI=1.03-1.13

### Palliative Care Program Registration by Age and Year, Halifax

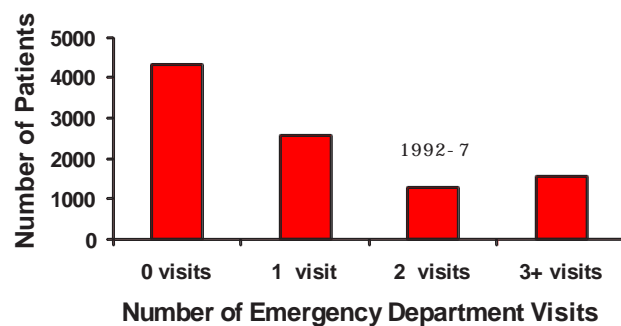


Data updated from: Burge F, Johnston G, Lawson B, Dewar R, Cummings I (2002) Population Based Trends in Referral of the Elderly to a Comprehensive Palliative Care Program. *Palliative Medicine* 16:255-256



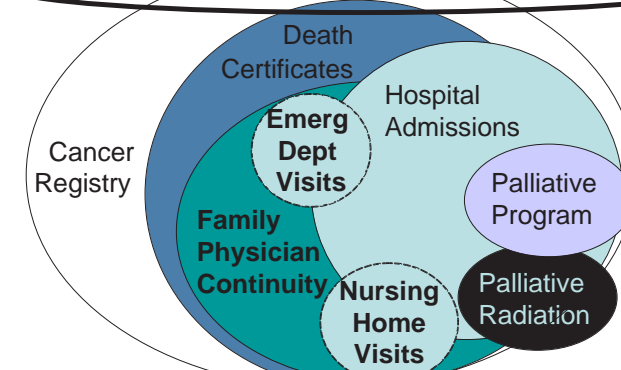
Cancer patients experiencing low and moderate family physician continuity made significantly more Emergency Department visits than those experiencing high continuity. Low continuity: Relative Risk (RR) 3.90; 95%CI 3.55, 4.28 Moderate continuity: RR 2.25; 95%CI 2.13, 2.38

Burge F, Lawson B, Johnston G. (2003) Family Physician Continuity of Care and Emergency Department Use in End-of-Life Cancer Care. *Medical Care* 41(8):992-1001



### Link to Census

Postal code > Census Area > Census > SES



Develop Community Socioeconomic Status using postal code; Indicators of Continuity of Family Physician Care, Emergency Department Visits, Nursing Home Visits from Physician Billings

### Multivariate Analysis: Family Physician Visits associated with Hospital Days

Family Physician Visits	RR (e <sup>β</sup> )	95% CI
Regular office hours	1.0	-
0	1.0	-
1-4	0.75	0.72-0.79
≥5	0.59	0.55-0.62
After hours in office	1.0	-
0	1.0	-
≥1	0.82	0.71-0.94
In patient's own home	1.0	-
0	1.0	-
≥1	0.88	0.84-0.92
In a long term care facility	1.0	-
0	1.0	-
≥1	1.26	1.17-1.35

### Multivariate Analysis: Other Patient Factors associated with Hospital Days

Characteristic	RR* (e <sup>β</sup> )	95%CI
Cancer cause of death	1.0	-
Lung	1.13	1.05-1.22
Colorectal	0.85	0.79-0.92
Prostate	1.17	1.08-1.27
Other	1.14	1.09-1.20
Survival (days)	1.0	-
<61	0.54	0.50-0.59
61-120	0.27	0.26-0.29
≥121	1.0	-
Hospital death	1.0	-
No	1.0	-
Yes	2.09	1.99-2.20

\* RR >1 is associated with more days in hospital

### Multivariate Analysis: Other Care Factors associated with Hospital Days

Characteristic	RR (e <sup>β</sup> )	95%CI
Palliative radiation	1.0	-
No	1.16	1.10-1.21
Yes	1.0	-
Palliative care program - Halifax Region only	1.0	-
No	1.12	1.04-1.21
Yes	1.0	-

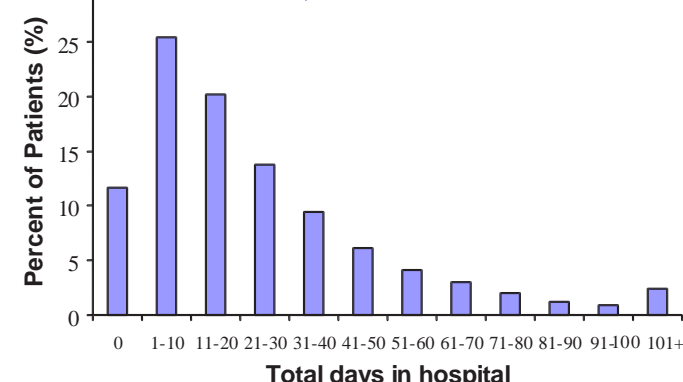
**Note:** In the multivariate analysis, two additional factors were dropped because they were not significant (p<.01); however univariate results were significant:  
**Emergency Department Visits:** (0:RR=1) 1:RR=0.61,95%CI:(0.57-0.64); 2:RR=0.56; 3+:RR=0.54  
**Community Income:** (High:RR=1) High-Mid:RR=1.08; Mid:RR=1.10; Low-Mid:RR=1.15; Low=1.20

## Palliative Care Program Referral, Sydney, 1994 to 2003

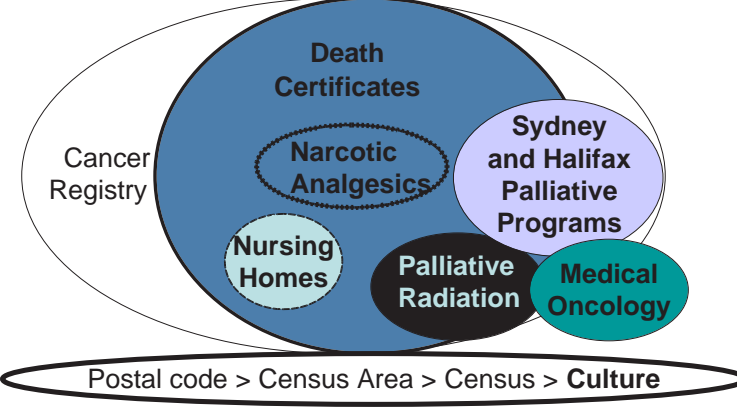
When data for a second palliative care program (PCP) in the province were examined, very similar patterns were found for Sydney, as had been found in Halifax. For example, for both, PCP enrollment was associated with an increased likelihood of home death, and if enrolled, likelihood of dying at home increased if the initial enrollment was more than two weeks prior to death.

Variable	Crude OR	Adjusted OR (95% CI)
Sydney (Cape Breton) PCP Referral	1.3	1.4 (1.1-1.7)
Length of time in PCP:		
17-45 days	1.7	1.5 (1.1-2.1)
46-124 days	1.8	1.5 (1.1-2.0)
125+ days	2.4	1.8 (1.3-2.5)

## Hospital Days in Last Six Months of Life, 1992-1998



### Link second urban Palliative Program; Test link to Hospital Pharmacy Database



Use address to create Community Culture; extend Nursing Home indicator; Develop Medical Oncology care indicators

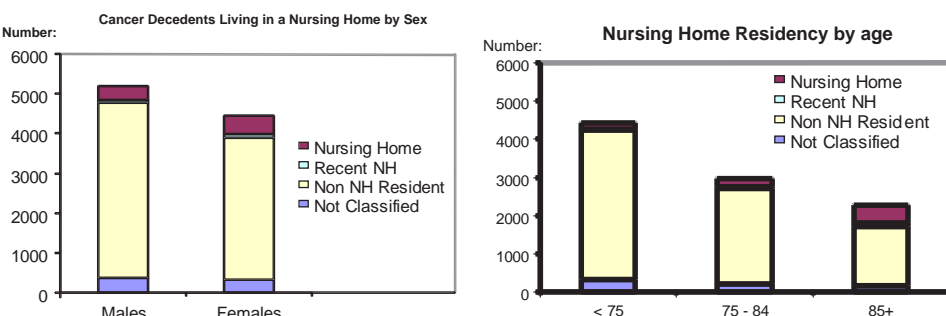
### Predictors of Dying out of Hospital for Adult Cancer Decedents, 1994-2003

DEMOGRAPHIC FACTORS	Crude	Adjusted
Age (20-44 years)	1.0 (0.8-1.2)	1.1 (0.9-1.4)
45-64	1.0 (0.8-1.2)	1.2 (0.9-1.4)
65-74	1.0 (0.8-1.2)	1.2 (0.9-1.4)
75-84	1.3 (1.1-1.5)	1.5 (1.2-1.8)
≥85	2.1 (1.7-2.5)	2.3 (1.9-2.8)
Sex (male)	1.4 (1.3-1.4)	1.3 (1.2-1.3)
Female	1.4 (1.3-1.4)	1.3 (1.2-1.3)
CLINICAL SITUATION		
Time lived after cancer diagnosis (all days)	2.0 (1.9-2.3)	2.2 (2.0-2.5)
61-120	2.0 (1.9-2.3)	2.2 (2.0-2.5)
≥121	2.6 (2.4-2.8)	2.6 (2.4-2.8)
Tumor group (Lung)		
Bladder	1.9 (1.7-2.1)	1.2 (1.0-1.3)
Colorectal	1.6 (1.4-1.7)	1.2 (1.1-1.3)
Prostate	1.6 (1.4-1.8)	1.1 (1.0-1.3)
Other	1.2 (1.1-1.3)	1.0 (0.9-1.1)
COMMUNITY OF RESIDENCE		
Odds Ratios (95% Confidence Intervals)		
Region (Halifax County)		
Cape Breton County	0.6 (0.4-0.7)	0.7 (0.6-0.7)
All other counties	0.7 (0.6-0.7)	0.7 (0.7-0.8)
Immigrant (No)		
Yes	1.5 (1.3-1.6)	1.2 (1.1-1.3)
Median Income (\$0-25,499)		
25,500-31,999	0.9 (0.8-1.0)	1.0 (0.9-1.1)
32,000-37,499	0.9 (0.8-1.0)	1.0 (0.9-1.1)
37,500-45,999	0.9 (0.8-1.0)	1.0 (0.9-1.1)
46,000+	1.2 (1.1-1.3)	1.2 (1.1-1.3)
HEALTH SERVICES		
Nursing Home Resident (No)		
Yes	22.8 (18-128.7)	24.0 (18.6-30.9)
Palliative Radiation (No)		
Yes	0.9 (0.8-0.9)	0.9 (0.8-0.9)
Medical Oncology Consultation (No)		
Yes	0.8 (0.8-0.9)	0.8 (0.8-1.0)

Data updated from: Burge F, Lawson B, Johnston G. (2003) Trends in Place of Death of Cancer Patients. *Canadian Medical Association Journal* 168(3):265-270

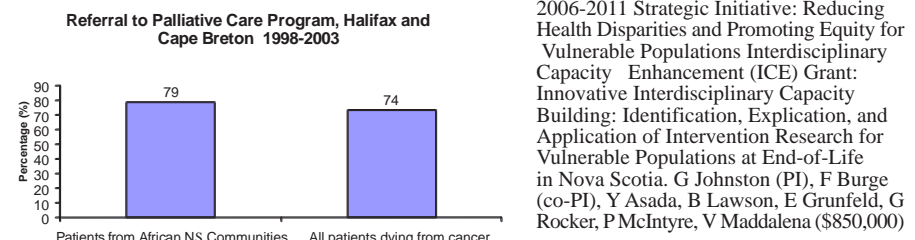
In Nova Scotia 70% cancer decedents die in hospital, yet up to 90% prefer to die at home. Historic decisions to publicly fund hospital and physician care in Canada contribute to the high rates of dying in hospital. Canada has had no national comprehensive palliative care plan; end-of-life care has evolved in response to local leadership. Determining factors associated with spending less time in hospital is important in developing policies and programs to optimize use of health care resources and help people spend their last days at home. Nova Scotia has no community hospices, and wait times to enter nursing homes can be long.

## Nursing Home Residency, 2000-2003



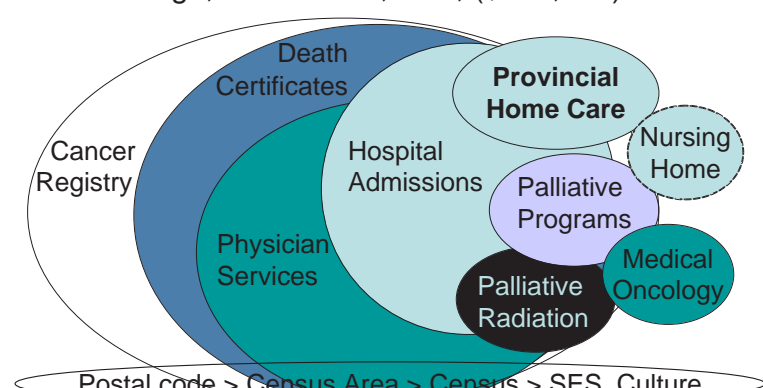
## Current Funding from Canadian Institutes for Health Research:

2004-9 **New Emerging Team (NET):** Palliative and End-of-Life Care Strategic Grant. Palliative Care in a Cross Cultural Context: A NET for equitable and quality cancer care for ethnically diverse populations across three provinces. R Doll (PI, BC) A Kazanjian (Co-PI, BC), A Leis (Sask), G Johnston (NS), G Fyles (BC), MC Barroetavena (BC). (\$1,396,327)



2006-2011 Strategic Initiative: Reducing Health Disparities and Promoting Equity for Vulnerable Populations Interdisciplinary Capacity Enhancement (ICE) Grant: Innovative Interdisciplinary Capacity Building: Identification, Explication, and Application of Intervention Research for Vulnerable Populations at End-of-Life in Nova Scotia. G Johnston (PI), F Burge (co-PI), Y Asada, B Lawson, E Grunfeld, G Ricker, PMcIntyre, V Maddalena (\$850,000)

**2005-7 Operating Grant:** Inequalities in end-of-life care for cancer patients: Do they exist? What contributes to them? F Burge, G Johnston, et al, (\$119,044)



### Update Years of End of Life Dataset to 2003

2004-5 Palliative and End of Life **Pilot Project Grant:** Quality indicators for end-of-life breast cancer care: Testing the use of administrative databases in two provinces. E Grunfeld (PI), L Paszat, F Burge, G Johnston, C Earle (\$89,978)

**Example of Quality Care Indicators: Place of Death for women dying of breast cancer, 1998-2002,**

E Grunfeld et al, 2006

Indicator	Statistic description	Nova Scotia	Ontario
Place of death	In hospital	63.4%	52.9%

## Conclusions:

Our methods used the linkage of administrative databases to provide indicators of palliative care program access, time in hospital in the last six months of life, emergency department use, associations with family physician continuity, nursing home residency, and oncology specialist referral, as well as associated demographic, community and clinical factors, for persons dying of cancer in a geographic area. The methods and data we developed will help to develop models of care for the expected increase in need as the baby boomer cohort ages. Network of End of Life Studies has emerged from the linked end of life database developed over time for persons dying of cancer in Nova Scotia.