

# Reaping the Benefits of Cancer Registries: Examples from End of Life Studies

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June 15, 2006 Regina, Saskatchewan



#### Outline

Beginnings

Cancer Registry
Context

#### Growth

Linkage to Population Administrative Databases

**Data Quality Assessment** 

**Expertise and Experiences** 

#### Harvest

**Publications** 

Research Grants

New Collegial Relationships



#### Beginning: Cancer Registry

Cancer Registry data back to 1960's

Death Clearance
Mortality Rates, and
Survival Statistics

Death Certificate Only Rates, and Mortality to Incidence Ratios

50% of people diagnosed with cancer die of cancer



#### Context

Canadian Health Care System
Provincial administered; publicly funded
Hospital care
Fee for service Physician visits

Senate Reports on Care of the Dying, 1995 ... Limited tertiary hospital based palliative medicine Virtually no hospice or other community care

#### Record Linkage

Statistics Canada Mortality Database Provincial Population Health Research Units Halifax Palliative Care Program - 1988



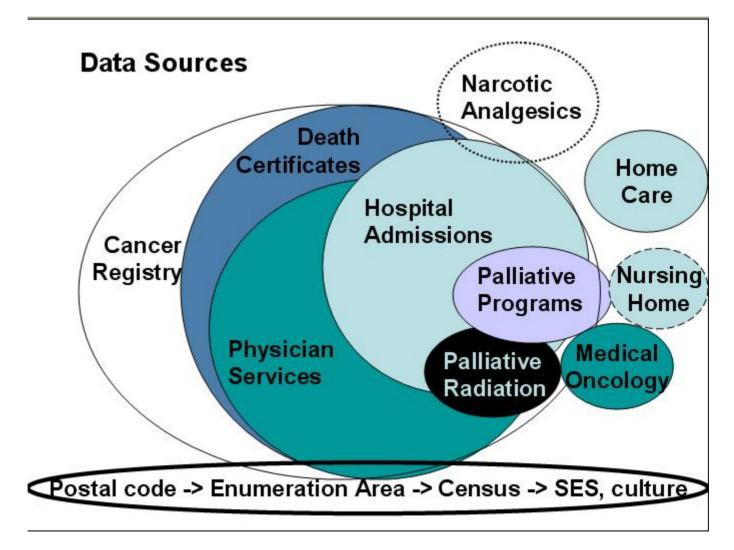
#### Growth

Linkage to Population Administrative Databases

Data Quality Assessment

Experiences

## Linkage of Cancer Registry Data to Population Based Administrative Databases





## Data Quality Framework to assess Administrative Databases being added

#### **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	data fields
constancy	complete
accuracy,	includes all
reliability	persons
validity,	includes all
interpreting	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

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

R Dewar, B Lawson, C Boyd, N St Jacques, J Gao, M O'Brien



#### Expertise

For Interpretation and Knowledge Translation:

Clinicians from
Family Medicine,
Palliative Care,
Palliative Radiation,
Medical Oncology, and
Pharmacy

F Burge, I Cummings, P McIntyre, D Orychock, P Joseph, D Rheaume, D Rayson, L Broadbent, E Grunfeld



#### Personal experiences

Health Services Administration

Family and Friends

Breast Cancer Survivor, and Dragon Boat Team Member



#### Harvest

**Publications** 

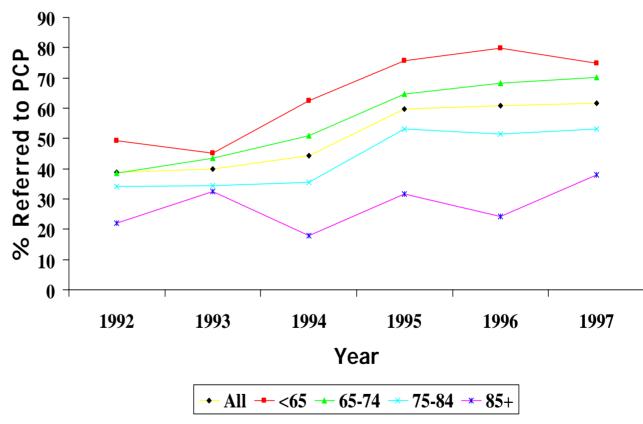
Research Grants

New Collegial Relationships



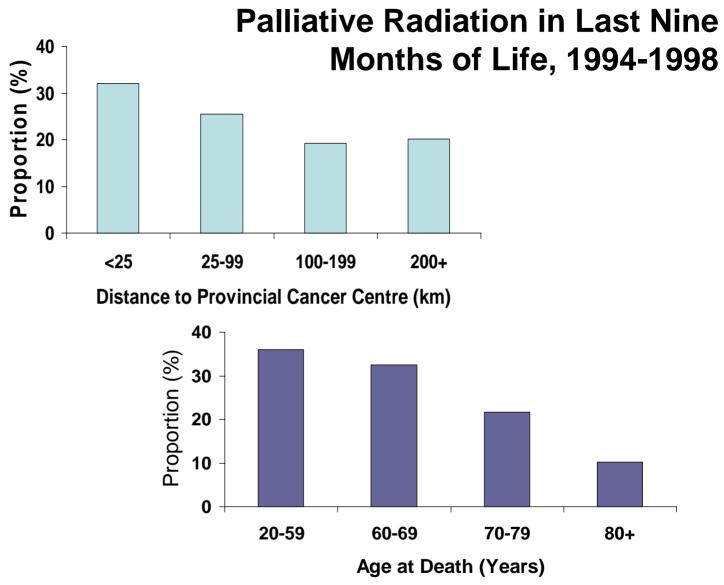
#### Initial publications

Palliative Care Program Referral by Age, Halifax



Johnston G, Gibbons L, Burge F, Dewar R, Cummings I, Levy I (1998) Need for Palliative Care in Nova Scotia. **Canadian Medical Association Journal** 158(13):1691-8 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



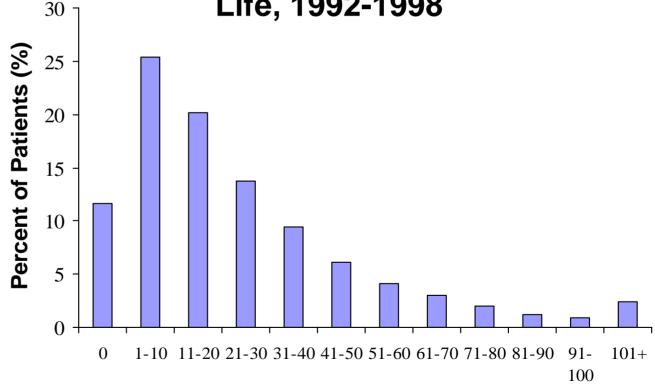


Johnston G, Boyd C, Joseph P, MacIntyre M (2001) Variation in Delivery of Palliative Radiotherapy to Persons Dying of Cancer In Nova Scotia, 1994 to 1998. **Journal of Clinical Oncology** 19(14): 3323-3332



# Canadian Institutes for Health Research (CIHR) Operating Grant

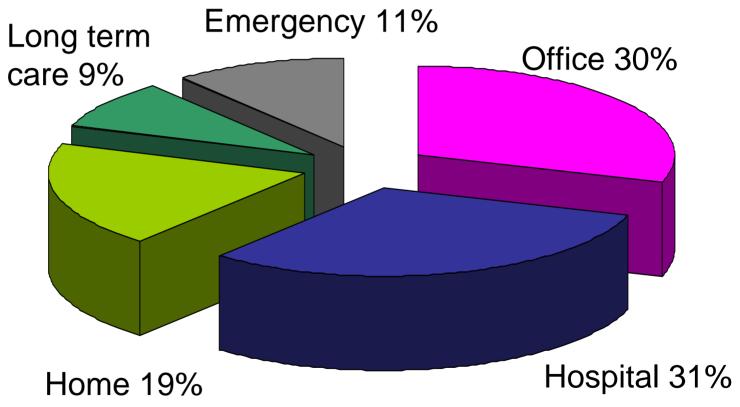
Hospital Days in Last Six Months of Life, 1992-1998



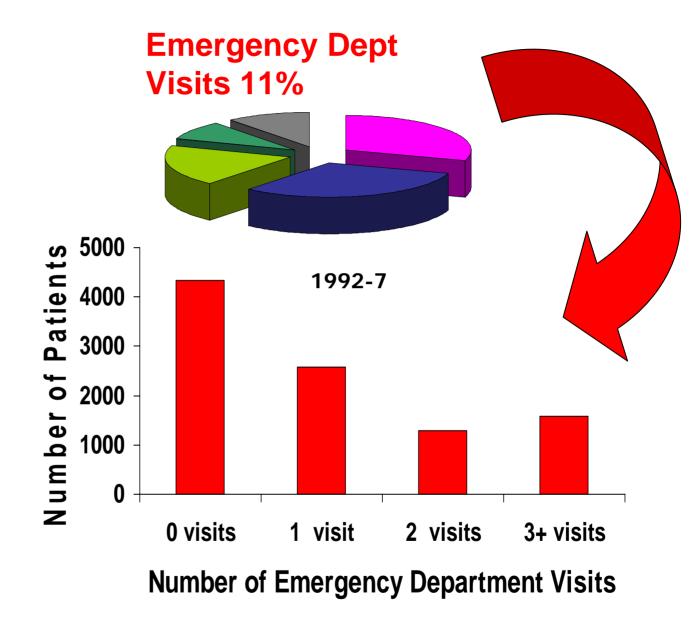
Total days in hospital



### Family Physician Visits in last six months of life, 1995







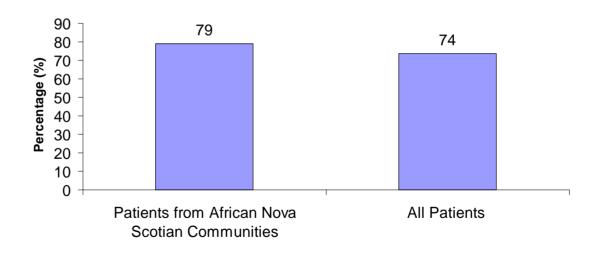
Burge F, Lawson B, Johnston G. (2003) Family Physician Continuity of Care and Emergency Department Use in End-of-Life Cancer Care. **Medical Care** 41(8):992-1001



#### CIHR Grant New Emerging Team (NET)

British Columbia, Saskatchewan, and Nova Scotia
Cultural indicators

Referral to Palliative Care Program, Halifax and Cape Breton 1998-2003



Postal code SES, at Death > Census Area > Census > Culture



# CIHR Interdisciplinary Capacity Enhancement (ICE) Grant for Equity in Access to End of Life Care for Vulnerable Populations

- 1 Surveillance System and Report of inequity in quality care
- 2 Defining vulnerable populations at end of life: Ethical Analysis
- 3 Quality pediatric terminal care and vulnerabilities
- 4 African Canadians and End-of-Life Care
- 5 Attaining a better understanding of gender and age at end of life
- 6 Quality end of life cancer care for vulnerable elderly
- 7 Community based quality care at end of life with COPD
- 8 Canadian Compassionate Care Benefit: Is it working?



## Interactions with other Canadian Colleagues

#### Study Subjects

Definitions of EOL study subjects vary. Further dialogue on inclusion, uncertain and exclusion criteria is required.

Persons with cancer as primary cause of death

Persons with cancer as another cause of death

Persons who had a cancer diagnosis but not cause of death

Grunfeld 2004

All persons dying of cancer who could benefit by receiving palliative care

Persons dying of cancer

Persons with cancer who died of other chronic disease eg Alzhemier's COPD, stroke,

Died of cancer treatment

-Gagnon 2005

Cancer diagnosis in
Cancer Registry prior to
death certificate (DC) linkage

Johnston 1998, 2001 Burge 2002, 2003 DC follow back identified (DCI) new cancer case, eg clinical diagnoses in long term care facilities. Majority >80 years

Death Certificate
Only (DCO) case:
date of diagnosis is
date of death



#### **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%

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



## Predictors of Home Death for Adults Dying of Cancer, Nova Scotia, 1994-2003

DEMOGRAPHIC FACTORS	C FACTORS Odds Ratios (95% Confidence Intervals)		
<b>Age</b> (20-44 years)	Crude	Adjusted	
45-64	1.0 (0.8-1.2)	1.1 (0.9-1.4)	
65-74	1.0 (0.8-1.2)	1.2 (1.0-1.4)	
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)			
Female	1.4 (1.3-1.4)	1.3 (1.2-1.3)	
CLINICAL SITUATION			
Time lived after cancer diagno	<b>sis</b> (<61 days)		
61-120	2.0 (1.8-2.3)	2.2 (2.0-2.5)	
121+	2.6 (2.4-2.8)	2.6 (2.4-2.9)	
Tumor group (Lung)			
Breast	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)	



## Predictors of Home Death for Adults Dying of Cancer, Nova Scotia, 1994-2003

COMMUNITY OF RESIDENCE	E Odds Ratios (95% Confidence Intervals)		
Region (Halifax County)	Crude	Adjusted	
Cape Breton County	0.6 (0.6-0.7)	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 <sup>1</sup> (No)			
Yes	22.8 (18.1-28.7)	24.0 (18.6-30.9)	
Palliative Radiation (No)			
Yes	0.9 (0.8-0.9)	0.9 (0.8-0.9)	
<b>Medical Oncology Consultation</b> (I	No)		
Yes	0.8 (0.8-0.9)	0.9 (0.8-1.0)	



### Research with other Canadian Colleagues

Costing Palliative Care in Five Canadian Cities,
S Dumont et al
Investigating Bias in Study Sample Selection,

Compare Study Decedents to Persons dying of cancer in same time period



#### **Products**

Assess Palliative Care Policy and Program

Surveillance Report Card

Research Program

Increased Access to Quality End of life Care



Network for End of Life Studies

**Questions?**