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

Grace Johnston, MHSA, PhD

Professor, School of Health Services Administration, Dalhousie University, and
Epidemiologist, Surveillance and Epidemiology Unit, Cancer Care Nova Scotia,
Halifax, Nova Scotia, Canada

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## 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

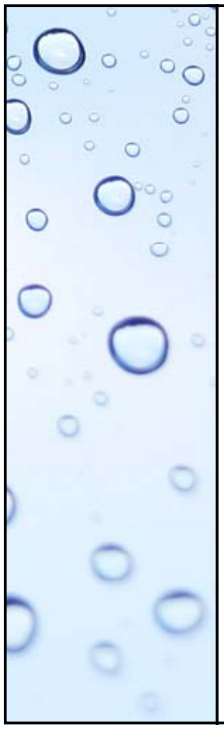
- Canadian Health Care System
  - Provincial administered; publicly funded
    - Hospital care
    - Fee for service Physician visits
- Senate Reports on Care of the Dying, 1995 …
  - Limited tertiary hospital based palliative medicine
  - Virtually no hospice or other community care
- Record Linkage
  - Statistics Canada Mortality Database
  - Provincial Population Health Research Units
  - Halifax Palliative Care Program - 1988

# Growth

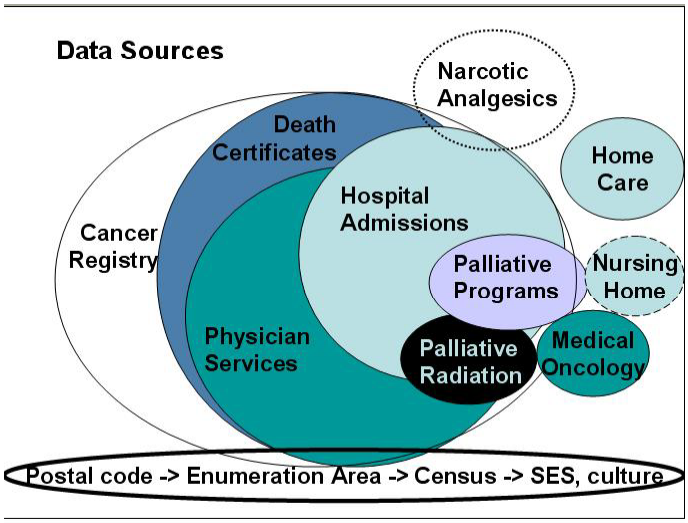
Linkage to Population Administrative Databases

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 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

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

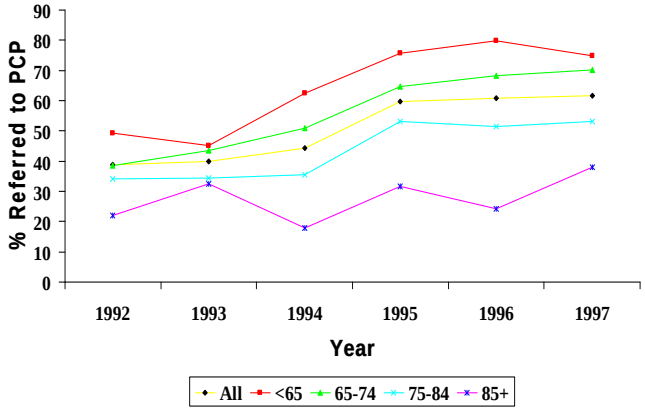
Publications

Research Grants

New Collegial Relationships

# Initial publications

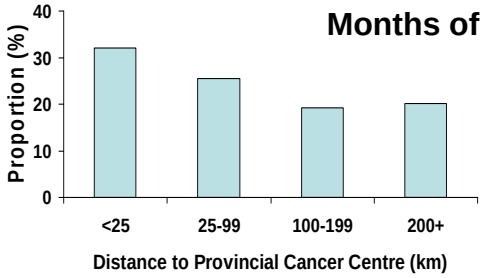
## Palliative Care Program Referral by Age, Halifax

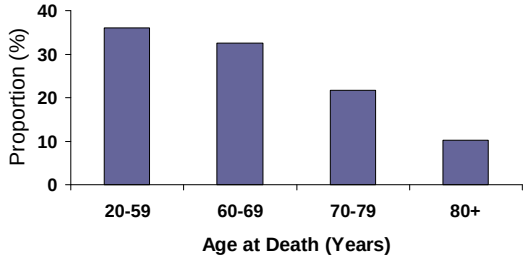



Johnston G, Gibbons L, Burge F, Dewar R, Cummings I, Levy I (1998) Need for Palliative Care in Nova Scotia. **Canadian Medical Association Journal** 158(13):1691-8

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

## Palliative Radiation in Last Nine Months of Life, 1994-1998

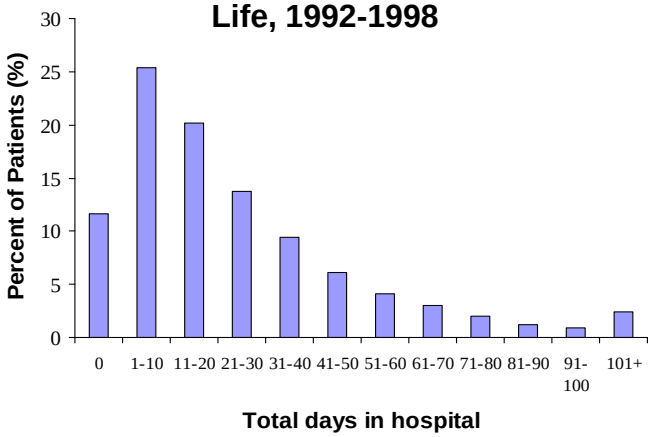


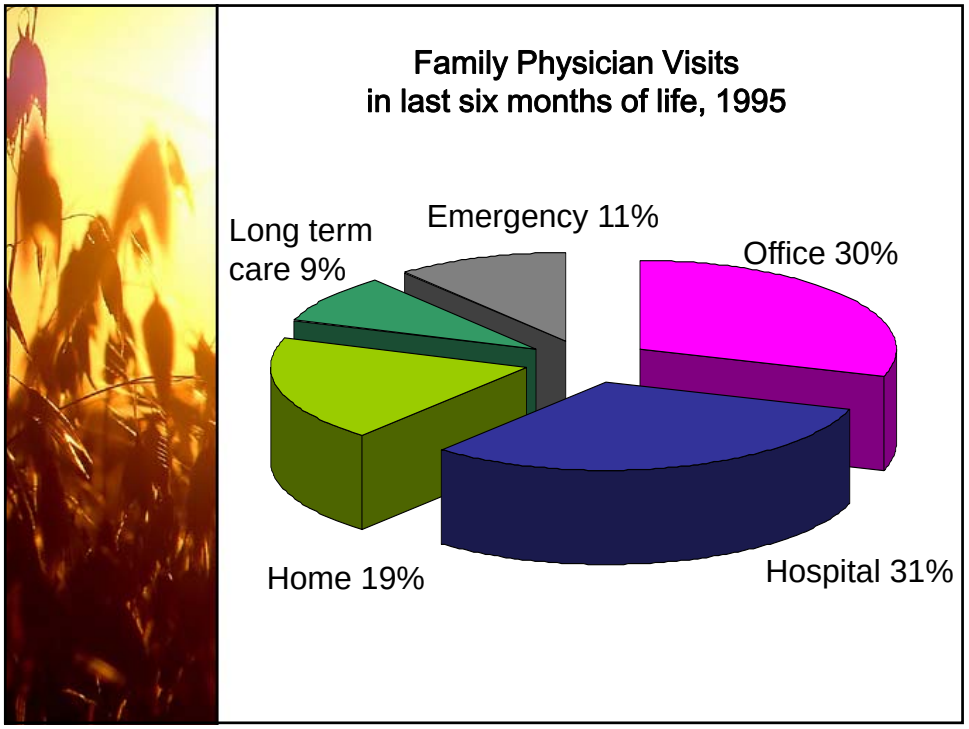



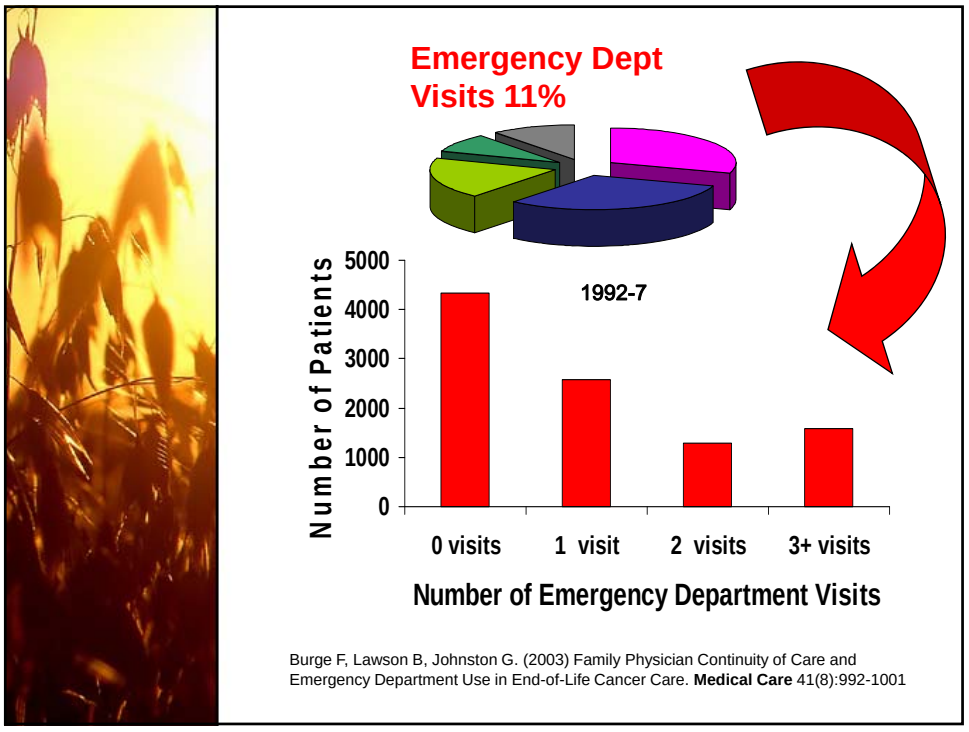

Johnston G, Boyd C, Joseph P, MacIntyre M (2001) Variation in Delivery of Palliative Radiotherapy to Persons Dying of Cancer In Nova Scotia, 1994 to 1998. **Journal of Clinical Oncology** 19(14): 3323-3332

## Canadian Institutes for Health Research (CIHR) Operating Grant

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





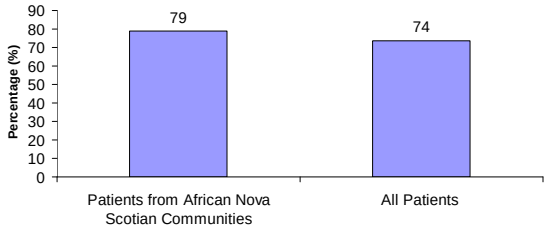

Burge F, Lawson B, Johnston G. (2003) Family Physician Continuity of Care and Emergency Department Use in End-of-Life Cancer Care. **Medical Care** 41(8):992-1001

# 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 at Death > Census Area > Census > SES, 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** | **Odds Ratios (95% Confidence Intervals)** | |
|---|---|---|
| **Age** (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 diagnosis** (<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** | **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**[1] (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) |
| **Medical Oncology Consultation** (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?