# Network for End of Life Studies (NELS)
## Interdisciplinary Capacity Enhancement (ICE)

**Community Health & Epidemiology Seminar Series**

Tuesday, October 24, 2006

Fred Burge and

Grace Johnston

DALHOUSIE UNIVERSITY
*Inspiring Minds*

# Overview

- Progress over 10 years
- New CIHR Operating Grant and NELS-ICE research funding


CAPITAL HEALTH

## Purposes of today's presentation

- To describe the evolution of a program of growing collaborative research
- To introduce potential areas for further collaboration and development

## Other Funding and other support/development

Funding and support from Health Canada, Family Medicine, Dalhousie Cancer Research Program,

Enabled CIHR end of life pilot projects with Ontario (EG), cross cultural end of life NET with BC (GJ), and international primary care collegial group (FB)

## Research Associates and Colleagues

Bev Lawson, Ron Dewar, Jun Gao, Meaghan O'Brien, Maureen MacIntyre, Ina Cummings, Paul MacIntyre, Dale Orychuk, Eva Grunfeld, Radiation and Medical Oncologists, and many others

## Purpose of Research

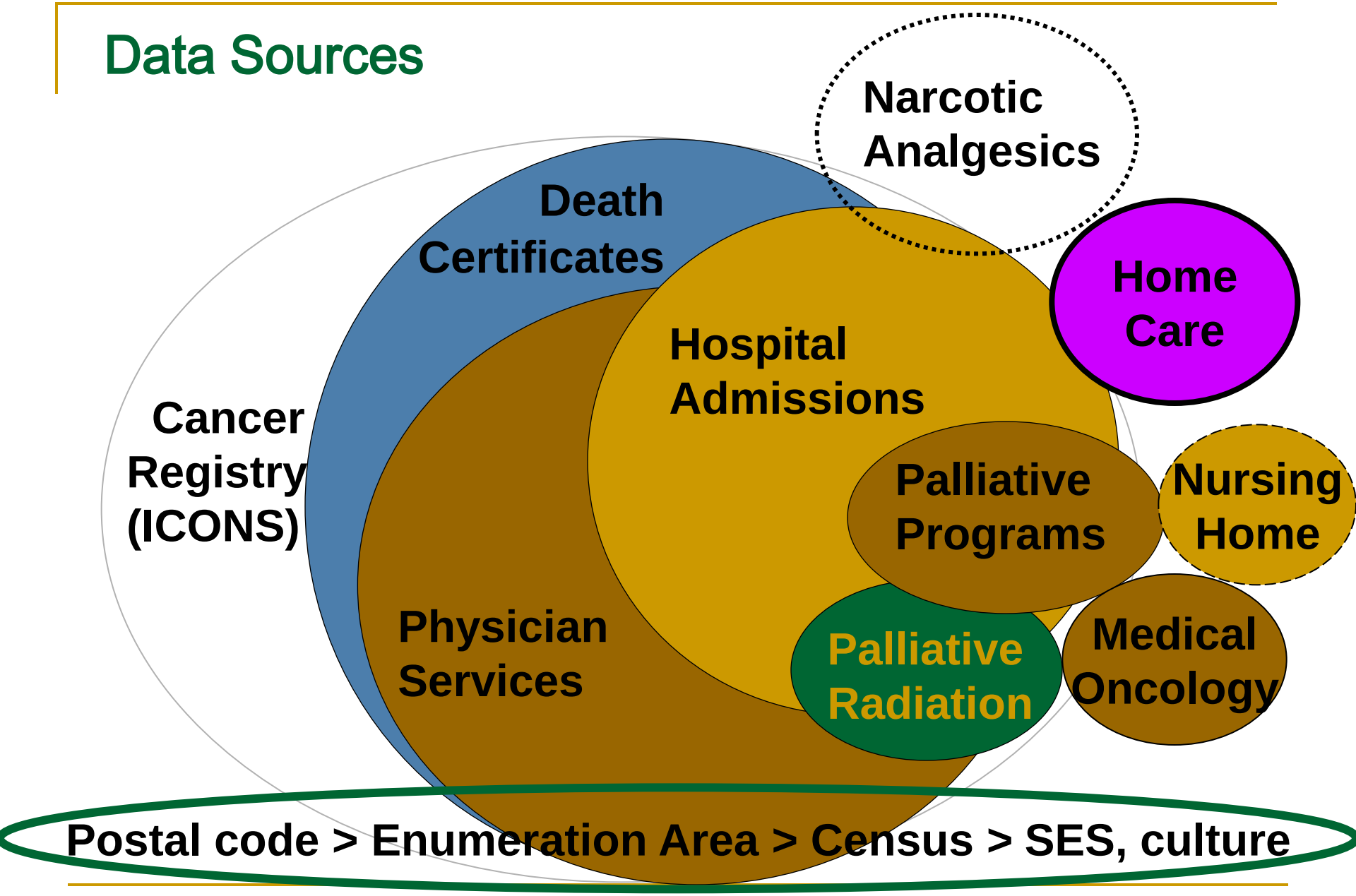
To determine types of care at end of life, and factors associated with these types of care

## Study Subjects

22,886 adults who died of cancer in Nova Scotia from 1994 to 2003 with their cancer diagnosis known prior to their date of death

2809 individuals who died of congestive heart failure in Nova Scotia from 1998 to 2001

# Data Sources



# CIHR Inequalities Operating Grant:

Funded 2005; update linked data to 1998-2003

During the end-of-life period for patients who die with cancer we will:

Examine health service utilization inequalities (**including home care**) and health care outcomes related to age and gender, and

Identify population characteristics and health care system factors contributing to these inequalities.

# Data Quality Framework

## 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 |

# Evolution of Research Studies

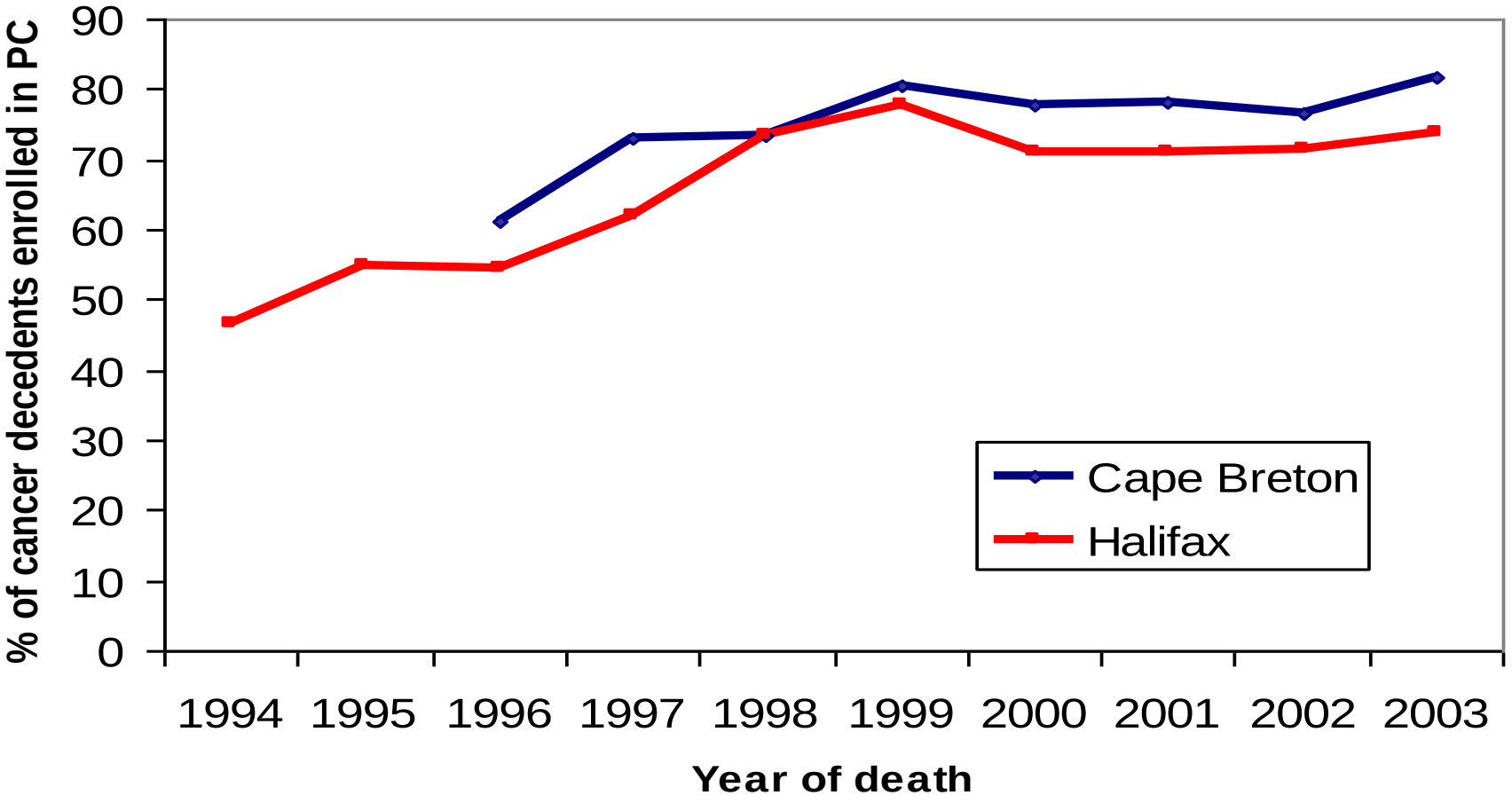
| | Initially | Recent interest |
|---|---|---|
| **Population** | Nova Scotia | Ontario, BC, Sask |
| | Adults | Children |
| **Cause of Death** | Cancer, then Congestive Heart Failure | Chronic Obstructive Pulmonary Disease, Other |
| **Methods** | Disparities, Retrospective, logistic regression | Equity, Prospective, CART, Quality indicators |

# Quality Indicators

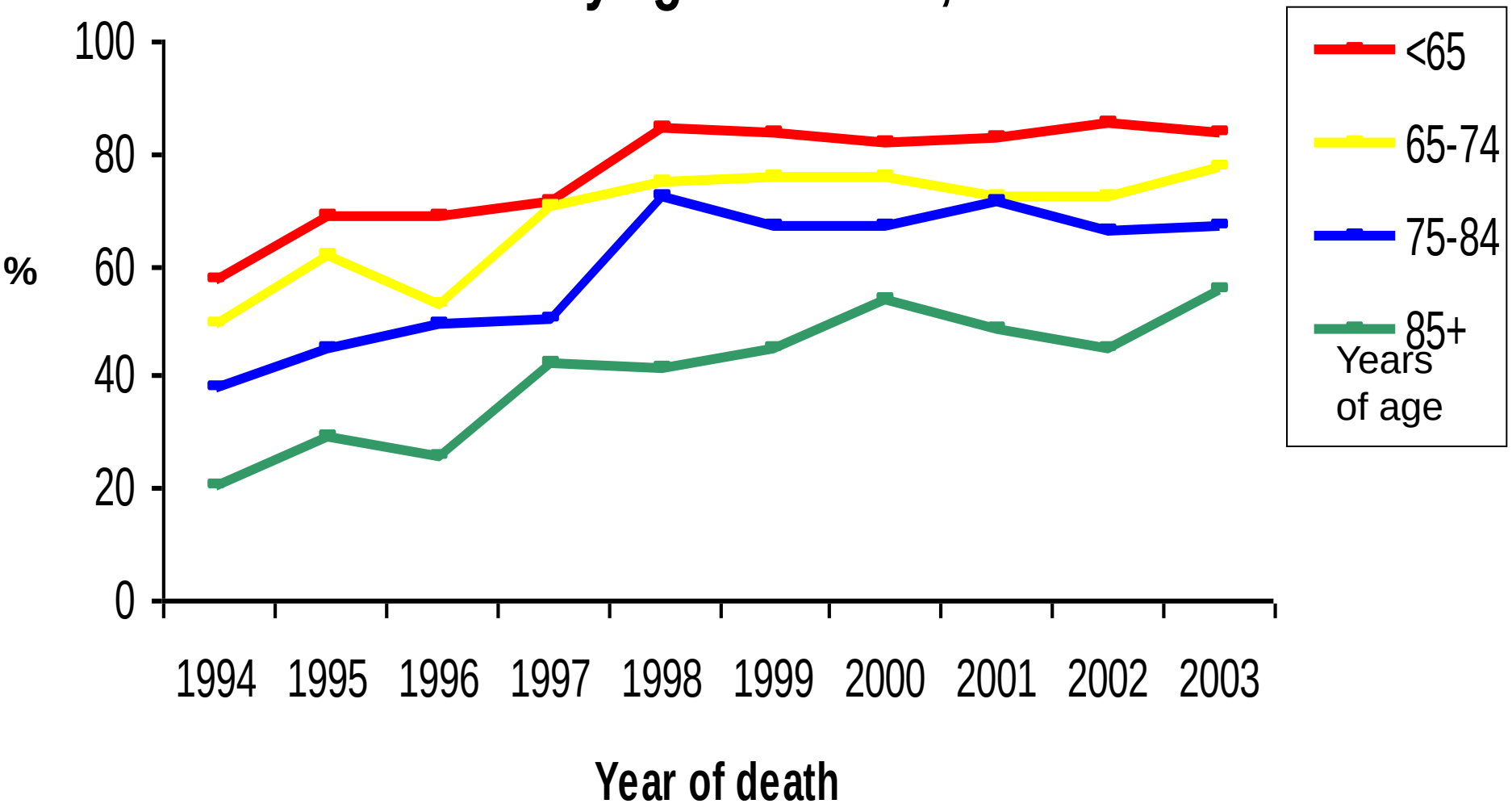
adapted from E Grunfeld et al, 2006

| Measurable | Partially Measurable |
|---|---|
| **1. Enrollment in palliative care**<br>**2. Frequency of ER visits**<br>**3. Place of death**<br>**4. Continuity of care**<br>5. Hospital days near death date<br>6. Intensive Care Unit near death<br>7. Interval between last chemotherapy treatment and death<br>8. Length of time with access to palliative care prior to death | 9. Radiation treatment for uncontrolled bone pain for bony metastases<br>10. Potent antiemetic for emetogenic chemotherapy |

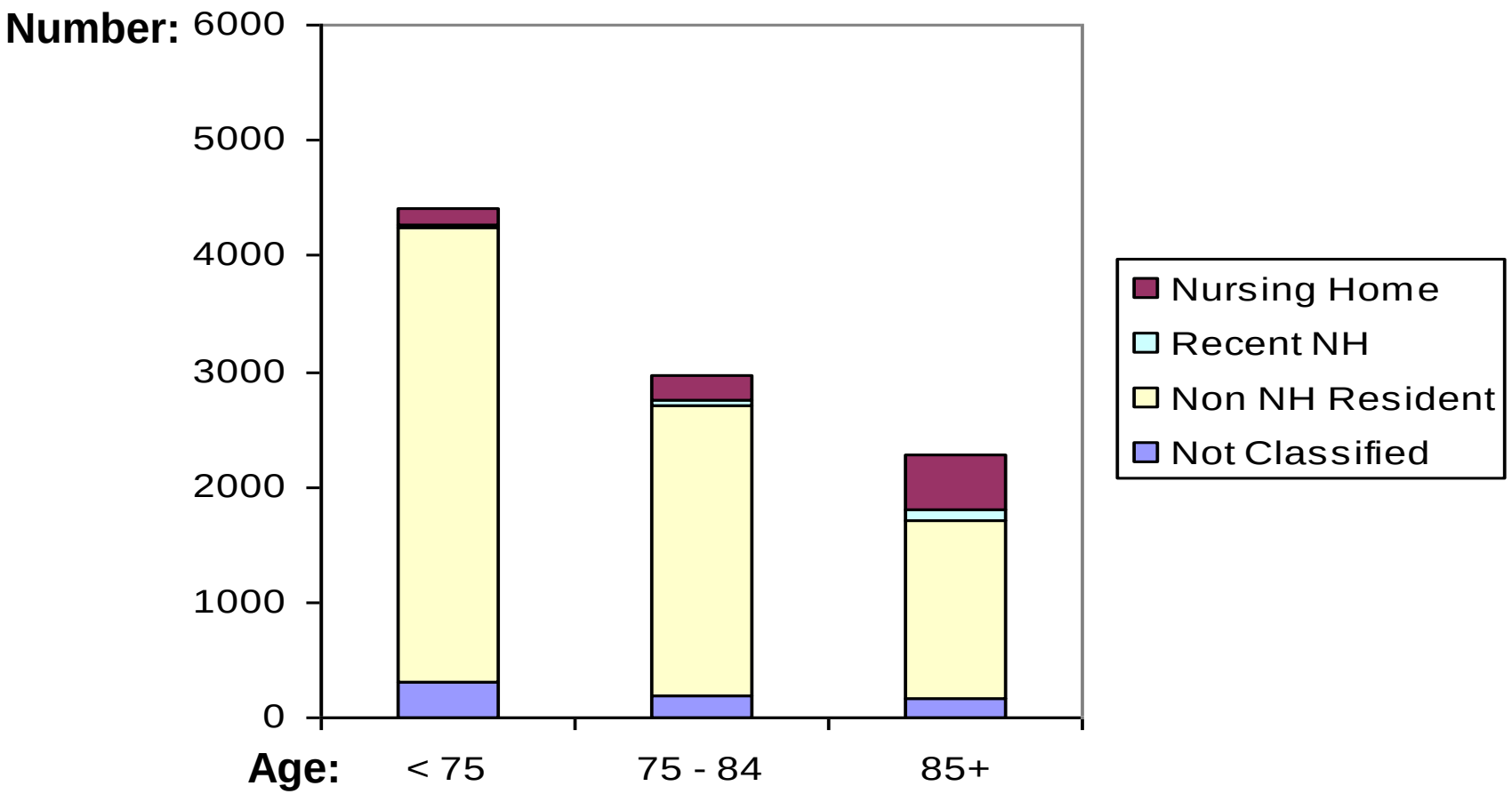
# Trends in palliative care enrollment rates for cancer decedents, Cape Breton and Halifax, 1994-2003



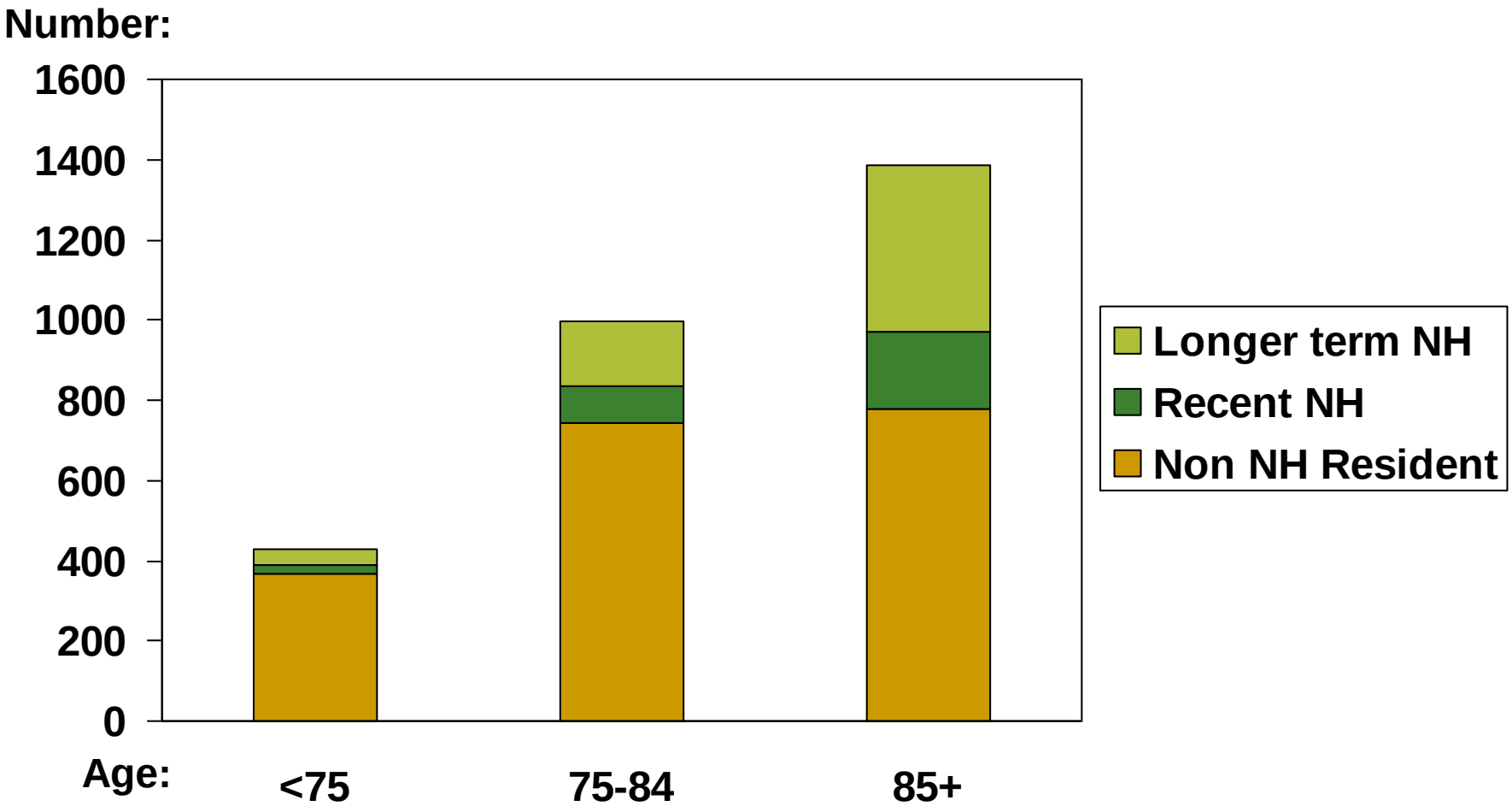
# Palliative Care Program Registration for Cancer Decedents by Age and Year, Halifax



# Cancer Decedents by Nursing Home Residency and Age



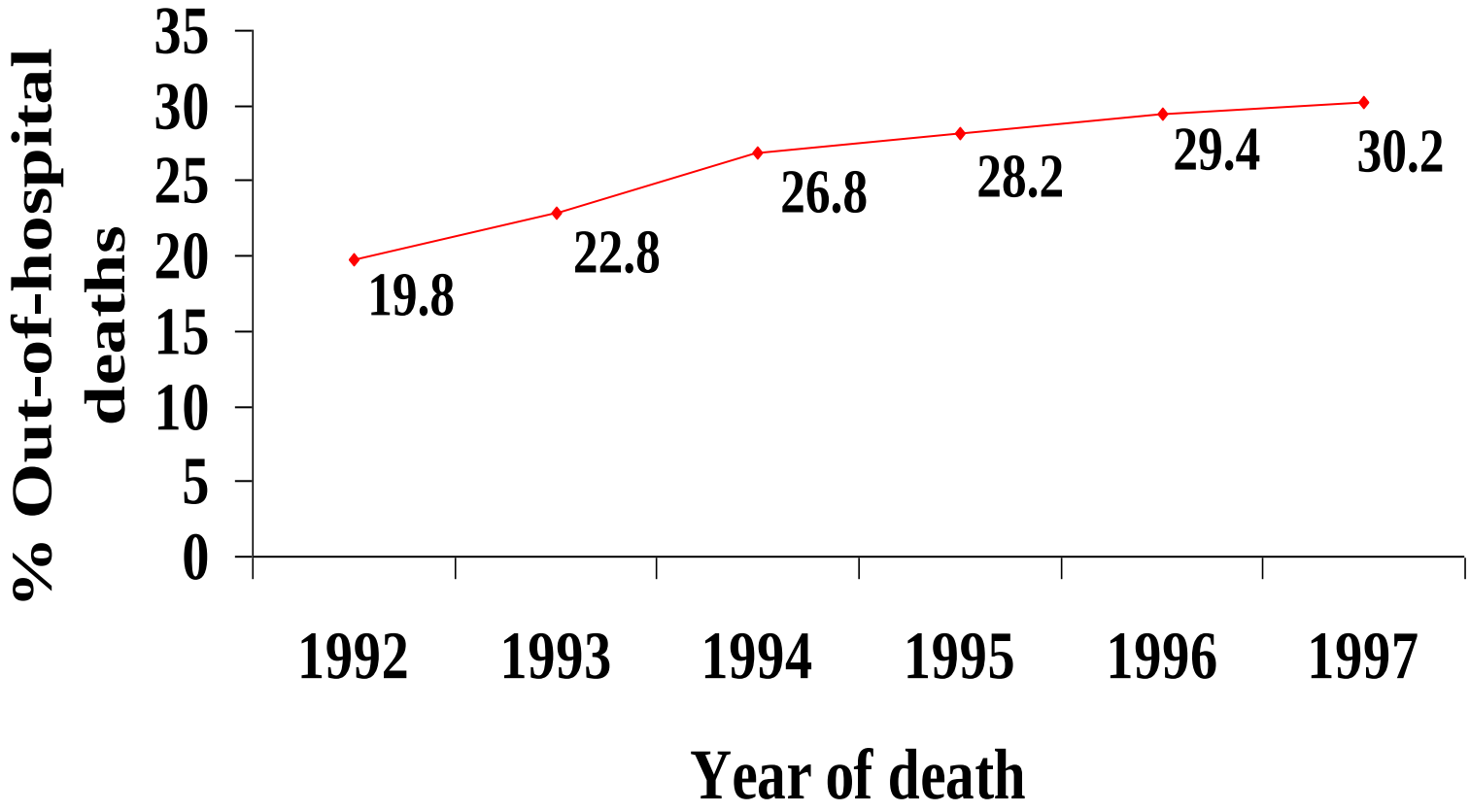
# Congestive Heart Failure Decedents by Nursing Home Residency and Age



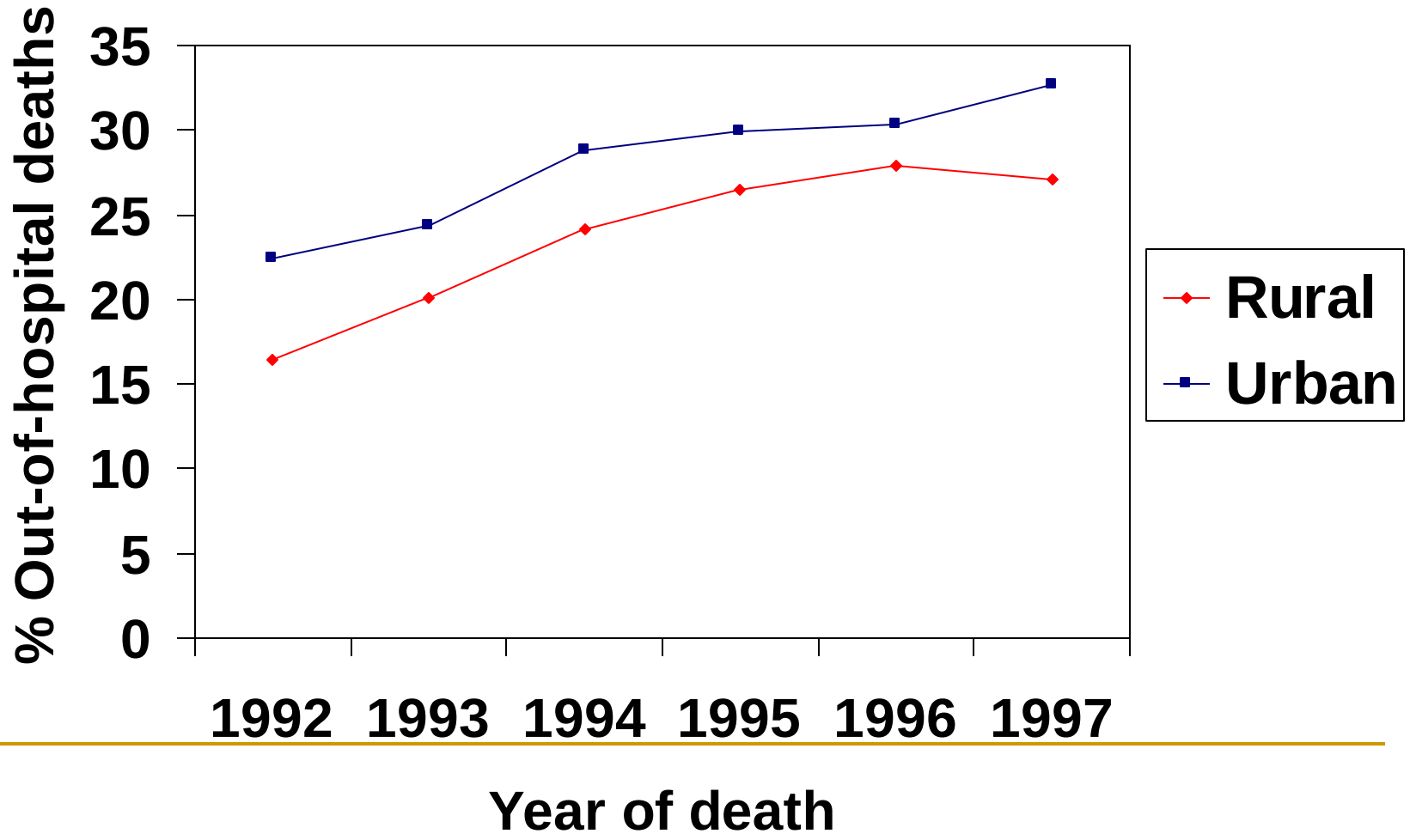
# Andersen model of health service applied to predictors of home death at end of life with cancer

| HEALTH SYSTEM | PREDISPOSING SOCIO-DEMOGRAPHICS | ENABLING RESOURCES | INDICATORS OF NEED | TREATMENT | OUTCOME |
|---|---|---|---|---|---|
| **Geographic Area**<br>•County<br>•Rural/urban<br>•Distance to cancer care<br>**Time Period**<br>•Year of death | •Age<br>•Sex<br>*Neighbourhood* ethnic mix, education, and rates of employment and immigration were not significant with county and income included. | •Nursing home<br>•Palliative care† program<br>•Home care†<br>•*Neighbourhood* Income | •Advanced cancer<br>•Tumour site<br>•Time from diagnosis | •Medical oncology<br>•Palliative radiation | **Quality of life**<br>•Home death |

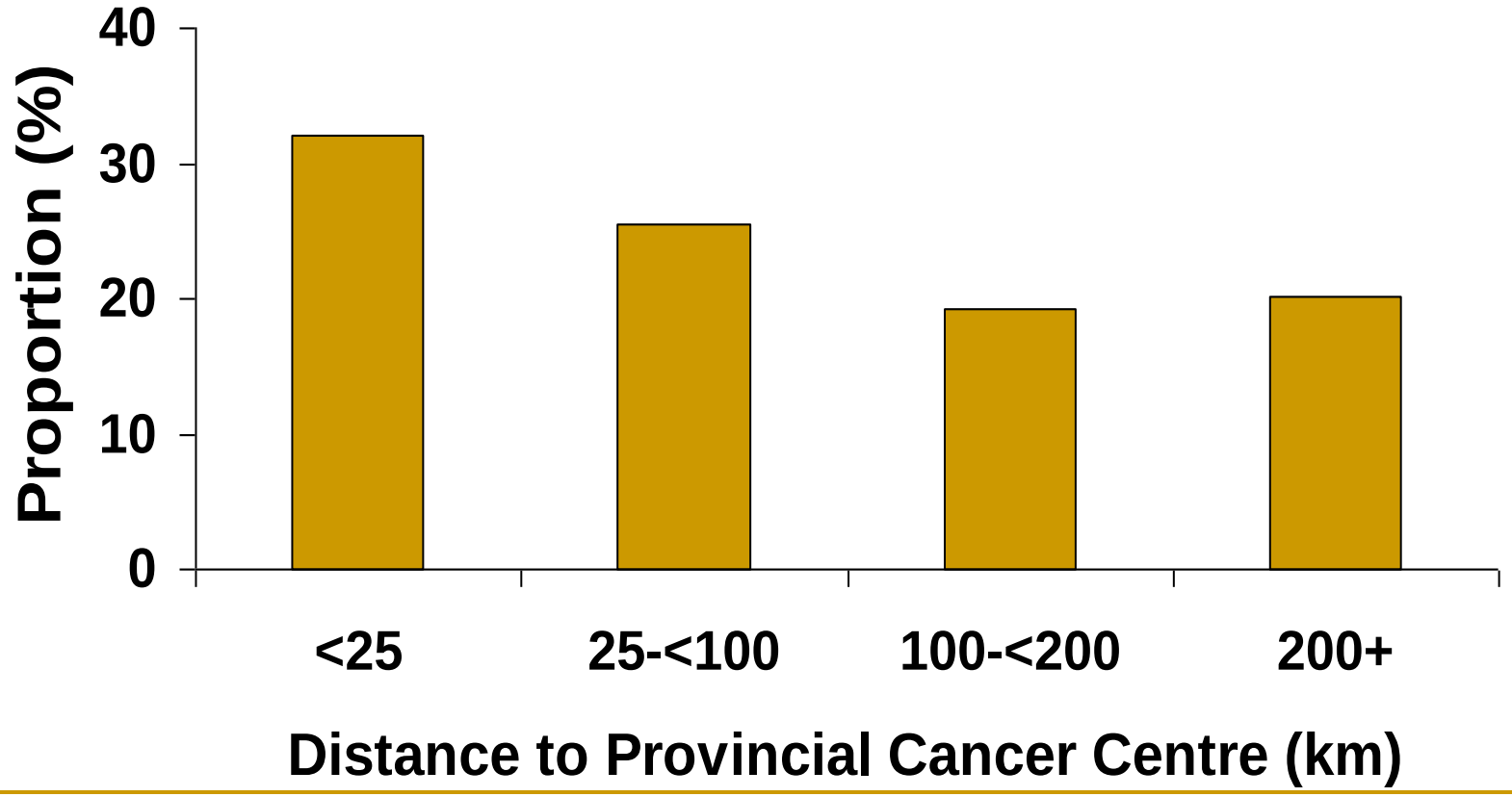
# Out of hospital (home) deaths among cancer decedents over time Nova Scotia 1992-1997



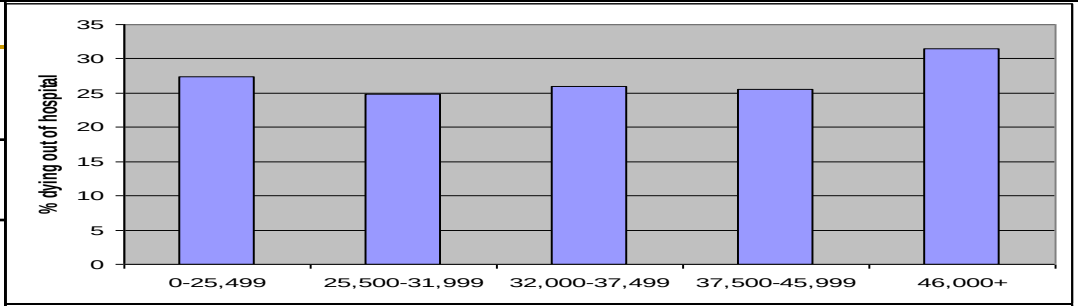
# Out of hospital deaths by EA urban/rural indicator over time, NS 1992-1997

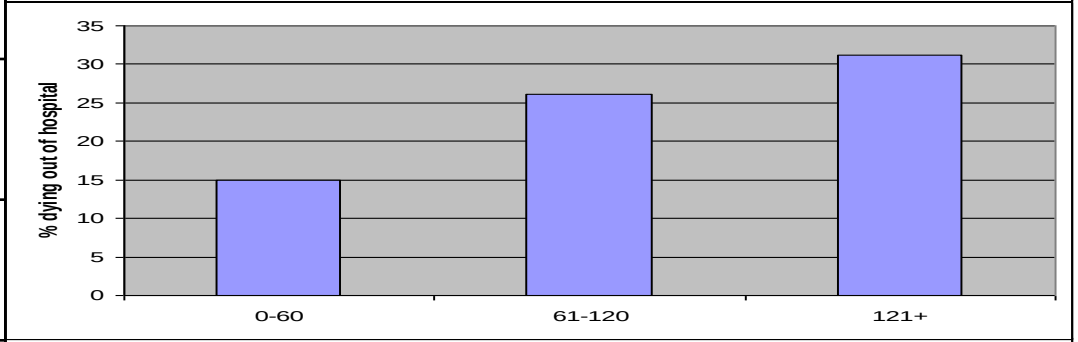


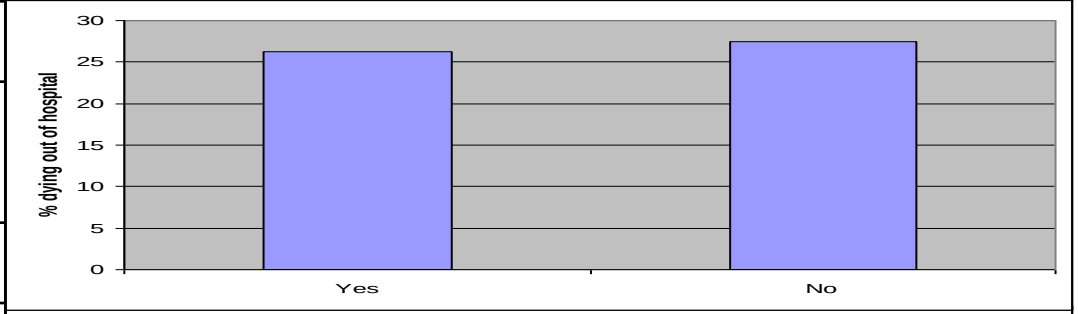
# Palliative Radiation in Final 9 Months by Distance to Provincial Cancer Center, 1994-8

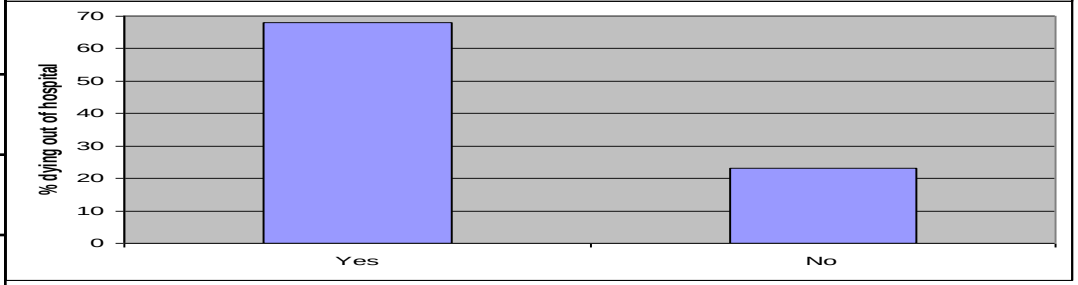


| Median neighbourhood income | |
|---|---|
| 0-25,499 | 1235 (27.4%) |
| 25,500-31,999 | 1235 (24.9%) |
| 32,000-37,499 | 1221 (25.9%) |
| 37,500-45,999 | 1214 (25.6%) |
| 46,000+ | 1458 (31.5%) |
| **Survival after diagnosis (days)** | |
| 0-60 | 776 (14.9%) |
| 61-120 | 643 (26.1%) |
| 121+ | 4943 (31.2%) |
| **Palliative radiation** | |
| Yes | 1731 (26.2%) |
| No | 4656 (27.5%) |
| **Nursing home resident (2000-2003 only)** | |



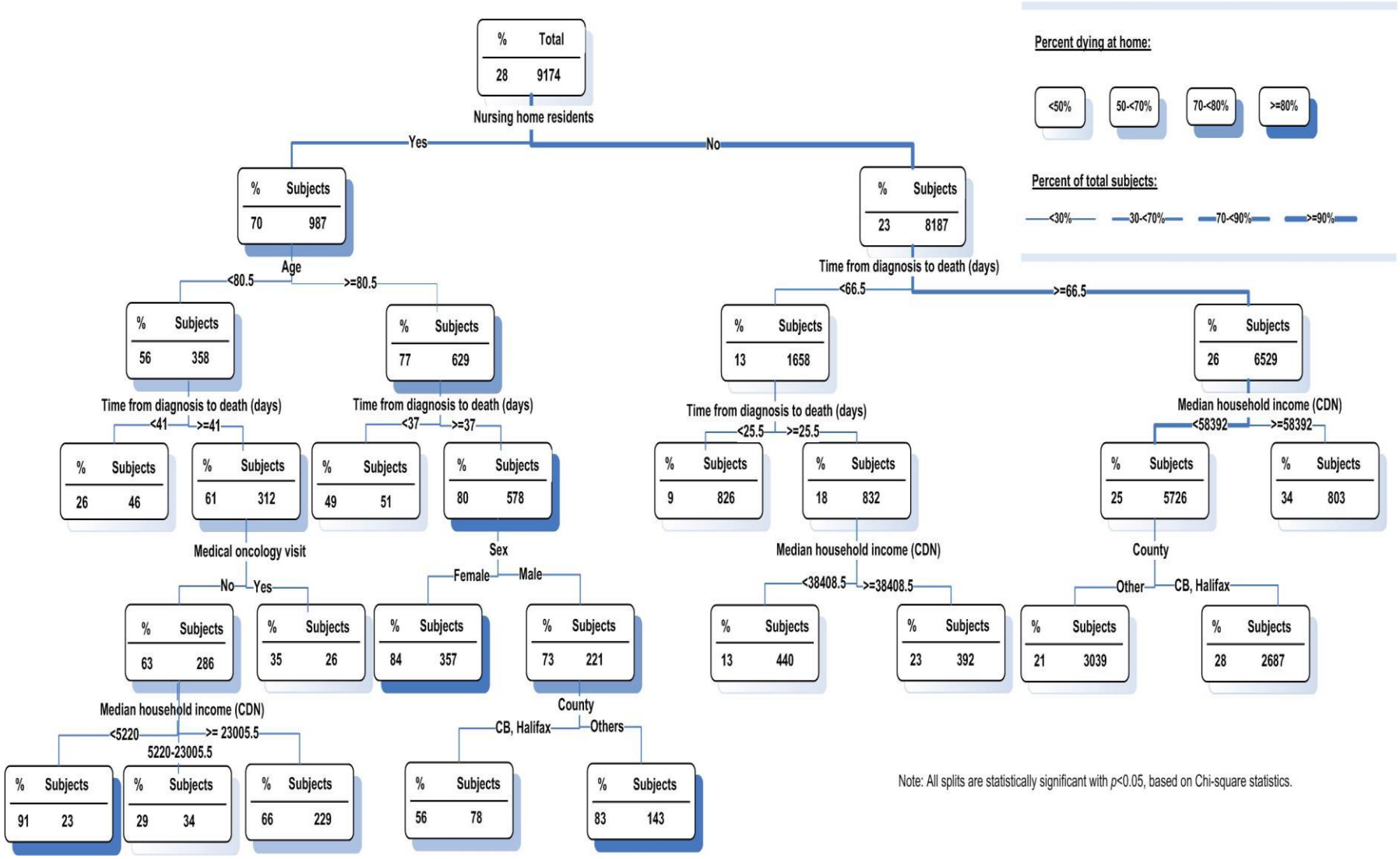




# Out of Hospital Cancer Deaths by Characteristics of NS Adults

| | | |
|---|---|---|
| **ENABLING RESOURCES** | | |
| **Median neighbourhood income ($0-25,499)** | | |
| 25,500-31,999 | 0.9 (0.8-0.97) | 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 (1.04-1.3) |
| **NEED** | | |
| **Survival after diagnosis (<61 days)** | | |
| 61-120 | 2.0 (1.8-2.3) | 2.1 (1.9-2.4) |
| 121+ | 2.6 (2.4-2.8) | 2.5 (2.3-2.8) |
| **Tumour group (Lung)** | | |
| Breast | 1.9 (1.7-2.1) | 1.1 (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) |
| **ONCOLOGY TREATMENT** | | |
| **Palliative radiation (No)** | | |
| Yes | 0.9 (0.9-0.997) | 0.9 (0.8-0.98) |
| **Medical oncology (No)** | | |
| Yes | 1.1 (1.0-1.2) | 1.0 (-) |

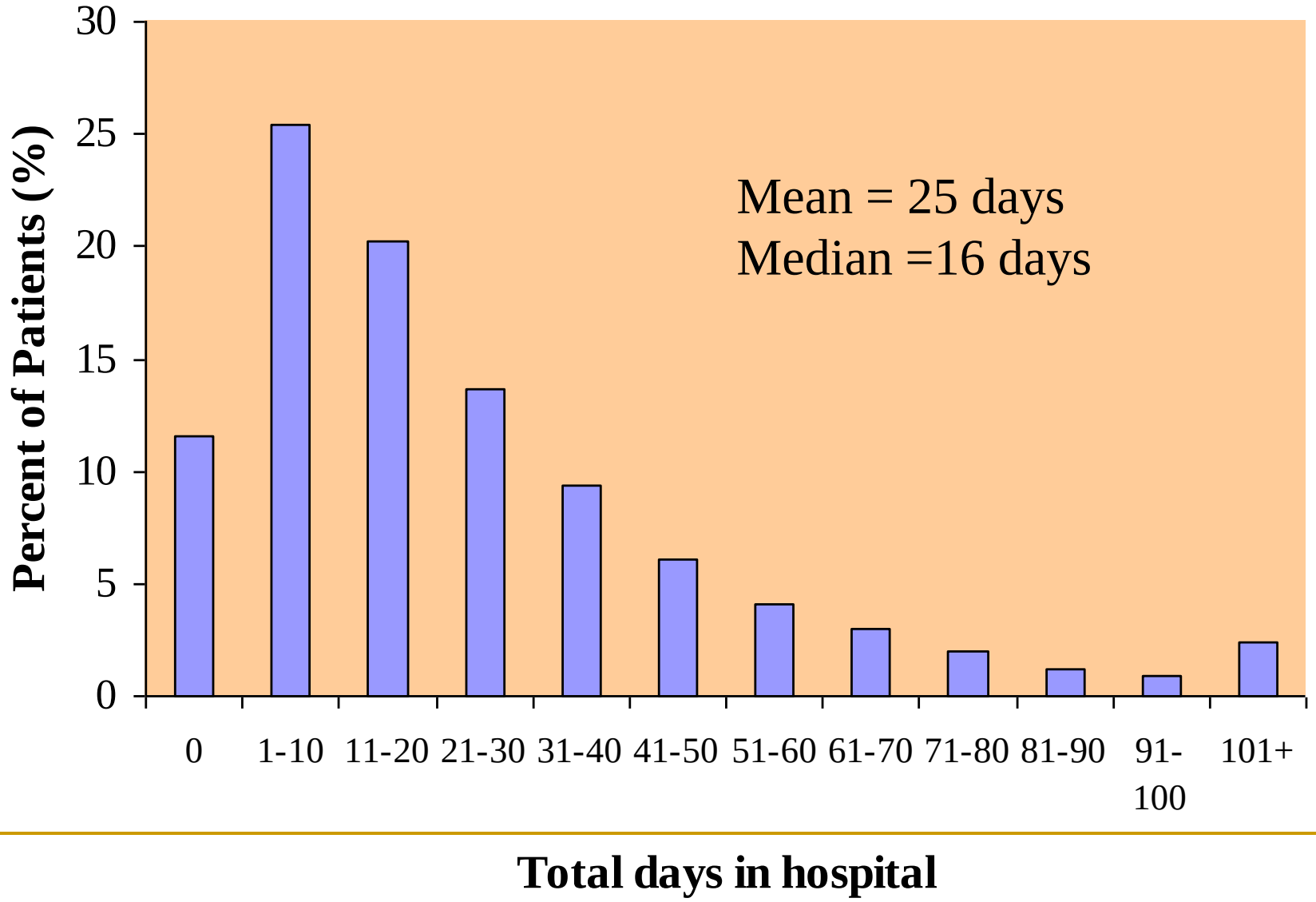
**Predictors of home death, 1994-2003, NS: Crude and adjusted OR and 95% CI**

## Figure 3. Classification and Regression Tree Analysis, 2000-2003: Percent (%) Dying at Home and Subjects in Node

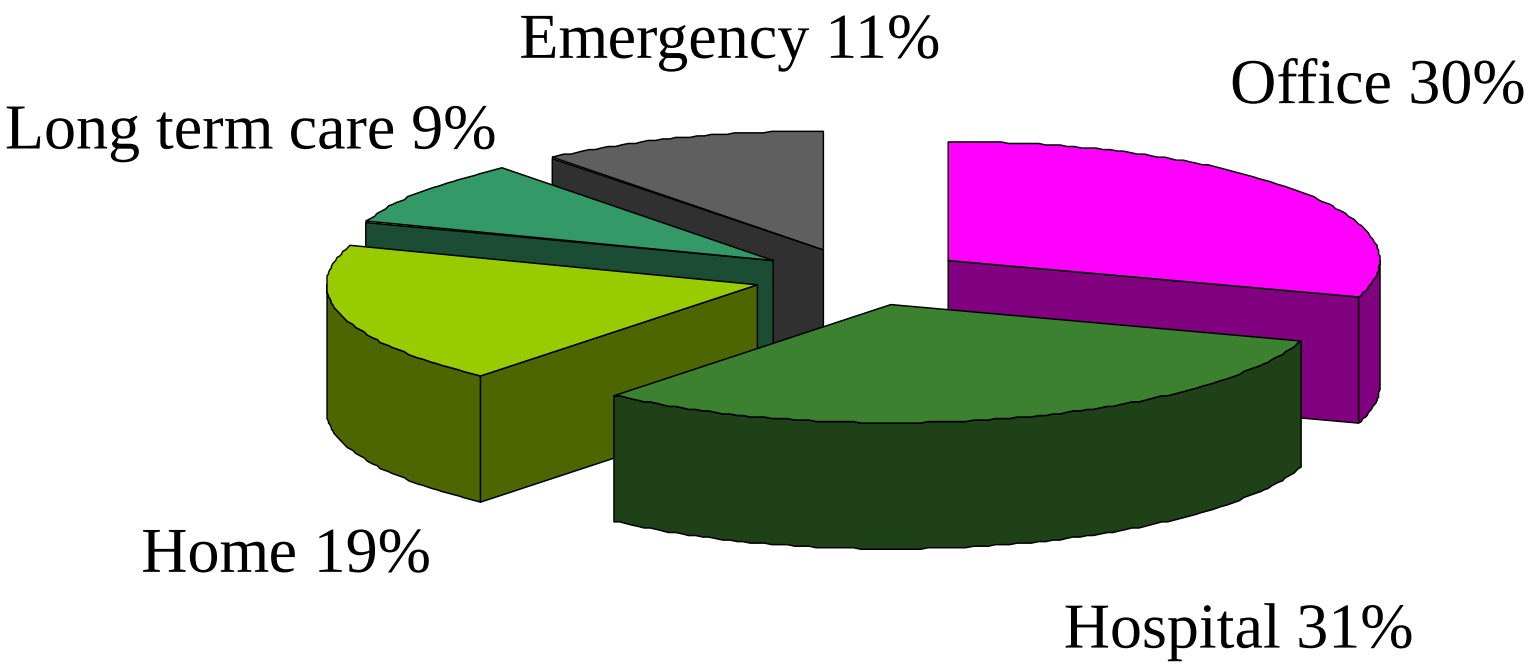



Note: All splits are statistically significant with $p<0.05$, based on Chi-square statistics.

# Hospital Days in Last 6 Months of Life, 1992-8



# Family Physician Visits in last 6 months of life

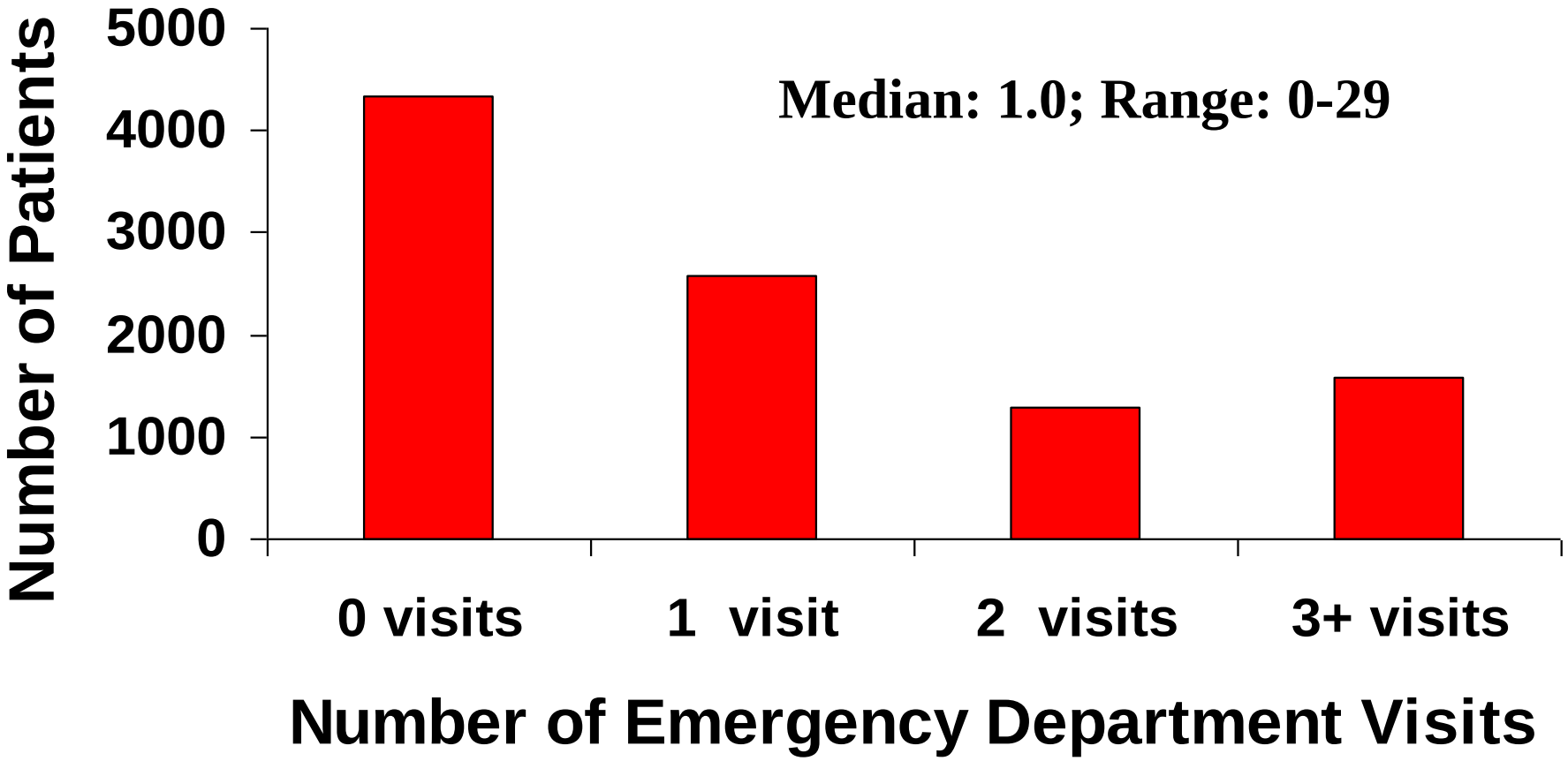


# Primary Care Continuity

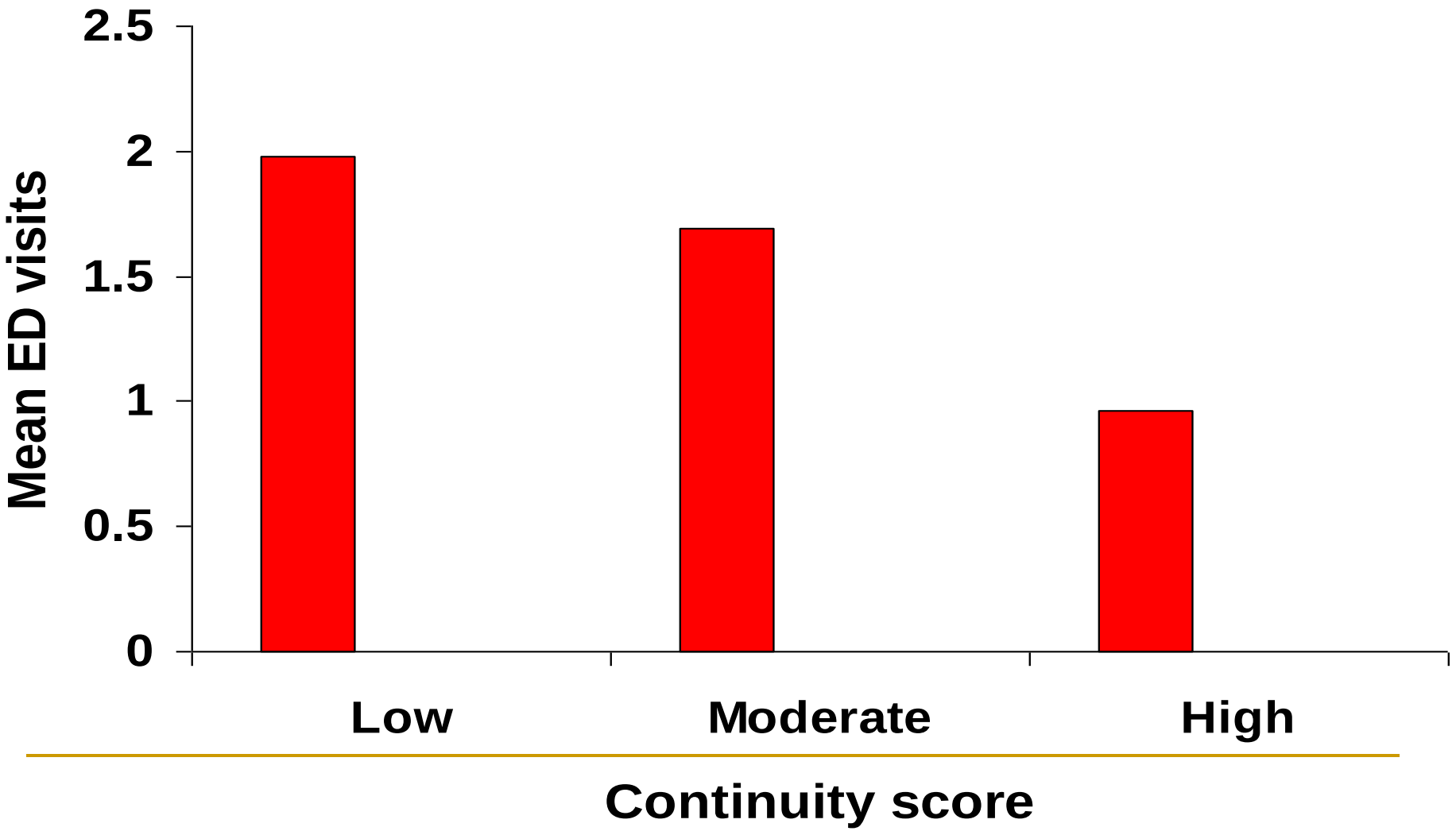
To determine if greater continuity of primary medical care for cancer patients during the end-of-life is associated with:

- Emergency department (ED) utilization
- Total length of hospital stay (LOS)
- Location of death

# Emergency Dept Visits in last 6 months, 1992-7



# Mean Emergency department visits in last 6 months of life by Family Physician continuity



# Association between continuity score and total number of ED visits at end-of-life

| | Emergency Department visit Rate Ratio (95% confidence interval) | |
|---|---|---|
| | Unadjusted | Adjusted* |
| **Continuity score** (vs high) | | |
| Low | 2.45 (2.12, 2.72) | 3.90 (3.55, 4.28) |
| Moderate | 1.83 (1.73, 1.95) | 2.25 (2.13, 2.38) |

*Adjusted for sex, age, survival, income, region, year of death, location of death, PCP, palliative radiation, total inpatient stay, total specialty & ambulatory visits.

# Relationship between FP continuity of care and total length of hospital stay during end-of-life

| | Total length of hospital stay Rate Ratio (95% confidence interval) | |
|---|---|---|
| Characteristic | Unadjusted | Adjusted* |
| Continuity score (vs high) | | |
| Low | 1.69 (1.54, 1.86) | 1.20 (1.08, 1.32) |
| Moderate | 1.27 (1.20, 1.34) | 1.09 (1.03, 1.15) |

*Adjusted for sex, age, survival, region, year of death, location of death, seen in LTC, palliative radiotherapy, & total ambulatory visits

# Nova Scotians receiving at least one FP home visit during the end of life by income

# Relationship between receiving at least one FP home visit and neighourhood income

| | Receipt of at least one home visit Odds ratio (95% confidence interval) | |
|---|---|---|
| | Unadjusted | Adjusted* |
| **Neighbourhood income (vs low)** | | |
| High | 1.82 (1.54, 2.14) | 1.72 (1.42, 2.09) |
| Upper middle | 1.36 (1.17, 1.57) | 1.32 (1.12, 1.57) |
| Middle | 1.42 (1.23, 1.63) | 1.36 (1.15, 1.60) |
| Lower middle | 1.07 (0.93, 1.24) | 1.06 (0.90, 1.25) |

*Adjusted for sex, age, survival time, receipt of palliative radiation, LOS, seen in LTC

# CIHR ICE:

To build research capacity to reduce health disparities and promote equity for vulnerable populations at end of life with chronic terminal disease

$820,000 over 5 years for
- Report Card development
- research trainees - Masters, PhD, post doc
- eight research pilot projects

# Network for End of Life Studies ICE Team

| Research Investigators | Collaborators - Local, National, International |
|---|---|
| Grace Johnston (PI)<br>Fred Burge (co-PI)<br>Eva Grunfeld<br>Graeme Rocker<br>Paul McIntyre<br>Yukiko Asada<br>Bev Lawson<br>Victor Maddalena | Gael Page, CHPCA<br>Dorothy Barnard, IWK<br>*Capital Health*<br>*Will Webster, Faculty of Health Professions, Dal*<br>*Gerry Johnston, Faculty of Medicine, Dalhousie*<br>> Julie LaChance, Health Canada<br>> Earle Craig, Dana-Farber, Boston<br>> Dan Hausman, Univ of Wisconsin and WHO |

# Network for End of Life Studies

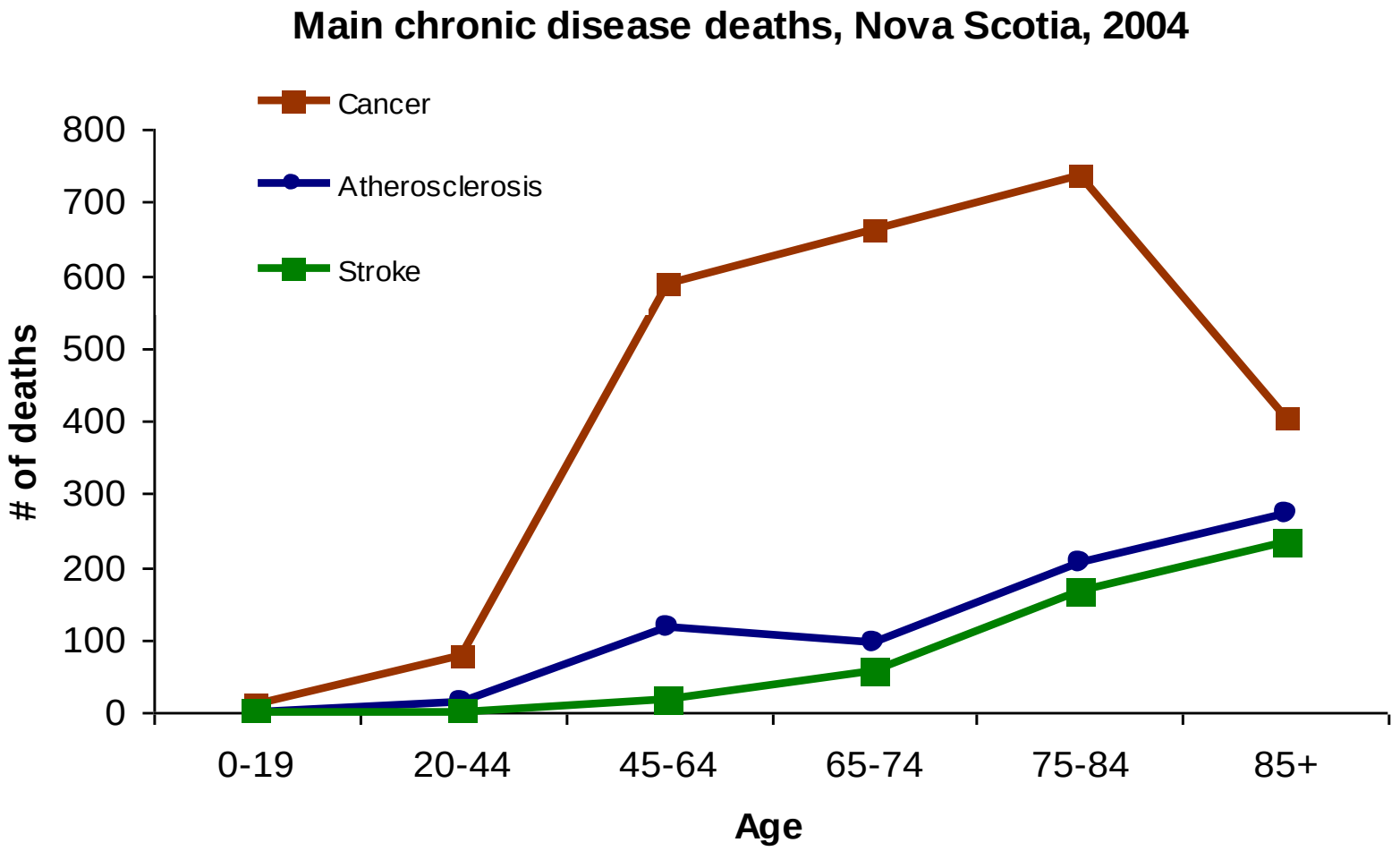
## Pilot Projects

| | | | |
|---|---|---|---|
| 1 | **Development of a Surveillance System and Report of inequity in quality care at end of life** | GJ, FB | NELS Team, Julie LaChance |
| 2 | **Defining vulnerable populations at end of life: Ethical Analysis** | YA | Dan Hausman |
| 3 | **Quality pediatric terminal care and vulnerabilities** | DB | IWK |
| 4 | **African Canadians and End-of-Life Care** | VM | HAAC |

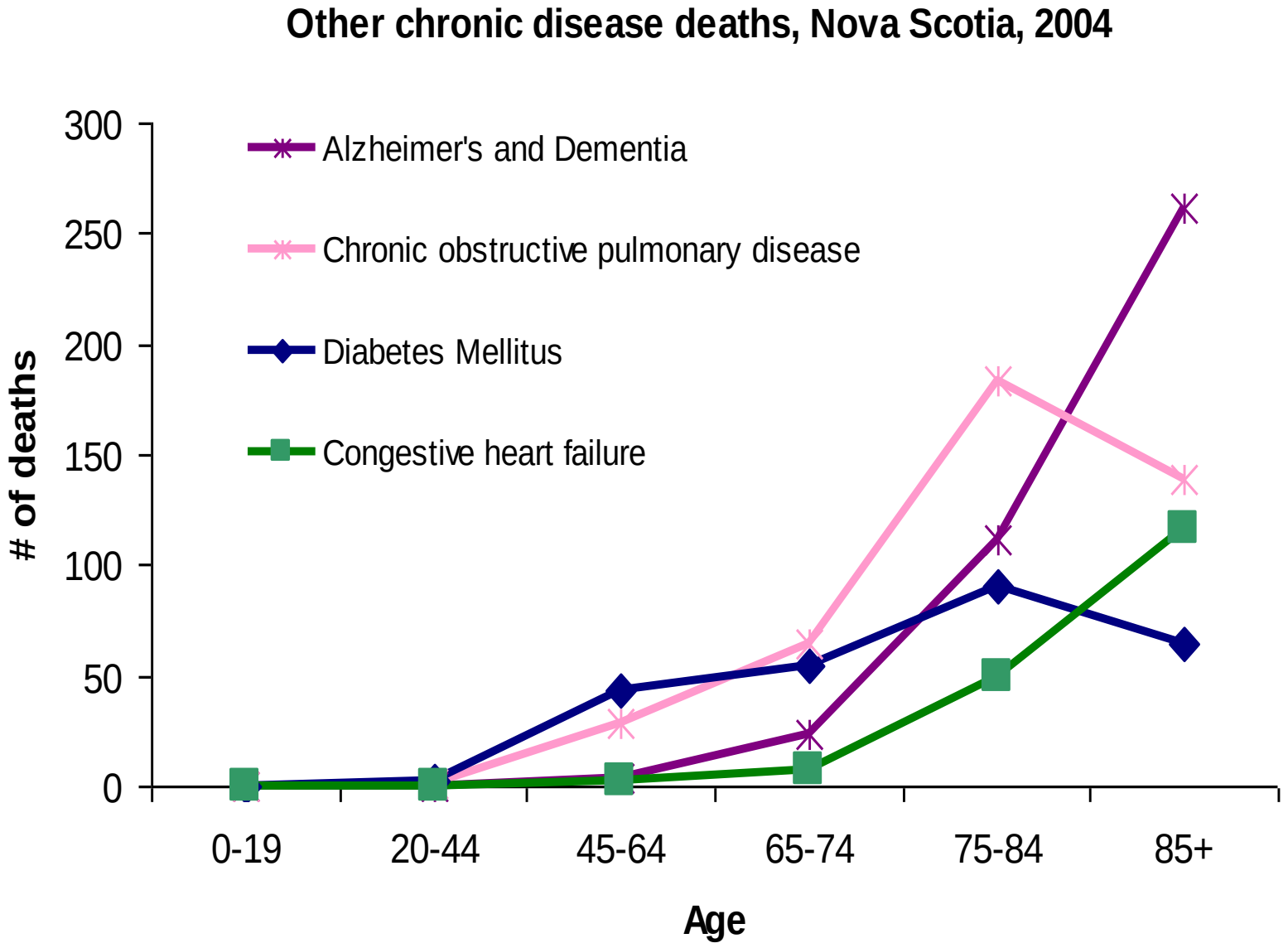
# Network for End of Life Studies

## Pilot Projects (continued)

| | | | |
|---|---|---|---|
| 5 | **Attaining a better understanding of gender and age at end of life** | BL, FB | TBA |
| 6 | **Quality end of life cancer care for vulnerable elderly** | PM, EG | Gael Page |
| 7 | **Community based quality care at end of life with COPD (Chronic Obstructive Pulmonary Disease)** | GR, PM | TBA |
| 8 | **Canadian Compassionate Care Benefit: Is it working?** | GJ, PM | Gael Page |




609 deaths due to an acute myocardial infarction were not included as these deaths are of an acute nature and any who survive an acute myocardial infarction, only to subsequently die from the sequelae of the infarction have their deaths coded as something other than an acute myocardial infarction


Other chronic disease deaths, Nova Scotia, 2004
300
250
200
150
100
50
0
# of deaths
Alzheimer's and Dementia
Chronic obstructive pulmonary disease
Diabetes Mellitus
Congestive heart failure
0-19
20-44
45-64
65-74
75-84
85+
Age

# Examples of other unanswered questions

- When is the beginning of end of life for purposes of population based cohort and intervention studies?
- What is the impact of co-morbidities?
- What is the optimal measure and how do end of life services vary by rural/urban?
- What is the profile of medications at the end of life, and the factors associated with their provision?