

# Assessing End of Life Care for Nova Scotians Dying of Chronic Terminal Disease

District Cancer Committee Meeting  
Cancer Care Nova Scotia

April 27, 2006

Grace Johnston



## Overview

- New CIHR ICE research funding
- Progress in last 10 years
- Next steps

Province wide Palliative Care Program (PCP)  
database?

1. Basic – persons enrolled and date of PCP enrollment
  - a. should “registration” and/or “referral” date be used to enroll?
  - b. can a provincial PCP enrolment database across all districts/programs be achieved?
2. What other data on all patients should be recorded from PCPs?

Canadian Institutes for Health Research (CIHR)  
 Interdisciplinary Capacity Enhancement (**ICE**) to  
 Reduce Health Disparities and Promote Equity for  
**Vulnerable Populations**

**Network for End of Life Studies**

\$850,000 over next 5 years for

- Report Card development
- research trainees - Masters, PhD, post doc
- research pilot projects

on **inequities** in quality end of life care; and  
 develop and test applications for persons  
 at end of life with chronic terminal disease

**Network for End of Life Studies ICE Team**

<b>Spokespersons for Vulnerable Populations</b>	<b>Trainees</b>
TBA	TBA
<b>NELS ICE staff:</b> TBA	
<b>Research Investigators</b>	<b>Collaborators - Local, National and International</b>
Grace Johnston (PI) Fred Burge (co-PI) Eva Grunfeld Graeme Rocker Paul McIntyre Yukiko Asada Bev Lawson Victor Maddalena	Gael Page, CHPCA Dorothy Barnard, IWK Andrew Padmos (Theresa Marie for transition) Don Ford (Barb Hall for transition), Capital Health Will Webster, Faculty of Health Professions, Dal Gerry Johnston, Faculty of Medicine, Dalhousie Univ > Julie LaChance, Health Canada > Earle Craig, Dana-Farber, Boston > Dan Hausman, Univ of Wisconsin and WHO
<b>New Investigators</b>	<b>New Collaborators</b>
TBA	Health Association of African Canadians

## Network for End of Life Studies

### Pilot Projects

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

## Network for End of Life Studies

### Pilot Projects (continued)

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

## Progress made in last 10 years

- Funding and support from Health Canada, CCNS, FM, Dalhousie Cancer Research Program, Capital Health, CIHR (Operating Grant in 2000-2; New Emerging Team with NS, BC, Sask 2004-9; Operating Grant 2005-7; 2 Pilot projects 2004-5)
- With Fred Burge, Bev Lawson, Ron Dewar, Jun Gao, Meaghan O'Brien, Ina Cummings, Paul MacIntyre, Dale Orychuk, Maureen MacIntyre, Eva Grunfeld, many others (NS, across Canada)

### Purpose

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

### Study Subjects

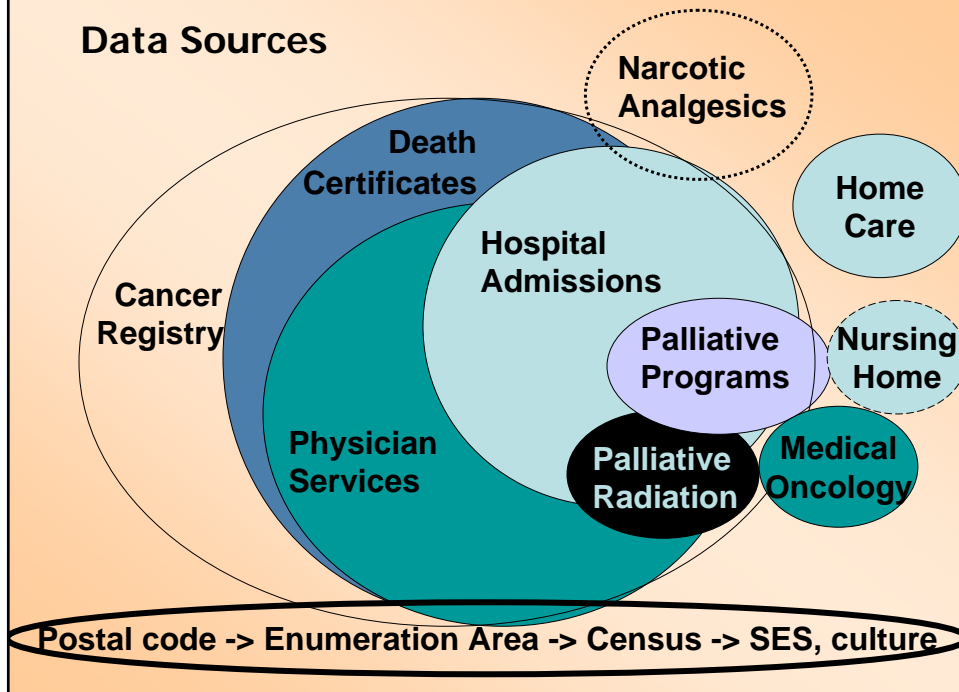
22,886 adults who died of cancer in Nova Scotia from 1994 to 2003 with their cancer diagnosis known prior to their date of death

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

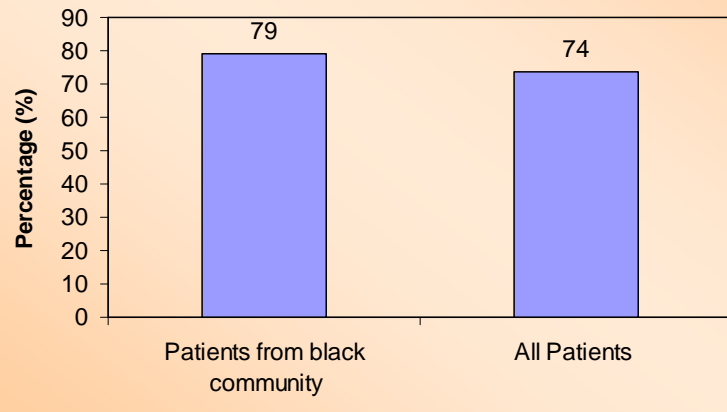
## Methods Evolution

	Current	Future
<b>Population</b>	Nova Scotia Adults	Other Provinces Children
<b>Cause of Death</b>	Cancer, Congestive Heart Failure	COPD, other
<b>Study Design</b>	Retrospective	<b>Prospective</b>
<b>Linked Databases</b>	See next slide	<b>Palliative Care Programs across NS</b>

## Data Sources



**Percentage of Cancer Patients  
Referred to PCP, Halifax and Cape  
Breton 1998-2003**



## 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

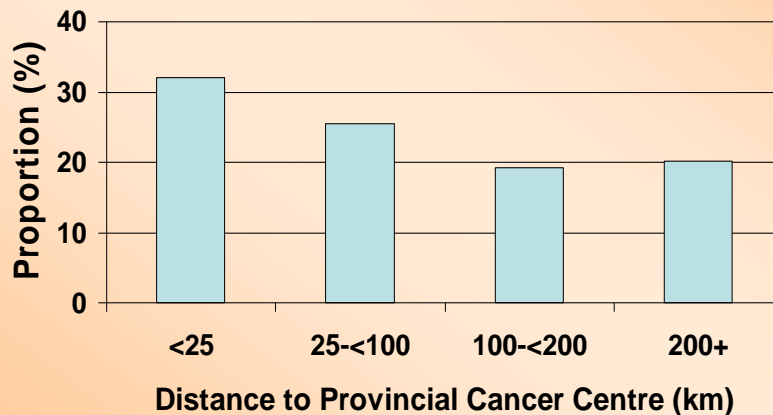
### Concepts

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

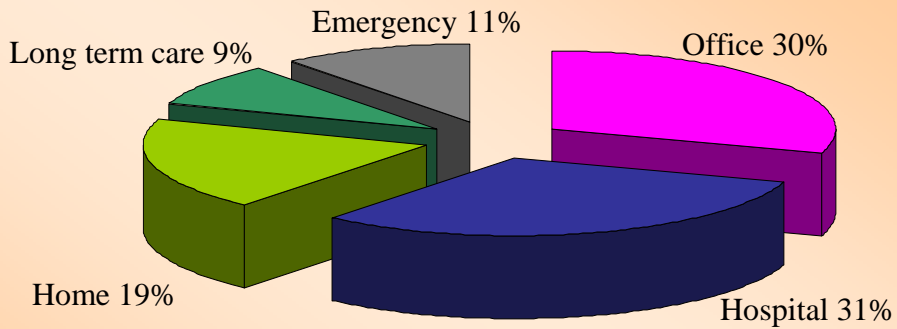
## Some early published papers

- 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):1691-1698
- Johnston G, Burge F, Boyd C, MacIntyre M (2001) End-of-Life Population Study Methods. **Canadian Journal of Public Health** 92(5):385-386
- Johnston G, Burge F. (2002) Analytic Framework for Clinician Provision of End-of-Life Care. **Journal of Palliative Care** 18(3):141-149
- 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

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



### Family Physician Visits in last 6 months of life 1995

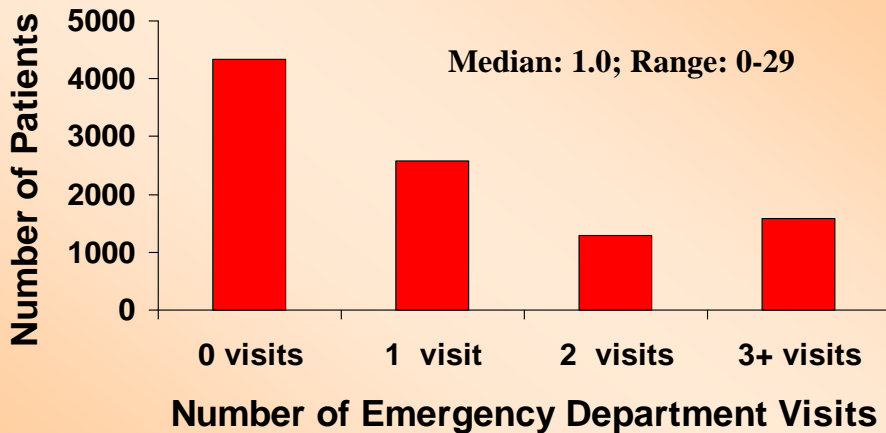


Burge F, Lawson B, Johnston G, Flowerdew G, Cummings I. (2005) Health care restructuring and family physician care for those who died of cancer. **BioMedCentral – Family Practice** 6:1-6

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 – Pall 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

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



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

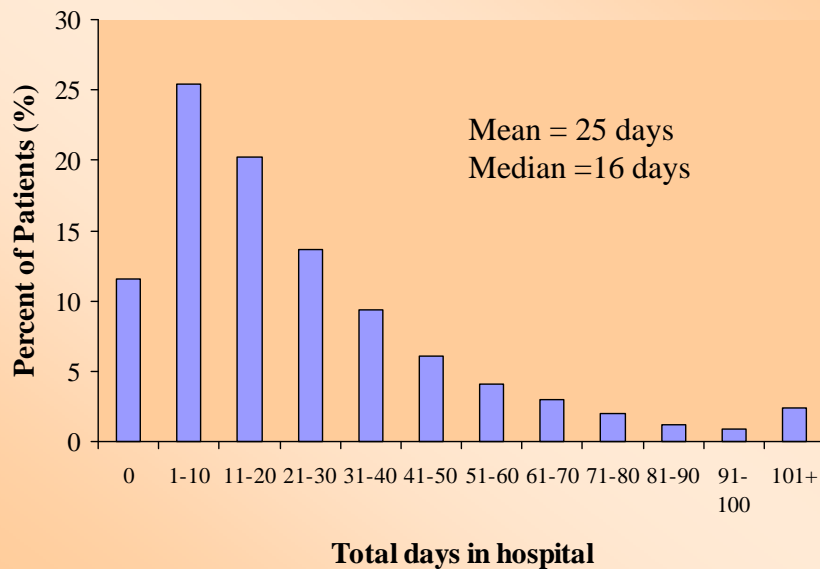


## Emergency Room (ER) Visits for women dying of breast cancer, 1998- 2002 as an indicator of quality of care

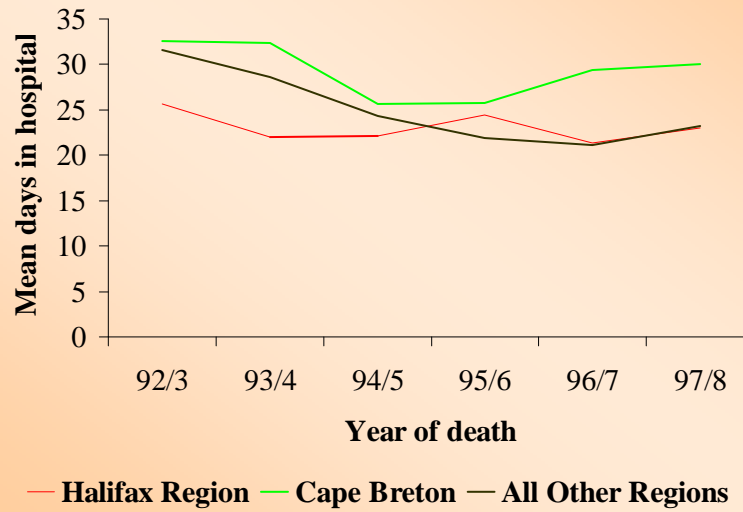
E Grunfeld et al, 2006

Indicator	Statistic description	NS	Ontario
ER visits	% with > 1 ER visit in last month	5.6%	6.9%
	average # ER visits in last month	0.41	0.44

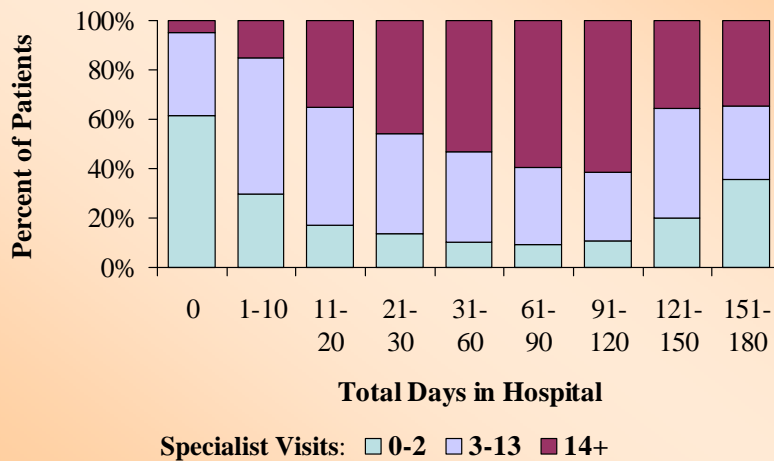
## Hospital Days in Last 6 Months of Life, 1992-8



### Hospital Days in last 6 months by Year and Geographic Area



### Hospital Days by Number of Specialist\* Visits



\* Physicians with specialty training who are not family physicians

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

**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%

**Variables associated with increased likelihood of Home Death for adults dying of cancer from 1994 to 2003 in Cape Breton and Capital Health**

Variable	Crude OR	Adjusted OR (95% CI)
<b>Cape Breton PCP Referral</b>	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)
<b>Capital Health PCP Registration</b>	1.3	1.5 (1.3-1.7)
Length of time in PCP – 17-45 days	1.8	1.8 (1.5-2.2)
– 46-124 days	2.1	2.1 (1.7-2.5)
– 125+ days	1.9	1.8 (1.5-2.2)

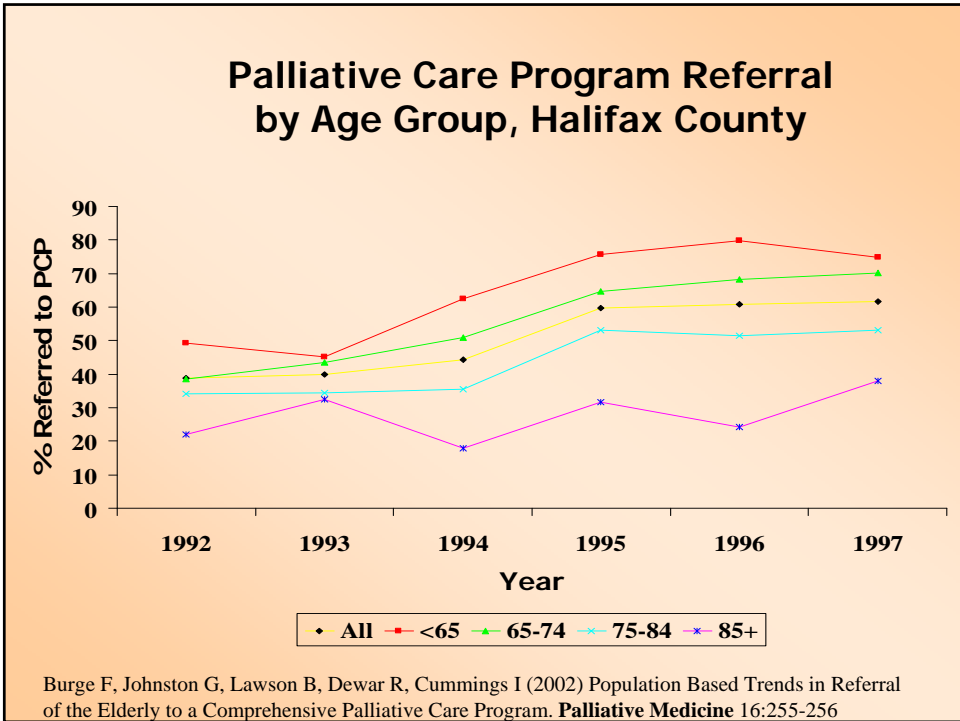
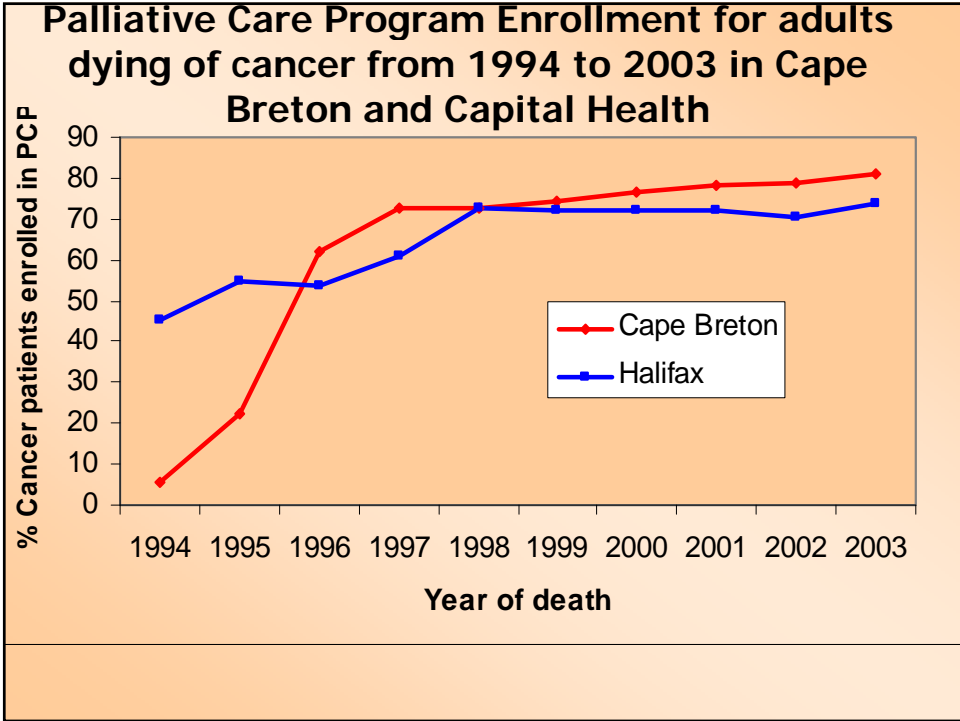
M O'Brien (2005) An analysis of access to end of life care for adults dying of cancer in Nova Scotia. MHSa thesis, School of Health Services Administration, Dalhousie University

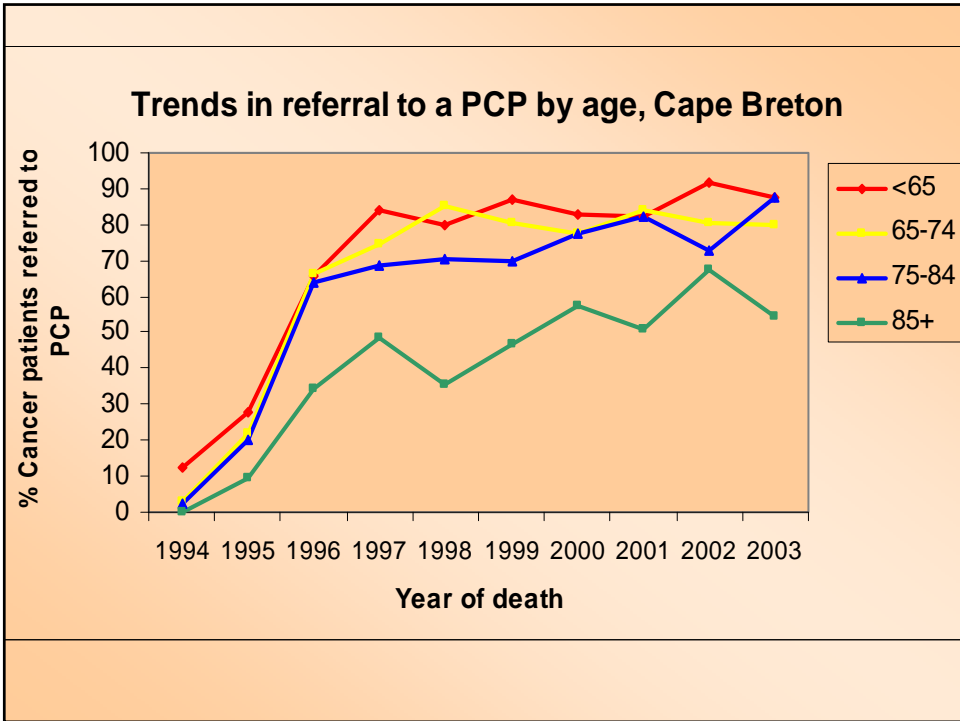
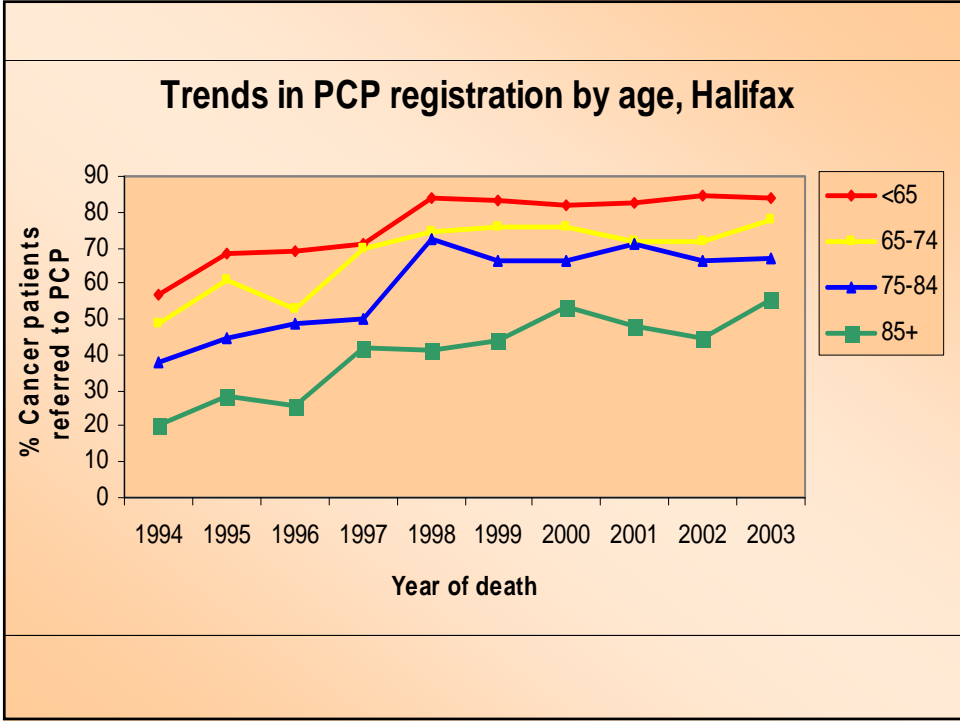
## Quality Indicators for Women with Breast Cancer. E Grunfeld et al, 2006

Measurable	Partially Measurable
1. Place of death 2. Frequency of ER visits 3. Hospital days near death date 4. Intensive Care Unit near death 5. Continuity of care 6. Time and location of care 7. Interval between last chemotherapy treatment and death 8. Adverse events	8. <b>Enrollment in palliative care</b> 9. <b>Length of time with access to palliative care prior to death</b> 10. Radiation treatment for uncontrolled bone pain for bony metastases 11. Potent antiemetic for emetogenic chemotherapy 12. Multidisciplinary care 13. Access to care 14. Interval between new chemotherapy and death

## Palliative Care Program Enrollment for women dying of breast cancer, 1998-2002 E Grunfeld et al 2006

Indicator	Statistic description	NS	Ontario
Enrolled in palliative care program	Halifax and Cape Breton Counties only	78.3%	NA





## Basic Data Fields from all Palliative Care Programs for each Patient

- Patient's first and last name
- date of birth
- health card number
- date of **registration** in (and/or **referral** to) palliative care program (PCP)



**GOAL 1:** Agreement on province-wide collection of the same basic PCP data fields

## Other Population-wide data collection on each person dying of chronic disease

**GOAL 2:** Agreement on additional province-wide (and/or local) collection of additional data fields for all persons dying of chronic disease regardless of location of care eg PCP, homecare, nursing home, etc

Such as

- Diagnoses, including definition of start of end of life for prospective studies
- Symptoms
- Quality indicators
- Outcomes
- ***Vulnerable populations***



## Network for End of Life Studies

