Chronic Disease and Palliative Care Program Data Linkage and Analysis Project: *The 3x3 Network for End of Life Study (NELS)*

Palliative Care Programs

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NELS | Network for End of Life Studies
ICE | Interdisciplinary Capacity Enhancement

Background

- It is increasingly being recognized that end of life (EOL) care requires greater attention
- Evidenced-based decision making requires reliable data
- Much of the research on EOL care has focused on cancer
  - Other diseases have a terminal phase
  - The occurrence of co-morbidities can affect service requirements
- Linked administrative datasets are a valuable tool to study EOL care issues

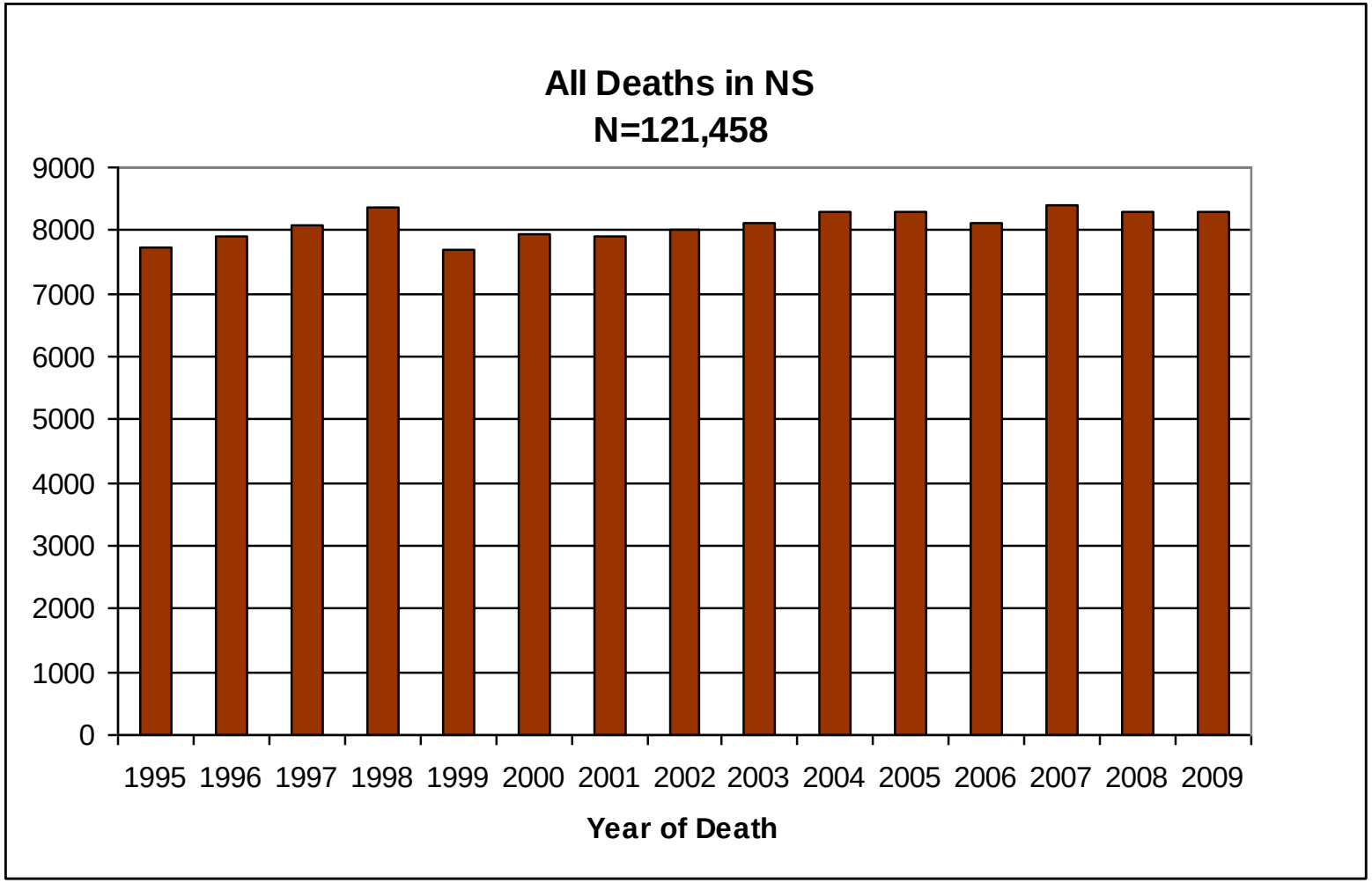
Data Sources

- Link data from 3 disease registries and 3 Palliative Care Programs to Vital Statistics Death Certificate data
- Registry data:
  - Cancer
  - Diabetes
  - Cardiovascular
- Palliative Care Program (PCP) data
  - Capital Health
  - Cape Breton
  - Colchester
- Probabilistic data linkage

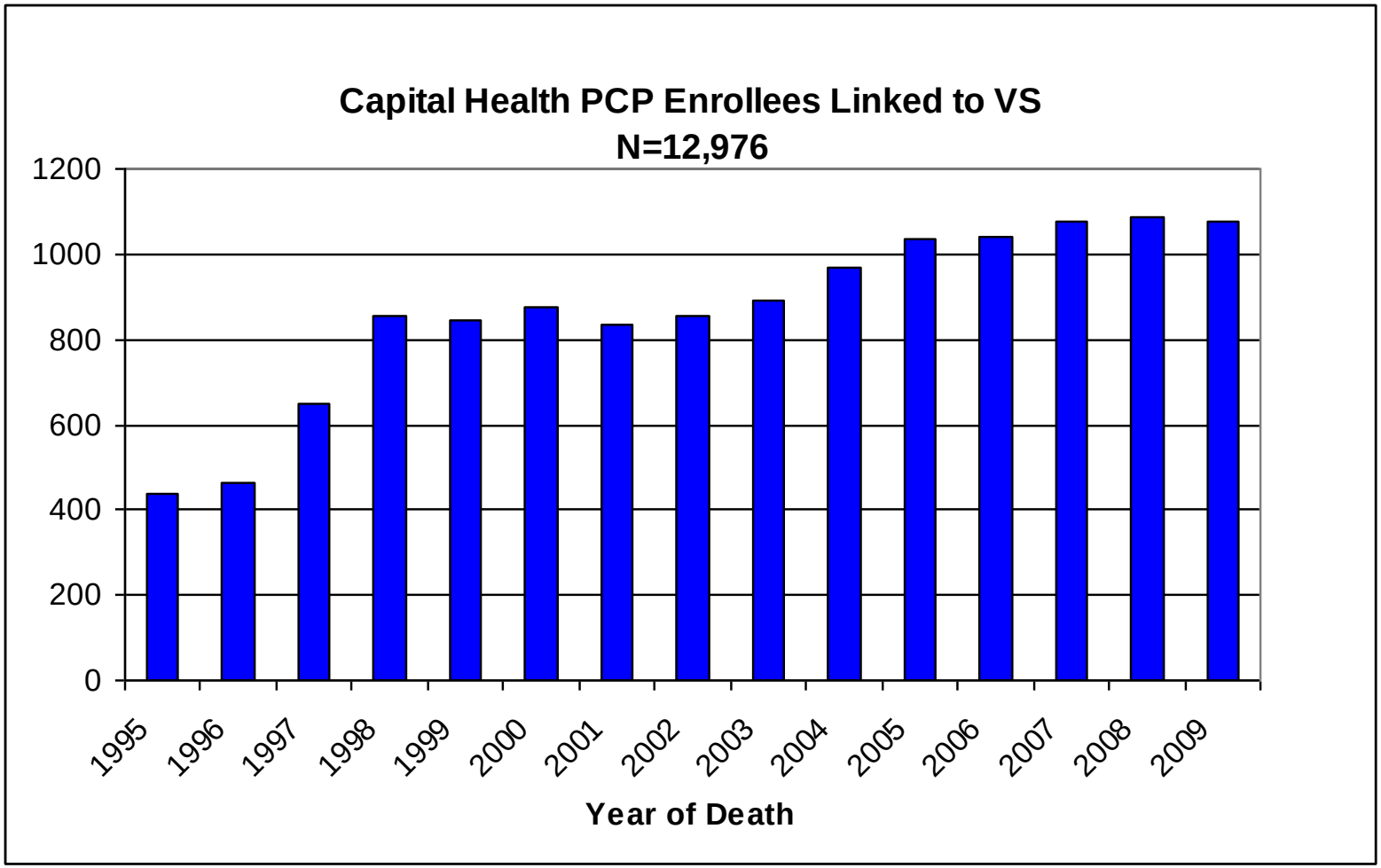
Study Subjects

- All deaths in Nova Scotia as defined by NS Vital Statistics 1995-2009
- Total number of deaths: 121,458
- Since we only have PC data from 3 DHAs, many of the statistics are based on the population in those DHAs only
  - e.g. percentage enrolled in a palliative care program is based on the population in corresponding DHA
- To determine DHA, a residential postal code is required
  - 6,178 (5.1%) in total have a missing postal code

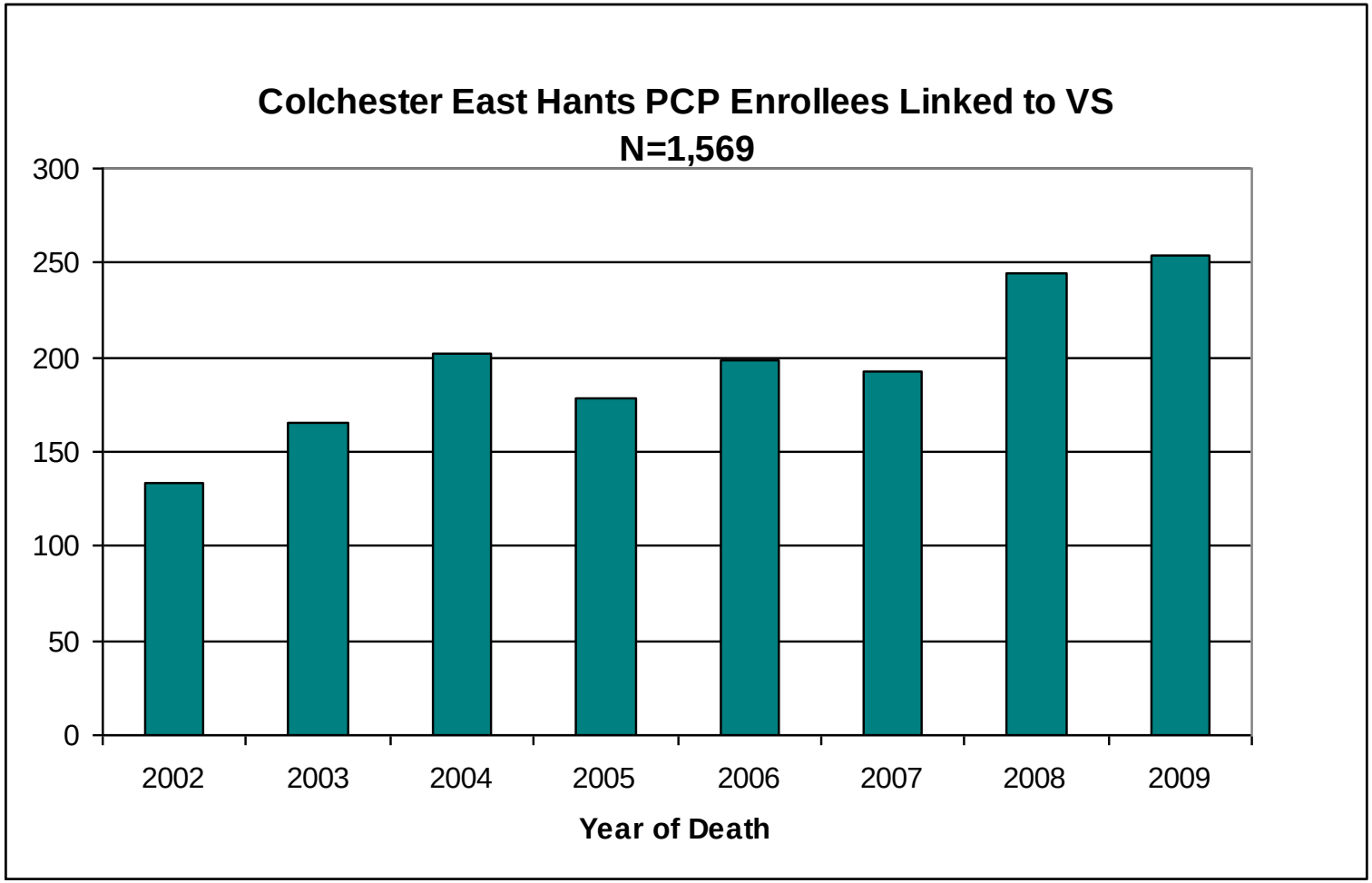
Vital Statistics



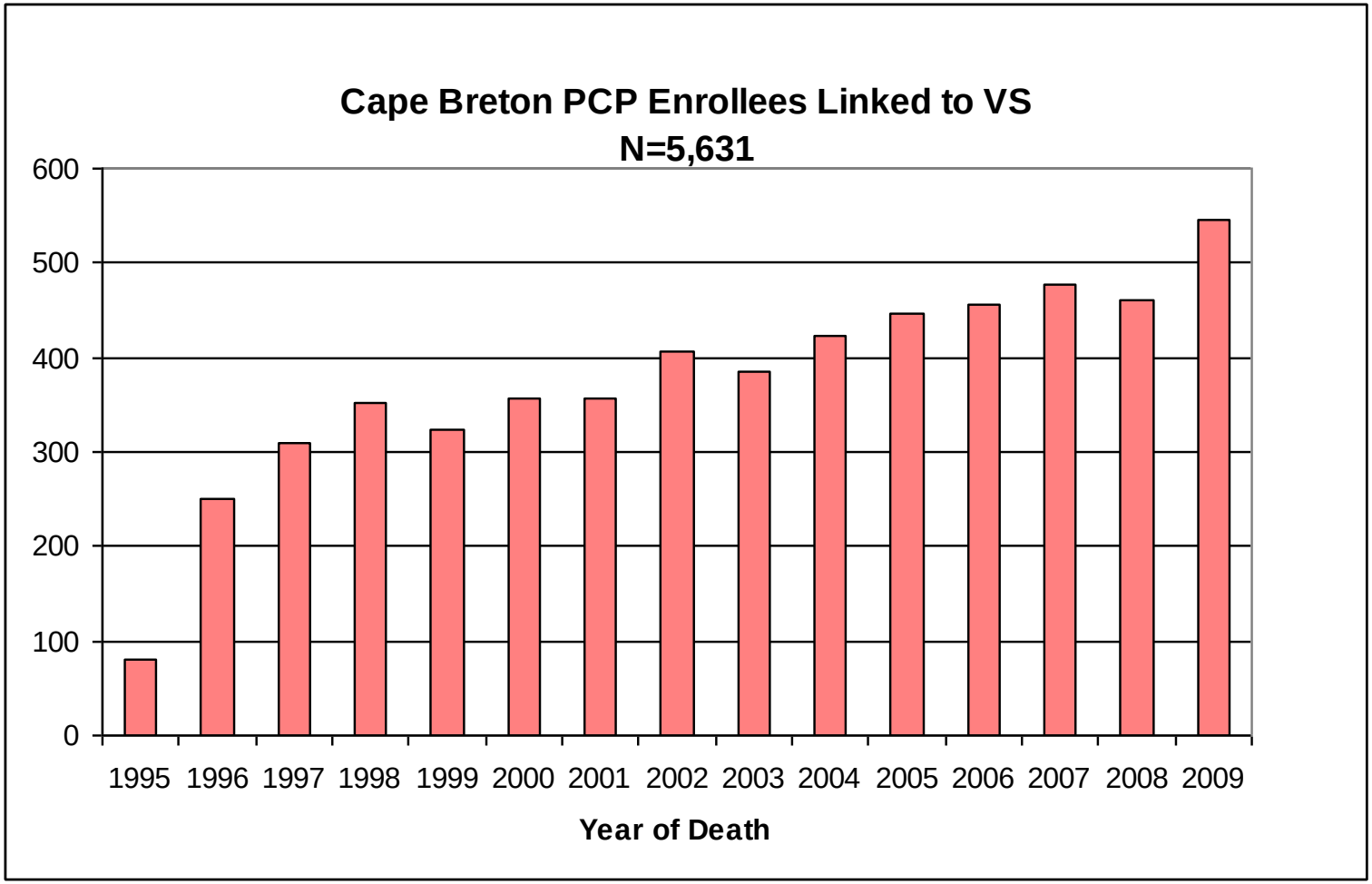
Year of Death – Capital Health PCP



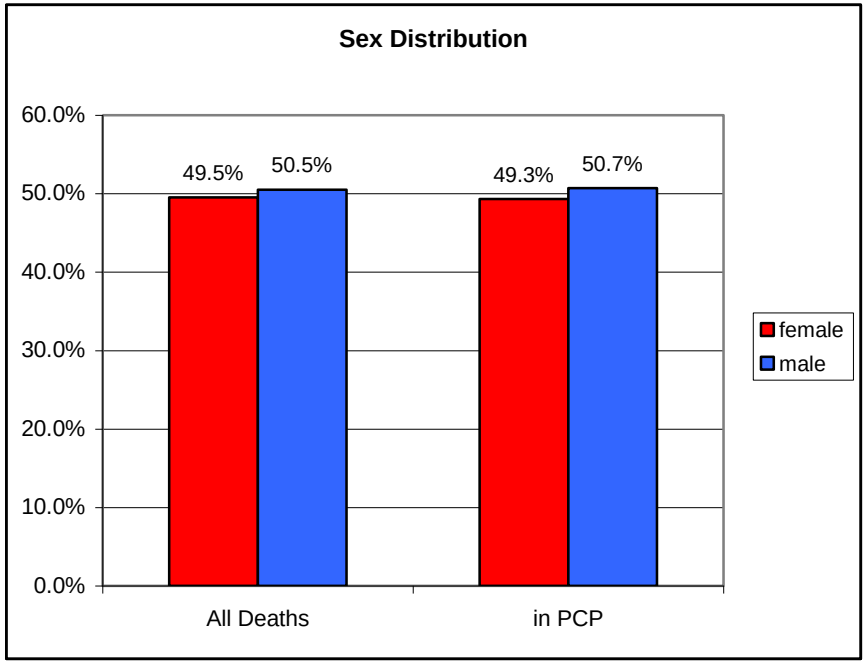
Year of Death –Colchester PCP

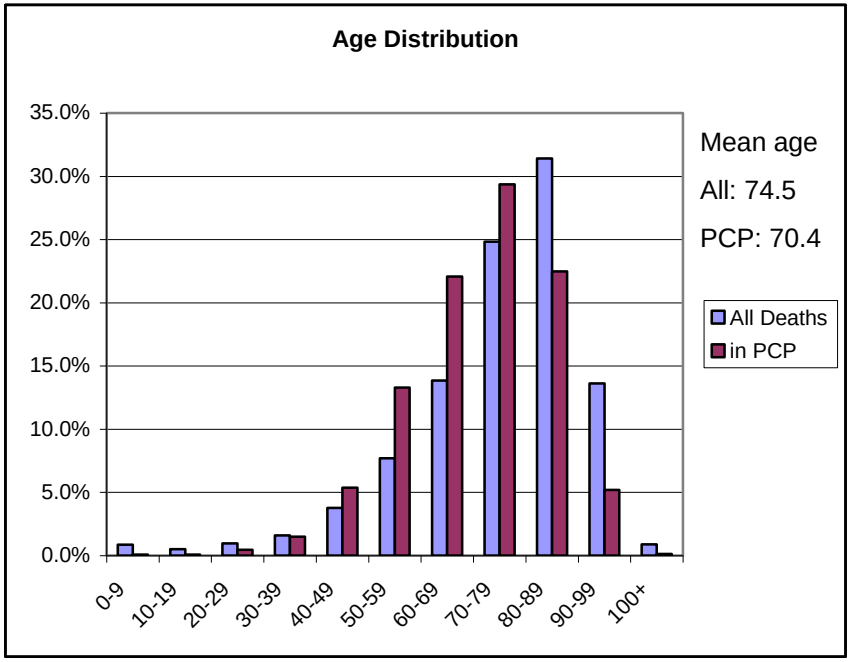


Year of Death – Cape Breton PCP

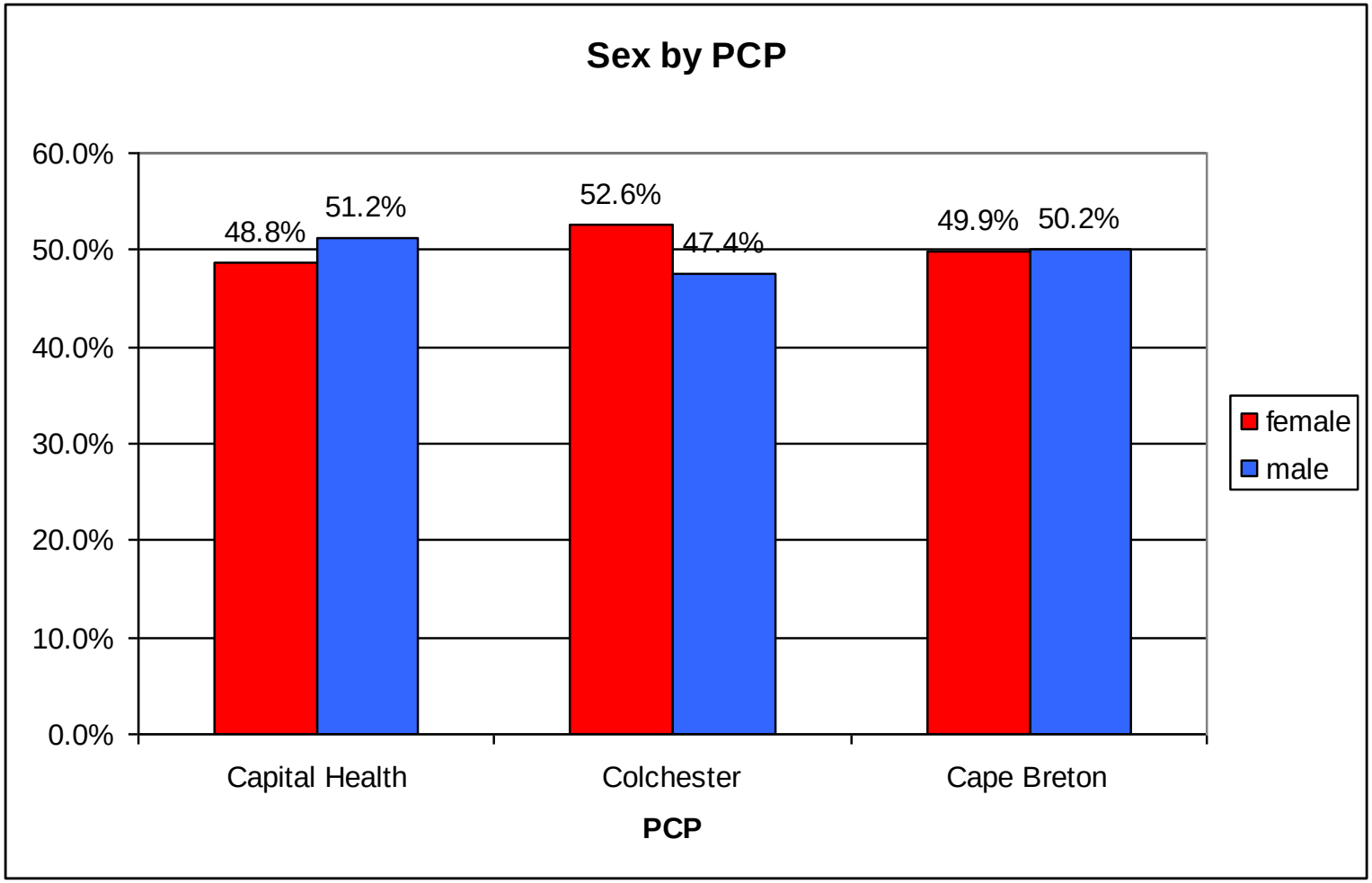


Age and Sex Distribution
All Deaths and PCP Enrollees

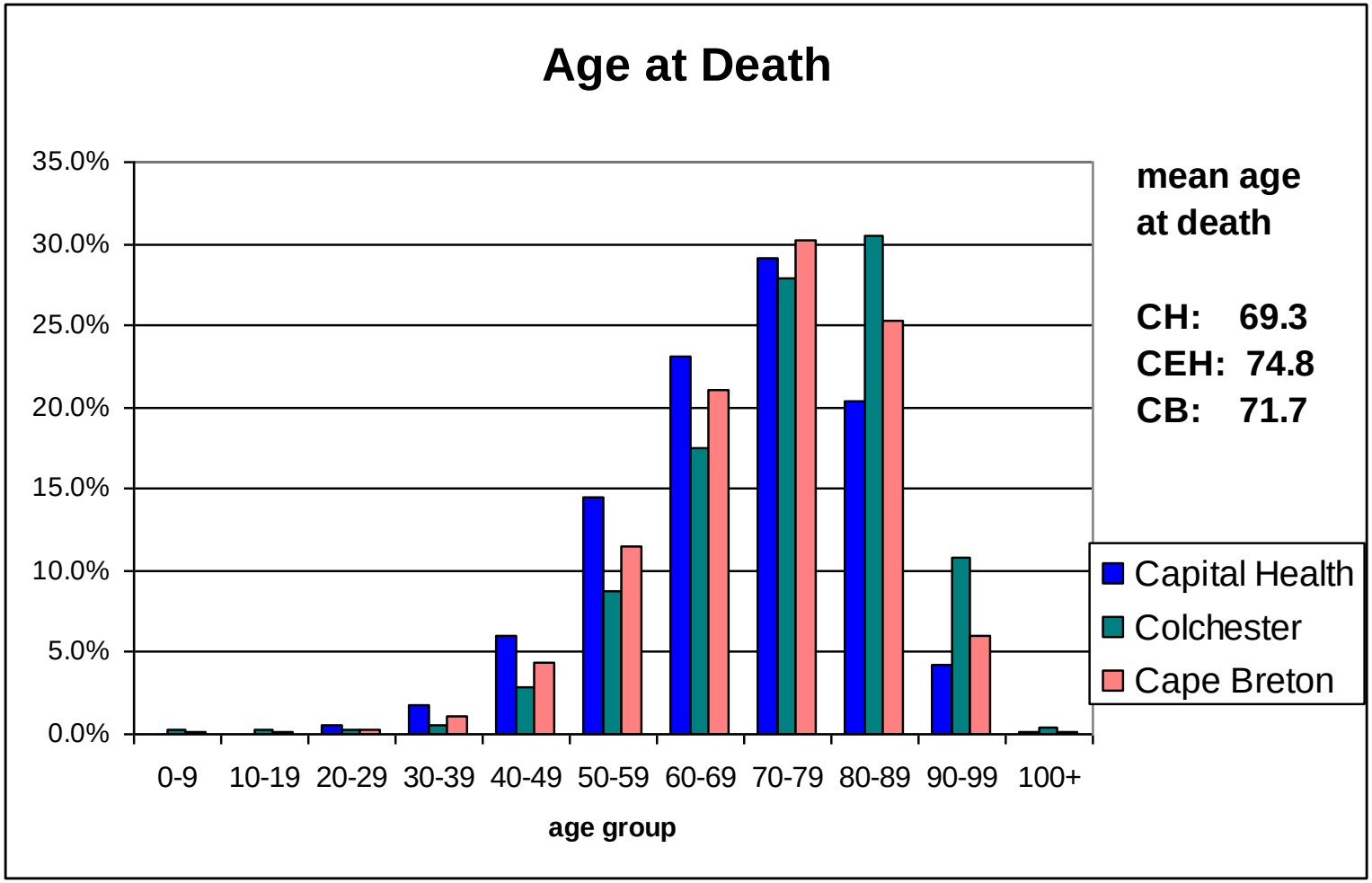




Sex Distribution by PCP



Age Distribution by PCP



Where Do PCP Enrollees Reside?

- Residential Postal Code information used to determine resident DHA
- Postal Code information obtained from VS
  - If missing, other data sources used where available
- Missing/Invalid Postal Code information
  - 1.6% of all PCP Enrollees

Residential DHA by PCP

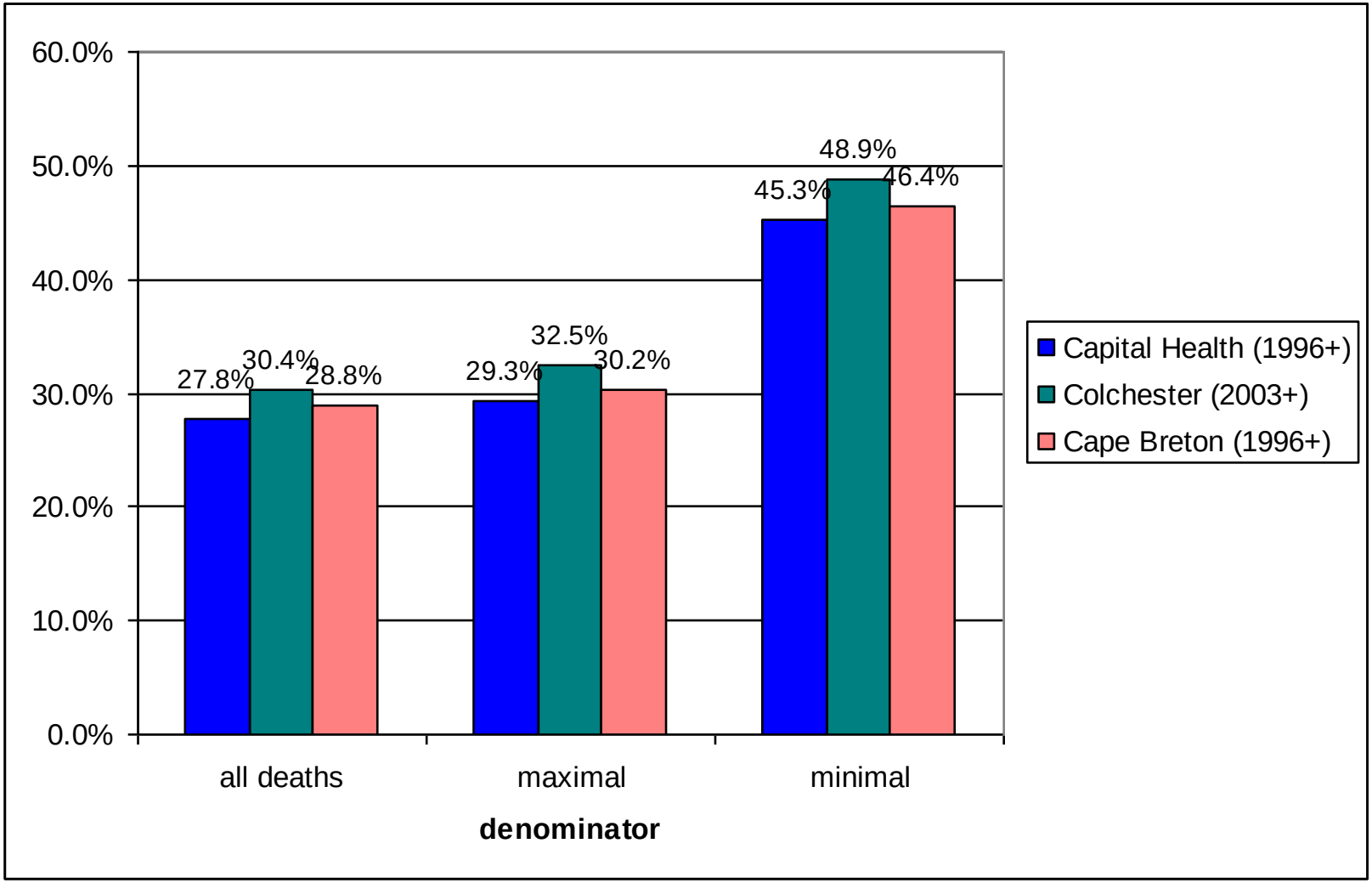
	Capital Health	Colchester	Cape Breton
South Shore	3.45%	0.13%	0.05%
South West	2.27%	0.19%	0.02%
Annapolis Valley	2.79%	0.45%	0.00%
Colchester East Hants	4.62%	**90.70%**	0.04%
Cumberland	1.20%	2.82%	0.02%
Pictou	1.55%	1.28%	0.05%
Guysborough/ Antigonish	1.64%	0.26%	2.21%
Cape Breton	1.62%	0.13%	**97.35%**
Capital	**80.86%**	4.04%	0.27%

PCP Enrollment

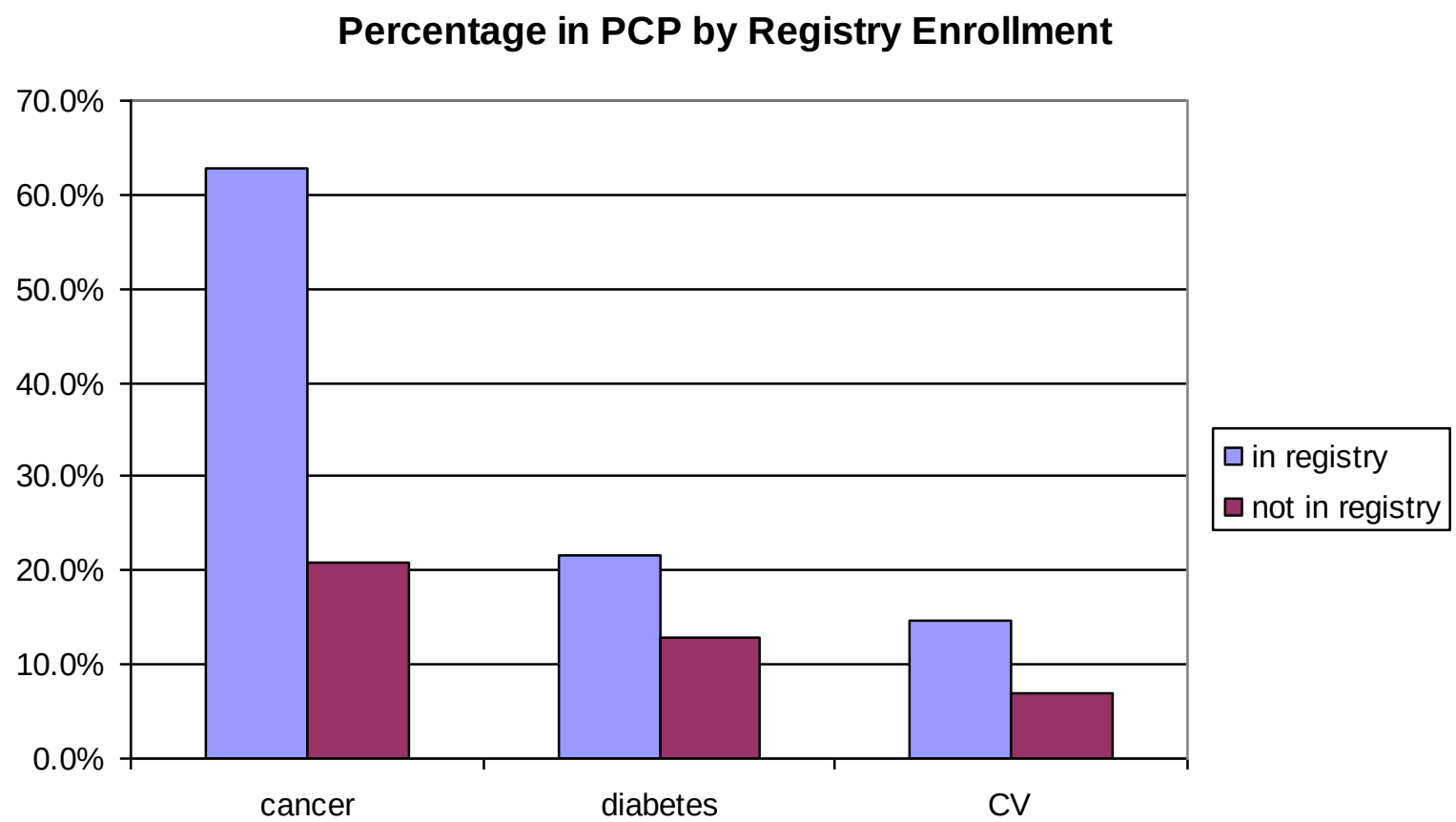
- Percentage of deaths enrolled in PCPs
- District Health Authority population
  - All deaths
  - Conditions which could potentially benefit from PCP (Rosenwax et al*)
    - Maximal Estimate: all deaths except pregnancy-related and sudden deaths
    - Minimal Estimate: 10 conditions
- Limited years
  - Capital Health: 1996-2009
  - Colchester East Hants : 2003-2009
  - Cape Breton: 1996-2009

* Source: Rosenwax, LK, Blackmore AM, Holman CDJ (2005) Estimating the Size of a Potential Palliative Care Population *Palliative Medicine* 19: 556-562.

PCP Enrollment



PCP Enrollment for those in Disease Registries

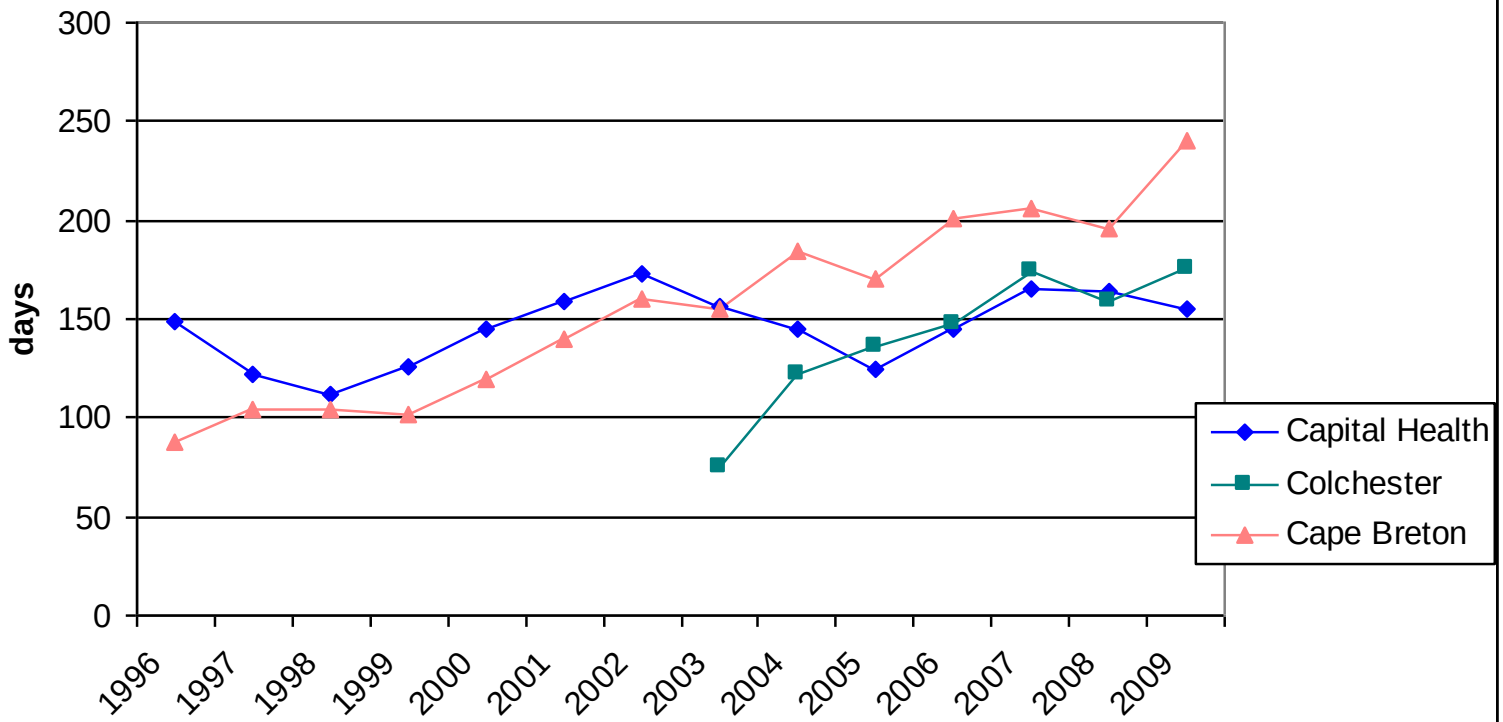


Denominator includes those in Capital Health, Colchester East Hants or Cape Breton DHA who have the corresponding disease cause on death certificate.

Enrollment Days

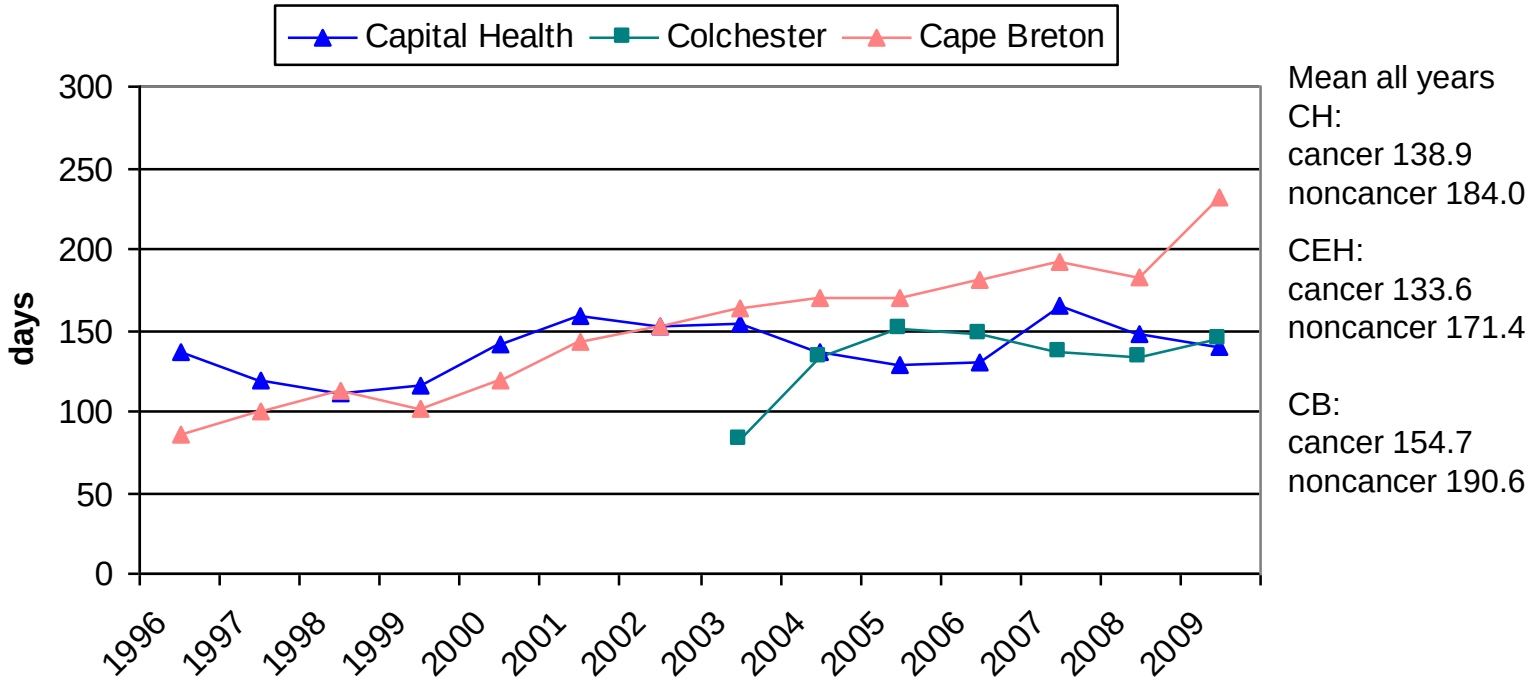
- Days enrolled in PCP
  - Used as a quality care indicator
- First referral date until death used for Colchester and Cape Breton
- First PCP visit until death used for Capital Health
  - 1996-2004 > 90% have missing value for referral date
  - Mean days between first referral and first visit for Capital Health where both dates are non-missing (2005-2009):
    - 4.39 days when referral date is not the same as the first visit date
    - 40.5% had the same referral and first visit date

Enrollment Days Over Time



note: days from first visit to death used for CH while first referral used for CEH and CB

Enrollment Days Over Time – With Cancer



Mean all years
CH:
cancer 138.9
noncancer 184.0

CEH:
cancer 133.6
noncancer 171.4

CB:
cancer 154.7
noncancer 190.6

note: days from first visit to death used for CH while first referral used for CEH and CB

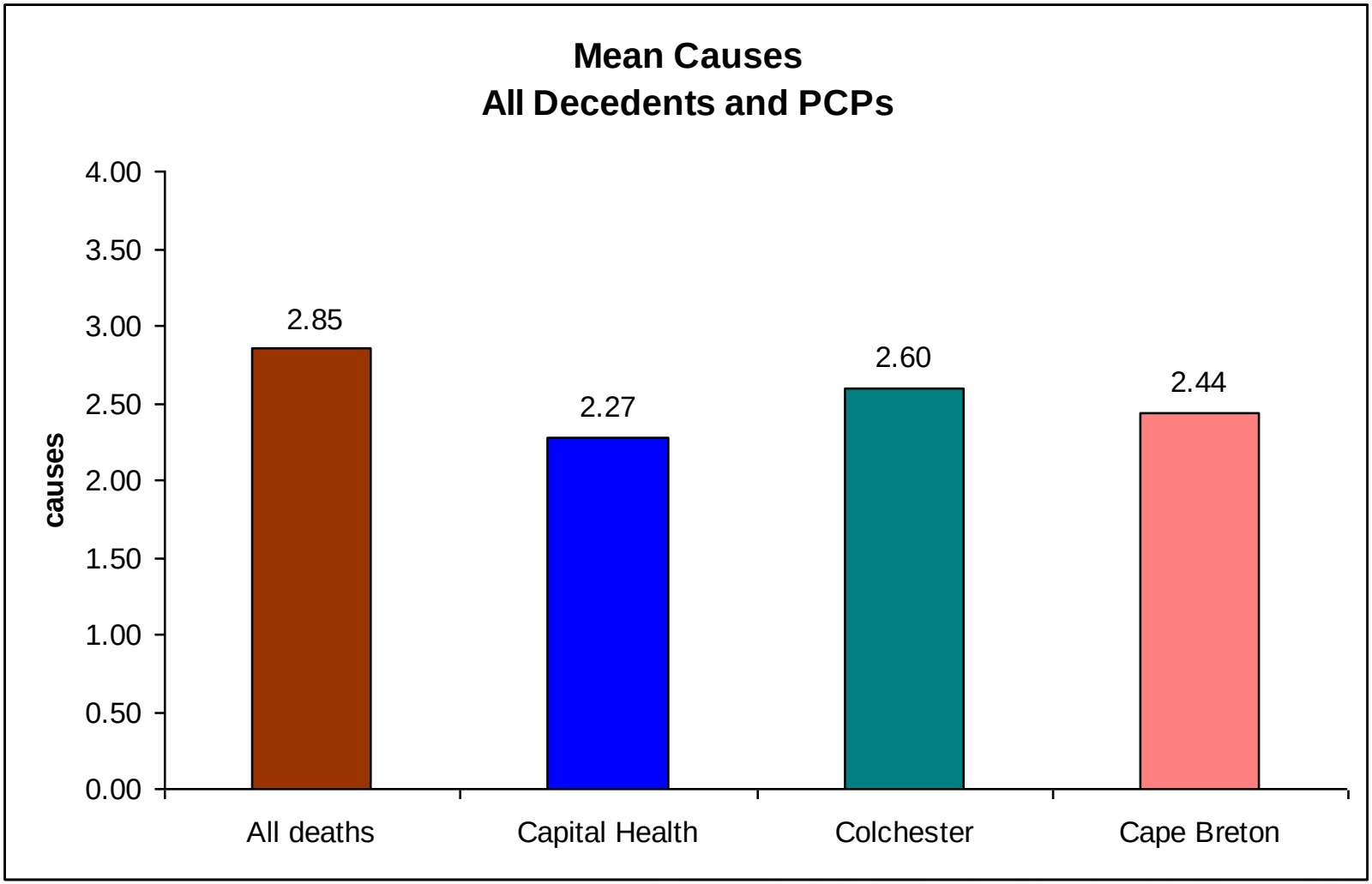
Time from Palliative Care Enrollment to Death

Days	Palliative Care Program				
	Capital Health (2005-2009)		Colchester East Hants (2002-2009)		Cape Breton (1996-2009)
	first referral	first visit	first referral	first visit	first referral
≤7 days	19.2%	20.7%	22.6%	23.5%	20.4%
≤14 days	28.7%	30.2%	31.2%	32.5%	28.8%

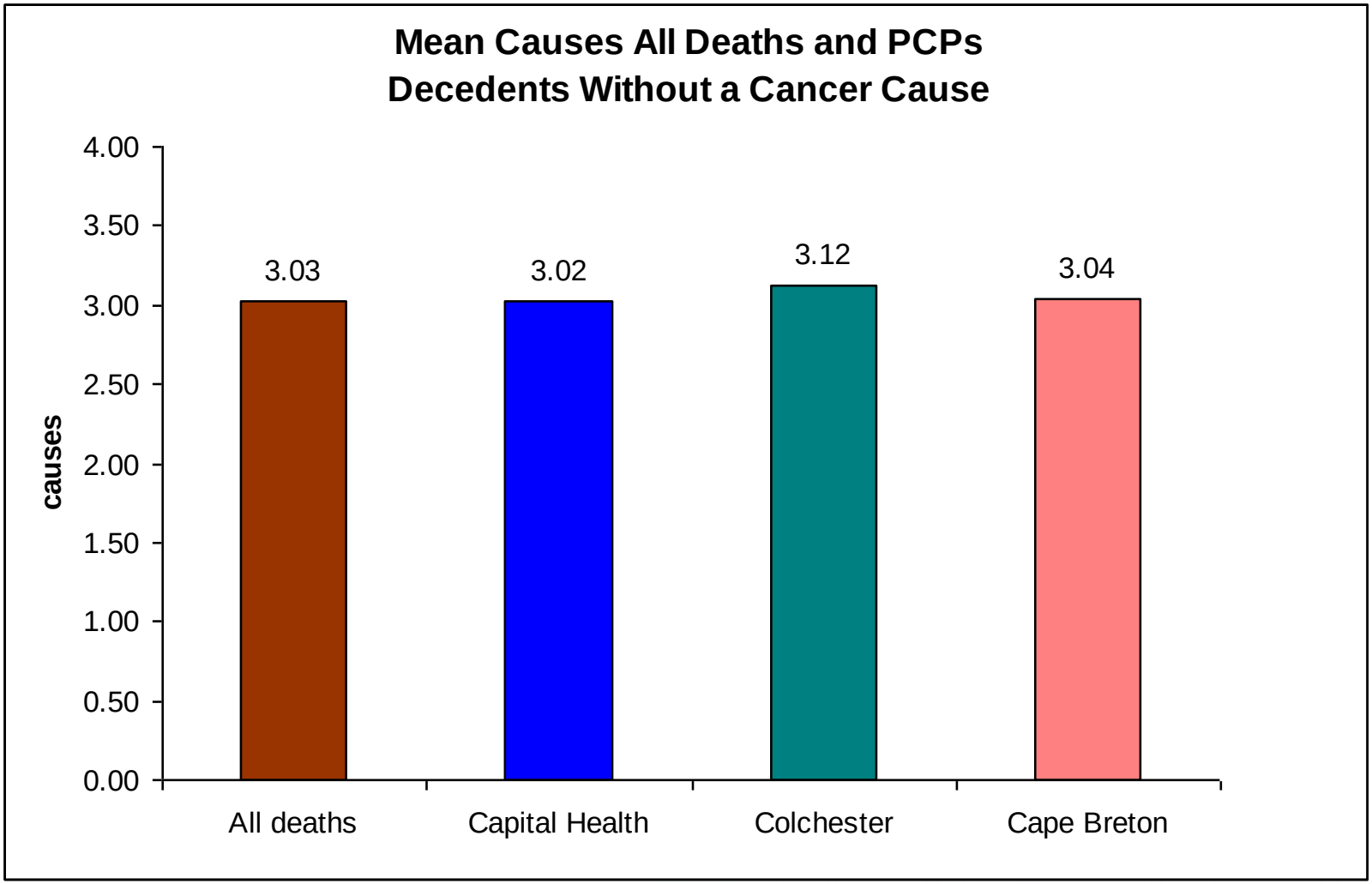
Causes of Death

- All causes of death from death certificate utilized
- Can be up to 13 causes of death listed
- Disease types were identified through ICD coding used on the death certificate

Number of Death Causes



Number of Death Causes – without Cancer Cause

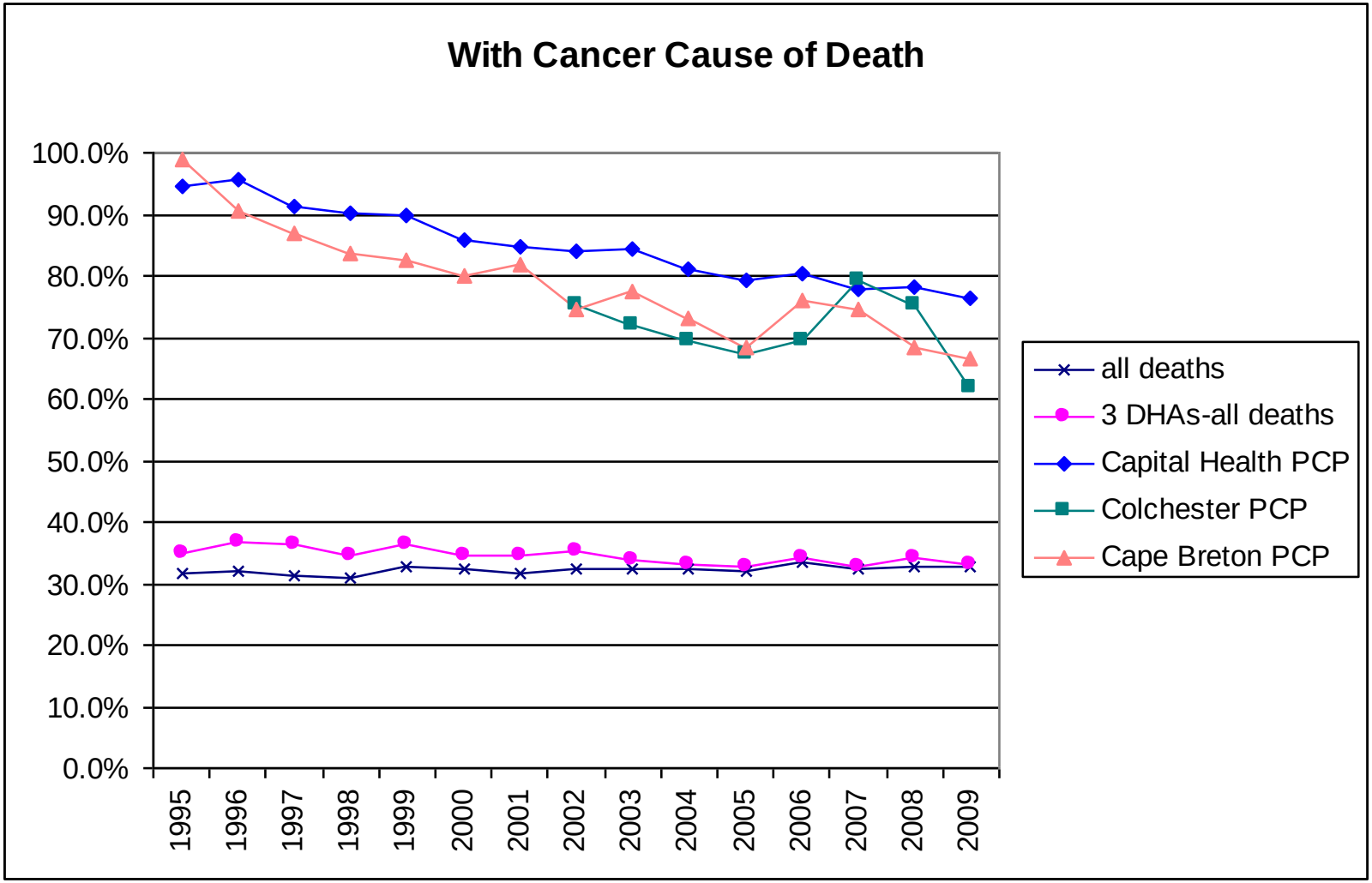


Cause of Death Frequencies

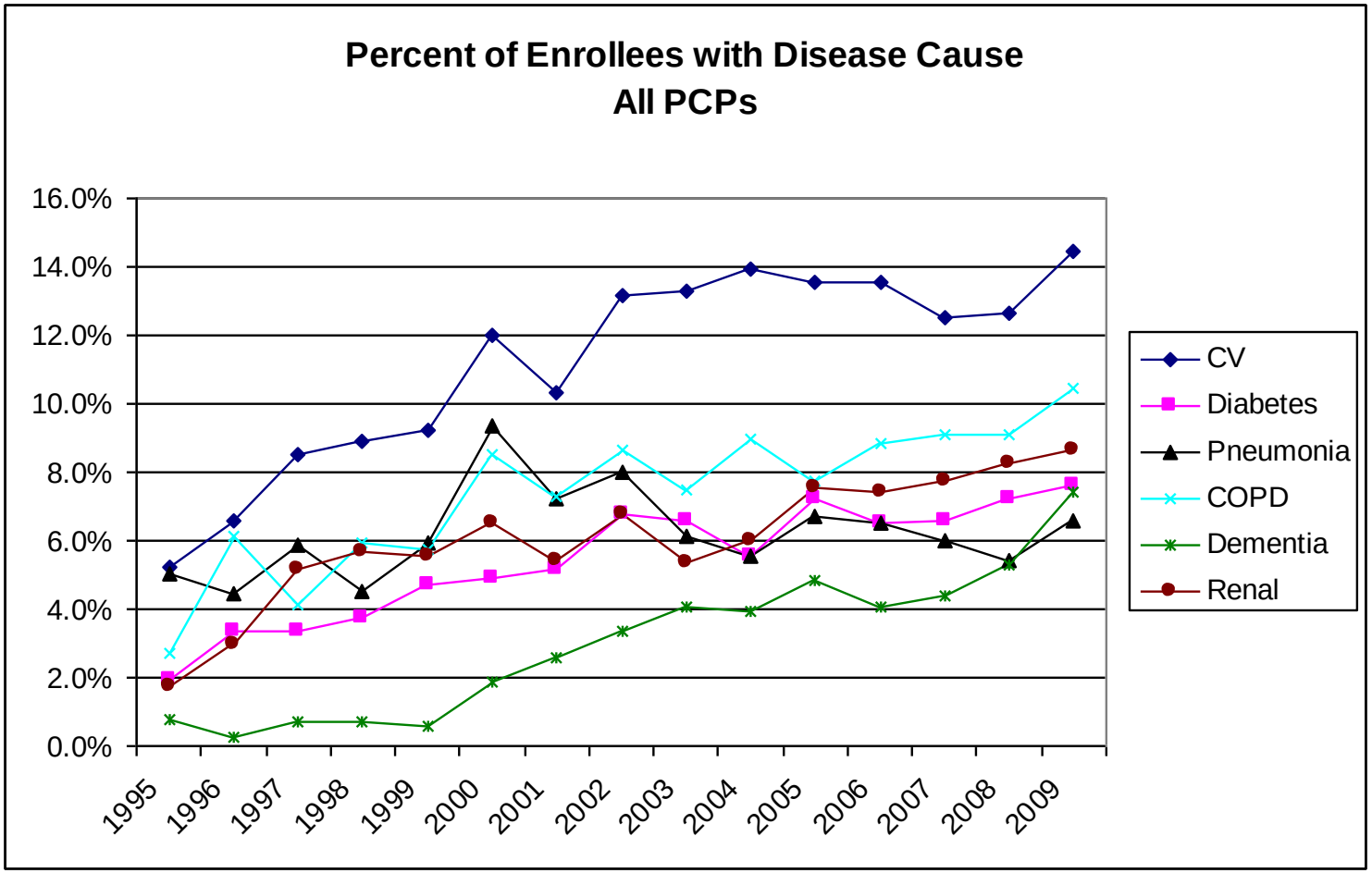
Program	All Deaths	CH	CEH	CB	All PCPs
Cancer	32.2%	83.6%	70.9%	76.5%	80.5%
Cardiovascular Disease	31.6%	10.1%	16.4%	14.0%	11.8%
Diabetes	10.6%	4.9%	8.6%	7.5%	5.9%
Pneumonia	11.7%	6.2%	8.2%	6.2%	6.3%
COPD	11.5%	6.3%	11.9%	10.4%	7.9%
Dementia/Alzheimer's	10.2%	2.6%	7.6%	4.4%	3.5%
Renal	8.8%	6.6%	6.7%	6.5%	6.5%
observations	121,458	12,976	1569	5631	19,835

* Categories are not mutually exclusive.

Cancer Cause of Death Trends



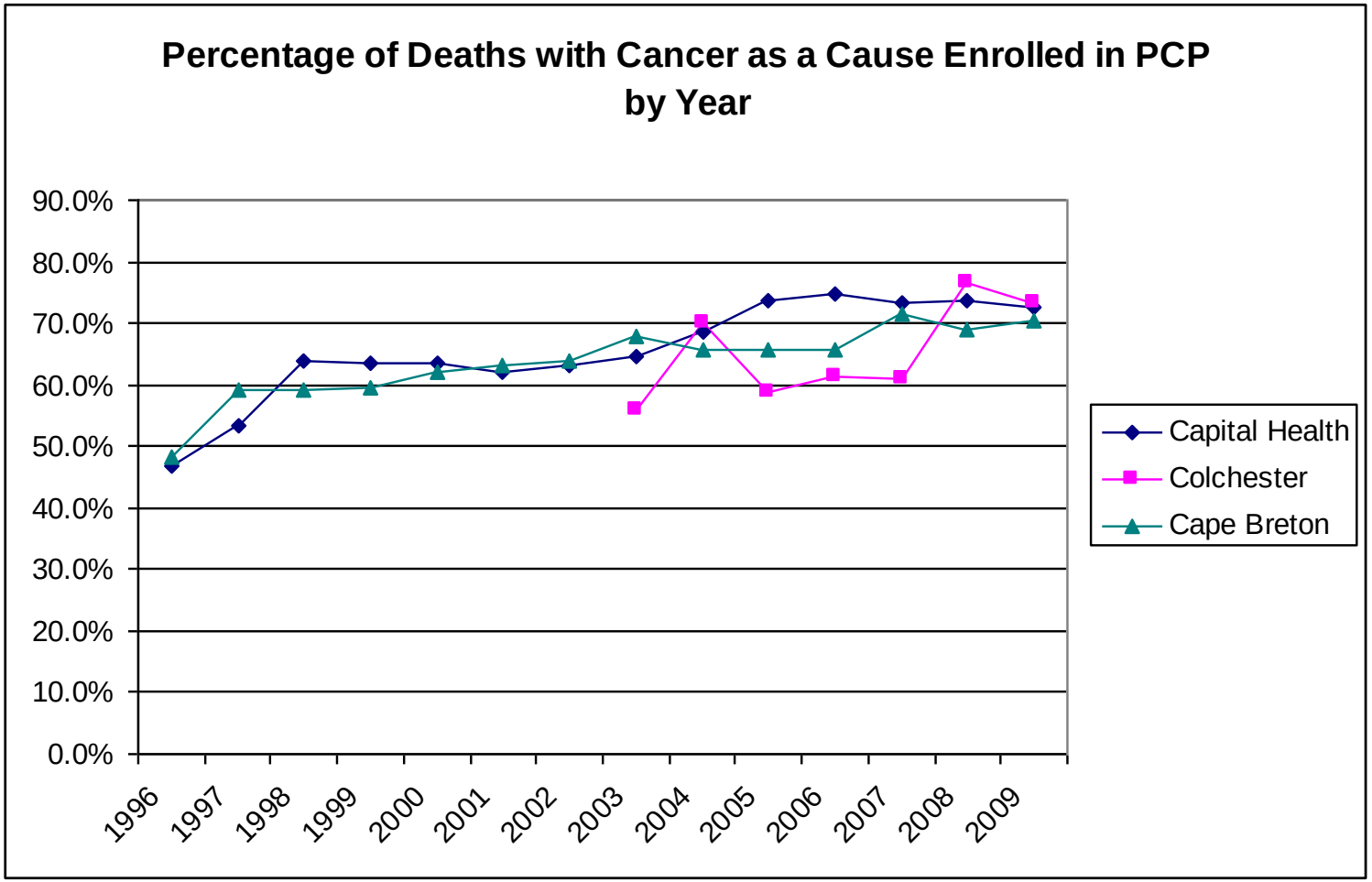
Non-Cancer Causes



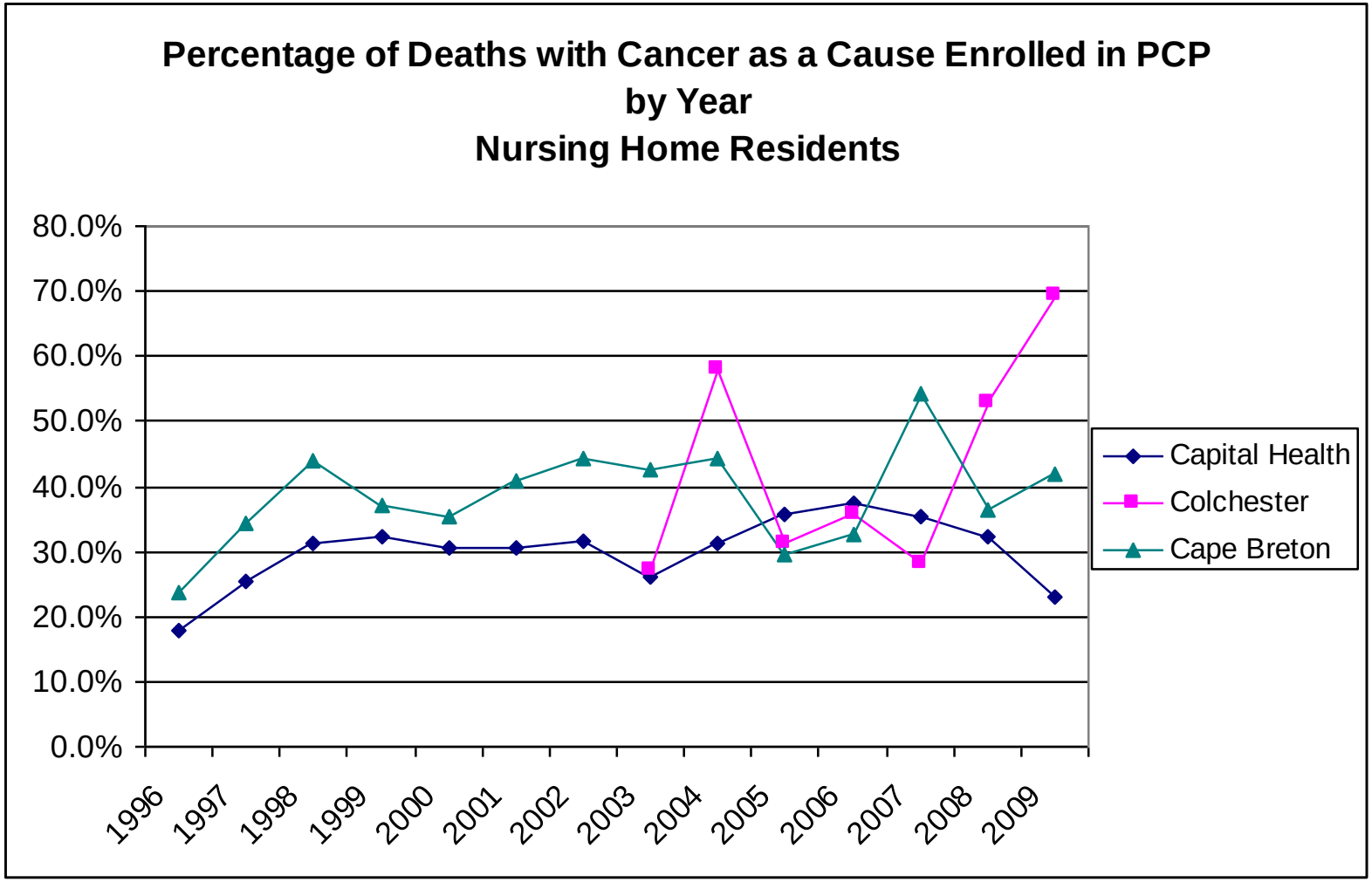
Trends

Average Annual Change in Percent of Enrollees with Disease Cause All PCPs	
Cancer	-1.57%
Cardiovascular Disease	0.58%
Diabetes	0.36%
Pneumonia	0.07%
COPD	0.41%
Dementia/Alzheimer's	0.45%
Renal	0.37%

Percentage of Cancer Decedents Seen by Palliative Care Program in Nova Scotia



Nursing Home Residents Dying of Cancer seen by a Palliative Care Program



Palliative Care Programs Diagnosis Data

- Capital Health PCP uses ICD-9 codings (as is used on the death certificates)
  - Two variables available to indicate health condition
    - Primary Diagnosis
    - Comorbidity

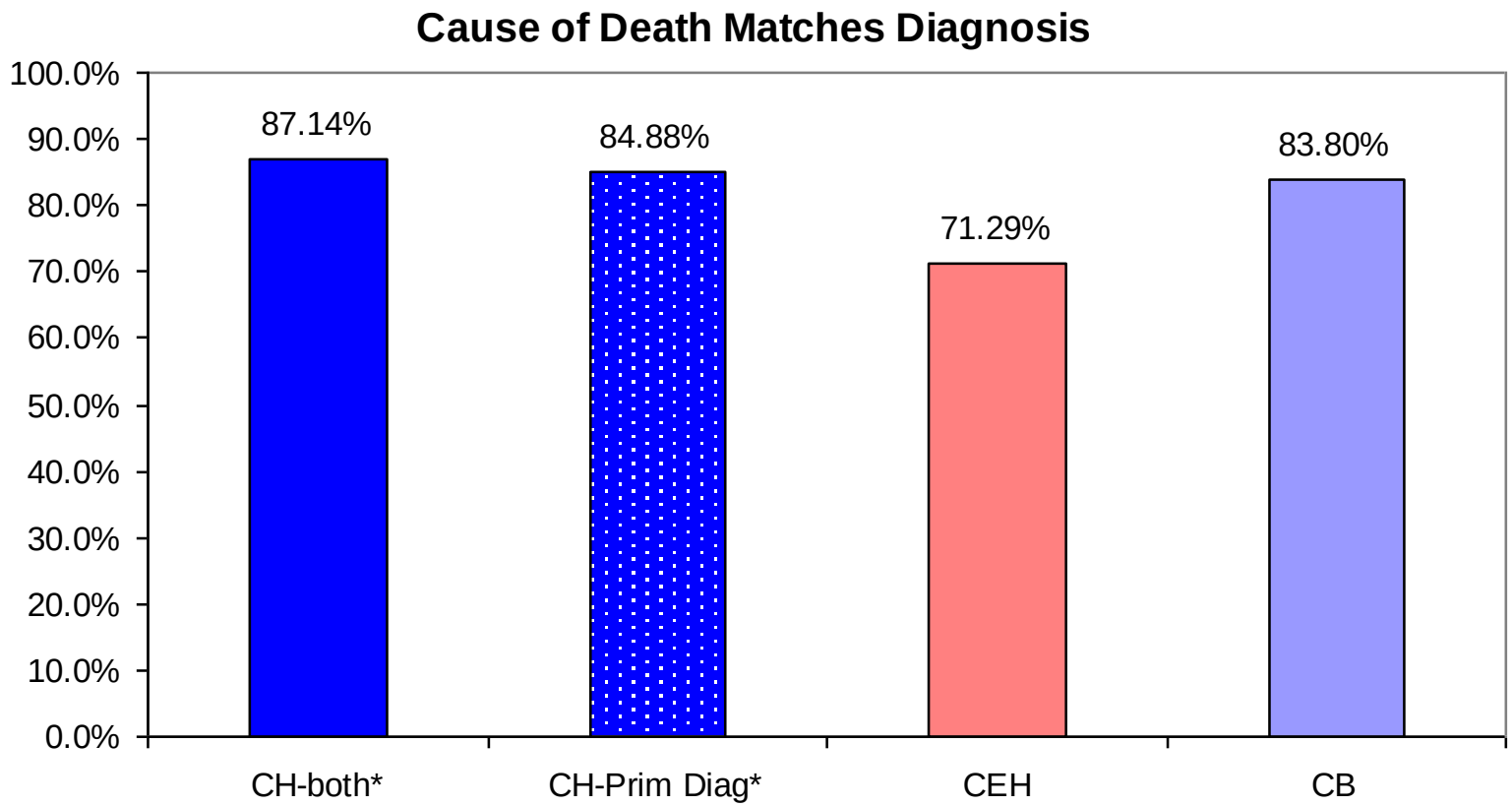
- Colchester East Hants and Cape Breton PCPs utilize free text to indicate diagnosis
  - The program searches the diagnoses variables for a list of words and phrases to indicate the various diseases.
  - There could be multiple conditions listed

PCP Diagnoses Frequencies

	CH		CEH	CB
Program	Primary Diagnosis or co-morbidity	Primary diagnosis	Diagnosis	Diagnosis
Cancer	85.9%	84.3%	63.9%	78.2%
Cardiovascular Disease	6.8%	2.5%	2.5%	3.5%
Diabetes	5.1%	2.5%	0.13%	0.23%
Pneumonia	0.90%	0.47%	1.2%	0.60%
COPD	5.3%	1.6%	4.1%	4.6%
Dementia/Alzheimer's	2.3%	0.82%	2.4%	2.1%
Renal	3.3%	1.8%	4.9%	4.6%
observations	12,976	12,976	1,569	5,631

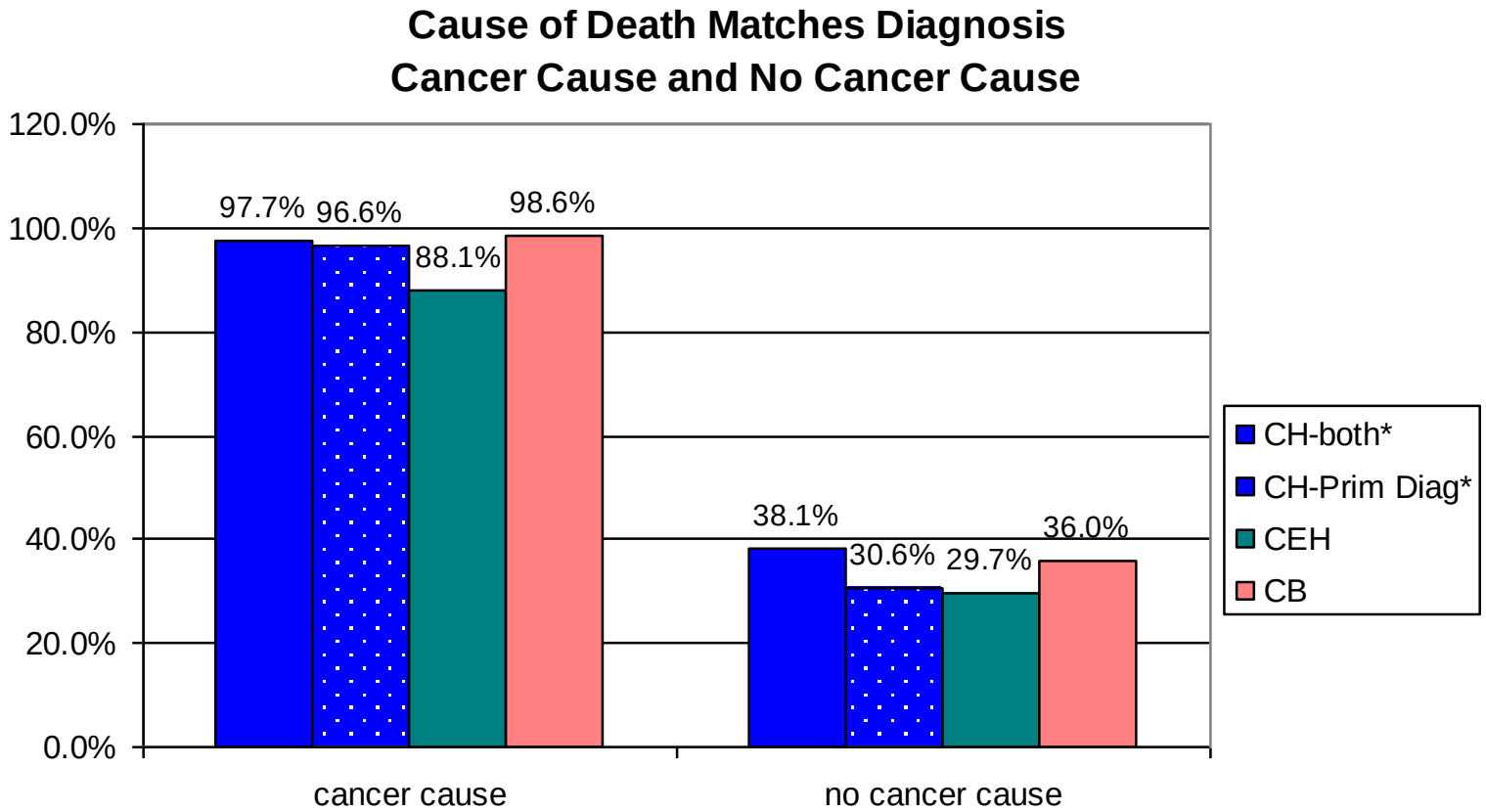
Note: Categories are not mutually exclusive
Other conditions not listed due to small numbers

PCP Diagnosis and Cause of Death



For any of 7 conditions: cancer, CV, diabetes, renal, pneumonia, COPD, dementia
* CH-both indicates a match using either the priamry diagnosis or co-morbidity variable
CH-Prim Diag indicates a match using the priamry diagnosis variable only

PCP Diagnosis and Cause of Death



For any of 7 conditions: cancer, CV, diabetes, renal, pneumonia, COPD, dementia

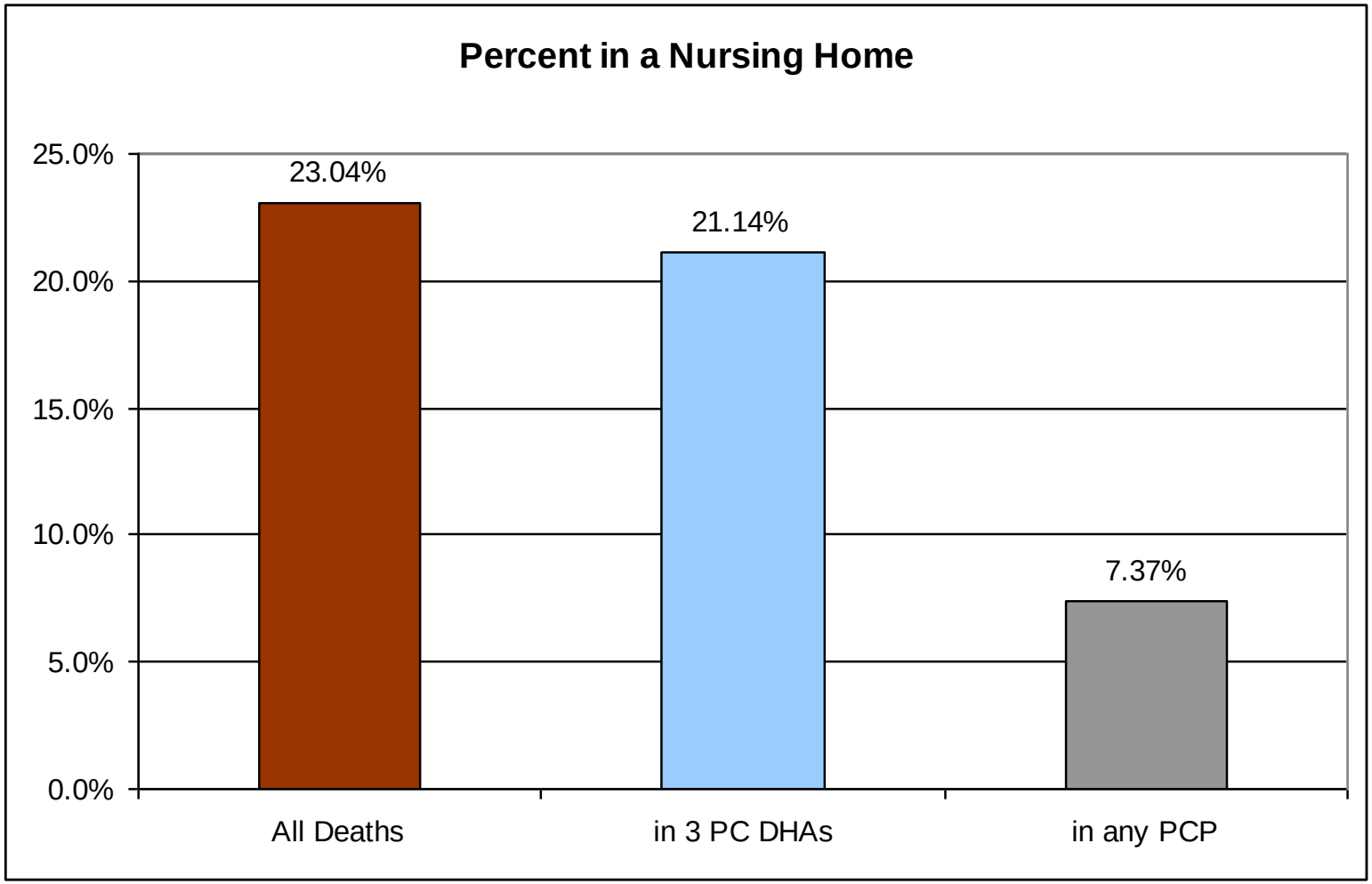
* CH-both indicates a match using either the priamry diagnosis or co-morbidity variable

CH-Prim Diag indicates a match using the priamry diagnosis variable only

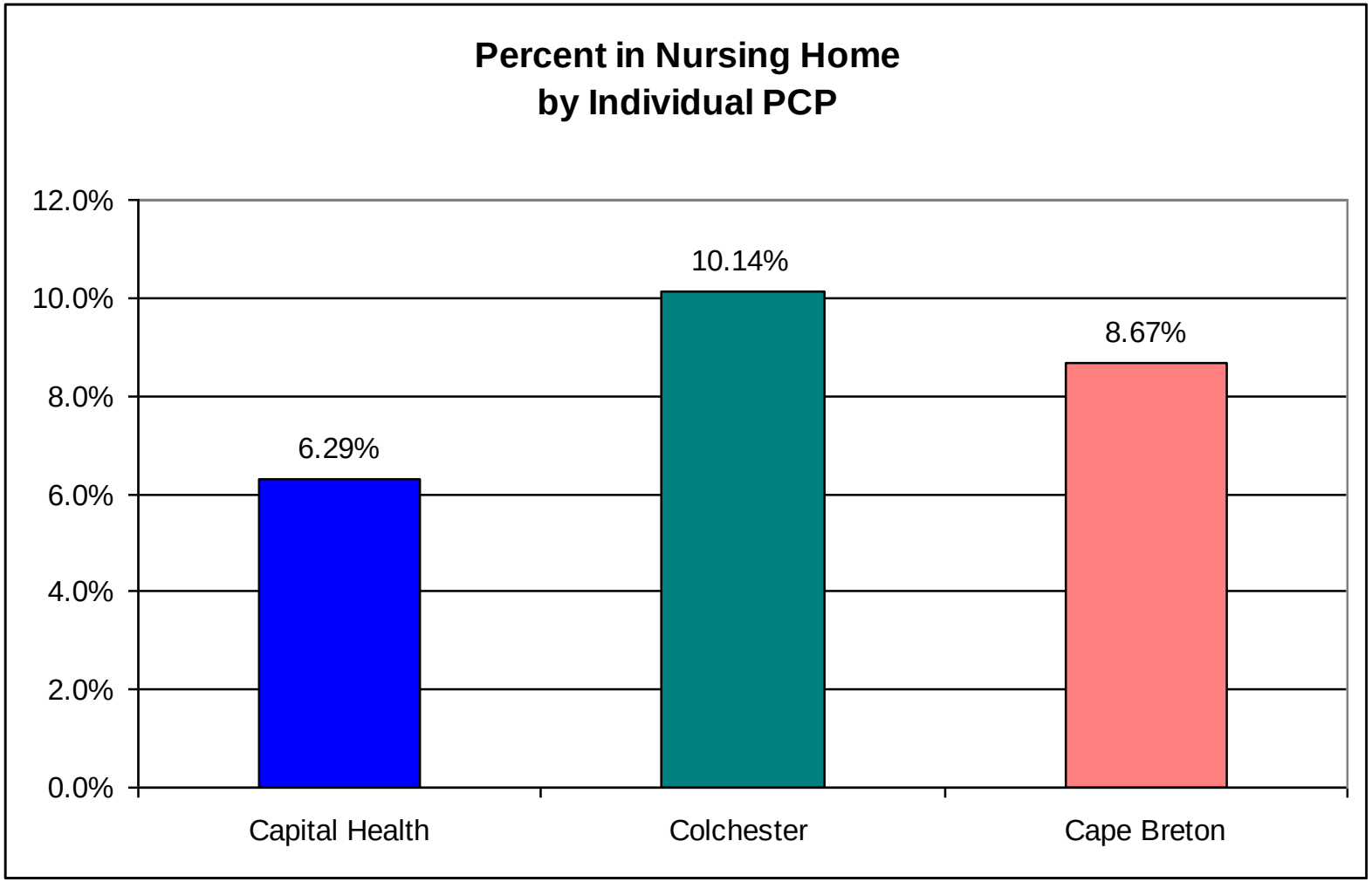
Nursing Home Residents and PCPs

- 9 indicators of residence in a nursing home in 3x3 data
    - 2 from VS data
    - 2 using CCNS algorithm using address information
    - 2 from cardiovascular registry
    - 2 from Cape Breton PCP data
    - 1 from Colchester PCP data
- The time period and populations covered varies across indicators
- The 2 CCNS variables cover the entire study period and population

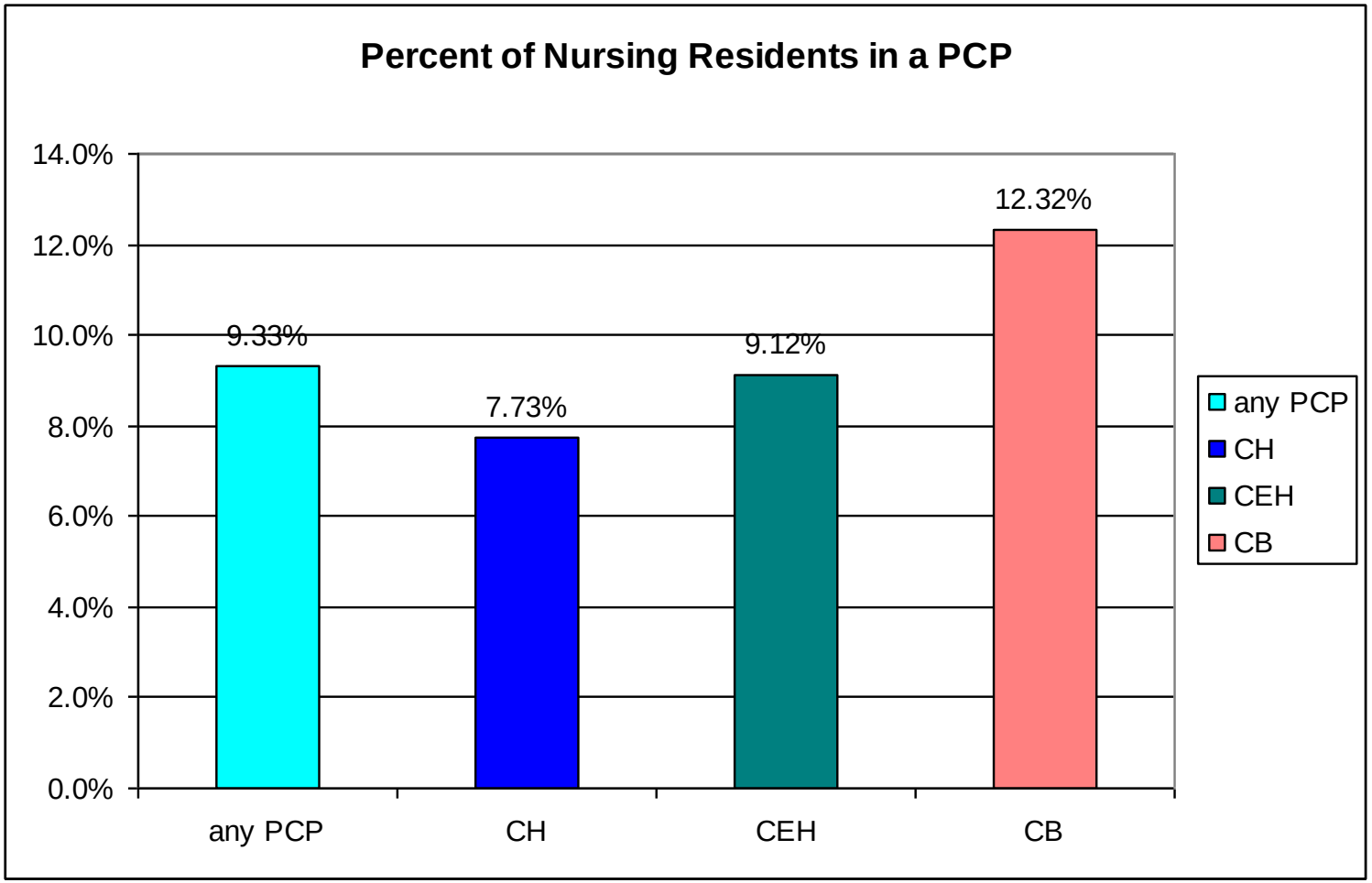
Nursing Home Residents



Nursing Home Residents by PCP



NH Residents in a PCP



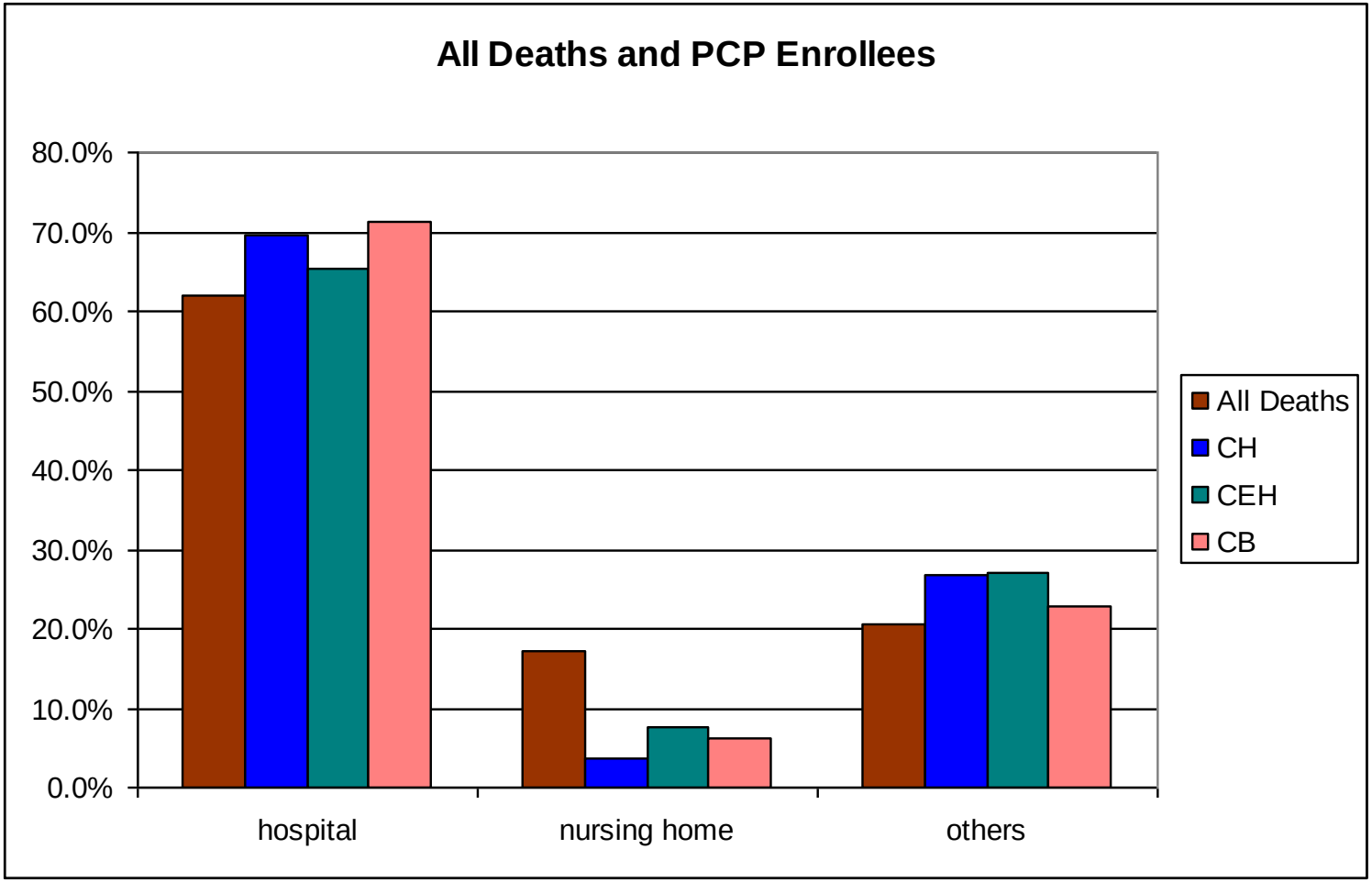
Place of Death

- Location of death is an indicator of quality care near the end of life
- Most patients prefer to die at home
- An algorithm developed by CCNS is used to determine place of death
- Variable constructed indicates if the death occurred in hospital, nursing home or “other”

Place of Death

- "place of death" is distinguished from "location of care" in the last weeks of life
- Decedents may be admitted to the hospital in the last few days of life
- In recent work, researchers have measured the location of care in the last weeks of life
- Further data linkages to the 3x3 NELS data are required to explore location of care during end of life
  - e.g. hospital admission/discharge data

Place of Death



Thank you for your attention!