Chronic Disease and Palliative Care Program Data Linkage and Analysis Project:
NSVS Data Quality report from 3x3 NELS

Descriptive Results

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with Krista Dewey, NSVS

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
- As death approaches, health services required vary depending on health conditions
- 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
- Administrative data linked at the individual level are a valuable tool to study EOL care issues

Data Sources

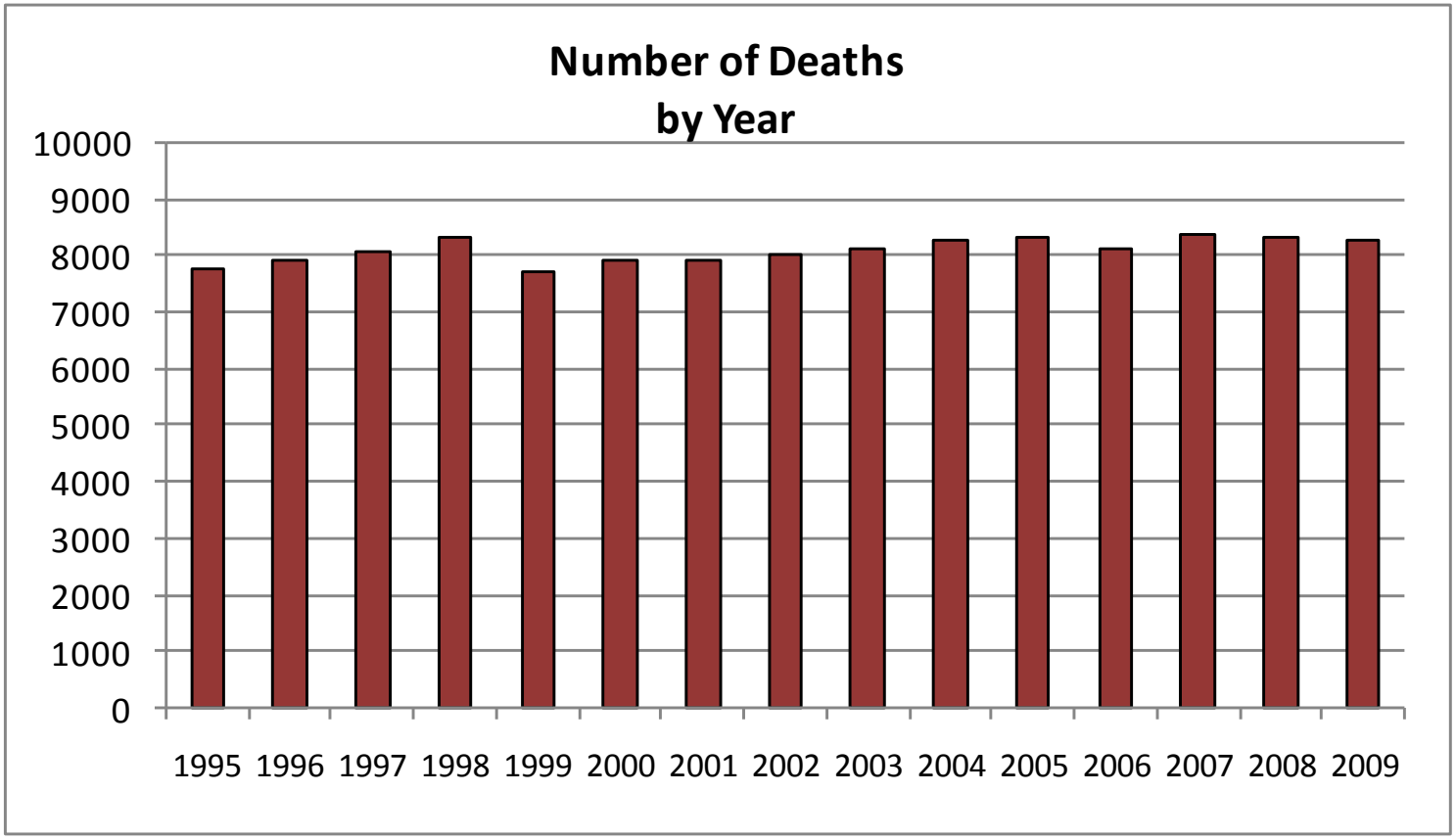
- Link data from 3 disease registries and 3 Palliative Care Programs to Vital Statistics Death Certificate data
- Registry data:
  - Cancer
  - Diabetes
  - Cardiovascular
- Palliative Care Program (PCP) data
  - Capital Health
  - Cape Breton
  - Colchester
- Probabilistic data linkage

Study Subjects

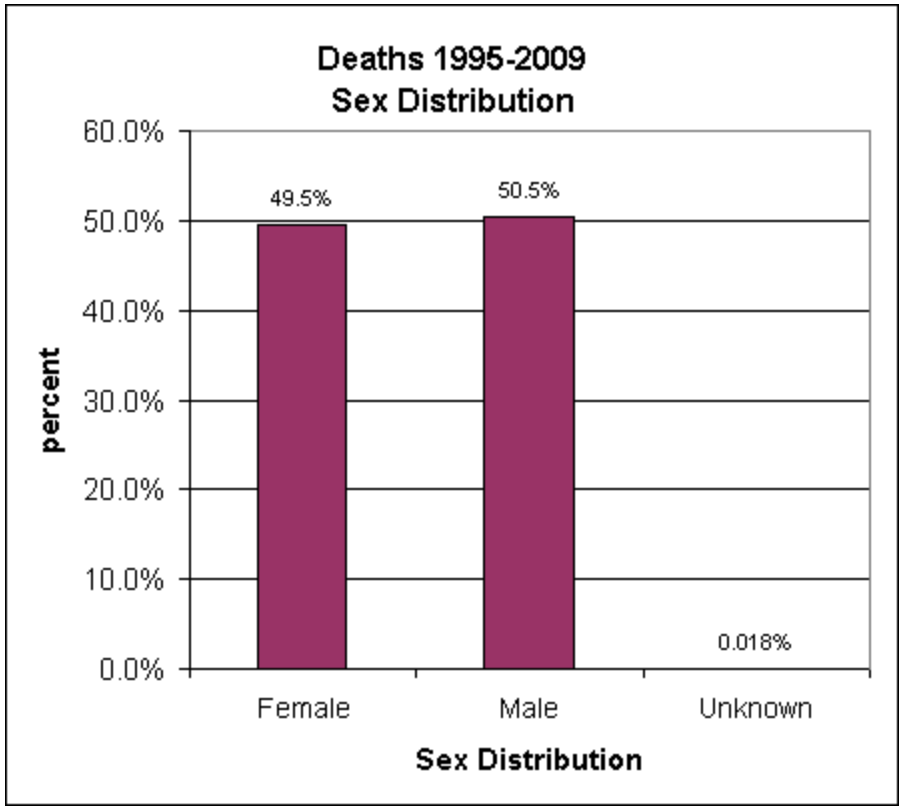
- All deaths in Nova Scotia as defined by NS Vital Statistics 1995-2009
- Total number of deaths: 121,458
- Data sources vary in terms of population covered and year
  - Not all statistics calculated for entire province/all study years
  - ie only have PCP data for 3 DHAs
- To determine DHA, a residential postal code is required
  - 6,178 (5.1%) in total have a missing postal code

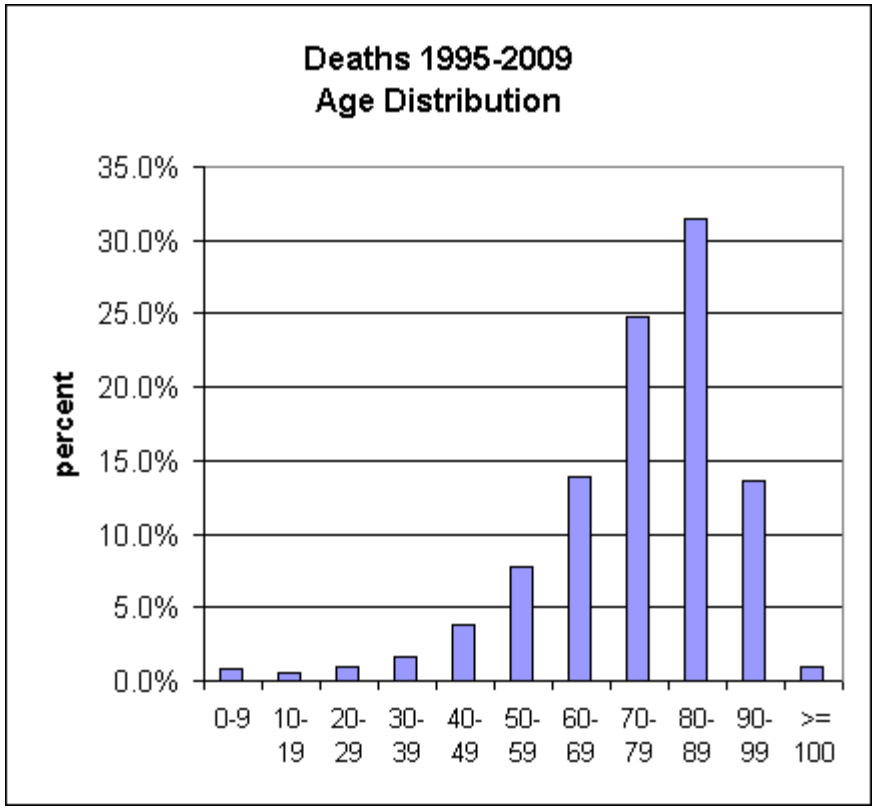
Vital Statistics

Total Deaths 1995-2009: 121,458



Age and Sex Distribution





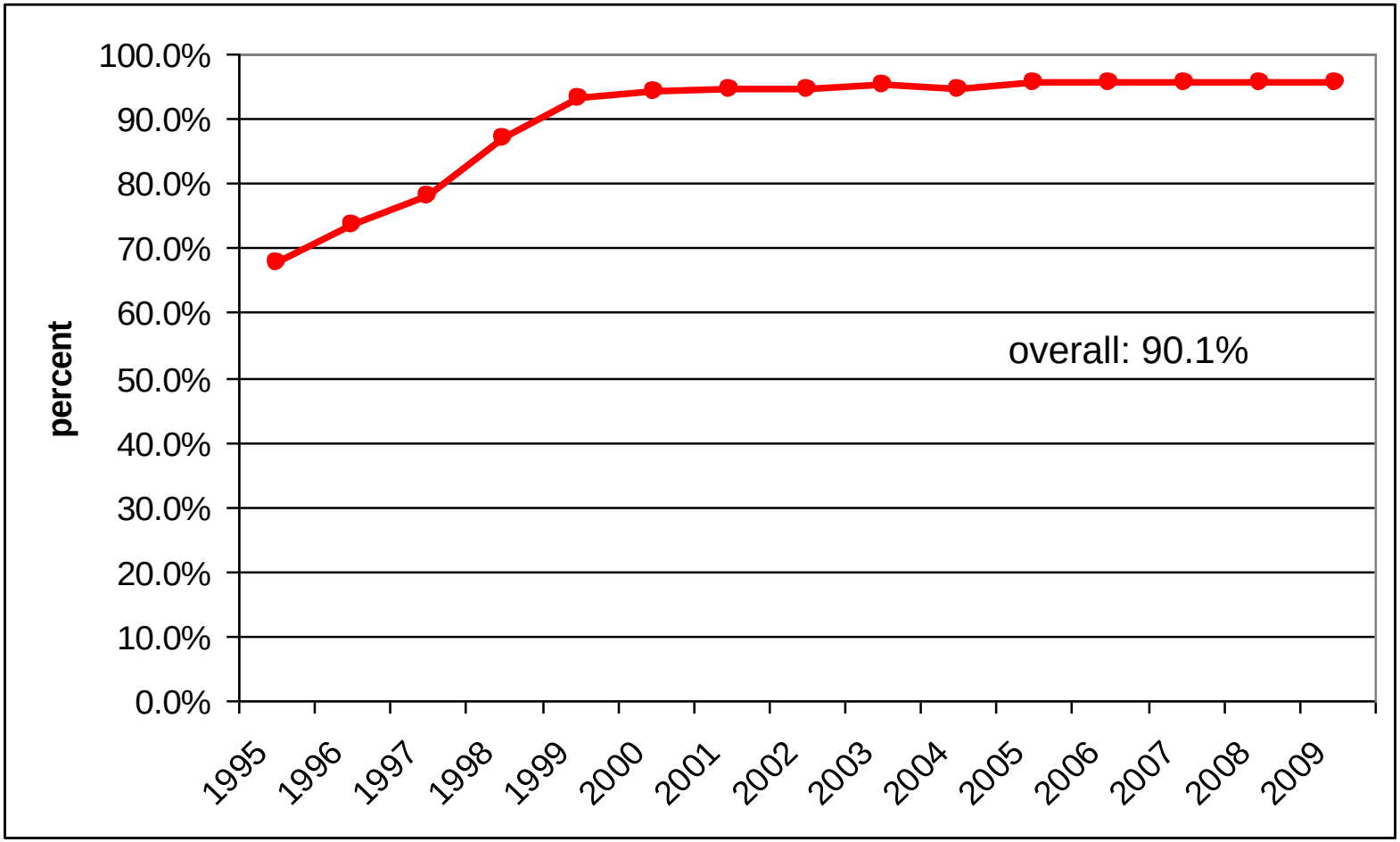
Health Card Numbers

- The 3x3 data do not include HCN! Not required for the analysis
- However, it is helpful to understand the extent missing HCNs after the probabilistic linking as further data linkages may be included in future projects
  - eg physician billings and hospital data
- Probabilistic linkage analyst provided variables which indicate whether a HCN number is available for each individual and the source of the HCN

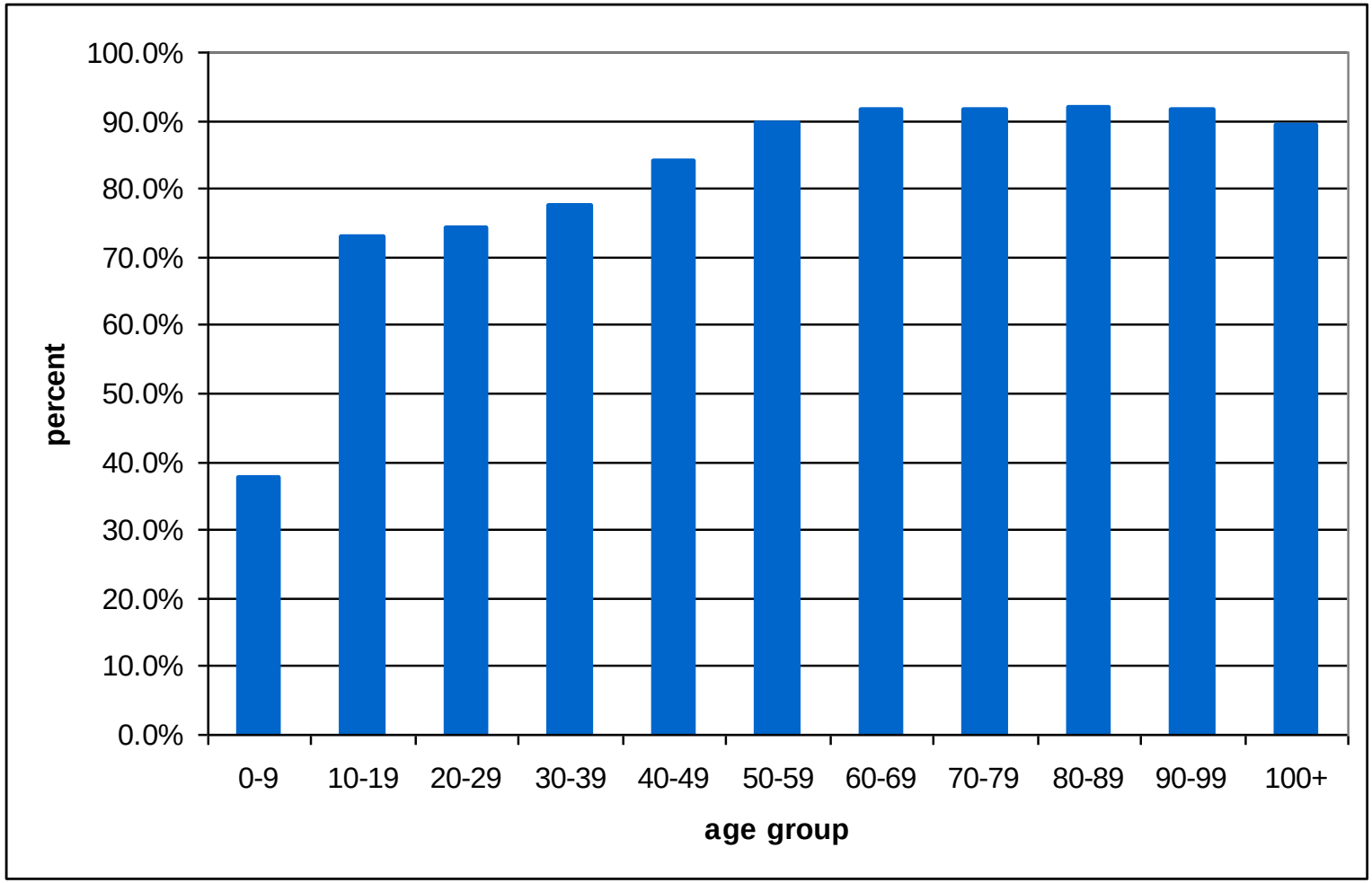
Source of HCNs

Total non-missing	**109,444**	**90.1%**
Source of HCN VS CCNS CV CBPC CEHPC CHPC	 100,959 7088 1453 43 13 154	 92.2% (% of non-missing) 6.5% 1.3% 0.04% 0.01% 0.14%
Source of HCN both VS and other	266	0.24% (% of non-missing)
Note: The only linking variable available from the diabetes registry was HCN, therefore it could not be used to fill in missing HCNs.		

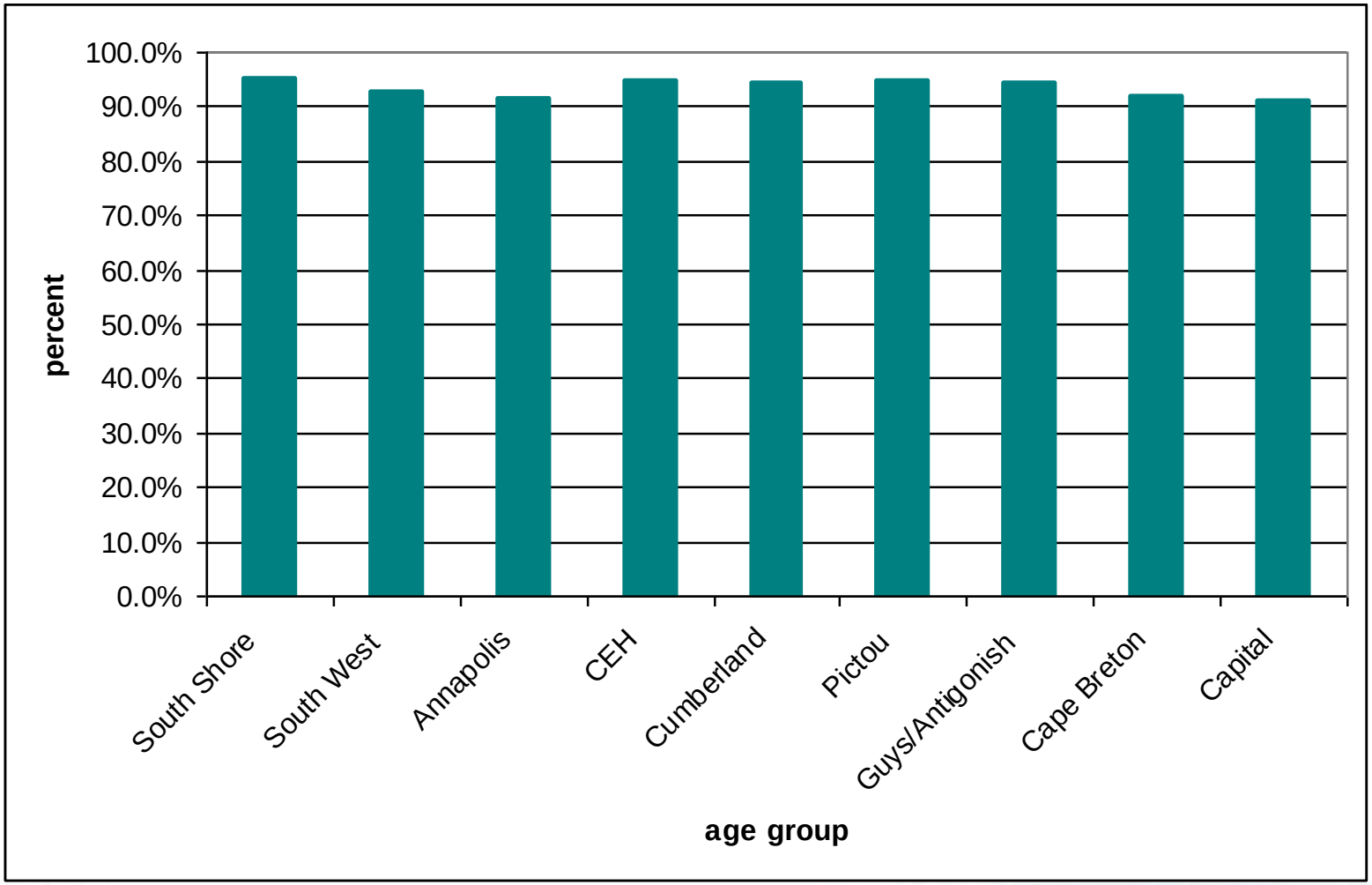
Non-Missing Health Card Numbers by Year



Non-Missing Health Card Numbers by Age Group



Non-Missing Health Card Numbers- by DHA



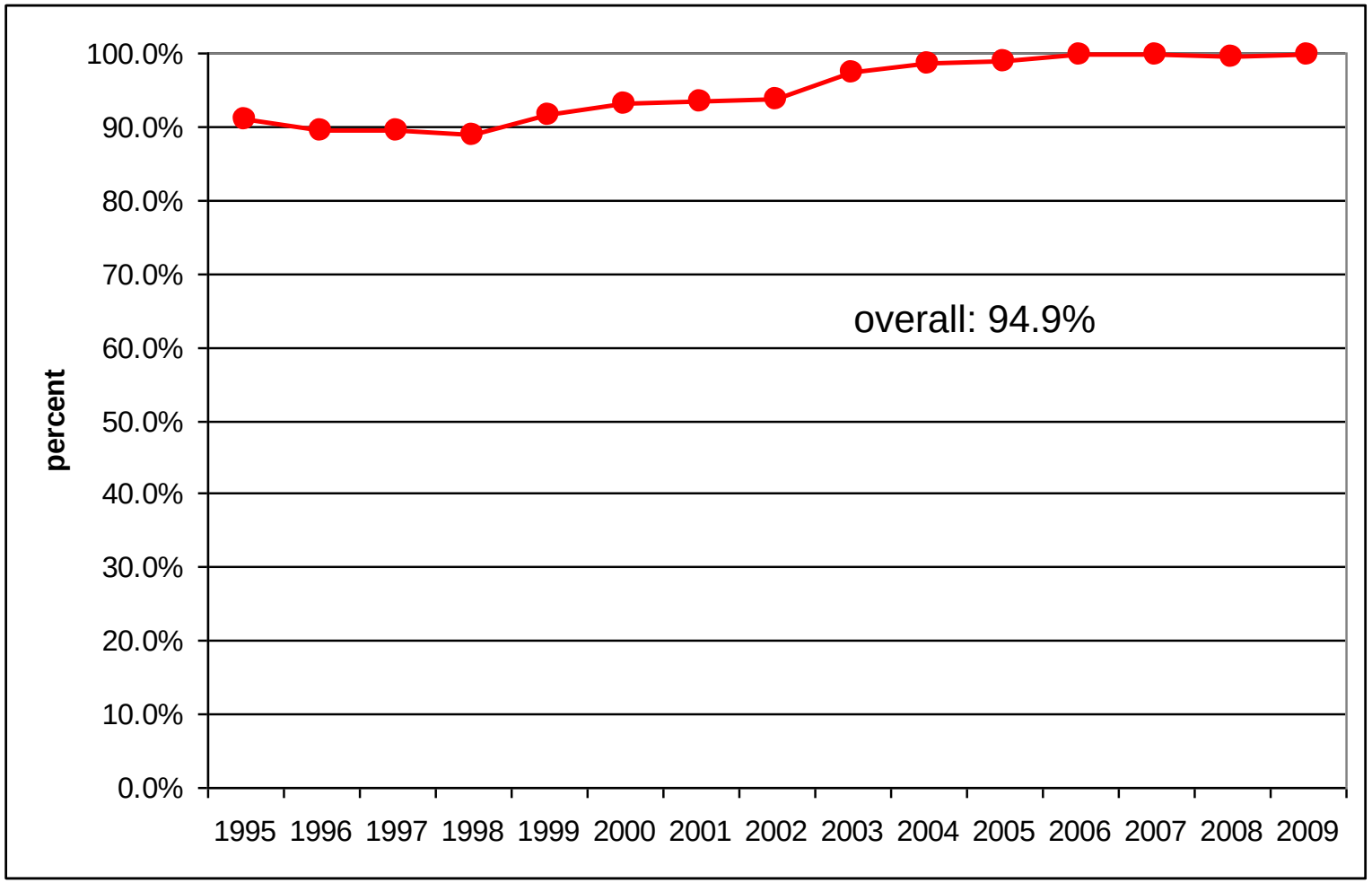
Postal Code Information

- Used to help determine residence in nursing home
- Link Census information
- Can be used to group results into comparison categories
  - rural/urban
  - DHAs

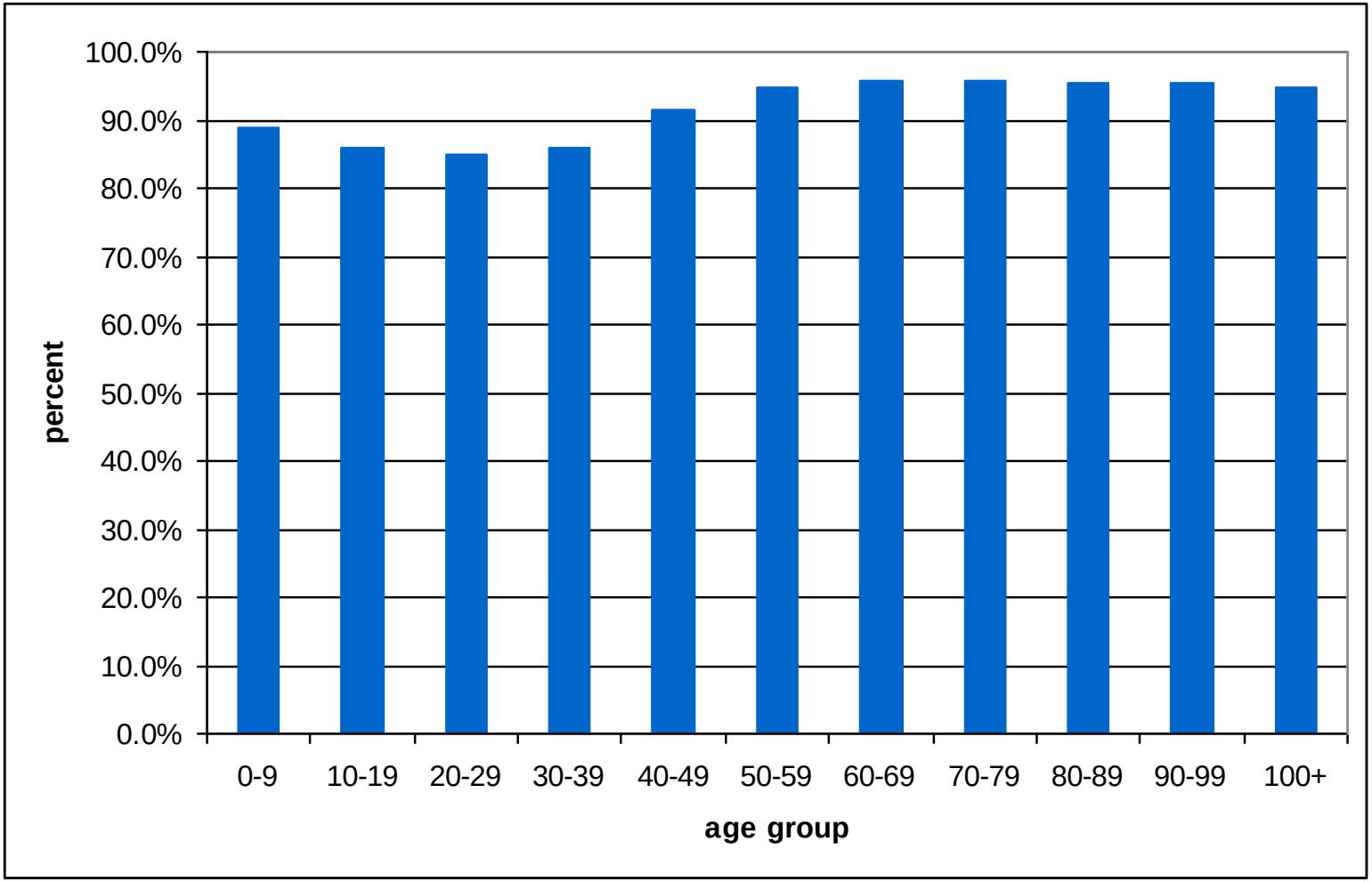
Postal Codes

	Resident Postal Codes	%
non-missing	**115,280**	**94.9%**
source VS source CCNS source PCP or CV*	109,945 3877 1458	90.5% 3.2% 1.2%
Note: Diabetes data did not have address information		

Non-Missing Postal Codes by Year



Non-Missing Postal Codes by Age



Nursing Home Residents Indicators

- Indicators of residence in a nursing home in 3x3 data
  - VS data (2 indicators)
  - CCNS algorithm using address information
  - Cardiovascular registry – admit. to/discharge from
  - Cape Breton PCP data (2 indicators)
  - Colchester PCP data
- The time period and populations covered varies across indicators
- The CCNS indicator covers the entire study period and population

Agreement Statistics

- 2 x 2 tables
  - Both negative
  - Both positive
  - Non-agreement

- Kappa statistic
  - Measure which accounts for chance agreement
  - > 0.75 represents excellent agreement
  - 0.40 to 0.75 represents fair to good
  - < 0.40 represents poor agreement

Vital Statistics Internal Comparisons

	VS Extended Care (2002-2009)		
VS Nursing Home Flag (2008-2009)		no	yes
	no	6670 (81.8%)	123 (1.5%)
	yes	1 (0.01%)	1386 (16.7%)
	Actual agreement: 8056 (98.5%)		
Kappa Statistic (CI) : 0.948 (0.939 – 0.957)			
Deaths in 2009 Observations: 8280			

Vital Statistics CCNS Comparisons

	CCNS		
VS Nursing Home Flag (2008-2009)		no	yes
	no	6313 (76.2%)	580 (7.0%)
	yes	201 (2.4%)	1186 (14.3%)
	Actual agreement: 7499 (90.5%)		
Kappa Statistic (CI) : 0.695 (0.675 – 0.715)			
Deaths in 2009 Observations: 8280			

Vital Statistics CCNS Comparisons

	CCNS		
VS Extended Care (2002-2009)		no	yes
	no	43,966 (76.1%)	5154 (8.9%)
	yes	312 (0.54%)	8376 (14.5%)
	Actual agreement: 52,342 (90.6%)		
Kappa Statistic (CI) : 0.699 (0.692 – 0.706)			
Deaths in 2003-2009 Observations: 57,808			

Vital Statistics CV Comparison

	Cardiovascular Registry NH indicator		
VS Nursing Home Flag (2008-2009)		no	yes
	no	1981 (76.4%)	256 (9.9%)
	yes	200 (7.7%)	155 (6.0%)
	Actual agreement: 2136 (82.4%)		
Kappa Statistic (CI) : 0.302 (0.253 – 0.351)			
Deaths in 2009 who were in the CV registry Observations: 2592			

Vital Statistics CV Comparison

	Cardiovascular Registry NH indicator		
VS Extended Care (2002-2009)		no	yes
	no	12,761 (78.0%)	1651 (10.1%)
	yes	1076 (6.6%)	882 (5.4%)
	Actual agreement: 13,643 (83.4%)		
Kappa Statistic (CI) : 0.298 (0.278 – 0.318)			
Deaths in 2003-2009 who were in the CV registry Observations: 16,370			

Vital Statistics CB PCP Comparison

	CB PCP NH indicator		
VS Nursing Home Flag (2008-2009)		no	yes
	no	497 (91.0%)	15 (2.8%)
	yes	9 (1.7%)	25 (4.6%)
	Actual agreement: 522 (95.6%)		
Kappa Statistic (CI) : 0.652 (0.523-0.781)			
Deaths in 2003-2009 who were in the CB PCP Observations: 546			

Vital Statistics CB PCP Comparison

	CB PCP NH indicator		
VS Extended Care (2002-2009)		no	yes
	no	2959 (92.6%)	66 (2.1%)
	yes	36 (1.1%)	134 (4.2%)
	Actual agreement: 3093 (96.8%)		
Kappa Statistic (CI) : 0.708 (0.654 – 0.761)			
Deaths in 2009 who were in the CB PCP Observations: 3195			

Vital Statistics CEH PCP Comparison

	CEH PCP NH indicator		
VS Nursing Home Flag (2008-2009)		no	yes
	no	211 (83.1%)	29 (11.4%)
	yes	2 (0.79%)	12 (4.7%)
	Actual agreement: 223 (87.8%)		
Kappa Statistic (CI) : 0.386 (0.222 – 0.549)			
Deaths in 2009 who were in the CEH PCP Observations: 254			

Vital Statistics CEH PCP Comparison

	CEH PCP NH indicator		
VS Extended Care (2002-2009)		no	yes
	no	1267 (88.3%)	84 (5.9%)
	yes	42 (2.9%)	42 (2.9%)
	Actual agreement: 1309 (91.2%)		
Kappa Statistic (CI) : 0.355 (0.267 – 0.442)			
Deaths in 2003-2009 who were in the CEH PCP Observations: 1435			

Nursing Home Indicators

	Percent In Nursing Home		
	Source Indicator	CCNS	Both
CCNS algorithm (all deaths) residence or death address (1995-2009)	23.0%	23.0%	23.0%
VS nursing home (all deaths)			
nursing home indicator (2009)	16.8%	21.3%	14.3%
extended care (2003-2009)	15.0%	23.4%	14.5%
CV chronic care admission/discharge			
CV registrants only (1998-2009)	15.5%	20.1%	10.7%
PCP			
CB PCP enrollees (1996-2009)	5.6%	8.7%	5.0%
CEH PCP enrollees (2003-2009)	8.8%	10.7%	5.3%

Place of Death

- Location of death is an indicator of quality care near the end of life
- Most patients prefer to die at home
- The CCNS algorithm is used to determine place of death
  - Two hospital identifier variables is used so it was done by linkage analyst
- The variable constructed indicates if the death occurred in the hospital, a nursing home or “other”

Place of Death Data Source

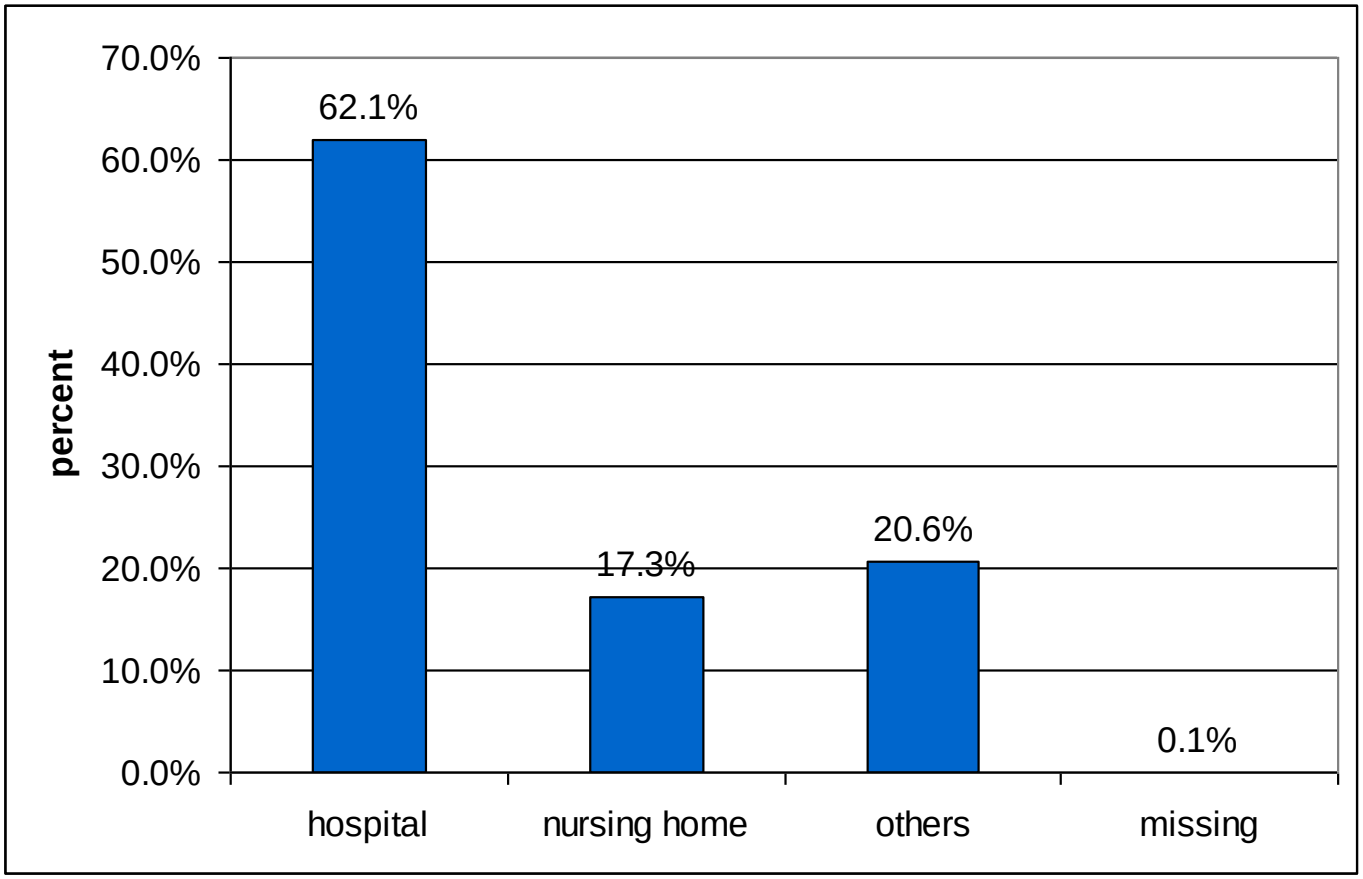
- Hospital discharge data is another source used to measure percent dying in a hospital
- Neutel et al (2005) report discrepancies depending on data used
  - e.g. Cancer Deaths in hospital:
    VS death certificate: 80%
    Hospital separation: 46%
- Difference possibly due to:
  - ED deaths (not included in hospital data)
  - Differences in defining a cancer death

Neutel et al (2005) Proportion of Cancer Deaths Occurring in Hospital, Canada, 1994-2000. Canadian Journal of Public Health. Vol 96 (4) pp 264-268.

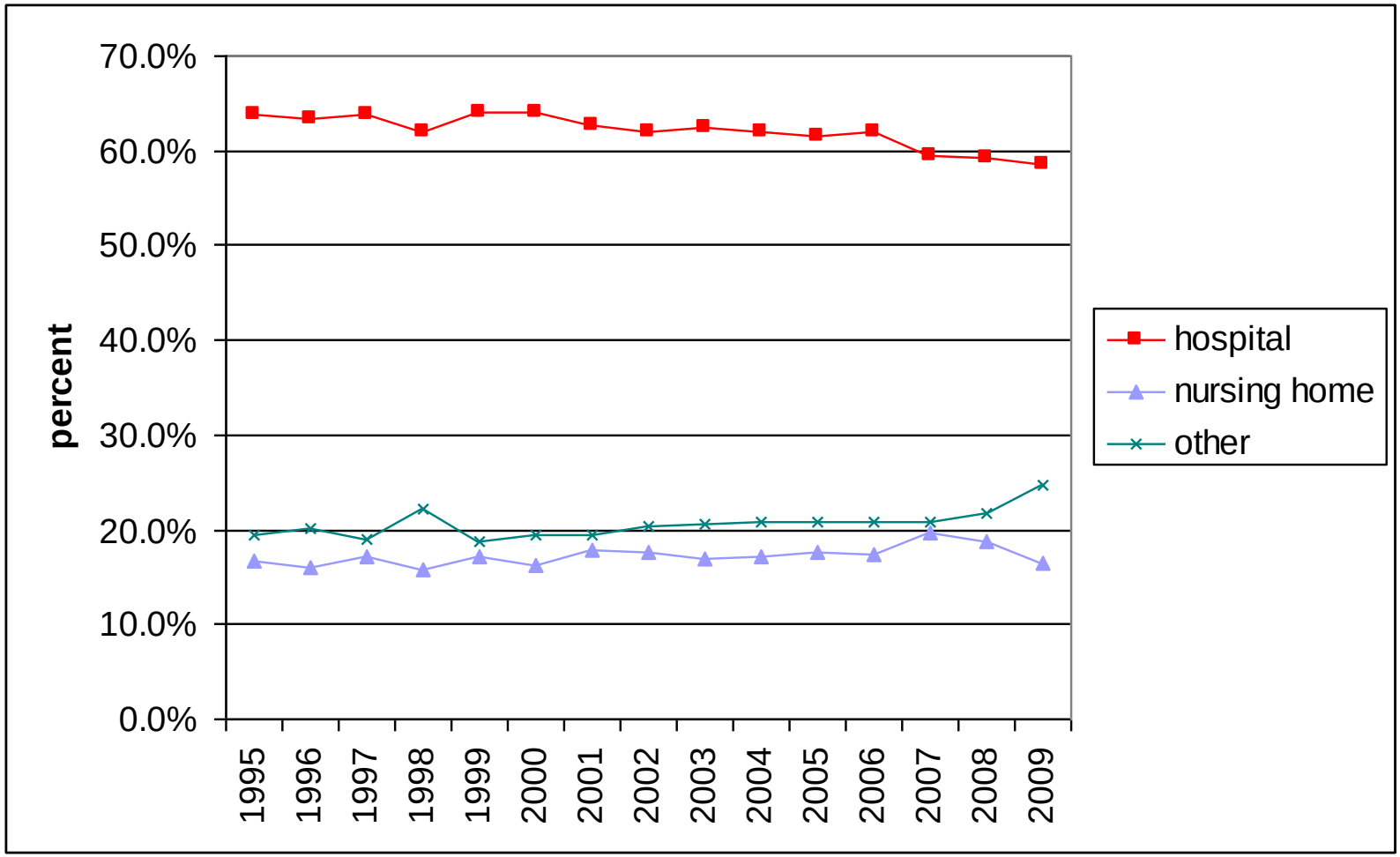
Place of Death vs Location of Care

- “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

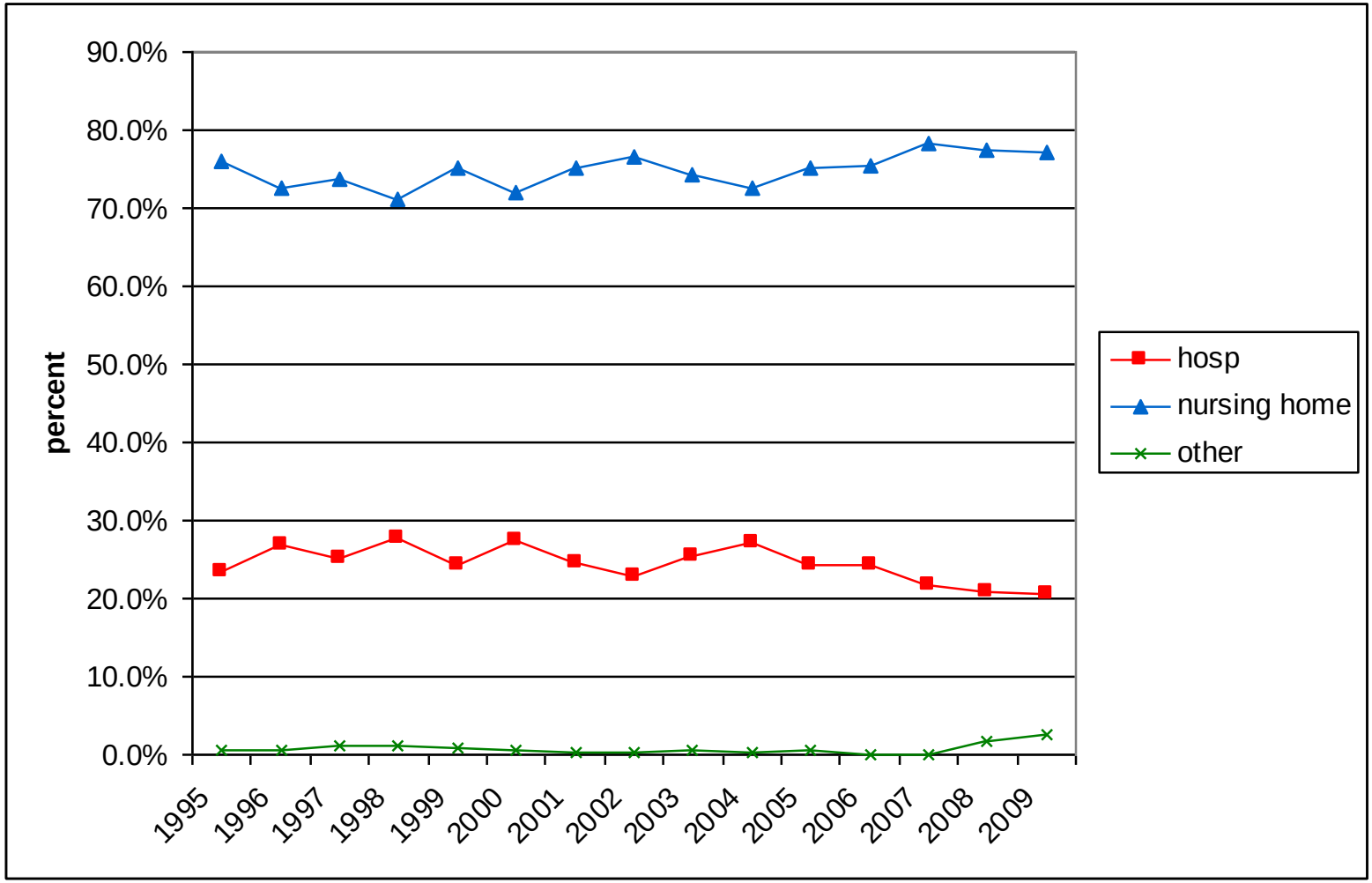
Place of Death



Place of Death by Year



Place of Death by Year- Nursing Home Residents



Cause of Death

- Can be up to 13 causes of death listed on the death certificate
- ICD-9 used 1995-1999; ICD-10 used 2000-2009
- Some causes were suppressed by VS for confidentiality reasons
  - “sudden death”
  - “other”

Diagnosis Codes Used For Analysis

Program	Disease	ICD-9	ICD-10
CANCER			
	Cancer	140-208	C00-C91
CARDIOVASCULAR			
	Congestive Heart Failure	428.0	I50.0
	Acute MI	410	I21-I22
	Chronic Ischemic Heart Disease	412-414, 429.2	I25
	Unstable Angina	411.1	I20.0
	Atrial Fibrillation	427.3	I480
	Other Ischemic Heart Disease	414.1-414.9	I124
DIABETES			
	Diabetes	250	E10-E14

Vital Statistics patients whose causes of death include program diseases

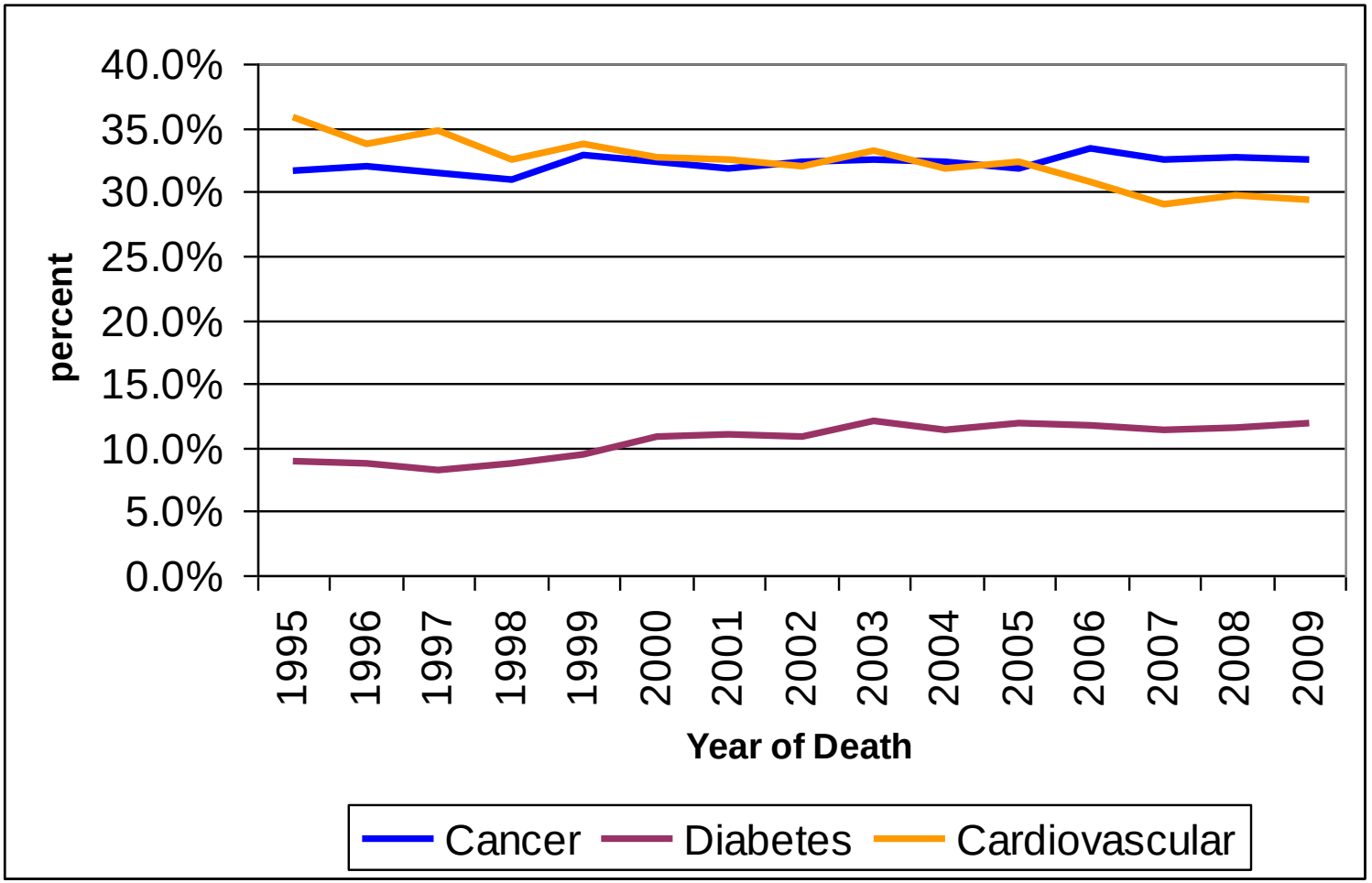
Program	Percent
Cancer	32.18
Cardiovascular	32.23
Diabetes	10.58

* Categories are not mutually exclusive.

Causes of Death by Year

Year	Cancer	CV	Diabetes
1995	31.54%	35.84%	8.92%
1996	31.95	33.74	8.65
1997	31.42	34.83	8.23
1998	30.96	32.54	8.73
1999	32.88	33.69	9.40
2000	32.25	32.67	10.77
2001	31.78	32.55	11.02
2002	32.38	31.93	10.85
2003	32.46	33.10	12.10
2004	32.38	31.87	11.43
2005	31.86	32.39	11.89
2006	33.28	30.66	11.75
2007	32.41	29.07	11.36
2008	32.65	29.69	11.48
2009	32.57	29.42	11.85

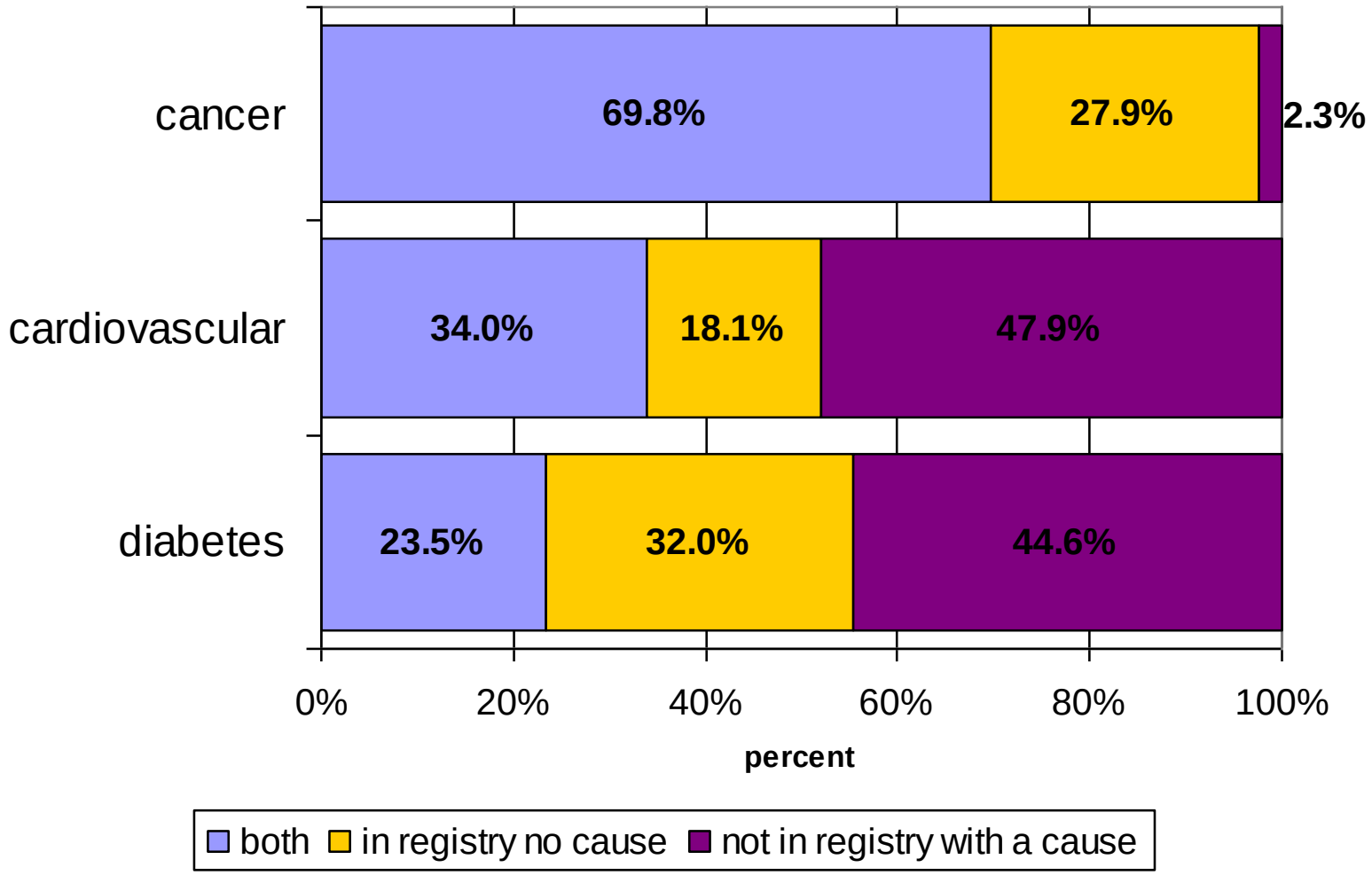
Causes of Death by Year



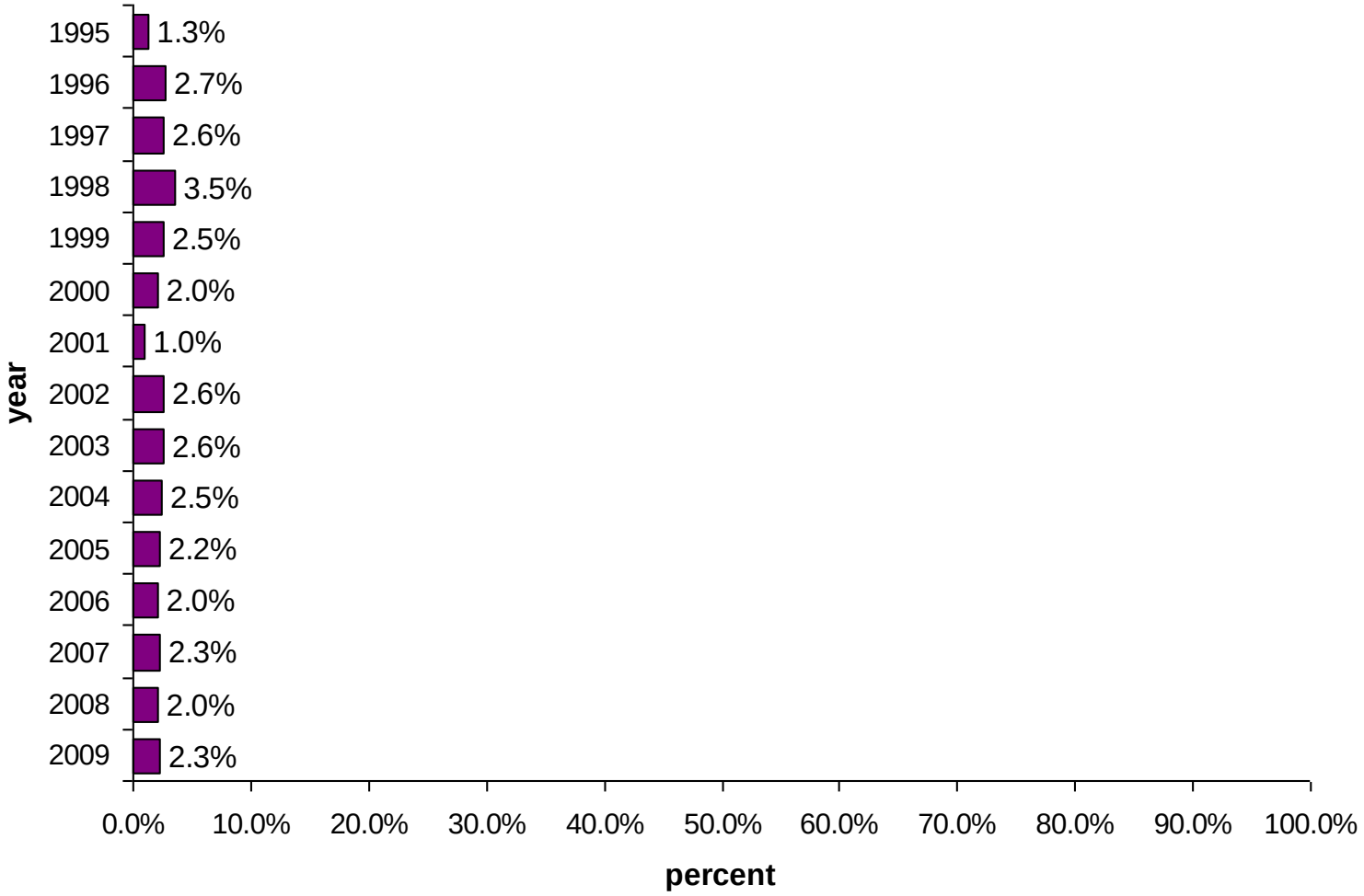
Patients with selected Causes of Death from Vital Statistics Found in the Registries

Program	Patient Found	Frequency
Cancer Deaths		
	Both	37,848
	Registry only	15,141
	Vitals only	1,243
	Total	*54,232*
Cardiovascular Deaths		
	Both	16,252
	Registry	8,656
	Vitals only	22,895
	Total	*47,803*
Diabetes Deaths		
	Both	4,436
	Registry only	6,035
	Vitals only	8,413
	Total	*18,884*

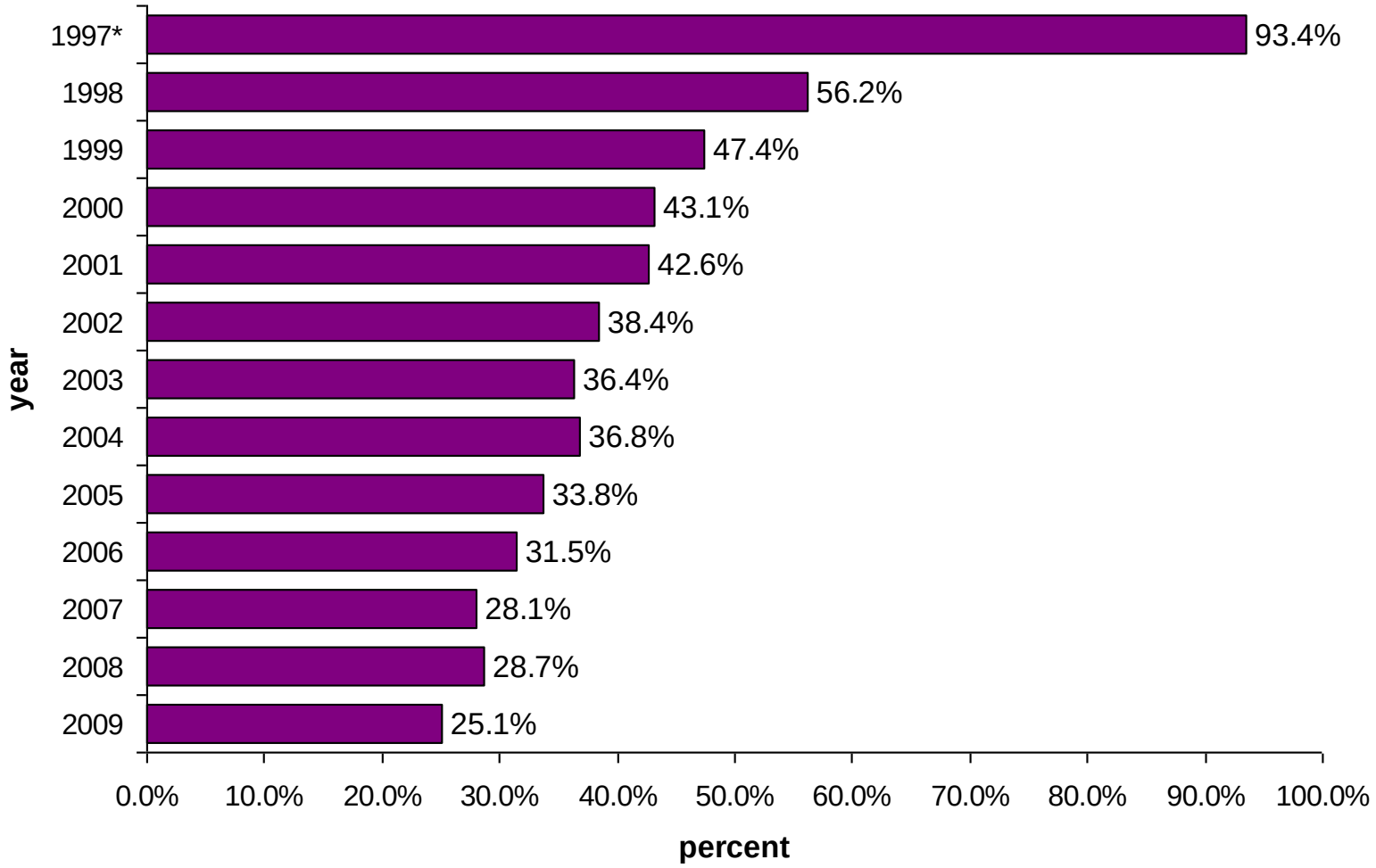
Patients with selected Causes of Death from Vital Statistics Found in the Registries



Percent Not in Registry for Those with an Indication of Cancer

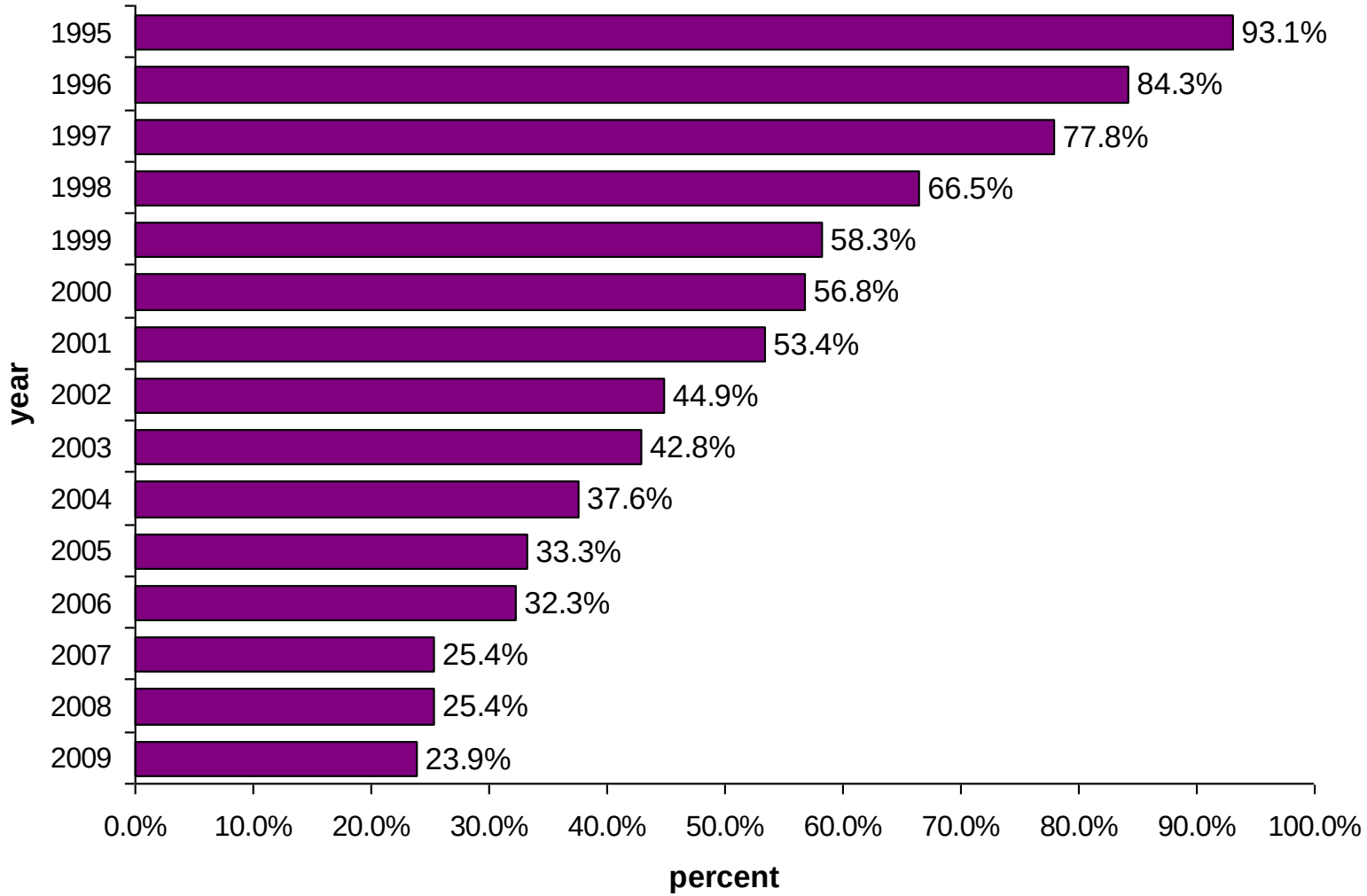


Percent Not in Registry for Those with an Indication of CV Disease



* The cardiovascular registry began November 1997 so a high percentage is expected that year.

Percent Not in Registry for Those with an Indication of Diabetes

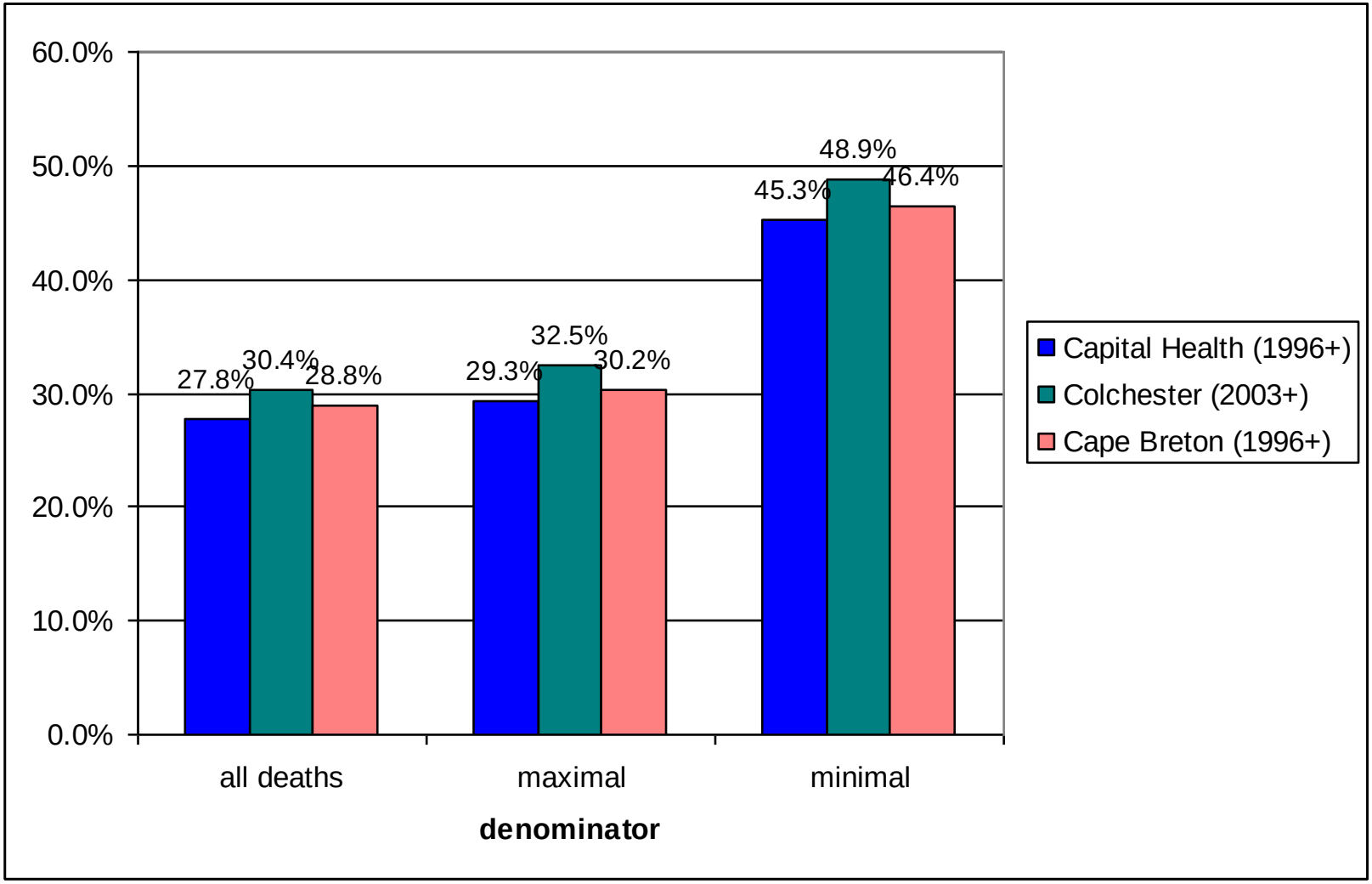


PCP Enrollment

- 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.

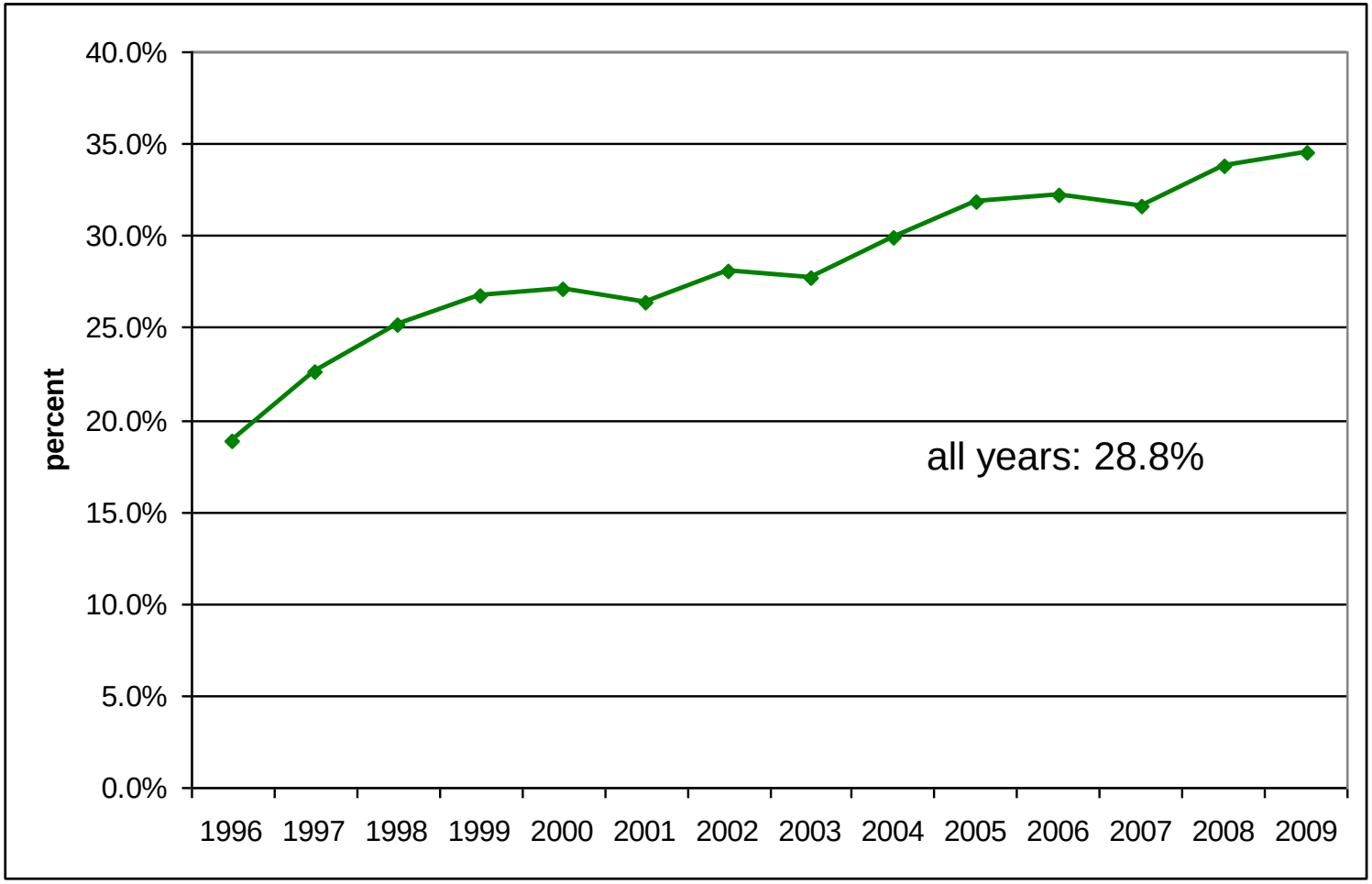
PCP Enrollment



Time from Palliative Care Enrollment to Death

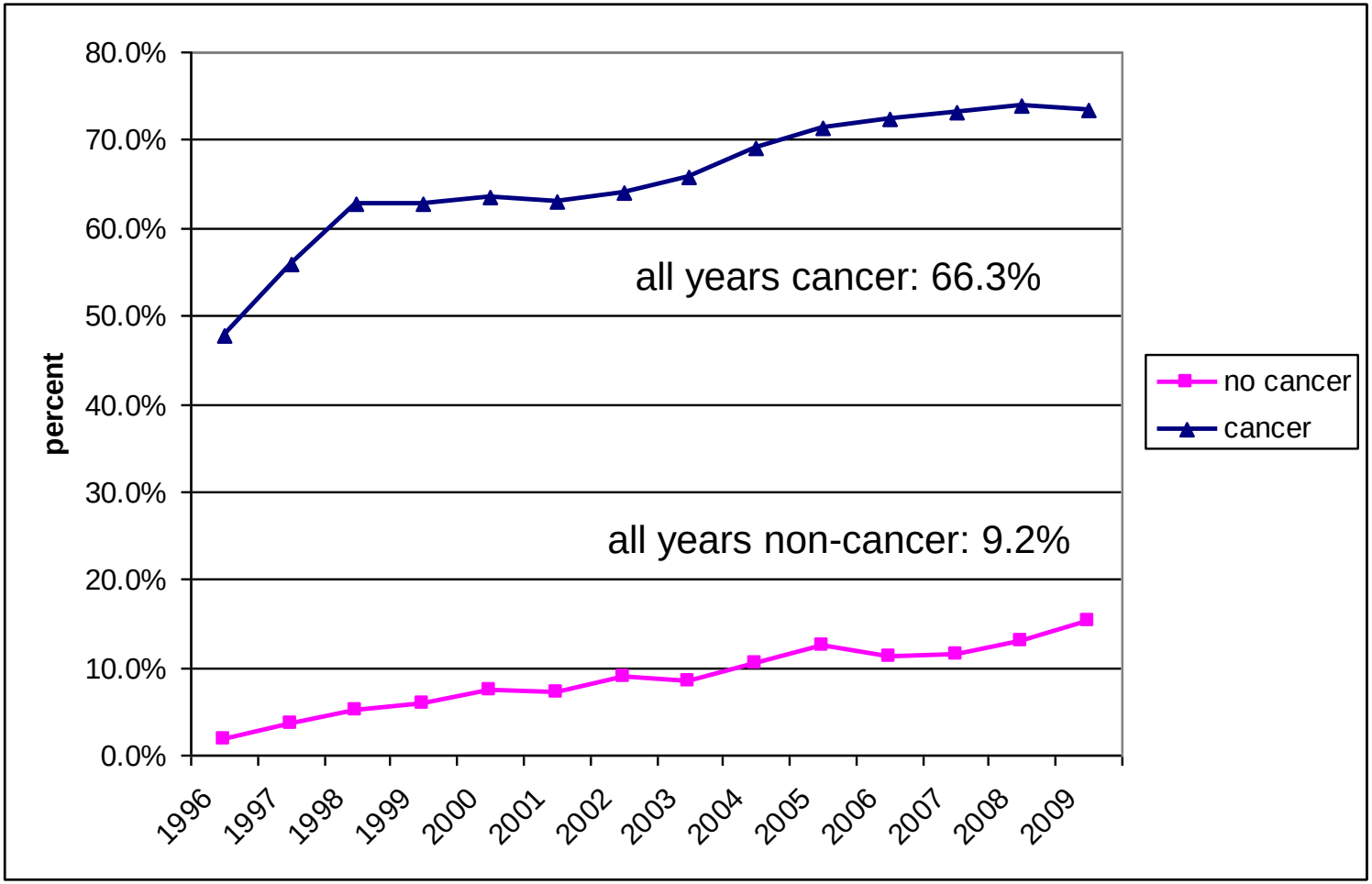
Days	Palliative Care Program				
	Capital Health (2005-2009)		Colchester East Hants (2002-2009)		Cape Breton (1996-2009)
	first referral	first visit	first referral	first visit	first referral
≤7 days	19.2%	20.7%	22.6%	23.5%	20.4%
≤14 days	28.7%	30.2%	31.2%	32.5%	28.8%

PCP Enrollment Over Time



Note: All deaths from CH and CB, 1996-2009 and from CEH, 2003-2009

PCP Enrollment Over Time – Cancer and Non-Cancer



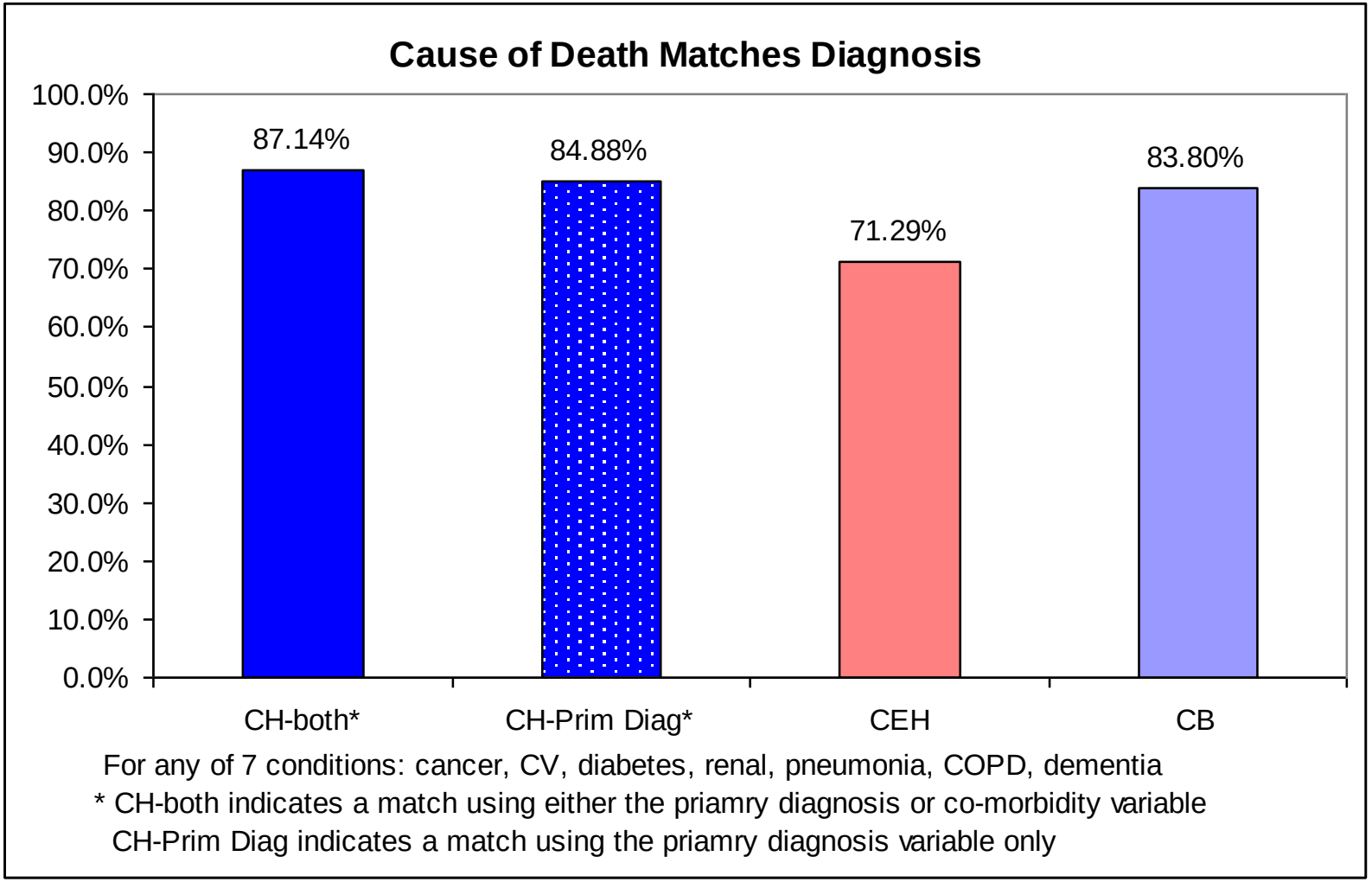
Note: All deaths from CH and CB, 1996-2009 and from CEH, 2003-2009

PCP Diagnoses Frequencies

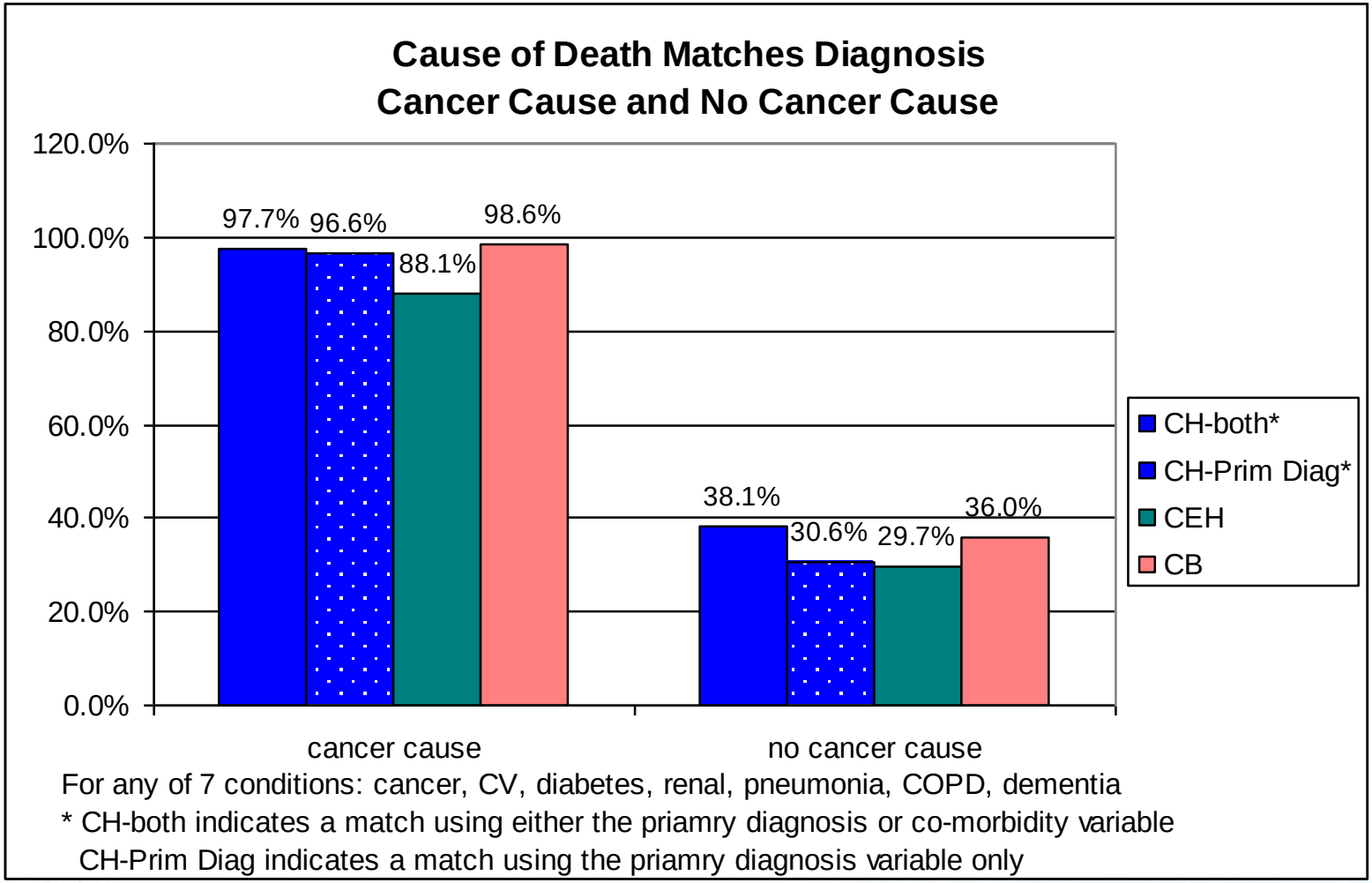
	CH		CEH	CB
Program	Primary Diagnosis or co-morbidity	Primary diagnosis	Diagnosis	Diagnosis
Cancer	85.9%	84.3%	63.9%	78.2%
Cardiovascular Disease	6.8%	2.5%	2.5%	3.5%
Diabetes	5.1%	2.5%	0.13%	0.23%
Pneumonia	0.90%	0.47%	1.2%	0.60%
COPD	5.3%	1.6%	4.1%	4.6%
Dementia/Alzheimer's	2.3%	0.82%	2.4%	2.1%
Renal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



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

Thank you for your attention!

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