# Nova Scotia Death Certificate Data Analysis for Chronic Diseases: NELS ICE Progress and Plans

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Work in Progress Session

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Capital Health

**DALHOUSIE UNIVERSITY**
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CIHR IRSC
Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

# **Outline**

- ❑ NELS ICE background
- ❑ Results from descriptive analysis and disease reports
- ❑ End of life trajectories
- ❑ Data linkages
- ❑ Quality indicators
- ❑ Future plans
- ❑ Questions and discussion

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# What is the Network for End of Life Studies?

- Research group based at Dalhousie University, Capital Health, Cancer Care Nova Scotia and the IWK Health Centre

- CIHR interdisciplinary capacity enhancement (ICE) grant: "Reducing Health Disparities and Promoting Equity for Vulnerable Populations" (2006-2011)

# NELS ICE Goal

❑ Improve end of life care for persons with terminal illness by:

■ Investigating factors associated with vulnerability at end of life

■ Identifying inequities in end of life care

■ Building research capacity

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# Methods

- All NS residents who died from January 1, 1998 to December 31, 2005

- Decedents identified from NS VS death certificate database maintained by PHRU

- Dataset contains 63,431 records and includes all age groups

# Death Certificate Variables

- Age
- Sex
- Date of death
- Hospital
- County of death
- Postal code of death
- Postal code of usual residence
- HCN indicator

- Causes of death
  - All causes (up to 13)
  - Underlying cause
    - (a) the disease or injury which initiated the train of morbid events leading directly to death, or
    - (b) the circumstances of the accident or violence which produced the fatal injury.
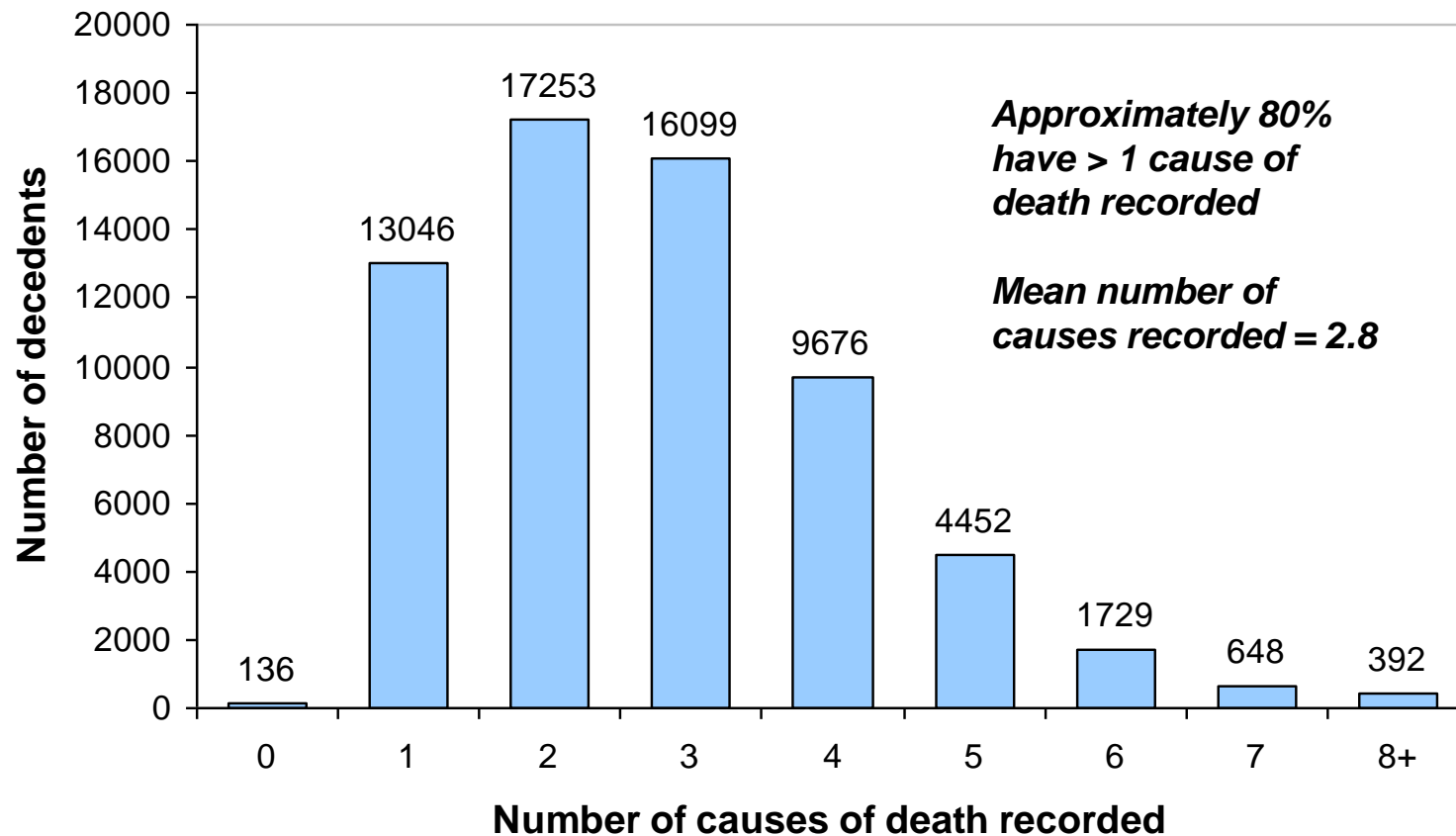  - (Statistics Canada)

# Descriptive Profile of Nova Scotia Decedents

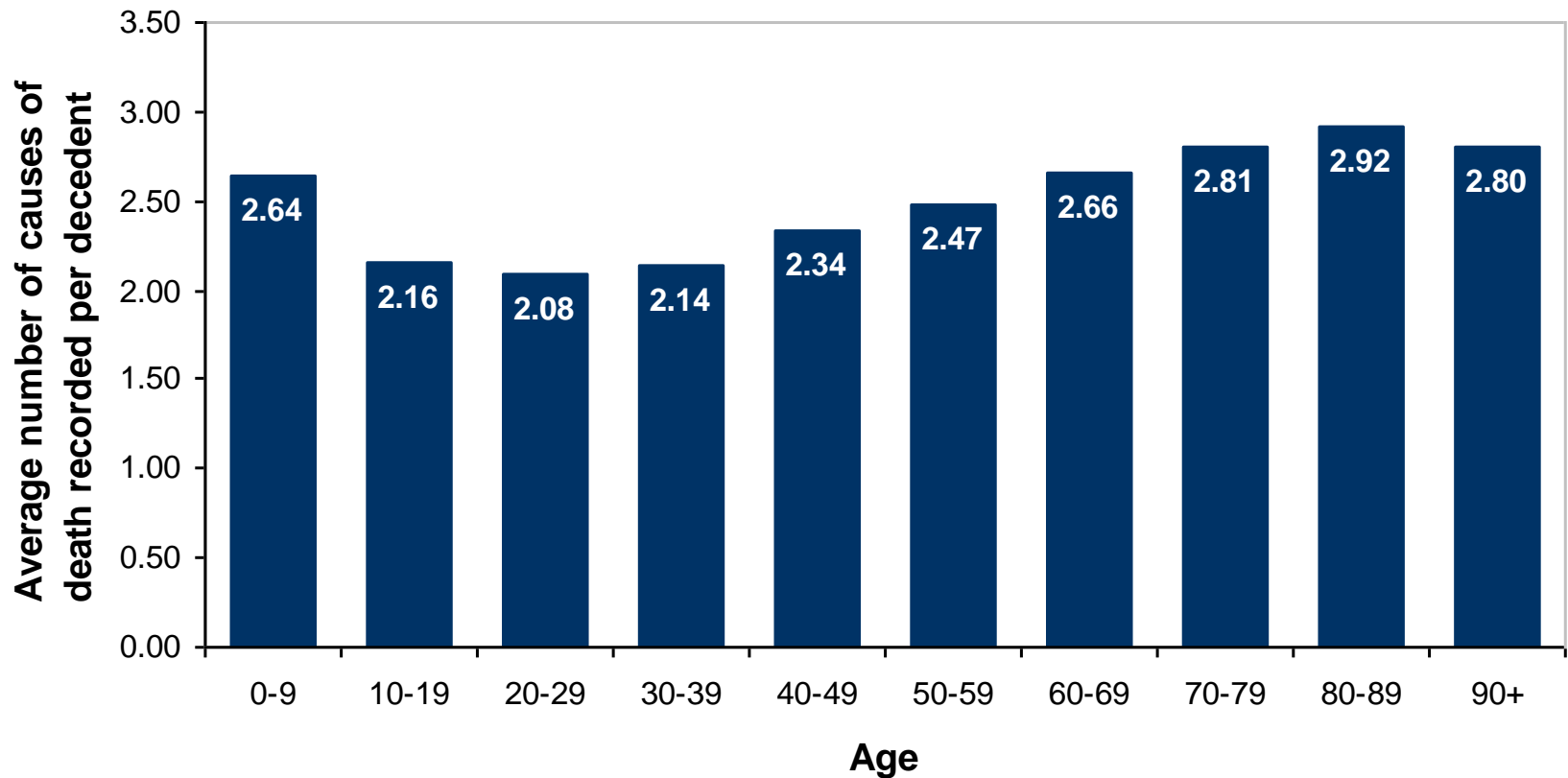| Age group | Male | | Female | | Total | |
|---|---|---|---|---|---|---|
| | N | % | N | % | N | % |
| 0-19 | 445 | 0.7 | 279 | 0.4 | 724 | 1.1 |
| 20-44 | 1,609 | 2.5 | 858 | 1.4 | 2,467 | 3.9 |
| 45-64 | 6,035 | 9.5 | 3,724 | 5.9 | 9,759 | 15.4 |
| 65-74 | 7,039 | 11.1 | 4,775 | 7.5 | 11,814 | 18.6 |
| 75-84 | 10,035 | 15.8 | 9,652 | 15.2 | 19,687 | 31.0 |
| 85+ | 6,638 | 10.5 | 12,342 | 19.5 | 18,980 | 29.9 |
| Total | 31,801 | 50.1 | 31,630 | 49.9 | 63,431 | 100 |

# Cause of Death Classification

- Source document: Medical Certificate of Death
  - Part I – conditions that lead directly to death
  - Part II – unrelated but contributory conditions
  - Completed by last attending physician or medical examiner
- Provinces register deaths but information is processed by Statistics Canada
- Causes of death coded using WHO's International Classification of Diseases (ICD)
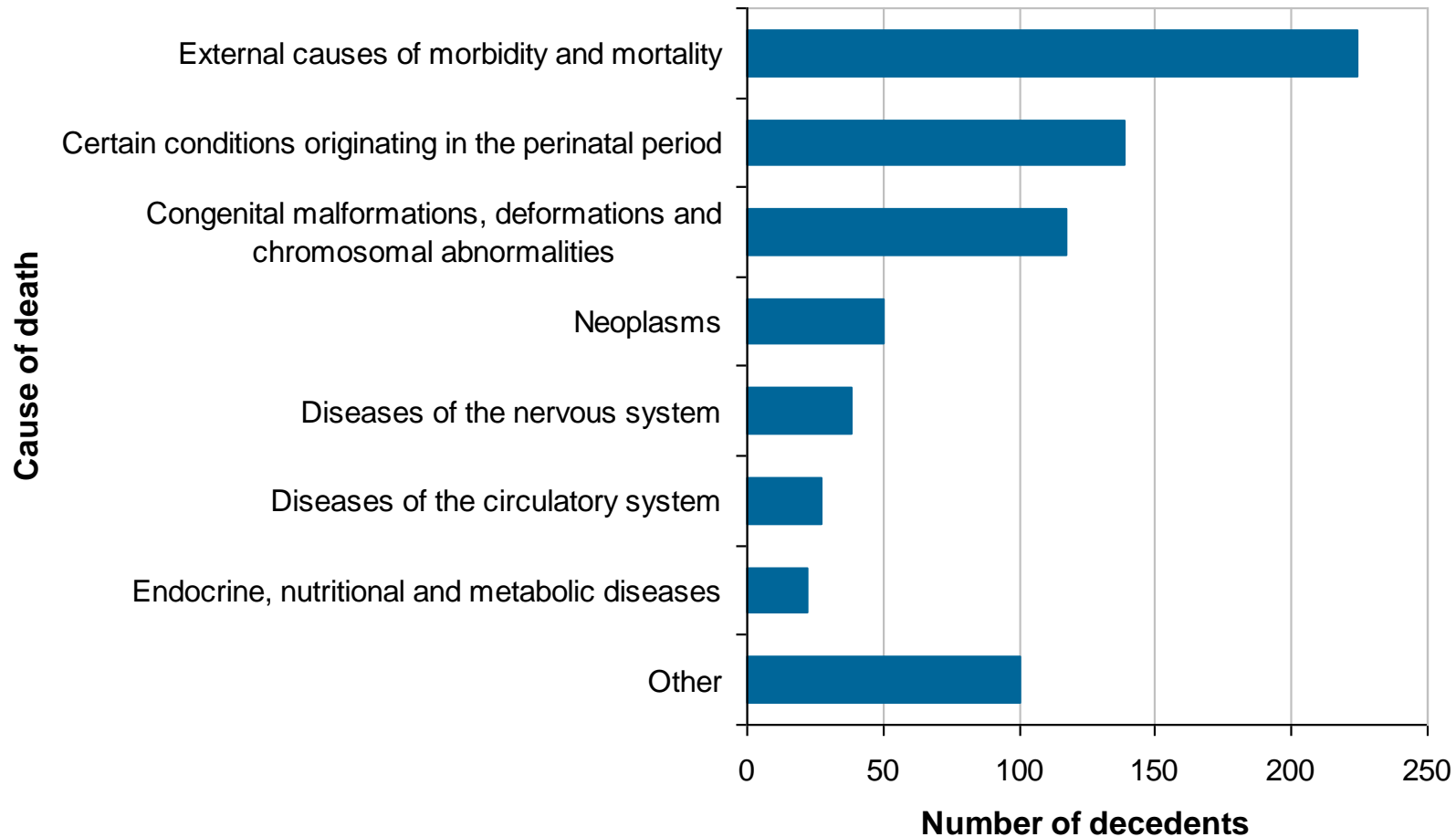- Underlying cause selected using set of rules developed by WHO

# Distribution of deaths by number of causes recorded



Approximately 80% have > 1 cause of death recorded

Mean number of causes recorded = 2.8

# Average number of causes per decedent, by age, 1998-2005

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# Major underlying causes of death, age < 20, 1998-2005

# Major underlying causes of death, age ≥ 20, 1998-2005
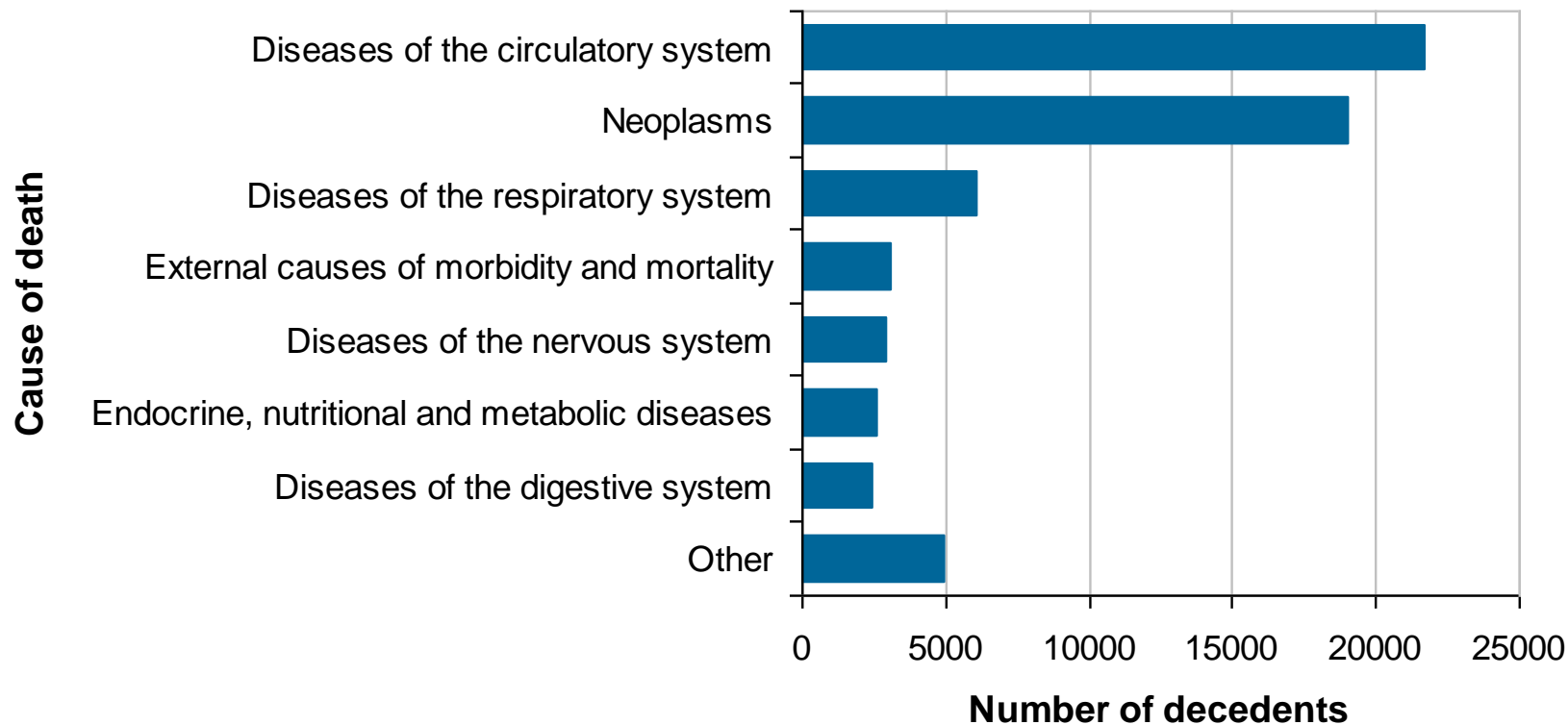
# Underlying cause only versus multiple cause of death data

- Mortality statistics usually based on underlying cause of death

- Analysis of underlying cause only ignores other conditions that contributed to death (comorbidities)

- Disease burden may be underestimated (Redelings et al. 2006)

# Ratio of mentioned to underlying for selected causes, age ≥ 20

| Cause of death | Selected as underlying cause | Total mentions | Ratio of mentioned to underlying |
|---|---|---|---|
| Cancer | 18,617 | 20,875 | 1.1 |
| Motor neuron disease (includes ALS) | 185 | 214 | 1.2 |
| Chronic liver disease and cirrhosis | 483 | 697 | 1.4 |
| Multiple sclerosis | 96 | 162 | 1.7 |
| Cerebrovascular disease (stroke) | 4,295 | 7,674 | 1.8 |
| Chronic ischemic heart disease | 5,884 | 11,948 | 2.0 |

# Ratio of mentioned to underlying for selected causes, age ≥ 20

| Cause of death | Selected as underlying cause | Total mentions | Ratio of mentioned to underlying |
|---|---|---|---|
| Parkinson's disease | 426 | 900 | 2.1 |
| Alzheimer's disease and dementia | 2,797 | 6,322 | 2.3 |
| Chronic obstructive pulmonary disease | 3,036 | 7,351 | 2.4 |
| Diabetes mellitus | 1,929 | 6,914 | 3.6 |
| Congestive heart failure | 1,432 | 7,135 | 5.0 |
| Renal failure | 1,018 | 5,586 | 5.5 |

# What factors affect probability of multiple causes of death?

- Wall et al. (2005) examined factors associated with reporting multiple causes of death
- Groups with higher percentages of multiple causes:
  - > 25 years with below high school education
  - Native Americans
  - Dying in a hospital or nursing home
- Familiarity of death certifier with patient and their disease history
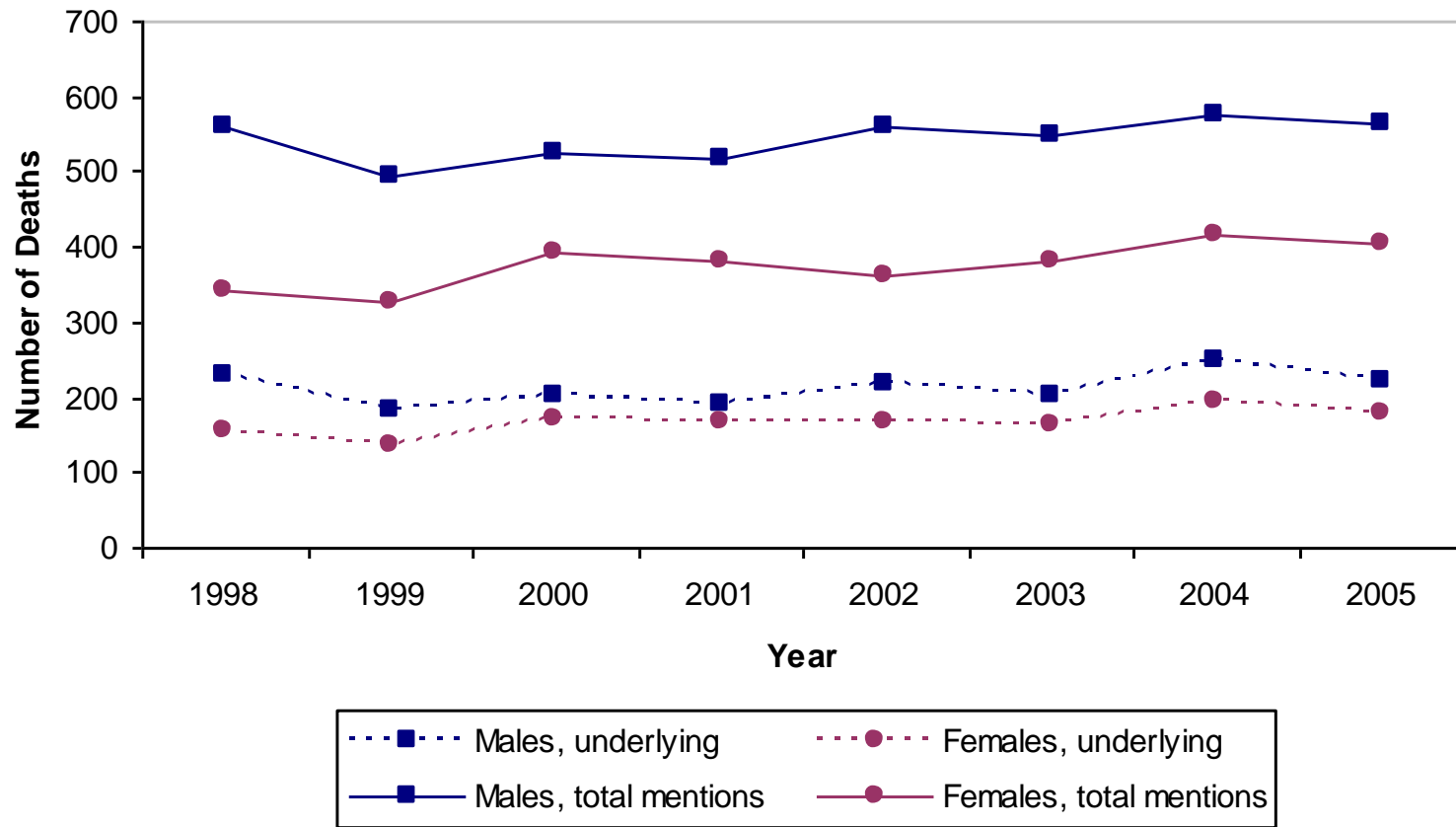
# Disease Reports

- Disease-focused death certificate data analysis
- Reports to date
  - COPD
  - Parkinson's disease
  - Cancer (in-progress)
- Future reports
  - Renal disease
  - CHF
  - Diabetes
  - Children and youth
  - Other chronic diseases

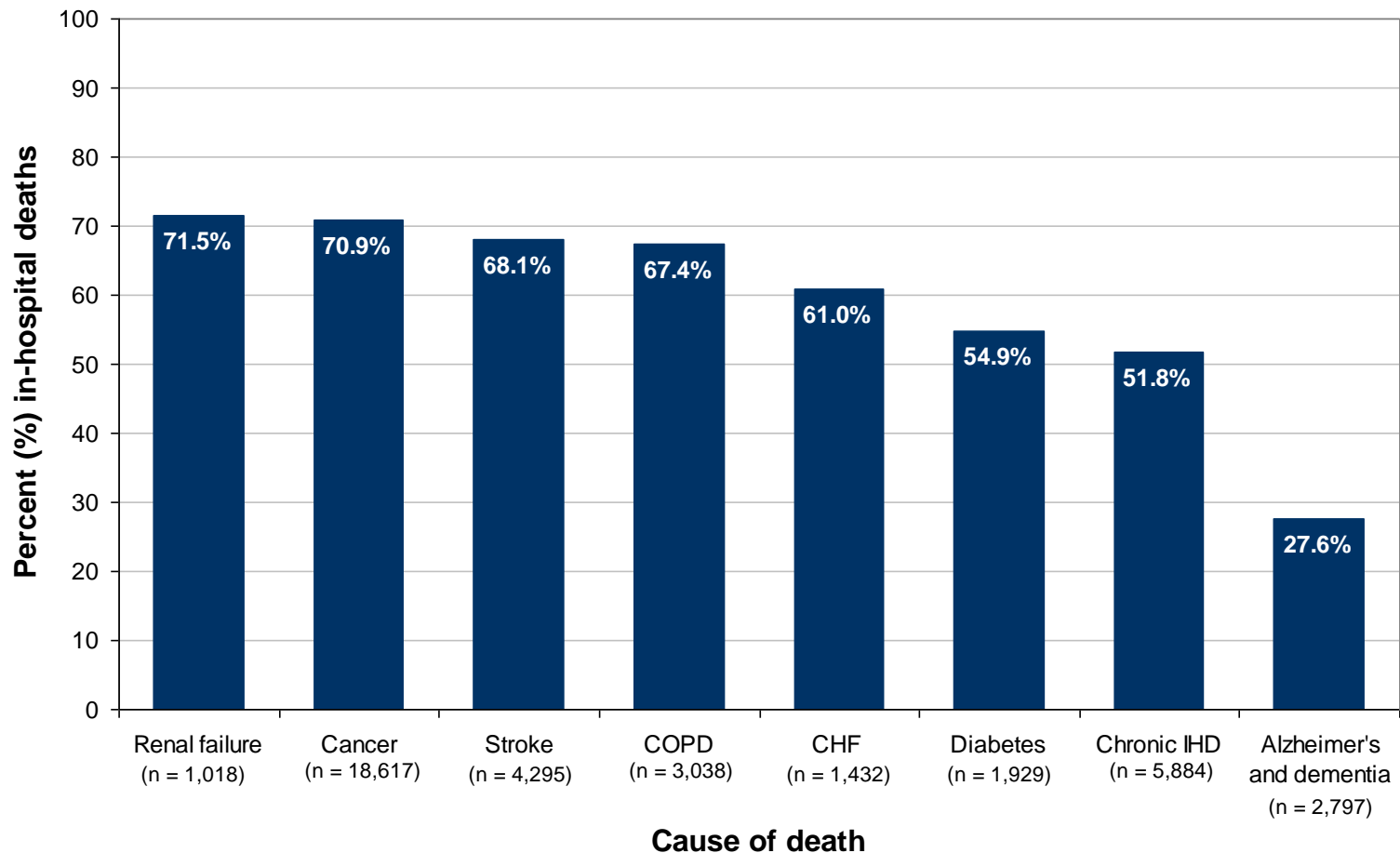# COPD as underlying cause or other cause, by age, 1998-2005
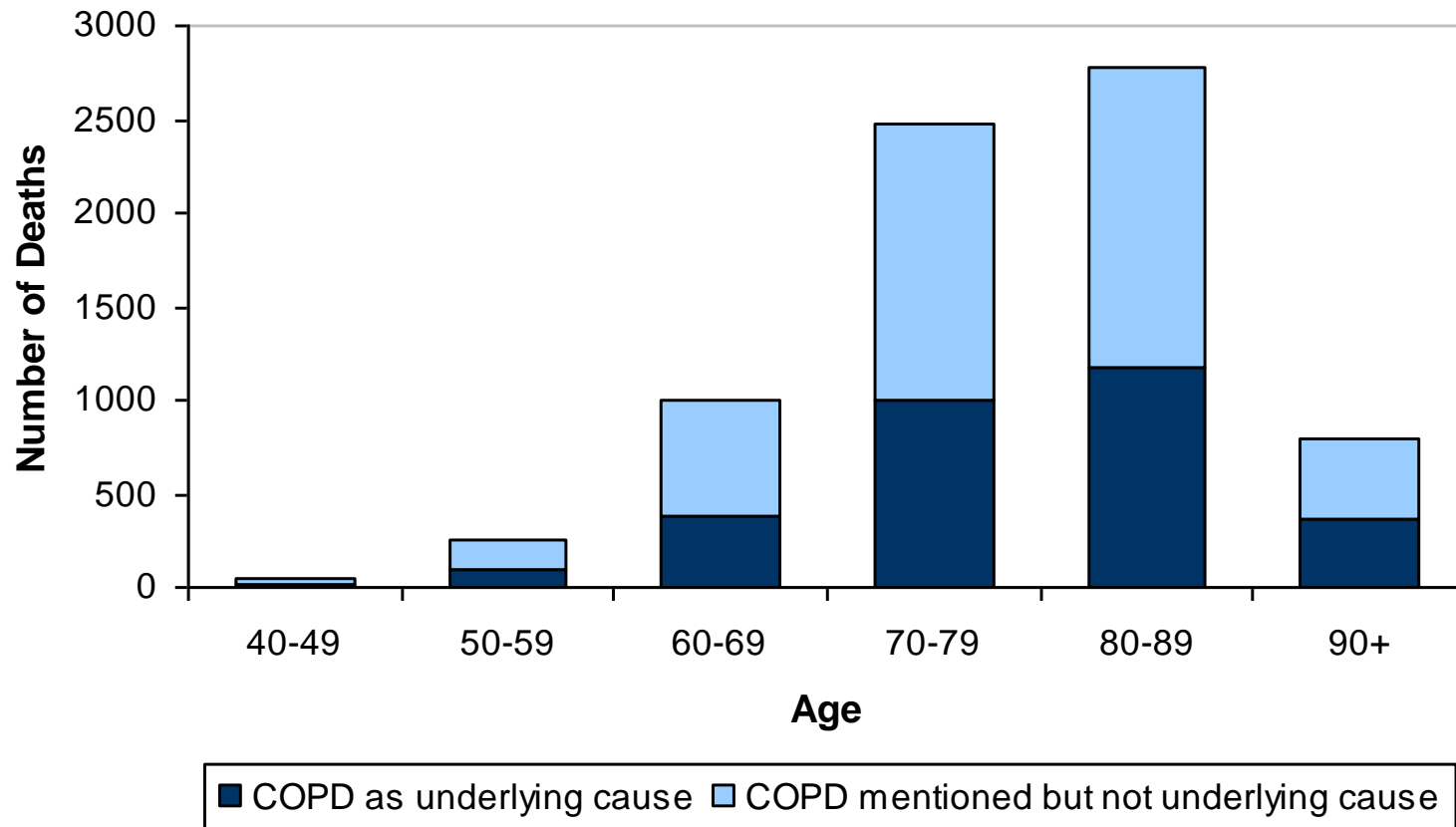
# COPD mentioned or underlying cause, by year and sex, age 40+

# Top ten underlying causes, any mention of Parkinson's disease

| Disease | Number of deaths | |
|---|---|---|
| | N | % |
| Parkinson's disease | 426 | 47.3 |
| Cancer | 63 | 7.0 |
| Stroke | 57 | 6.3 |
| Alzheimer's disease and dementia | 49 | 5.4 |
| Chronic IHD | 48 | 5.3 |
| Pneumonia | 34 | 3.8 |
| Acute MI | 27 | 3.0 |
| COPD | 21 | 2.3 |
| External causes | 17 | 1.9 |
| Pneumonitis due to solids and liquids | 13 | 1.4 |

# In-hospital deaths for selected causes, age ≥ 20, 1998-2005

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# Missing Data

- Linkage of PHRU VS data to other datasets not advised given following missing data:
  - 9% health card number
  - 6% postal code of death
  - 14% postal code of usual residence
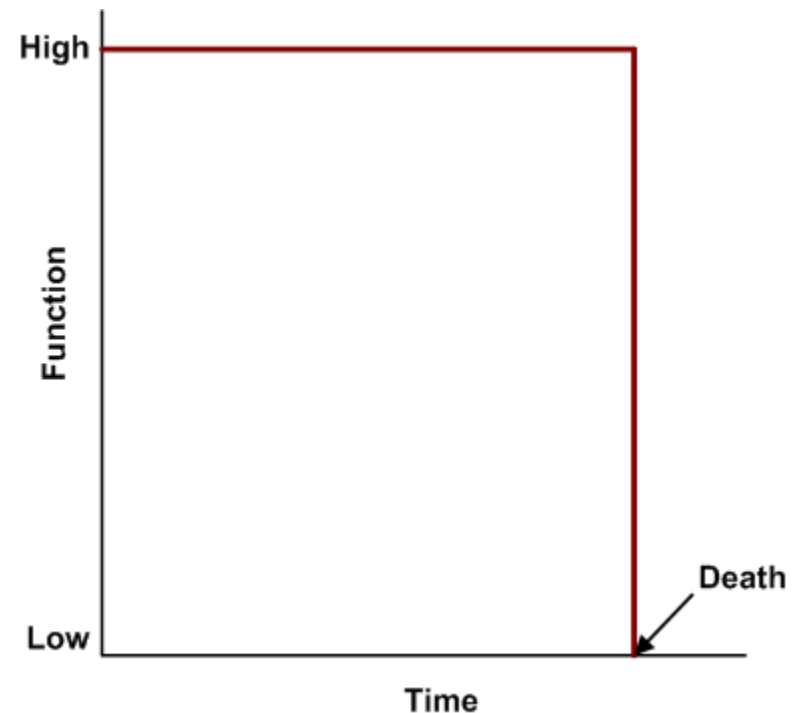- Cannot generate nursing home indicator without complete street addresses

# End of Life Trajectories
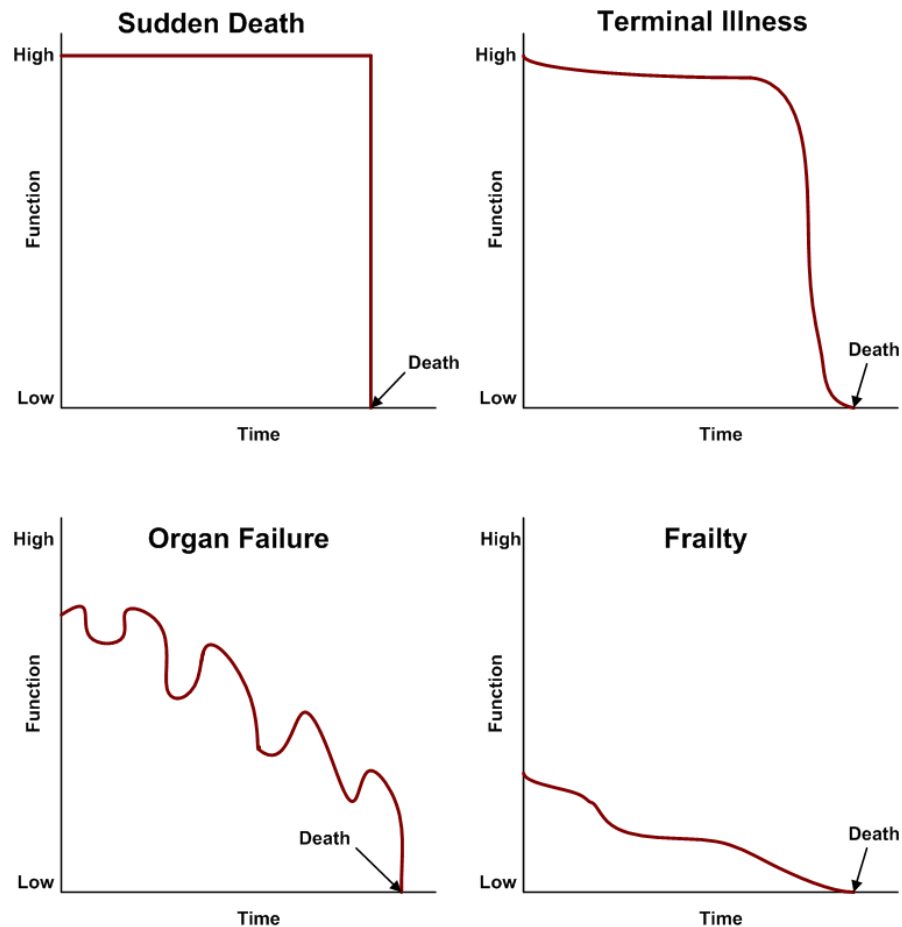


Lunney JR, Lynn J, Foley DJ, Lipson S, Guralnik JM. Patterns of functional decline at end of life. *JAMA.* 2003; 289:2387-2392.
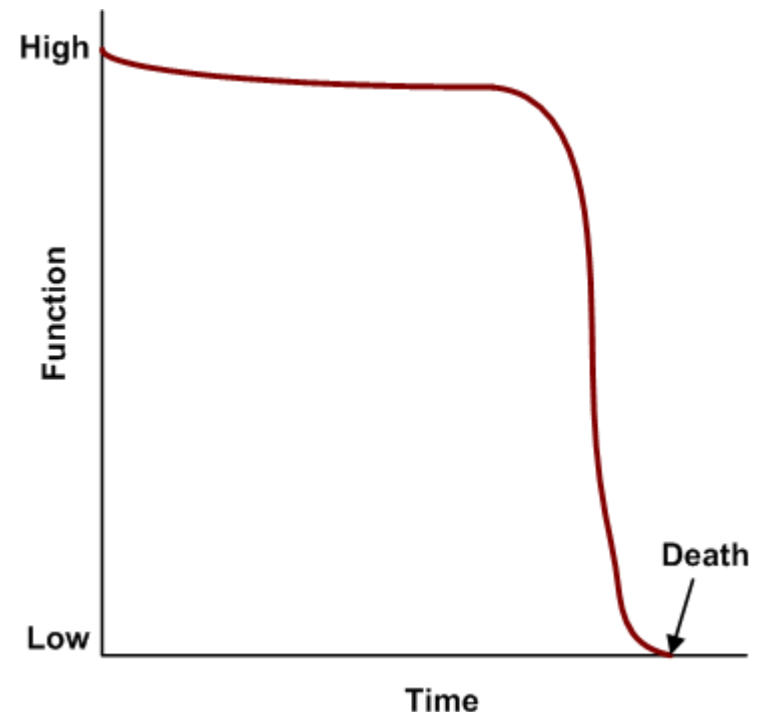
# Sudden Death

- Accidental death
- Falls
- Trauma



Lunney, J. R. et al. JAMA 2003;289:2387-2392

# **Terminal Illness**

- Cancer
- Motor neuron disease
- HIV-related diseases
- Chronic renal failure

- Short period of evident decline
- Time: Often a few years, but decline seems <2 months



**Lunney, J. R. et al. JAMA 2003;289:2387-2392**

# **Organ Failure**

- ☐ Congestive heart failure
- ☐ Chronic obstructive pulmonary disease

- ☐ Long term limitations with intermittent serious episodes
- ☐ Time: 2-5 years, but death seems "sudden"



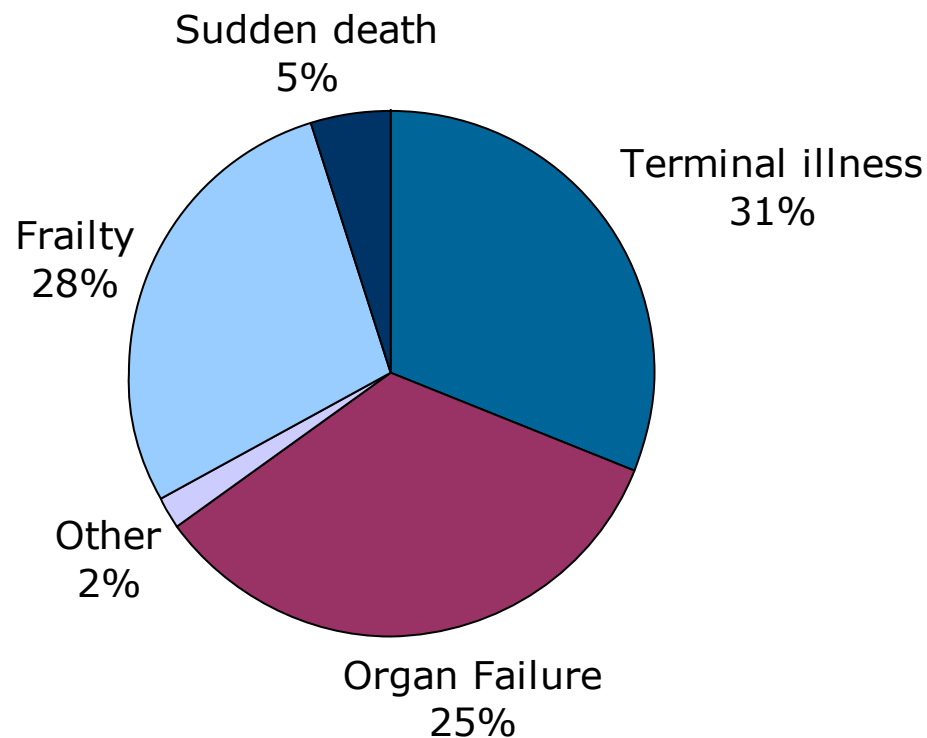**Lunney, J. R. et al. JAMA 2003;289:2387-2392**
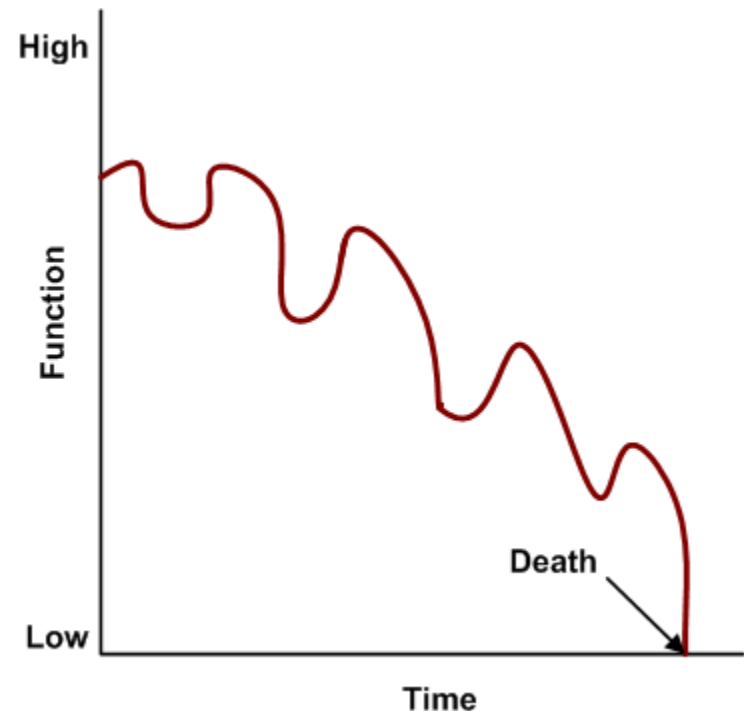
# **Frailty**

- ◻ Alzheimer's disease and dementia
- ◻ Neurological decline
- ◻ Stroke

- ◻ Prolonged dwindling
- ◻ Time: Variable – up to 6-8 years



**Lunney, J. R. et al. JAMA 2003;289:2387-2392**

# Deaths by trajectory of dying, 2000-2005



Decedents were assigned to trajectories using methods defined by:
K. Fassbender et al., *Costs and Utilization of Health Care Services at End-of-Life*
(Edmonton, Alta.: Institute for Public Economics Health Research Group, March 2006).

# Deaths by trajectory of dying and sex, 2000-2005
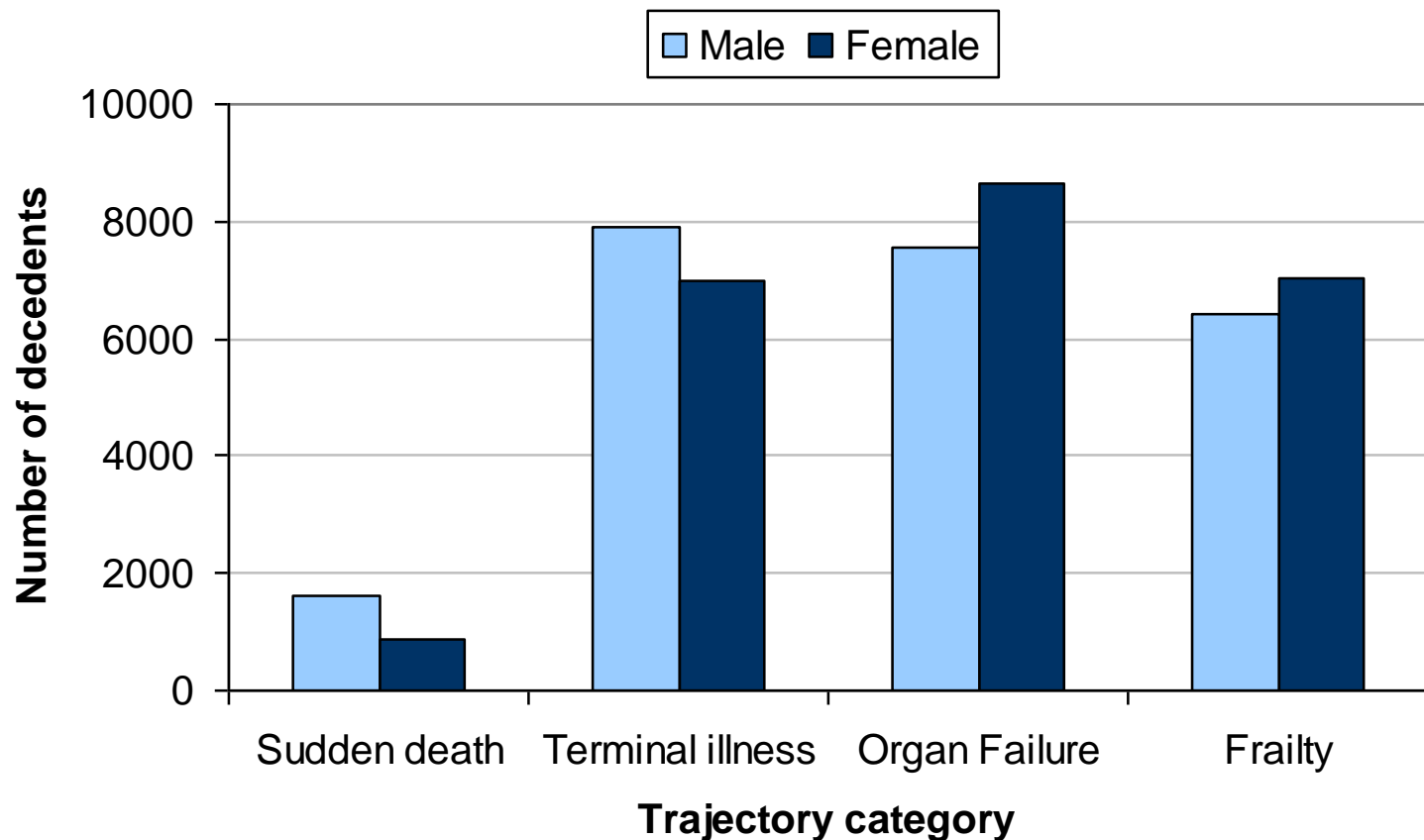
# Deaths by trajectory of dying and age, 2000-2005

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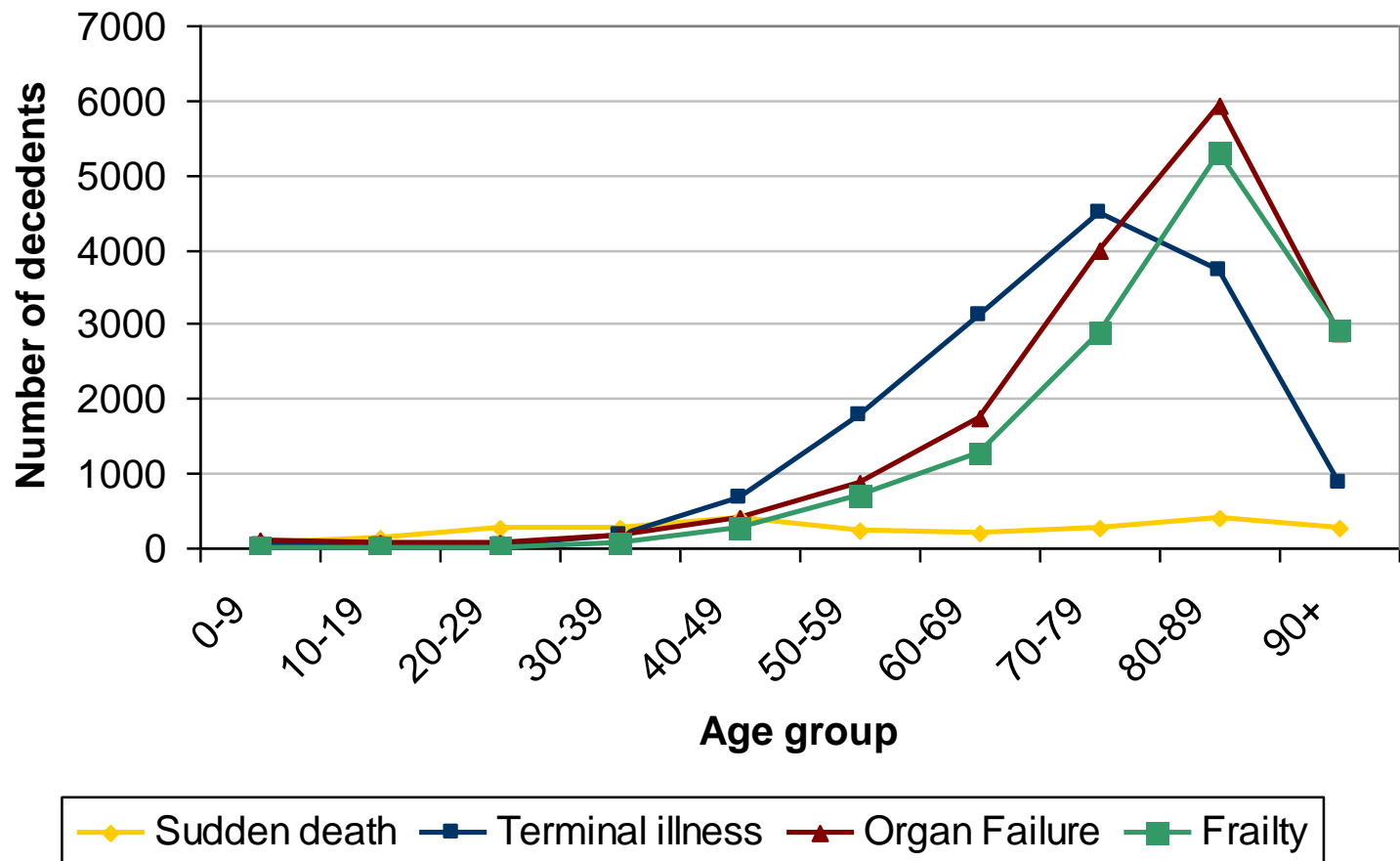
# Deaths by trajectory of dying and age, 2000-2005 (semi-log graph)

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# Dataset Development



DECEDENTS DATASET SERVICES

**Cancer Registry** (includes death information from Vital Statistics)

**Death certificate information** from Vital Statistics for all chronic conditions

**Disease registries for other chronic conditions**

**Dataset for Cancer and Other Chronic Conditions with an End of Life Care Phase**

**Halifax and Cape Breton Palliative Care Program Data**

**Hospital discharge data from Canadian Discharge Abstract Database**

**Palliative radiotherapy and medical oncology**

**Family and specialist physician billings data**

**Continuing care (home care & nursing home)**

**Cancer Patient Navigation Data**

**Palliative Care Program data for children/youth and from seven more rural districts**

**Emergency department visits, ICU/CCU and alternative care**

**Medication data**

Currently included in cancer data set

Proposed for chronic disease data set

# EOL Quality Indicators

□ Applied end of life quality indicators[1]

□ Compared results for nursing home residents and others ≥ 65 years dying of cancer, 2000-2003

□ Some were cancer-specific but many can be useful for any chronic disease

[1] Grunfeld E, Lethbridge L, Dewar R, Lawson B, Paszat LF, Johnston G, Burge F, McIntyre P, Earle CC. (2006). Towards using administrative databases to measure population-based indicators of quality end-of-life care: testing the methodology. *Palliative Medicine, 20*, 769-777.

# Quality Indicators: Examples

| Quality Indicators | Nursing Home (n = 893) | Non Nursing Home (n = 6237) |
|---|---|---|
| **HOSPITAL DAYS IN LAST MONTH OF LIFE (n = 7130)** | | |
| > 1 admission | 5% | 14% |
| > 14 days | 3% | 36% |
| Mean days | 5 | 12 |
| ≥ 1 ICU admission | 3% | 5% |
| > 1 ER visit | 3% | 6% |
| Died in hospital | 20% | 59% |
| **ACCESS TO PALLIATIVE CARE (CH/CB only, n = 3319)** | | |
| Enrolled in CH/CB PCP | 37% | 69% |

# Future Plans

- Carrying out basic logistic analysis of predictors of in/out of hospital death

- Networking with managers and clinicians responsible for various chronic diseases

- Encouraging graduate students, clinicians and medical residents to make use of data for publications or grant proposals

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