

## Death Certificate Data Analysis

With support from a Canadian Institutes of Health Research (CIHR) Interdisciplinary Capacity Enhancement (ICE) grant, the Network for End of Life Studies (NELS) continues to investigate vulnerable populations at end of life.

Death certificate data from Nova Scotia Vital Statistics (NSVS) has and will continue to be analysed to describe persons dying of chronic disease in Nova Scotia by causes of death and to estimate the size of the population that could benefit from palliative and end of life care.

Subsequent work will hopefully involve the linkage of NSVS data to administrative data from disease registries, palliative care program (PCP) databases, the Canadian Institute for Health Information (CIHI)

hospital discharge abstract database, SEAScape (single entry access - continuing care), medication databases and physician billings.

### Current Study Subjects

The data that NELS is analysing includes all NS residents who died from January 1, 1998 to December 31, 2005,

Decedents were identified from the NSVS death certificate database maintained by the Population Health Research Unit (PHRU) at Dalhousie University. NELS ICE also works directly with NSVS.

The data set contains 63,431 records and includes all ages, which is approximately 8,000 deaths per year.

## Chronic Disease Reports

Alison Zwaagstra prepared a series of reports describing persons dying from specific chronic diseases in Nova Scotia.

These reports differ from most mortality reports in that all causes of death are considered rather than only the underlying cause of death.

Analyses only considering the underlying cause of death data ignore other conditions that contributed to death and also underestimate the disease burden of conditions that do not often appear as the underlying cause such as Alzheimer's disease, diabetes, chronic obstructive pulmonary disease (COPD) and congestive heart failure (CHF).

Reports have been prepared on cancer, COPD, multiple sclerosis, Parkinson's disease, renal disease and diabetes. A report on Alzheimer's disease and dementia is planned

These reports have been shared with the provincial chronic disease programs such as Cancer Care Nova Scotia, Nova Scotia Renal Program and Diabetes Care Program of Nova Scotia.

The chronic disease reports can be found on the NELS ICE website, [nels.dal.ca](http://nels.dal.ca).

## Thanks to Alison Zwaagstra



Alison Zwaagstra, NELS ICE Information Analyst.

Alison Zwaagstra has worked with NELS ICE since January 2008 as an Information Analyst. She has been responsible for the important work and subsequent reports that have been completed to date.

In July 2009, Alison accepted a position as a Research and Statistical Officer at Quality with Addiction Prevention and Treatment Services, Capital District Health Authority.

"I will miss my colleagues at NELS ICE," said Alison. "But am excited for a new challenge and experience."

"It has been a pleasure working with NELS ICE over the last 1.5 years. I have experienced tremendous professional growth and will always cherish the it opportunities provided for me."

*NELS thanks Alison for her work and wishes her all the best.*

This issue of NELS News features NELS ICE work done by Alison Zwaagstra, Information Analyst.

To receive future issues of NELS News and notifications of upcoming events, please e-mail [nels@dal.ca](mailto:nels@dal.ca).

NELS News and Events are also posted on our website at [nels.dal.ca](http://nels.dal.ca).

## Underlying and Other Mentioned Causes of Death on Death Certificates

There can be up to 13 causes of death listed on the death certificate, however, only one can be designated as the underlying cause. When more than one cause of death is recorded the underlying cause is identified using a set of rules developed by the World Health Organization.

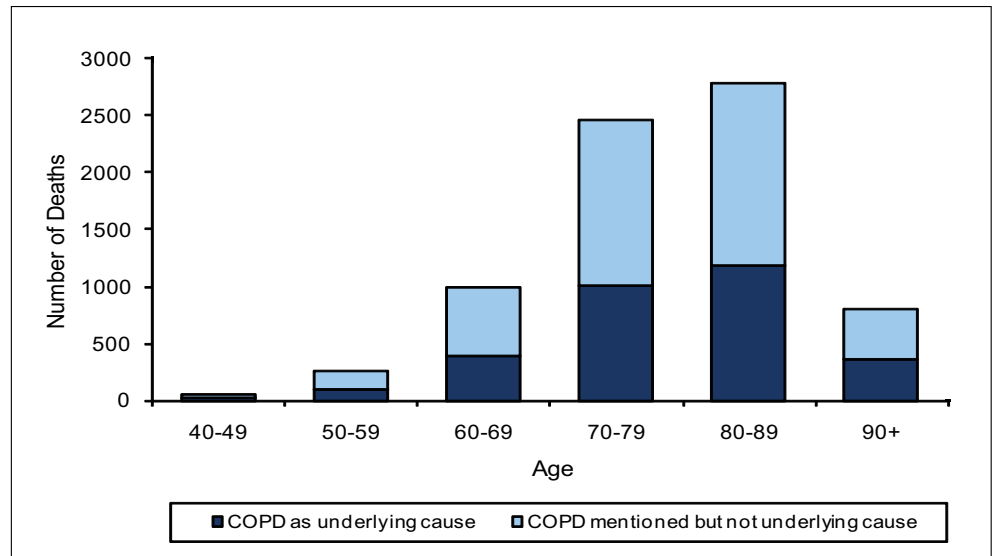
The underlying cause of death is defined by Statistics Canada as “(a) the disease or injury which initiated the train of morbid events leading directly to death, or (b) the circumstances of the accident or violence which produced the fatal injury.” When just the underlying causes are considered it is easy to underestimate the burden of each chronic disease.

Using COPD as an example, a total of 3,038 persons died from 1998 to 2005 in Nova Scotia with COPD as their underlying cause of death from 1998 to 2005 in Nova Scotia. This is 4.8% of all Nova Scotia deaths. A further 4,321 persons had COPD as a cause which was not selected as the underlying cause, for a total of 7,359 with COPD mentioned on their death certificate, which is 11.6% of all Nova Scotia deaths.

COPD was listed as the underlying cause for only 41.3% of all deaths where COPD was mentioned. Figure 1 shows the number of COPD underlying and other mentioned causes of death by age.

To gain a more complete understanding of the burden of each chronic disease, NELS ICE examined all records in which a disease is mentioned as a cause of death on the death certificate for the Chronic Disease Reports.

Figure 1: Number of death records with COPD as underlying cause and COPD mentioned but not underlying cause, by age, age 40+, Nova Scotia, 1998-2005.

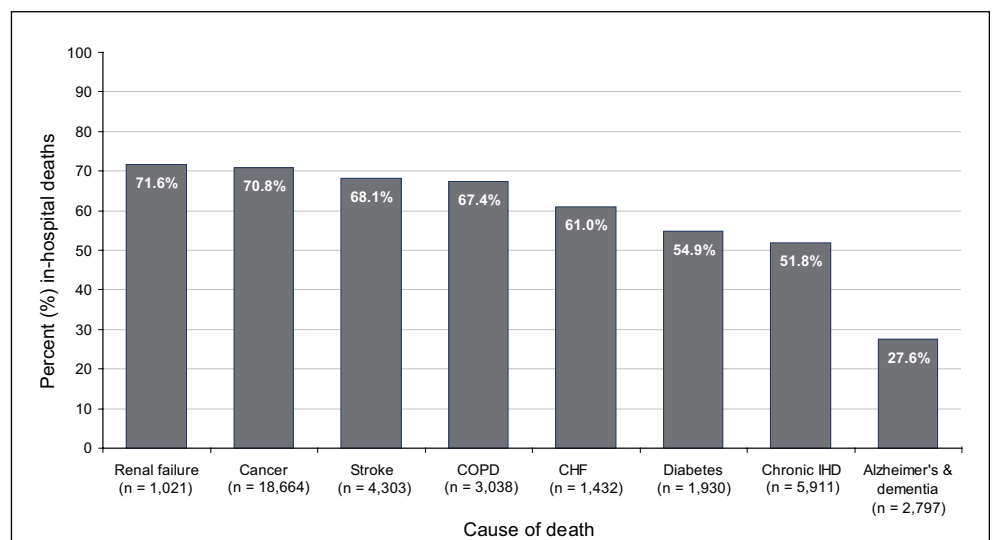


## Dying in Hospital

Most persons would like to die in their own home or in community based care rather than in-hospital if adequate home and community care is available.

The percentages of in-hospital deaths for eight major chronic diseases were compared for adult decedents in Nova Scotia (Figure 2). In Nova Scotia 62% of all adult deaths occurred in-hospital

Figure 2: Percentage of in-hospital deaths for selected underlying causes, all ages, Nova Scotia, 1998-2005



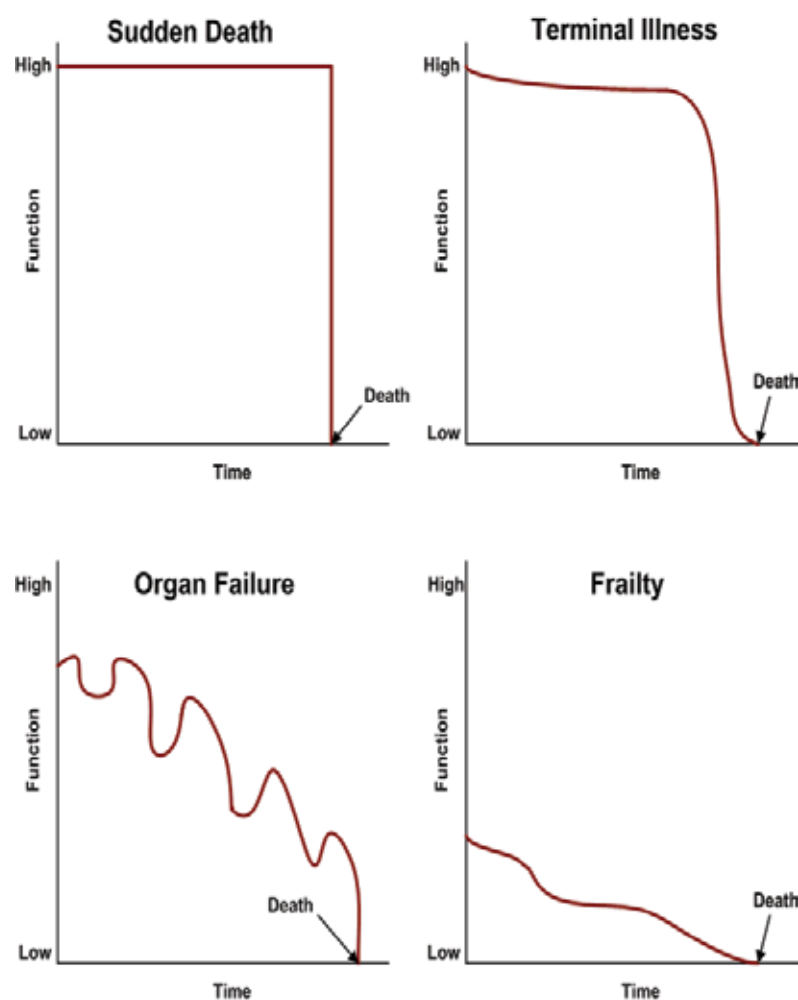
## End of Life Trajectories

End of life trajectories provide help in fostering dialogue on planning the end of life care needs for the majority of decedents.

All persons dying in Nova Scotia from 2000 to 2005 were assigned to one of four trajectory groups by using the underlying cause of death (Figure 3). This shows that end of life care could be planned for 93-95% of all deaths in the province, that is all but the sudden deaths.

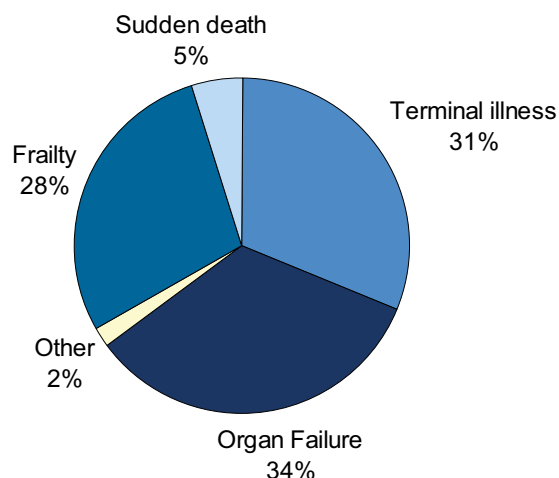
The four trajectories are shown in Figure 4.

Figure 4:  
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.

Figure 3:  
NS deaths by trajectory of dying, 2000-2005



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

### Sudden Death

Death caused by an external cause of mortality such as:

- Accidental death
- Falls
- Trauma

### Terminal Illness

People who declined over a short period of time due to:

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

### Organ Failure

People whose functional status gradually declined with intermittent, serious exacerbations due to:

- Congestive heart failure
- Chronic obstructive pulmonary disease

### Frailty

People who experienced prolonged dwindling due to:

- Alzheimer's disease and dementia
- Neurological decline
- Late effects of stroke

## Comorbidities when Cancer is Underlying Cause of Death in Nova Scotia

As a person ages they are likely to be diagnosed with more than one chronic disease. These comorbidities can greatly affect the care that is needed at end of life. As seen in Table 1, when lung cancer is the underlying cause of death, 13% had COPD as an other condition on their death certificates. Among men dying of prostate cancer, 7.2% also had Alzheimer's disease listed as contributing to their death. Diabetes, heart disease and renal failure were also comorbidities.

Table 1:  
Number and percent of decedents with selected non-cancer causes of death when cancer was the underlying cause (n = 18,664), by major cancer sites, Nova Scotia, 1998-2005.

Non-Cancer Disease	Cancer Site									
	Breast (n = 1,426)		Colorectal (n = 2,349)		Lung (n = 5,209)		Prostate (n = 762)		All other (n = 8,918)	
	N	%	N	%	N	%	N	%	N	%
Chronic obstructive pulmonary disease	26	1.8	95	4.0	712	13.7	51	6.7	380	4.3
Pneumonia	82	5.8	81	3.4	444	8.5	50	6.6	539	6.0
Chronic ischemic heart disease	45	3.2	128	5.4	319	6.1	62	5.2	461	8.1
Diabetes mellitus	72	5.0	129	5.5	227	4.4	50	6.6	528	5.9
Renal failure	26	1.8	89	3.8	77	1.5	79	10.4	444	5.0
Cerebrovascular disease (stroke)	27	1.9	51	2.2	131	2.5	30	3.9	247	2.8
Congestive heart failure	42	2.9	63	2.7	106	2.0	31	4.1	234	2.6
Alzheimer's and dementia	63	4.4	65	2.8	68	1.3	55	7.2	177	2.0
<b>Total with ≥ 1 non-cancer cause(s)<sup>†</sup></b>	<b>663</b>	<b>46.5</b>	<b>1,177</b>	<b>50.1</b>	<b>2,824</b>	<b>54.2</b>	<b>431</b>	<b>53.5</b>	<b>4,767</b>	<b>56.6</b>

## Estimating Potential Palliative Care Population

By employing a method used by researchers in Western Australia, that uses the underlying cause of death, the estimated size of population in Nova Scotia who could potentially benefit from palliative care is given in Table 2. The model was used to provide one district health authority with an estimate of hospice palliative care service needs.

Table 2:  
Number of deaths in Nova Scotia from 1 January 2000 to 31 December 2005 for the Minimal and Maximal Estimates of the potential palliative care population

	Descriptions of estimates	Number of deaths
Nova Scotia	All deaths from 1 January 2000 to 31 December 2005 excluding records missing the underlying cause of death (n = 13)	47,895
Minimal Estimate	Death from at least one of 10 causes: neoplasm (ICD-10 C00-D48), heart failure (ICD-10 I11.0, I13.0, I13.2, I50), renal failure (ICD-10 I12.0, I13.1, N17-N19), liver failure (ICD-10 K70.4, K71.1, K72), chronic obstructive pulmonary disease (ICD-10 J40-J44), motor neuron disease/amyotrophic lateral sclerosis (ICD-10 G12.2), Parkinson's disease (ICD-10 G20-G21), Huntington's disease (ICD-10 G10), Alzheimer's disease (ICD-10 G30) and HIV/AIDS (ICD-10 B20-B24)	21,191 (44.2% of all deaths)
Maximal Estimate	Deaths from all causes, except during pregnancy, childbirth or the puerperium (ICD-10 O00-O99); originating during the perinatal period (ICD-10 P00-P96); resulting from injury, poisoning and certain other external causes (ICD-10 S00-T98); or resulting from external causes of morbidity and mortality (V01-Y98)	45,297 (94.6% of all deaths)

## NEWS & EVENTS

### Call for Posters

NELS will host a **Poster Event** on Wednesday, **December 16, 2009**.

Abstract submissions are being accepted until September 25, 2009. More information is available at <http://nels.dal.ca/PosterEvent2009.html>

### Call for New Investigators

New Researchers are encouraged and supported by NELS ICE to continue research associated with improving quality care for vulnerable populations at end of life. Research support funding of up to \$5,000 per New Investigator is currently available. Visit <http://nels.dal.ca> for requirements and applications.

## ACKNOWLEDGEMENT

NELS ICE research development is supported by funding from the Canadian Institutes for Health Research through a strategic initiative grant (# HOAOA-80067) for "Interdisciplinary Capacity Enhancement (ICE) Reducing Health Disparities and Promoting Equity for Vulnerable Populations".

## UPCOMING ISSUES

NELS News will continue to be released with issue themes based on NELS ICE Project Streams.

More information on NELS and NELS ICE can be found on the website at [nels.dal.ca](http://nels.dal.ca).

NELS News questions and comments can be directed to the ICE Coordinator at [nels@dal.ca](mailto:nels@dal.ca).