CANCER-RELATED MORTALITY IN NOVA SCOTIA FROM 1998 TO 2005: A DESCRIPTIVE ANALYSIS USING BOTH UNDERLYING AND MULTIPLE CAUSES OF DEATH

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

Introduction

With support from a Canadian Institutes of Health Research (CIHR) Interdisciplinary Capacity Enhancement (ICE) grant (#HOA-80067), the Network for End of Life Studies (NELS) is investigating end of life care for persons dying of chronic diseases. Phase One is an analysis of Nova Scotia Vital Statistics (NSVS) death certificate data. Subsequent phases are planned involving the linkage of the NSVS data to administrative data from disease registries, palliative care program (PCP) databases, the CIHI hospital discharge abstract database, SEAscape (continuing care), medication databases (e.g. Pharmacare) and physician billings. Refer to Appendix A for a diagram of proposed data linkages.

These chronic disease analyses use and build on the methods developed over more than ten years of studies focusing on palliative and end of life care for cancer decedents (Burge, Johnston, Lawson, Dewar, & Cummings, 2002; Burge, Lawson, & Johnston, 2003; Burge, Lawson, Johnston, & Grunfeld, 2008; Grunfeld et al., 2006; Grunfeld et al., 2008; Johnston et al., 1998; Johnston, Boyd, Joseph, & MacIntyre, 2001; Johnston, Burge, Boyd, & MacIntyre, 2001; O'Brien and Gao, 2005; O'Brien, Johnston, Gao, & Dewar, 2007). The Surveillance and Epidemiology Unit at Cancer Care Nova Scotia (CCNS) has been a key partner in this work.

This report is unique in comparison to previous CCNS-based work in that it features cancer as the underlying or other mentioned cause of death and identifies non-cancer causes of death for persons with cancer on their death certificate. This cancer report is one of a series of reports from NELS ICE describing persons dying from specific chronic diseases in Nova Scotia. To date, NELS ICE has completed parallel reports for chronic obstructive pulmonary disease (COPD), multiple sclerosis (MS), and Parkinson's disease. Reports are planned for children and youth, diabetes, Alzheimer's disease and dementia, renal disease, congestive heart failure, and cerebrovascular disease (stroke).

Purpose

The purposes of this report are to:

- share a synthesis of cancer findings from an analysis of NSVS chronic disease death data;
- dialogue with persons interested in further building research and surveillance to improve care available to people at end of life with cancer; and,
- examine disparities in health service use for populations at risk for reduced access to quality end of life care.

Methods

Study Subjects: The study population is Nova Scotia residents of all ages who died from January 1, 1998 to December 31, 2005 (N = 63,431). These decedents were identified from the NSVS death certificate database maintained by the Population Health Research Unit (PHRU) at Dalhousie University. While all deaths were included, the International Classification of Disease (ICD) codes for injuries, poisonings and other external causes of death were provided as XXX.
Classification of Cancer Causes of Death: Cancer deaths among the 63,431 total deaths were identified with ICD cause of death codes. From 1979 to 1999, causes of death were coded using the ninth revision of ICD (ICD-9). Since January 1, 2000, causes of death have been coded using the

tenth revision of ICD (ICD-10). The ICD-9 codes for cancer are 140-208 and the ICD-10 codes are C00-C97.

Multiple Causes of Death: There can be up to 13 causes of death listed on the death certificate. When only one cause of death is recorded, this cause of death is selected 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 (Statistics Canada, 2005). The underlying cause of death is defined by Statistics Canada (2007) 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." All records for which cancer was mentioned as any of the up to 13 causes of death on the death certificate were examined for this report.

Results

Deaths with Cancer Mentioned or Selected as Underlying Cause: A total of 18,664 persons died with cancer as their underlying cause of death from 1998 to 2005 in Nova Scotia. This is 29.4% of all Nova Scotia deaths. A further 2,259 persons had cancer as a cause of death which was not selected as the underlying cause. Thus, a total of 20,923 persons had any mention of cancer on their death certificate, which is 33.0% of all Nova Scotia deaths.

Cancer was listed as the underlying cause for 89.2% of all deaths where cancer was mentioned (Table 1). The number of cancer deaths slightly increased from 1998 to 2005 (Table 2).

Table 1: Number of deaths with cancer mentioned or selected as the underlying cause, by sex, Nova Scotia, 1998-2005.

	Male	Female	Total
Cancer as the underlying cause **N (% of total mentions)**	9,915 (88.6)	8,749 (89.9)	18,664 (89.2)
Cancer mentioned but not the underlying cause **N (% of total mentions)**	1,275 (11.4)	984 (10.1)	2,259 (10.8)
Total mentions	11,190	9,733	20,923

Table 2: Number of deaths with cancer mentioned or selected as the underlying cause, by year of death, Nova Scotia, 1998-2005.

	1998	1999	2000	2001	2002	2003	2004	2005
Cancer as the underlying cause **N (% of total mentions)**	2,246 (88.6)	2,255 (89.9)	2,316 (89.4)	2,268 (89.0)	2,354 (89.4)	2,407 (90.0)	2,423 (88.3)	2,395 (89.0)
Cancer mentioned but not the underlying cause **N (% of total mentions)**	290 (11.4)	252 (10.1)	274 (10.6)	281 (11.0)	280 (10.6)	267 (10.0)	320 (11.7)	295 (11.0)
Total Mentions	2,536	2,507	2,590	2,549	2,634	2,674	2,743	2,690

Over 80% of all cancer deaths appear after age 60 (Table 3 and Figure 1). The mean age of cancer decedents is 72.1 years. The percentage of deaths where cancer is mentioned but is not the underlying cause increases with age. The non-cancer underlying causes are reported in Table 6.

Table 3: Number of deaths with cancer mentioned or selected as the underlying cause, by age, Nova Scotia, 1998-2005.

	Age						
	< 40	**40-49**	**50-59**	**60-69**	**70-79**	**80-89**	**90+**
Cancer as the underlying cause N (% of total mentions)	321 (97.0)	842 (95.8)	2,277 (96.1)	3,975 (93.9)	5,727 (90.1)	4,490 (82.6)	1,032 (78.4)
Cancer mentioned but not the underlying cause N (% of total mentions)	10 (3.0)	37 (4.2)	92 (3.9)	258 (6.1)	629 (9.9)	949 (17.4)	284 (21.6)
Total Mentions	331	879	2,369	4,233	6,356	5,439	1,316

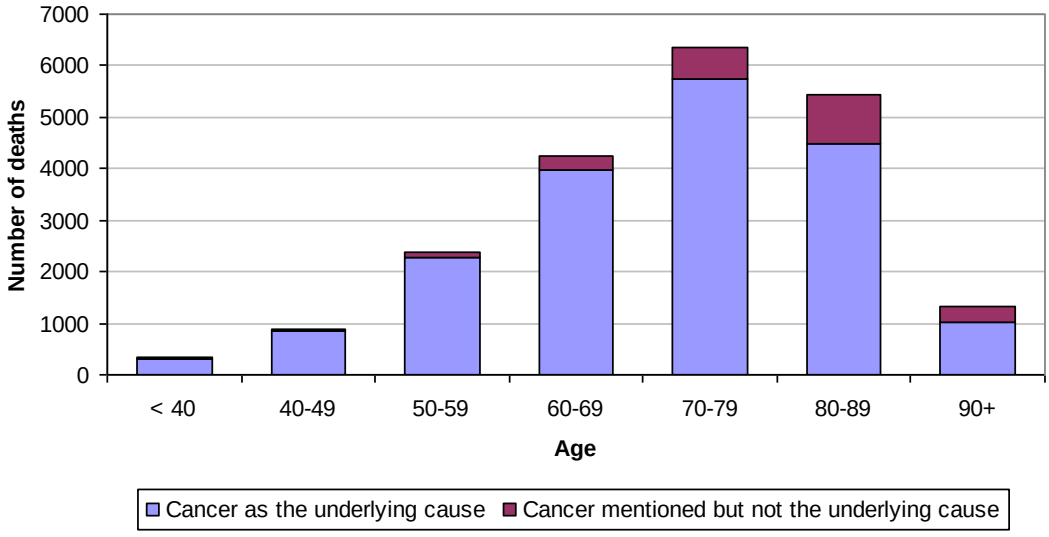


Figure 1: Number of death records with cancer as underlying cause and cancer mentioned but not underlying cause, by age, Nova Scotia, 1998-2005.

Non-Cancer Causes of Death Mentioned for Persons with Cancer as Underlying Cause: Among the 18,664 deaths with cancer selected as the underlying cause, other non-cancer causes of death included diseases such as respiratory disease, diabetes mellitus and cardiovascular disease (Table 4). Since there could be up to 12 other causes of death beyond cancer, an individual may be reported in more than one row of Table 4. For example, if a person had cancer, pneumonia, and diabetes on their death certificate, this person would be one of the 1196 pneumonia counts as well as one of the 1006 diabetes mellitus counts. Refer to Appendix B for a listing of the ICD codes used.

The percentage of decedents having an underlying cause of cancer and at least one non-cancer cause of death mentioned increased with age (Table 4). Under age 70, 46.1% also had a non-cancer cause mentioned and over age 80, the proportion with non-cancer causes was 62.2%.

Table 4: Number and percent of decedents with selected non-cancer causes of death when cancer was the underlying cause (n = 18,664), by age group, Nova Scotia, 1998-2005.

Non-Cancer Disease	Aged < 70 (n = 7,415)		Aged 70-79 (n = 5,727)		Aged 80+ (n = 5,522)		Overall (n = 18,664)	
	N	%	N	%	N	%	N	%
Chronic obstructive pulmonary disease	351	4.7	510	8.9	403	7.3	1,264	6.8
Pneumonia	405	5.5	367	6.4	424	7.7	1,196	6.4
Chronic ischemic heart disease	219	3.0	362	6.3	434	7.9	1,015	5.4
Diabetes mellitus	295	4.0	342	6.0	369	6.7	1,006	5.4
Renal failure	192	2.6	222	3.9	301	5.5	715	3.8
Cerebrovascular disease (stroke)	129	1.7	146	2.5	211	3.8	486	2.6
Congestive heart failure	70	0.9	129	2.3	277	5.0	476	2.6
Alzheimer's and dementia	15	0.2	89	1.6	324	5.9	428	2.3
Total with ≥ 1 non-cancer cause(s)[‡]	***3420***	***46.1***	***3008***	***52.5***	***3434***	***62.2***	***9,862***	***52.8***

[‡] Columns do not add up to the totals for this table because a cancer decedent may have more than one non-cancer cause of death mentioned. The total with ≥ 1 non-cancer cause(s) is the total number of decedents having an underlying cause of cancer and at least one non-cancer cause mentioned on their death certificate.

Other non-cancer causes of death by major cancer site were also examined (Table 5). As expected, chronic obstructive pulmonary disease and pneumonia rates were higher when the underlying cause of death was lung cancer. Decedents with prostate cancer had the highest rates of renal failure and Alzheimer's disease/dementia. This was not surprising considering the mean age of prostate cancer decedents was 79 years of age.

Table 5: 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
Total with ≥ 1 non-cancer cause(s)[‡]	***663***	***46.5***	***1,177***	***50.1***	***2824***	***54.2***	***431***	***53.5***	***4,767***	***56.6***

[‡] Columns do not add up to the totals for this table because a cancer decedent may have more than one non-cancer cause of death mentioned. The total with ≥ 1 non-cancer cause(s) is the total number of decedents having an underlying cause of cancer and at least one non-cancer cause mentioned on their death certificate.

Underlying Non-Cancer Causes when Cancer was Other Mentioned Cause: Among the 2,259 deaths where cancer was mentioned but not given as the underlying cause, major non-cancer underlying causes of death included chronic ischemic heart disease, chronic obstructive pulmonary disease and cerebrovascular disease (stroke) (Table 6).

Table 6: Number and percent of decedents with selected non-cancer underlying causes of death when cancer was mentioned but not the underlying cause (n = 2,259), Nova Scotia, 1998-2005.

Non-Cancer Disease	N	%
Chronic ischemic heart disease	334	14.8
Chronic obstructive pulmonary disease	214	9.5
Cerebrovascular disease (stroke)	214	9.5
Alzheimer's and dementia	132	5.8
Diabetes mellitus	101	4.5
Congestive heart failure	83	3.7
Pneumonia	57	2.5
Renal failure	45	2.0
Other non-cancer underlying causes	1079	47.8
Total	2259	100

Dying In-Hospital: These vital statistics data, which were obtained from the Population Health Research Unit (PHRU), only report location of death as in-hospital or out-of-hospital. Using a more complete data set obtained directly from Nova Scotia Vital Statistics, out-of-hospital can be subdivided into private residence and nursing home.

Place of death has been used as an indicator of quality of care at end of life (Burge et al., 2003; Grunfeld et al., 2006; NELS ICE, 2008a). Most persons would like to die in their own home or community based care rather than in hospital if adequate home and community care is available (Grunfeld et al., 2008). In Nova Scotia, using the PHRU NSVS data from 1998 to 2005, 62.6% of all adult deaths occurred in hospital. This rate of hospital death is considered relatively high compared to rates in other countries such as the US, UK and some other European countries.

For 1998 to 2005, 70.3% of all deaths where cancer was mentioned on the death certificate occurred in hospital (Table 7). The percentage dying in hospital tends to decrease as age increases with approximately 75% dying in hospital among those under 70 years, and around 60% dying in hospital among those 80 years and over.

Table 7: Number and percent of hospital deaths with cancer mentioned or selected as the underlying cause, by age, Nova Scotia, 1998-2005.

	Aged <70		Aged 70-79		Aged 80+		Overall	
	N	%	N	%	N	%	N	%
Cancer as the underlying cause	5,606	75.6	4,191	73.2	3,425	62.0	13,222	70.8
Cancer mentioned but not the underlying cause	303	76.3	445	70.8	738	59.9	1,486	65.8
Total Mentions	5,909	75.6	4,636	72.9	4,163	61.6	14,708	70.3

The percentages of in-hospital deaths for cancer and seven other major chronic diseases were compared for adult decedents in Nova Scotia (Figure 2). Renal failure has the highest percentage of in-hospital deaths at 71.5% while Alzheimer's and dementia have the lowest percentage of in-hospital deaths at 27.6%.

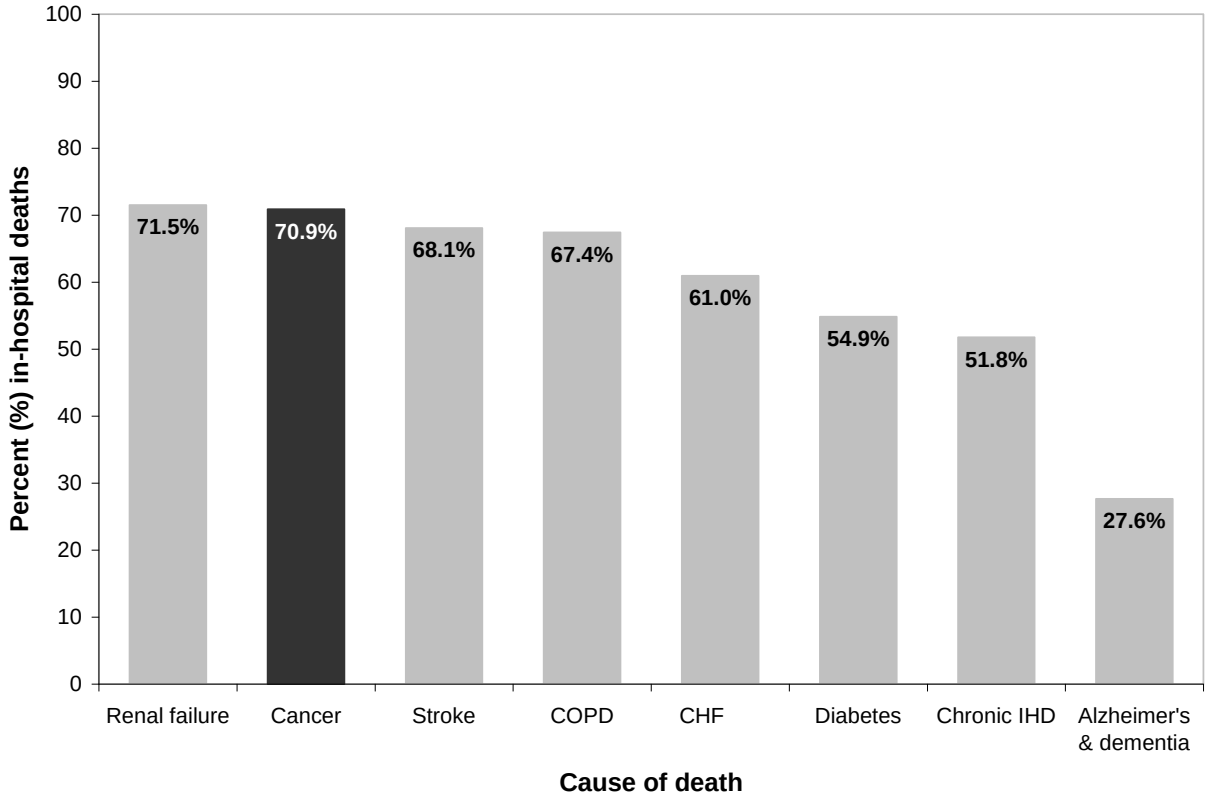


Figure 2: Percentage of in-hospital deaths for major underlying chronic disease causes of death, age 20+, Nova Scotia, 1998-2005.

Limitations of PHRU NSVS Data

There are limitations with the NSVS data obtained from PHRU. Nearly 9% of all deaths from 1998 to 2005 are missing health card numbers, 6% are missing death postal codes and around 14% are missing residence postal codes. Nursing home residence cannot be identified using the algorithm developed by Jun Gao because complete address information is not available in the vital statistics database at PHRU. Furthermore, since the PHRU NSVS data cannot be adequately linked to other health administrative databases because of missing health card numbers, it is not possible to examine inequalities in health service utilization at end of life from the data within PHRU.

Further NELS ICE Work with Cancer Care Nova Scotia

NELS ICE wishes to build on this cancer end of life work through continued collaboration with Cancer Care Nova Scotia (CCNS). On February 25th, 2009, Grace Johnston provided a Lunch and Learn presentation on NELS ICE which connected with CCNS and other chronic disease programs on the 5th floor of the Bethune Building (Nova Scotia Renal Program, Diabetes Care Program of Nova Scotia and Cardiovascular Health Nova Scotia).

The NELS ICE team is pleased that CCNS is including the palliative care program (PCP) enrollment indicator for Halifax and Cape Breton counties (NELS ICE, 2008a) in a quality indicators report being released by CCNS in June 2009. NELS ICE wishes to work with CCNS to obtain PCP data from other DHAs with electronic databases including Colchester-East Hants and Annapolis Valley.

Judith Fisher, the new NELS ICE post-doctoral fellow (2009-2010), will be developing proposals to use Pharmacare and Prescription Monitoring Program (PMP) data in order to examine medication use at end of life. Judith will be added as a researcher on the colorectal cancer NET ACCESS team and will work with an end of life cohort derived from the larger colorectal cancer linked data files. Grace Johnston and Fred Burge are leading the NET ACCESS end of life project. This summer, Judith will be participating in the Dalhousie University College of Pharmacy's Drug Use Management and Policy Residency Program. Her project will involve working with Medavie Blue Cross and the Department of Health, specifically with the PMP, to establish guidelines to facilitate the identification of appropriate opiod use at end of life. She will also be exploring the linkage of PHRU NSVS and Pharmacare data.

Future NELS ICE surveillance reports are being planned in addition to the End of Life Care in Nova Scotia Surveillance Report (NELS ICE, 2008a). A consultation process took place in June 2008 to obtain feedback on this first NELS ICE surveillance report (NELS ICE, 2008b). Yukiko Asada, Department of Community Health and Epidemiology, Dalhousie University, is leading a report focusing on measures of inequity in end of life care. Alison Zwaagstra, NELS ICE Health Information Analyst, is planning a report summarizing the findings from the analysis of Nova Scotia Vital Statistics death certificate data for cancer and other chronic diseases.

Another project is a new CIHR-funded follow-back study led by Fred Burge and Beverley Lawson, with Grace Johnston as a co-investigator, which will identify and interview next of kin nine months after death to better understand adequacy of end of life care. Fred and Beverley will be working directly with NSVS to carry out this study.

NELS ICE team members are also involved with examining the costs of end of life care. Community costs for end of life care were collected for 50 Capital Health palliative care patients, and a parallel study is now underway for 50 persons from Colchester East Hants. These cross-Canada CIHR-funded costing studies are being led by Serge Dumont with Fred Burge and Grace Johnston as co-investigators. A new economist, David Haardt, will be joining the School of Health Administration at Dalhousie University in July 2009 and is expected to be working on the analysis of these data. NELS ICE will also be collaborating with Louise Parker and Trevor Dummer who have received funding from the Nova Scotia Health Research Foundation (NSHRF) to assess the quality of death registration data in Nova Scotia. On February 24th and 25th, NELS ICE team members met with IWK colleagues to explore end of life data and research development for infants, children and youth. A follow-up meeting for April 2009 is to be organized by Trevor Dummer.

Conclusion

The intent of NELS ICE is to increase capacity for interdisciplinary research development to improve care at the end of life for vulnerable populations. The development of an expanded end of life dataset and the dissemination of findings from the analyses of these data is one aspect of this capacity development. You are being provided with this report with the hope that you and your colleagues may find these data of use, e.g., for your annual reports to the District Health Authorities (DHAs), and that you will continue to be part of the data development process for palliative and end of life care.

References

Burge, F., Johnston, G., Lawson, B., Dewar, R., & Cummings, I. (2002). Population based trends in referral of the elderly to a comprehensive palliative care program. *Palliative Medicine*, *16*, 255-256.

Burge, F., Lawson, B., & Johnston, G. (2003). Trends in the place of death of cancer patients, 1992-1997. *Canadian Medical Association Journal*, *168,* 265-270.

Burge, F. I., Lawson, B., Johnston, G. M., & Grunfeld, E. (2008). A population-based study of age inequalities in access to palliative care among cancer patients. *Medical Care*, *46*, 1203-1211.

Grunfeld, E., Lethbridge, L., Dewar, R., Lawson, B., Paszat, L. F., Johnston, G., et al. (2006). Towards using administrative databases to measure population-based indicators of quality of end-of-life care: testing the methodology. *Palliative Medicine*, *20*, 769-777.

Grunfeld, E., Urquhart, R., Mykhalovskiy, E., Folkes, A., Johnston, G., Burge, F. I., et al. (2008). Toward population-based indicators of quality end-of-life care: Testing stakeholder agreement. *Cancer, 112*, 2301-2308.

Johnston, G. M., Boyd, C. J., 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*, 3323-3332.

Johnston, G. M., Burge, F. I., Boyd, C. J., & MacIntyre, M. (2001). End of life population study methods. *Canadian Journal of Public Health*, *92*, 385-386.

Johnston, G. M., Gibbons, L., Burge, F. I., Dewar, R. A., Cumming, I., & Levy, I. G. (1998). Identifying potential need for cancer palliation in Nova Scotia. *Canadian Medical Association Journal*, *158*, 1691-1698.

NELS ICE. (2008a). End of Life Care in Nova Scotia Surveillance Report. Network for End of Life Studies (NELS) Interdisciplinary Capacity Enhancement (ICE), Dalhousie University, Halifax, Nova Scotia, Canada.

NELS ICE. (2008b). Listening to Stakeholders Report of Consultation on "End of Life Care in Nova Scotia Surveillance Report." Network for End of Life Studies (NELS) Interdisciplinary Capacity Enhancement (ICE), Dalhousie University, Halifax, Nova Scotia, Canada.

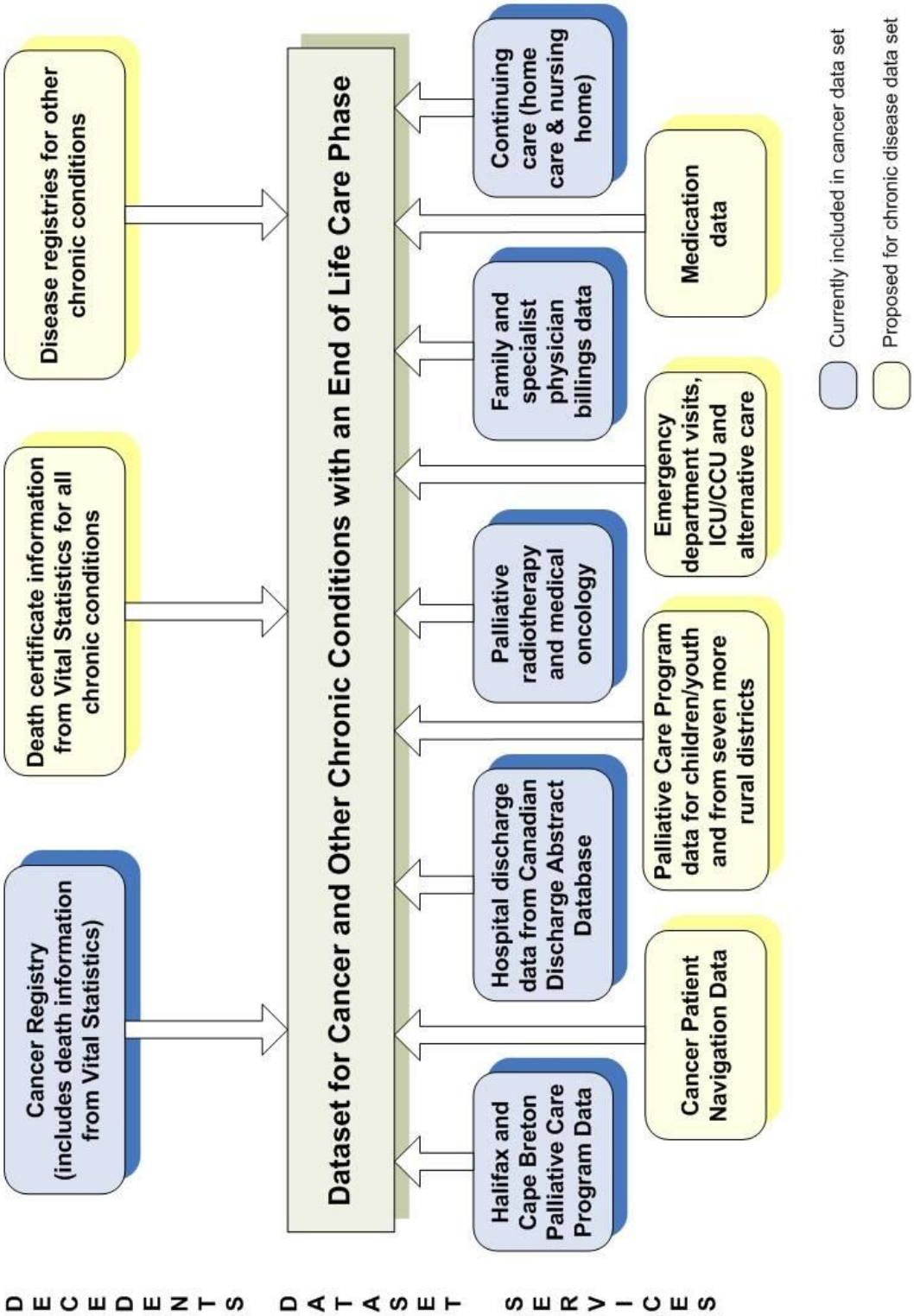
O'Brien, M., & Gao, J. (2005). *Detailed methods of data preparation for research on access to end of life care for adults dying of cancer in Nova Scotia.* Network for End of Life Studies (NELS) at Cancer Care Nova Scotia. Available at: http://www.cancercare.ns.ca/site-cc/media/cancercare/DetailedMethods.pdf (Accessed March 2009).

O'Brien, M. B., Johnston, G. M., Gao, J., & Dewar, R. (2007). End-of-life care for nursing home residents dying of cancer in Nova Scotia, Canada, 2000-2003. *Supportive Care in Cancer*, *15*, 1015-1021.

Statistics Canada. (2005). *Comparability of ICD-10 and ICD-9 for mortality statistics in Canada.* Available at: http://www.statcan.ca/english/freepub/84-548-XIE/84-548-XIE2005001.pdf (Accessed March 2009).

Statistics Canada. (2007). *Causes of death: Definitions*. Available at: http://www.statcan.gc.ca/pub/84-208-x/2007001/4067449-eng.htm (Accessed March 2009).

Appendix A


DECEDENTS
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
Dataset for Cancer and Other Chronic Conditions with an End of Life Care Phase
SERVICES
Halifax and Cape Breton Palliative Care Program Data
Hospital discharge data from Canadian Discharge Abstract Database
Palliative radiotherapy and medical oncology
Palliative Care Program data for children/youth and from seven more rural districts
Cancer Patient Navigation Data
Emergency department visits, ICU/CCU and alternative care
Family and specialist physician billings data
Medication data
Continuing care (home care & nursing home)
Currently included in cancer data set
Proposed for chronic disease data set

Appendix B

Selected chronic diseases and their corresponding International Classification of Diseases (ICD) codes

Disease	ICD-9 (1979-1999)	ICD-10 (2000-present)
Cancer	140-208	C00-C97
Chronic obstructive pulmonary disease (excluding asthma)	490-492, 496	J40-J44
Pneumonia	J12-J18	480-486
Chronic ischemic heart disease (excluding myocardial infarction)	I20, I25	412-414, 429.2
Diabetes mellitus	250	E10-E14
Renal failure	584-586, 588, 589	N17-N19
Cerebrovascular disease (stroke)	430-434, 436-438	I60-I69
Congestive heart failure	428	I50
Alzheimer's disease and dementia	290, 331.0	F00-F03, G30