

Lessons Learned and Opportunities for the Provincial Disease Programs from the 3x3 NELS Study

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Grace Johnston is responsible for the content of this report. Lynn Lethbridge completed the data analysis. Others who have contributed to this report are not responsible for any errors that may be identified, and they may have different interpretations and perspectives than those herein.

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Executive Summary

This report is a summary of what has been learned and opportunities for making further progress on access to quality data and the generation of quality indicators for palliative and end of life care in Nova Scotia (NS). This report is based on 3x3 NELS¹ research findings and provides some *key lessons learned and opportunities* for the future. While this report focuses on care for persons at end of life, many of the issues discussed herein relate to provincial disease program needs that go beyond monitoring the care for persons at end of life.

1. Historically, palliative care has focused on persons at end of life from cancer. However, findings from the 3x3 NELS research show that persons dying of diseases other than cancer are increasingly also being enrolled in palliative care programs. In 1995, 5% of persons with cardiovascular disease as a cause of their death were enrolled in a palliative care program; by 2009, this rate averaged over 13%. In 1995, the palliative care program enrolment rate was 2% for persons dying of diabetes, renal disease, and chronic obstructive pulmonary disease. By 2009, these rates had risen to range from over 7% to over 10%. The 3x3 NELS research process resulted in knowledge exchange, analytic partnerships, and collaborative learning across the disease programs and with others. *Opportunity:* For these benefits to continue to accrue, *opportunities and processes are needed for the provincial disease programs to continue to work on collaborative projects, with researchers, and others directly involved with evidence-informed performance monitoring.*
2. *Feasibility has been demonstrated.* Probabilistic record linkage was used to link datasets to inform the population-based provision of care for persons approaching the end of life in NS. Ongoing knowledge exchange, between the researchers and provincial disease programs, was mutually productive. *Opportunity:* The approach described herein could be used for *ongoing record linkage* across the provincial disease programs and include data feeds from palliative care programs (PCP) in each District Health Authority (DHA) to generate a platform for provincial end of life care surveillance. A first step could be the design of a next study building on what has been learned from 3x3 NELS. Also, resources permitting, an analyst with Research Ethics Board (REB) approvals could carry out analyses to determine the value added of *probabilistic versus deterministic linkage* in relation to the 3x3 NELS study.
3. *Timely access to complete death certificate data is imperative* for the provincial disease programs to understand the extent of the need for palliative and end of life care. The PCPs also need to carry out death clearance of their databases to compute their wait times from referral to assessment and death. The recent introduction of electronic death registration by funeral directors for submission to Nova Scotia Vital Statistics (NSVS) should improve the timeliness of access to electronic death registration. *Opportunity:* One common and timely method for the provincial disease programs to obtain complete electronic death certificate data should be developed and implemented. This process should include *backfilling missing health card numbers and postal codes* in death certificate data. This could be done by probabilistic linkage of multiple identity fields to the provincial Health Card Number

¹ For more information on the Network for End of Life Studies (NELS), see www.dal.ca/nels

- (HCN) database. Alternatively, if the provincial programs were given approval and resources, Cancer Care Nova Scotia (CCNS) has the skills and probabilistic software to backfill the HCNs missing from NSVS data by probabilistic linkage to the HCN database, e.g. through the Central Client Registry to which health programs have access.
4. The research lead for the 3x3 NELS project was the bridge between the provincial disease programs and NSVS. *Opportunity: The provincial disease programs would benefit by a formal collaborative process of knowledge exchange with NSVS directly or via the Department of Health and Wellness (DHW) to share and discuss the coding and interpretation of variables, development of new or changes to existing data fields, and solutions to data quality issues identified over time through research and provincial program operations.*
 5. The provincial disease programs see the need for including *nursing home residents* in provincial palliative and end of life care surveillance. Nursing home residents are unlikely to be enrolled in palliative care programs, but a palliative approach to their care should be considered. From the 3x3 NELS findings. Consistency in the definition of a nursing home resident was not apparent. *Opportunity: The Business Intelligence, Analytics and Privacy (BIAP) and Continuing Care sections of the Nova Scotia Department of Health and Wellness (DHW) and the Vital Statistics division of Service Nova Scotia should work together to develop one common and valid means of identifying nursing home residents, and nursing home as the place of death from Nova Scotia death certificate data. The provincial disease programs should then be provided with these data fields: identification of nursing home resident with dates of assessment, admission and discharge, and nursing home as place of death. These data should also include the identification of persons who were assessed and approved for nursing home placement but who were never admitted to a nursing home.*
 6. The DHW Continuing Care unit manages a provincial database that includes data on the assessment of Nova Scotians for care in one's own home or a nursing home through the Single Entry Access (SEAscape) program. These data follow accepted InterRAI and Canadian Institute for Health Information standards, and include symptom indicators. These data have been improving in completeness and quality over time. The assessment for nursing home and home care, *including the symptom indicator scales*, could be used as indicators of need for supportive care. Both the PCPs and the provincial disease programs would benefit from receiving an ongoing data feed from this database. *Opportunity: The DHW Continuing Care unit could provide the provincial disease registries with an ongoing data feed of persons approved for home care and admission to a nursing home and the date of this approval.*
 7. Most people at end of life have more than one cause of death. The extent to which people will have *multi-morbidities at end of life* is increasing as our population ages. All the disease registries need NSVS data for *case ascertainment*, and for *access to all causes of death* to adequately understand and coordinate end of life care needs across disease programs. *Opportunity: All provincial disease programs should be provided with access to all causes of death for all persons in their disease registries, and the opportunity to obtain information on death-certificate-only cases relevant to their disease focus.*

8. The provincial disease programs produce *quality indicators of care* across the disease continuum, including care *at the end of life*. The 3x3 NELS study demonstrated the feasibility of using *palliative care program (PCP) enrolment, time from PCP enrolment to death, and place of death* as indicators. Indicators of inadequate community-based care are *emergency department visits* and *long in-patient hospital stays*. Appropriate access to supportive care including *medications* for pain control and other forms of symptom management indicates good end of life care. There are also *disease-specific indicators*. Opportunity: A five to ten year plan should be developed and resourced to provide a set of indicators of quality care at end of life in Nova Scotia.
9. *Wait times are critical*. Timely enrolment in a PCP is another indicator of quality palliative care. A short time from PCP enrolment until death is not considered optimal. The percentage of persons enrolled in a PCP within fourteen days of death indicates suboptimal support. Approximately 30% of persons dying of cancer were enrolled in the last two weeks of their life. Opportunity: Resources permitting, an analyst with REB approval could carry out an analysis of the predictors of short time from PCP enrolment to death, and of the *timeliness of PCP enrolment* in relation to the timing of the registration in disease programs.
10. The 3x3 NELS study used NSVS death data to identify whether a person died in hospital or not. Persons who died in a hospital emergency department are considered to have had a hospital death if NSVS data are used. If hospital admission and discharge data (DAD) are used, the percentages are lower since only inpatient deaths are recorded as hospital deaths. Opportunity: The DHW should work to *reconcile* this inconsistency between DAD and NSVS data on hospital as the place of death, and use continuing care data to *create four measures: i) died in hospital as an inpatient (ideally identifying palliative care, ICU, or other unit), ii) died in hospital (e.g. in emergency department) but not as an inpatient, iii) died in own home which was not a nursing home, and iv) died in a nursing home*.
11. The provincial disease programs and the DHW monitor and promote evidence-informed care that is accessible to all Nova Scotians regardless of DHA, income, social status, or distance to care. From 3x3 NELS findings, *care varies by DHA, distance to a PCP, urban/rural status, income quintile, and social deprivation*. Opportunity: Resources permitting, the provincial disease programs could carry out ongoing postal code to census linkage and production of palliative care quality indicators by distance to care, urban/rural status, income and social status, and through *geographic mapping*.
12. The provincial disease programs are well positioned to work together to operationalize and maintain 3x3 NELS type production of population-based reports on need and performance indicators. The NS DHW has committed resources to the Maritime SPOR Support Unit. BIAP has renewed its multi-year agreement with Health Data NS (HDNS) for DAD, MSI Physician billings and Pharmacare data. BIAP is working with MSSU and DHW partners to plan next steps in collaborating on approaches for operations and research to improve data and thereby health outcomes for Nova Scotians. A clear governance structure for decision-making, data access and transfer, and reporting is under development. Opportunity: Through

these developments, the provincial programs and others could work together to build the next steps in the development of a surveillance database for care at end of life, modelled on the 3x3 NELS study. This requires that the programs *embrace and are resourced for this palliative and end of life care mandate*.

13. While some persons will favour developing one large data warehouse to house and process all NS electronic health data, I advocate grass-roots data development and quality control, along with enabled data linkage across databases using curated data practices. Opportunity: Development of a Dataset Enrollee File for End of Life (DEFEL) could be considered to quickly identify which datasets actually have data on persons who have died, and thereby enable more efficient, timely and focused research and operations for end of life care surveillance and research projects for NS.

The need for care for persons at end of life is increasing. This care requires redevelopment to become more community-based, evidence-driven, and coordinated. The provincial disease programs are well positioned to be a key component in addressing these challenges, and the provision of performance indicators of this care. This report provides next steps to develop palliative and end of life care surveillance in Nova Scotia by learning that has been attained from the 3x3 NELS study.

Background and Purpose of this Report

In 2006, the Network for End of Life Studies (NELS) was awarded a multi-year, \$820,000 Interdisciplinary Capacity Enhancement (ICE) grant by the Canadian Institutes of Health Research to build research capacity that would improve care for vulnerable populations. The NELS ICE grant focused on team building, education, and infrastructure² development in Nova Scotia (NS) to enable research to improve care for vulnerable persons at end of life. Principal Investigator (PI) for NELS ICE was Dr. Grace Johnston. NELS funds ended in 2013,

Historically, palliative care and palliative care research focused on persons at end of life with cancer³. However, persons dying of other diseases also needed support at end of life. Therefore, the NELS ICE PI, with the assistance of the NELS ICE data analysts, built upon the prior research to initiate the development of the *3x3 NELS linked administrative data* study that *included all persons who died in NS from 1995 to 2009*, not just those who died of cancer. Along with including all deaths, the inclusion of disease registries beyond the cancer registry was another unique aspect of the 3x3 NELS study.

² While this report relates primarily to linked administrative database development, there were many other components of NELS ICE including support for the training of graduate students, post doctoral fellows and others in research at end of life; hosting Visiting Scholars in Halifax; developing a website: dal.ca/nels, newsletters, and reports: enabling the development of new research grants and research team development; many local, national and international conference presentations; and the publication of research findings.

³ Papers published from Nova Scotia cancer-based palliative care research using linked administrative data that began prior to receiving the NELS ICE grant included:

Gao J, **Johnston GM**, Lavergne MR, McIntyre P (2011) Identifying population groups with low palliative care program enrolment using classification and regression tree analysis. **Journal of Palliative Care** 27(2): 98-106

Lavergne MR, **Johnston GM**, Gao J, Dummer TJB, Rheume DE (2011) Variation in the use of palliative radiotherapy at end of life: Examining demographic, clinical, health service, and geographic factors in a population-based study. **Palliative Medicine** 25(2):101-110

Burge F, Lawson B, **Johnston G**, Grunfeld E (2008) A population based study of age inequalities in access to palliative care among cancer patients **Medical Care** 46(12):1203-1211

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

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

Burge F, Lawson B, **Johnston G**, Flowerdew G, Cummings I. (2005) Health care restructuring and family physician care for those who died of cancer. **BioMedCentral – Family Practice** 6:1-6

Burge F, Lawson B, **Johnston G** (2005) Home visits by family physician during the end-of-life: Does income or residency play a role? **BioMedCentral – Palliative Care** 4:1-9

Burge F, Lawson B, **Johnston G** (2005) Where a patient dies: The effect of rural residency. **Journal of Rural Health** 21(3):233-238

Burge F, Lawson B, **Johnston G** (2003) Primary care continuity and location of death for those with cancer. **Journal of Palliative Medicine**. 6(6):911-918

Burge F, Lawson B, **Johnston G** (2003) Family physician continuity of care and emergency department use in end-of-life cancer care. **Medical Care** 41(8):992-1001

Burge F, Lawson B, **Johnston G** (2003) Trends in the place of death of cancer patients. **Canadian Medical Association Journal** 168(3):265-270

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

Johnston GM, Boyd CJ, 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(14): 3323-3332

Johnston GM, Burge FI, Boyd CJ, MacIntyre MM (2001) End-of-life population study methods. **Canadian Journal of Public Health** 92(5):385-386

Johnston G, Gibbons L, Burge F, Dewar R, Cummings I, Levy I (1998) Need for palliative care in Nova Scotia. **Canadian Medical Association Journal** 158(13):1691-1698,

In 2010, the Diabetes Care Program of Nova Scotia (DCPNS), Cardiovascular Health Nova Scotia (CVHNS), and Surveillance and Epidemiology Unit (SEU) of Cancer Care Nova Scotia (CCNS) began their participation in the 3x3 NELS study⁴. The Nova Scotia Renal Program (NSRP) was involved in discussions but did not have data for the time period of this study.

The provincial disease programs span across the continuum of care from prevention to palliative care. However, to date, palliative⁵ and end of life care⁶ has not received as much attention as other components of the care continuum. Due to the aging of our population, high health care costs in the last year of life, and constraints in available resources, inevitably, palliative and end of life care will be receiving increasing attention.

This report has *three overarching understandings*:

1. *Nova Scotians are aging. Therefore, the need for palliative and end of life care will expand greatly over the next twenty years. Multi-morbidities will also increase.* Increasingly, advance care planning and palliative support is being encouraged for persons dying of advanced diseases other than cancer, as well as for those dying of cancer. Lengthy inpatient hospital stays and preventable emergency department visits are indicators of the need to improve community-based palliative support and thereby avoid unnecessary costs.
2. *Electronic medical records (EMRs) and both clinical and management decision support systems are steadily becoming more mainstream.* EMRs should be developed to include markers of need and care provision for persons in their last year of life. Disease programs and registries should be partners in these developments.
3. *3x3 NELS type data should be developed as part of the ongoing provincial disease programs operating mandate to estimate needs and provide performance indicators.* These data should also be used for research.

The purposes of this report are to present the lessons learned from the 3x3 NELS study and to identify opportunities to:

1. Improve the quality of the administrative data available to prepare reports and carry out studies of care at end of life for persons dying in NS, and
2. Generate quality indicators for palliative and end of life care in NS.

⁴ Full name of the 3x3 NELS study is "Chronic Disease and Palliative Care Program Data Linkage and Analysis Project: The 3x3 Network for End of Life Studies (NELS) Project".

⁵ For purposes of this report, *palliative care* refers to enrollment in a palliative care program. 3x3 NELS data also includes palliative radiation in the last nine months of life for a person diagnosed with cancer, but analyses of this variable are yet to be carried out.

⁶ *End of life care* includes palliative care as well as curative, rehabilitative, supportive and other services provided to persons at end of life. Since there is no accepted definition of the beginning of end of life, arbitrary cut points, such as the last six months, nine months or year of life, are used. Study subjects are thus defined as all persons who died, and then their time at end of life is retrospectively defined.

The 3x3 NELS Study Data

The 3x3 NELS study⁷ includes data from palliative care programs (PCP) in three district health authorities (DHA): Colchester East Hants, Capital Health, and Cape Breton, and three provincial disease registries (Cancer, Cardiovascular, and Diabetes) linked to the Nova Scotia Vital Statistics (NSVS) deaths to assess data quality and produce quality indicators of care for persons at end of life. This *population-based method using linked administrative data* has been used in Canadian Institute of Health Institution (CIHI) reports⁸ and is *dependent on complete, accurate and timely death certificate information*. A PCP operates in each DHA in NS but only three had more than five years of electronic patient data⁹.

NSVS data were used to define the 3x3 NELS study subjects. The 3x3 NELS dataset includes the 121,458 deaths in NS of NS residents from 1995 to 2009. Variables in the linked data include key quality indicators: enrollment in a PCP or not, time from PCP enrollment to death, and place of death (hospital, nursing home, own home). Covariates included are: age, sex, all causes of death, date of diagnosis and diagnoses from the disease registries and PCPs, dates of enrollment in disease registries and PCPs, palliative services recorded by disease programs, and postal code of residence at death. The postal codes at death were used to create distance from place of residence to PCP and DHA of residence, and were linked to the 2006 census data to produce neighbourhood social, economic, urban/rural, and minority group indicators. The 3x3 NELS data dictionary provides further details on these variables¹⁰.

Since there were missing and invalid Health Care Numbers (HCNs) in the datasets, *probabilistic linkage* was used to create the 3x3 NELS dataset. The identifying information used for the linkage included HCNs, names, dates of birth and death, hospital code at death, and postal code of residence at death. Ron Dewar, a CCNS SEU analyst with many years of probabilistic record linkage experience, carried out the linkage. He was the only individual with access to these personal identifiers; he has no access to the 3x3 NELS analysis data. The personal identifiers were replaced by a new 3x3 NELS study identifier for each study subject prior to creating and providing the 3x3 NELS study data to 3x3 NELS study analysts.

Research Ethics Board (REB) approval was received from Capital Health, Cape Breton and Colchester East Hants Health Authorities. The 3x3 NELS analysts were paid by ICE funds from a CIHR research grant (see <http://www.dal.ca/sites/nels/research/ice.html>) to NELS. The aim of NELS ICE funding was to build interdisciplinary capacity for research to identify and address the needs of vulnerable populations at end of life. Increasingly, it has been recognized that persons with advanced diseases need improved palliative support. Given this CIHR ICE funding, the NELS program of research moved from a cancer focus to study a range of diseases that can advance to being life limiting.

⁷ 3x3 NELS study protocol is at http://www.dal.ca/content/dam/dalhousie/pdf/sites/nels/protocol_3x3NELS.pdf

⁸ Canadian Institute for Health Information (2011) Health Care Use at the End of Life in Atlantic Canada. Ottawa; Canadian Institute for Health Information (2007) Health Care Use at the End of Life in Western Canada. Ottawa

⁹ For more information on the need to develop standardized province-wide PCP data collection, see Johnston G (2012) Plan for Discussion: Palliative Care Database development in Nova Scotia, at: http://www.dal.ca/content/dam/dalhousie/pdf/sites/nels/report_PCPdataplan2012.pdf

¹⁰ The 3x3 NELS data dictionary is at: <http://www.dal.ca/content/dam/dalhousie/pdf/sites/nels/3x3datadictionary.pdf>

Lessons Learned

The 3x3 NELS study supported the provincial disease programs in working together on data development pertaining to palliative and end of life care. While it took time to develop processes and carry out the study, the value is now apparent in terms of identifying data quality issues that need to be addressed, a greater understanding of service patterns and multi-morbidities at end of life, and clarity of opportunities for the disease programs to help improve palliative care and the provision of quality indicators for assessing this care.

Ongoing 3x3 NELS study discussions helped the disease programs individually and collectively to better understand palliative and end of life care needs. An example of this learning is the distribution of Nova Scotians by the end-of-life trajectories of functional decline of Lunney et al¹¹ (Figure 1). About 5% of Nova Scotians have a sudden death where advance care planning is not possible. Approximately a third of Nova Scotians die of a terminal illness such as cancer. Another third follow an organ failure functional decline; the last third have a frailty trajectory. With concerted effort, it is possible to enable advance care planning¹² and palliative support to most of these persons as death approaches.

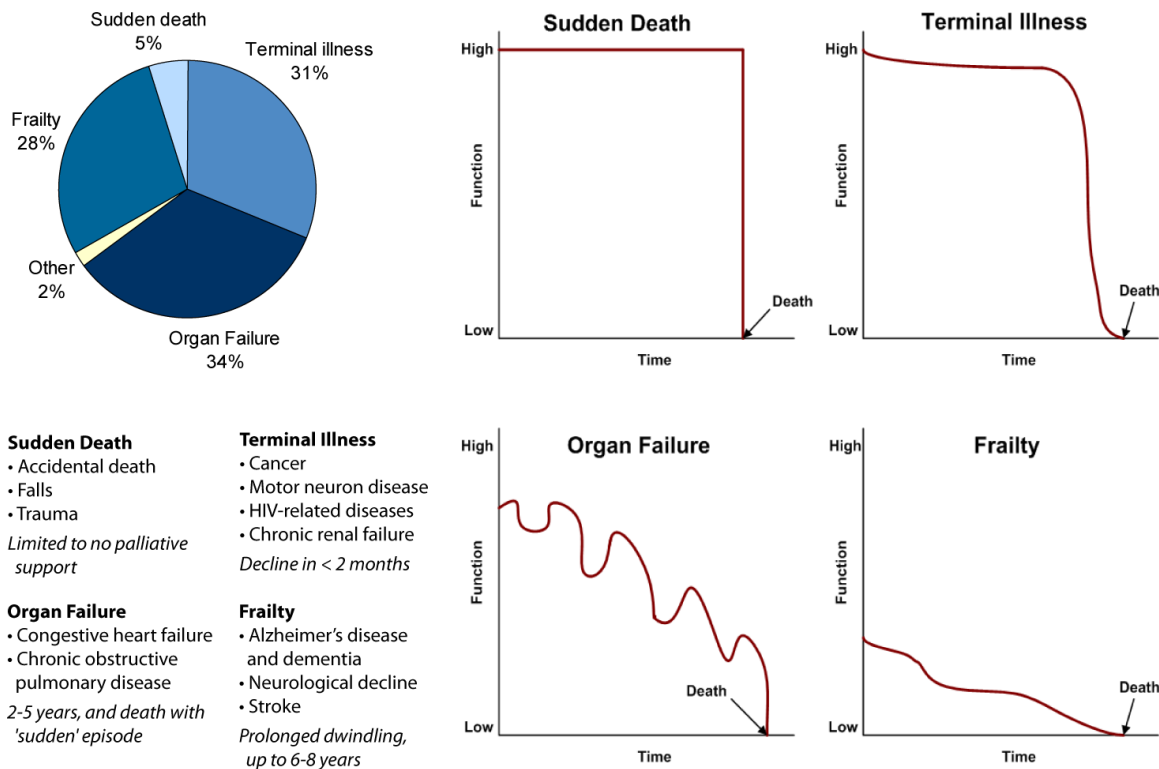


Figure 1: Proportion of Nova Scotians dying from 1995-2009 by end-of-life care trajectory

¹¹ Lunney JR, Lynn J, Foley DJ, et al. Patterns of functional decline at the end of life. *JAMA*. 2003;289(18):2387-92.

¹² For more information on advance care planning in Canada, see <http://www.advancecareplanning.ca/>. A parallel initiative in the US is: <http://theconversationproject.org/>

Historically, palliative care has focused on persons at end of life with cancer. 3x3 NELS study data show that an average of over 60% of the people dying of cancer from 1998 to 2003 were enrolled in a palliative care program. By 2008-9, the rates averaged over 70%. (Figure 2)

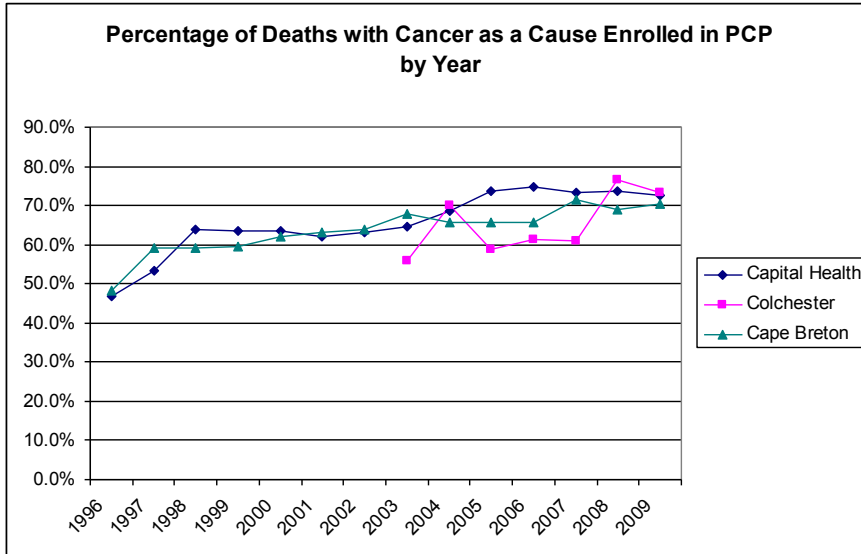


Figure 2: Trend over time in proportion of persons dying of cancer in three Nova Scotia District Health Authorities who were enrolled in a palliative care program

Concurrent with this slow and steady increase in the percent of persons dying of cancer being enrolled in a palliative care program, a much more rapid increase in palliative care program enrolment was observed for persons with non-cancer causes of death (Figure 3).

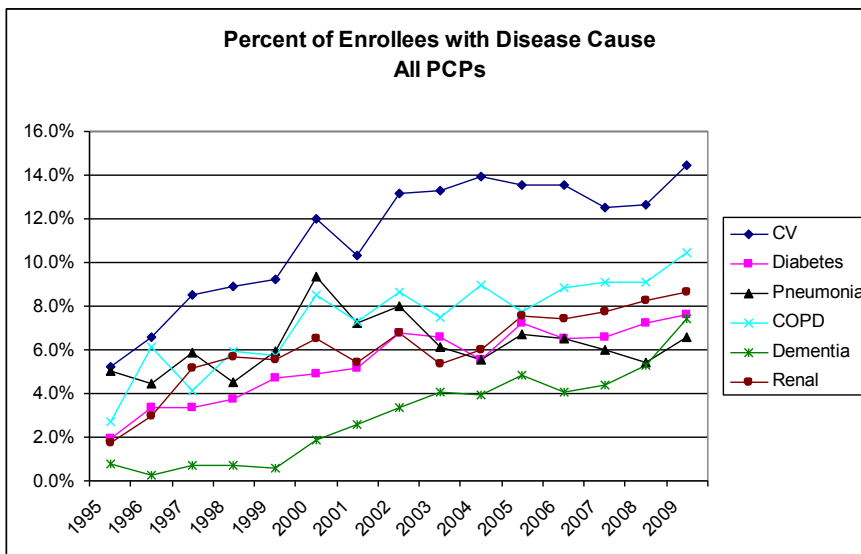


Figure 3: Trend over time in proportion of persons dying of disease other than cancer in three Nova Scotia District Health Authorities who were enrolled in a palliative care program

In 1995, approximately 5% of persons dying with cardiovascular (CV) disease as one of their causes of death were enrolled in a palliative care program. By 2009, the palliative care program enrolment rate averaged over 13% for persons with cardiovascular disease either primarily causing or contributing to their death. For persons with diabetes as one of their causes of death, the rise in palliative care program enrolment increased from 2% to almost 8% over the fifteen-year 3x3 NELS study time period. Persons dying with renal disease as one of their causes of death experienced a similar increase in their palliative care program enrolment rate. The enrolment rate was slightly greater (10% by 2009) for persons with chronic obstructive pulmonary disease (COPD) as a cause of their death.

Successful partnerships were established between the 3x3 NELS researchers and the four provincial chronic disease programs (cancer, cardiovascular, diabetes, renal), and across the three programs (cancer, cardiovascular, diabetes) that linked data from each of their disease registries for the first time. The 3x3 NELS researchers provided relevant materials over three years that increased the chronic disease programs' understanding of end of life care. The provincial programs are now aware of the extent to which their populations could benefit from a palliative approach to care, and they have begun to disseminate their increased knowledge with others. The programs benefited from increased methodological knowledge on the development of quality indicators for care at end of life, and also data quality assessment methods and findings pertinent to the assessment of care at end of life. By working directly with the chronic disease programs, the 3x3 NELS researchers were able to better understand and therefore more meaningfully interpret the research findings. Collaborative learning, analytic partnerships, and dialogue with researchers are important to continue to further improve care for persons approaching end of life.

Data Quality

Ensuring the reliability and validity of data (including completeness and timeliness) is critically important for making informed policy and program decisions. For surveillance reports to be as accurate, sources of potential data errors need to be investigated. As part of the 3x3 NELS study, the data quality of four key variables was examined: Health Card Number (HCN), Postal Code of residence, Nursing Home Resident, and Causes of Death¹³.

Completeness of Health Card Number

Missing HCNs undermine the completeness and accuracy of record linkage. In NS, linkage to physician billings, in-patient hospital discharges, the prescription monitoring program, emergency health services, and some other databases are dependent on complete and accurate HCNs being available for each study subject since multiple personal identifiers are not readily available in these databases. Linkage of these databases to NSVS records also requires complete and accurate HCNs in the NSVS data.

To determine the completeness and accuracy of the HCNs in NSVS data, for each 3x3 NELS study subject, the probabilistic linkage analyst created variables to indicate whether a HCN number was recorded for all subjects in each data source (NSVS, PCPs, disease registries).

¹³ For the tables and figures that inform this section, see PPTs at: **Johnston G**, Lethbridge L (2013) Chronic Disease and Palliative Care Program Data Linkage and Analysis Project: NSVS Data Quality report from 3x3 NELS http://www.dal.ca/content/dam/dalhousie/pdf/sites/nels/slides_LethbridgeJan2013.pdf

Overall, probabilistic record linkage was effective for creating the 3x3 NELS dataset. However, because HCN was the only personal identifier available in the DCPNS database, some linkages to the DCPNS could have been missed in the creation of the 3x3 NELS dataset. For example, a person with diabetes as a cause of death could fail to be linked to the DCPNS database simply because the NSVS death certificate for this person did not have a HCN.

Among the 3x3 NELS study subjects, 83.1% had a HCN on their NSVS death certificate; among these, 266 (0.24%) had an incorrect HCN. For study subjects who did not have a NSVS HCN, the probabilistic linkage process was used to retrieve as many missing HCNs as possible. A HCN was available from CCNS data for a further 5.8%, and an additional 1.2% from the CVHNS registry. Less than 1% of additional HCNs were obtained from PCP data. Thereby, HCNs were available for 90.1% of the 3x3 NELS study subjects. As was expected, missing HCNs could be retrieved for persons who were in the cancer registry, but 100% retrieval of HCNs for all persons in the 3x3 NELS dataset was not expected since the 3x3 NELS dataset included some persons who were not in the cancer registry, CVHNS registry, or a PCP dataset with a HCN.

HCNs were more likely to be missing from NSVS death certificates for deaths occurring before 1999. In 1995, less than 70% of the deaths had HCNs in the NSVS data; from 1999 to 2009, HCNs were almost 95% complete. HCNs were most complete in the NSVS data for persons 60-99 years.

For 3x3 NELS study subjects who had a postal code, the completeness of HCNs by DHA was over 90% for each DHA. However, Capital Health and Cape Breton had rates closer to 90%, and Colchester East Hants was closer to 95%.

A common and timely method for the provincial disease programs to obtain complete death certificate data should be developed and implemented. As has been noted in the 2012 report for the PCPs in NS¹⁴, the PCPs also need the ability to carry out death clearance of their databases to better understand their wait times from referral to assessment and death. This process should include *backfilling missing health card numbers and postal codes* in death certificate data. This could be done by probabilistic linkage of multiple identity fields to the provincial HCN database. Alternatively, if the provincial programs were given approval and resources, CCNS has the skills and probabilistic software to backfill the HCNs missing from NSVS death certificate data by probabilistic linkage to the HCN database, e.g. through the Central Client Registry to which health programs have access. The recent introduction of electronic death registration by funeral directors for submission to Nova Scotia Vital Statistics (NSVS) should improve the timeliness of access to electronic death registration.

Completeness of Postal Codes

Postal codes of the study subjects were used for three purposes: create distance from place of residence to PCP, identify DHA of residence, and produce neighbourhood social, economic, urban/rural, and minority group indicators by linkage to 2006 census enumeration area data.

¹⁴ "Plan for Discussion: Palliative Care Database development in Nova Scotia" at: http://www.dal.ca/content/dam/dalhousie/pdf/sites/nels/report_PCPdataplan2012.pdf

For 90.5% of the 3x3 NELS study subjects, there was a postal code obtained from the place of residence address (or place of death if this was not a hospital) on their NSVS death certificates. For a further 3.2%, a postal code was obtained from the CCNS data, and for an additional 1.2% a postal code was obtained from the CVHNS or PCP data. Thus, overall, a postal code of residence was obtained for 94.9% of the study subjects. However, some of these postal codes were not valid postal codes. Postal codes were almost 100% complete for persons who died from 2005 onward. However, postal codes were only about 90% complete for deaths from 1995 to 1999.

Rates of postal code availability were lowest (about 85%) for persons aged 10 to 39. This age range also had lower HCN completeness. While the majority of deaths occur at older ages, understanding the extent and predictors of deaths to teens and younger adults also needs attention. All study subjects of all ages were included in descriptive statistics such as the age and sex distribution of the study subjects. However, *analyses by DHA, distance to PCP, and neighbourhood socioeconomic indicators will be missing varying rates of teens and younger adults. This problem is compounded in studies using linkage to multiple datasets that depend on the completeness of HCNs.*

Identification of Nursing Home Residents

The provincial disease programs do not as yet receive data identifying who are nursing home residents, and their nursing home admission and discharge dates. Furthermore, there is no universally accepted definition of who is a nursing home resident. Knowing who are nursing home residents is critically important in understanding care for persons at end of life. In our earlier dying of cancer research, we used proxy identifiers of nursing home residents.

Studies lead by Fred Burge¹⁵ used physician billings data to identify persons as nursing home¹⁶ residents if they had a physician billing indicating a physician visit to a nursing home. Two weaknesses of this physician billings indicator are: 1) some persons may have been admitted to a nursing home but not visited by a physician who billed MSI before the person died, and 2) physicians must decide on what is a nursing home. Does this include private-pay residential care facilities as well as provincially licensed and funded facilities?

For published studies led by Grace Johnston¹⁷, physician billings data were not available. However, the CCNS had access to the full street address of the place of residence and place

¹⁵ Burge F, Lawson B, **Johnston G**, Grunfeld E (2008) A population based study of age inequalities in access to palliative care among cancer patients **Medical Care** 46(12):1203-1211

Burge F, Lawson B, Johnston G. (2005) Home visits by family physician during the end-of-life: Does income or residency play a role? **BioMedCentral - Palliative Care** 4:1-9

Burge F, Lawson B, **Johnston G**. (2005) Where a patient dies: The effect of rural residency. **Journal of Rural Health** 21(3):233-238

Burge F, Lawson B, **Johnston G**. (2003) Primary Care Continuity and Location of Death for those with Cancer. **Journal of Palliative Medicine**. 6(6):911-918

¹⁶ The Burge et al publications use the term "long term care" facility, rather than nursing home. This wording differentiated between the studies led by Burge, and those led by Johnston in the method used to identify nursing home residents. There was about a 90% agreement in the designation of a nursing home resident when the two methods were compared by Bev Lawson.

¹⁷ Gao J, **Johnston GM**, Lavergne MR, McIntyre P (2011) Identifying population groups with low palliative care program enrolment using classification and regression tree analysis. **Journal of Palliative Care** 27(2): 98-106

of death on the NSVS death certificates. From these street addresses, a CCNS analyst developed an algorithm using the place of residence and place of death NSVS addresses to generate a nursing home flag¹⁸. In this algorithm, if either the death or residence address indicated a nursing home, then the study subject was labeled as a nursing home resident¹⁹. For this flag, only provincially licensed and funded facilities and veterans facilities were included. There are three types of facilities: nursing homes and homes for the aged, residential care facilities for seniors, and community-based options. All three were included as nursing home residences in the CCNS algorithm. One problem with the CCNS algorithm is that residents of facilities with a range of services e.g. including both nursing home and acute care or residential care were coded as nursing home residents even though this may not be their actual status. Also, as noted in the discussion of missing postal codes, missing NSVS street address was equally problematic.

Across the databases used to create the 3x3 NELS dataset, there were seven different indicators of residence in a nursing home, in addition to a flag indicating nursing home as the place of death. We could not determine a clear, unambiguous, universal definition of 'nursing home resident' for any of these indicators, including those now being recorded in NSVS records. The time periods and populations included varied across indicators, so this needed to be taking into account in the 3x3 NELS data quality analyses.

Two nursing home indicators were created by NSVS and are in NSVS death certificate data; one NSVS nursing home indicator was introduced in 2002 and the other in 2008. The indicator introduced in 2008 uses a drop down menu; a NSVS data entry person enters nursing home or not. The other appears to use address information to flag the individual of a nursing home resident but we do not know what the algorithm is.

The CVHNS registry retains the admit to/discharge from a nursing home flag in the inpatient hospital admission and discharge database. This flag does not identify nursing home residents that have not been hospitalized.

Cape Breton PCP data has two nursing home indicators. One is a variable to indicate the location of death; it includes names of nursing homes. The other is an indicator of the institution the patient was referred from which includes nursing homes. Colchester East Hants PCP data has one nursing home indicator, which is a variable called "resident_type" that includes nursing home and seniors options.

Given that the first objective of the 3x3 NELS study is the assessment of data quality, and nursing home residence is a key variable, the quality of the various nursing home flags was of concern. Since there is no 'gold standard' database identifying NS nursing home residents, we assessed the data quality of the various nursing home indicators through a set

Lavergne MR, **Johnston GM**, Gao J, Dummer TJB, Rheame DE (2011) Variation in the use of palliative radiotherapy at end of life: Examining demographic, clinical, health service, and geographic factors in a population-based study. **Palliative Medicine** 25(2):101-110

O'Brien MB, **Johnston GM**, Gao J, Dewar R (2007) End of life care for Nursing Home Residents Dying of Cancer in Nova Scotia, 2000-2003. **Supportive Care in Cancer** 15:1015-1021

¹⁸ For details on the development of the CCNS nursing home algorithm, see pages 26 to 32 of the report at: <http://www.cancercare.ns.ca/site-cc/media/cancercare/DetailedMethods.pdf>

¹⁹ Since the CCNS algorithm covers the entire 1995 to 2009 study period and could be used for all 3x3 NELS study subjects with a street address on their death certificate, the CCNS algorithm is used for 3x3 NELS papers prepared for publication and descriptive statistics of nursing home residents.

of cross tabulations, the assumption being that if they were all equally valid in identifying a nursing home resident, there should be a high agreement between the multiple nursing home flags for each 3x3 NELS study subject. If two nursing home indicators being compared indicate that the person is a nursing home resident or both indicate that the person was not a nursing home resident then this represents observed agreement. If they disagree, then this is non-agreement²⁰.

Since there are seven different indicators of a study subject being a nursing home resident in the 3x3 NELS data, this report does not include all possible cross-tabulations. Rather the *key study question was framed as: 'Now that NSVS has nursing home flags, can the NSVS flags be used in future studies as valid indicators of who is a nursing home resident?'*

Using the CCNS algorithm as the 'gold standard', there was about 90% agreement between both NSVS nursing home flags with the CCNS-derived flag. Kappa (0.7) indicates good but not excellent agreement. The substantial difference is that the NSVS flags underestimate the number of nursing home residents by 7-9%, in comparison to the CCNS indicator.

As would be expected, there was considerable agreement between the two NSVS flags. While there was not a perfect agreement between the Nursing Home and Extended Care NSVS flags (98.5%), for purposes of this report, the agreement appeared close enough. Therefore, only the NSVS Extended Care flag that was available for full years from 2003 onward was included in the remaining comparisons.

When both indicators of a nursing home resident in the Cape Breton PCP data were combined to create a CB PCP nursing home resident flag, there was high agreement (96.8%) with the NSVS Extended Care flag. This finding possibly supports the validity of the NSVS nursing home flag, in that there is strong agreement with this separate indicator of a person being a nursing home resident. This conclusion assumes that the CB PCP location of death flag is not based on the Extended Care flag from NSVS, for example, indirectly through a linkage to the provincial HCN database. Beyond this, there are other limitations: data are only for Cape Breton (CB) and only for persons that are enrolled in the CB PCP. It cannot be assumed that the NSVS Extended Care Resident flag is equally valid for persons in Cape Breton who are not enrolled in the PCP. For example, PCP staff may be completing death certificates, by referencing their own PCP records.

Colchester East Hants (CEH) PCP data had only one nursing home indicator. The CEH PCP had lower agreement with the NSVS Extended Care flag (91.2%); Kappa (0.36) indicates that the agreement approaches the cut-level for being labeled as poor. In other words, the labeling of who is and is not a nursing home resident approaches that of a being a chance finding. Thus, in contrast the to CB PCP findings, the CEH PCP findings do not strongly support the validity of the NSVS Extended Care indicator. However, we cannot tell from these data whether this is a NSVS and/or a CEH issue.

²⁰ The Kappa statistic was computed as a measure of agreement that accounts for chance agreement. For example, two people each flipping coins will show agreement some of the time, simply due to chance. The Kappa statistic accounts for this. Kappa is based on probability theory; the probability of 2 events occurring together is the product of each individual probability if the 2 events are independent. $K = [P(\text{actual}) - P(\text{chance})] / [1 - P(\text{chance})]$; chance=expected; P=probability. Kappa is considered to be conservative. Kappa generally runs from 0 to 1 although there are some circumstances where there can be a negative value (agreement occurs less than by chance alone). Although guidelines differ and are admittedly arbitrary - Fleiss suggests > .75 excellent; 0.40-0.75 is fair to good and < .4 is poor.

The poorest agreement (83.4%) was observed between the CVHNS registry nursing home flag and the NSVS Extended Care flag. Kappa (0.3) is in the poor agreement range. The 6.6% for whom the NSVS data indicate that study subject was a nursing home resident, but the CVHNS registry does not confirm this, was not unexpected since the source of the CVHNS flag is the provincial hospital inpatient DAD data. Thus, under-identification of nursing home residents in the CVHNS database was expected since the CVHNS had no way to flag persons in their registry as nursing home residents, if they were not admitted to hospital. *The unexpected finding was that for 10.1% of the 3x3 NELS study subjects registered in the CVHNS registry as nursing home residents, NSVS death certificate data did not confirm this. This raises the question on whether the provincial DAD data and the provincial NSVS data code nursing home residency in the same way.*

So, what percentage of those who die in NS are nursing home residents? The answer to this question is far from clear. Since the CCNS indicator is available for all years and has been the indicator used in previous publications, and since the province of NS may not have a registry of nursing home residents, the nursing home flag created for all 3x3 NELS study subjects *using the CCNS algorithm* might be used as the gold standard. Thereby, one *would conclude that 23.0%* of the NS who died from 1995 to 2009 in NS were nursing home residents.

However, *if either of the NSVS flags were used, then the rate would be either 16.8% or 15.0%* depending on which indicator and thereby years are used. Since the years included were less than the full range of 3x3 NELS study years, the nursing home resident rates restricted to the NSVS indicator years, was calculated using the CCNS algorithm. These rates (21.3% and 23.4%) were not substantially different from the rate for the full range of years (23.0%). Thus, the years included does not appear to explain the difference between the nursing home rate using the NSVS versus CCNS indicators.

Given these observations, as well as the 9.5% missing postal code (address) rate in NSVS records, there is support for concluding that there *may be substantial (more than 50%: 23.4%/15.5% = 1.56) under-reporting of nursing home residency in the NSVS data* by comparison with the CCNS algorithm.

The fact that the CVHNS nursing home flag indicated a lower percentage of nursing home residents (15.5%) was not surprising. Persons who were registered in the CVHNS may after their hospital discharge be admitted to a nursing home at a later time, and their nursing home residency would probably be included on their death certificate but not in CVHNS data.

What was more surprising was that only 10.7% of the 3x3 NELS study subjects in the CVHNS registry were nursing home residents when defined as both the CVHNS and CCNS flags need to indicate that a person is a nursing home resident. The almost 50% difference between the 15.5% and 10.7% implies that the *CCNS algorithm-derived identifier of nursing home residents may be an under-report*, in that some of the CVHNS nursing home flagged study subjects (15.5%) did not have a CCNS algorithm indication of being a nursing home resident. *This could be due to the missing addresses in the NSVS data, a more inclusive definition of nursing home resident in the DAD database, or other sources of lack of congruence.*

Using the CCNS algorithm for the 3x3 NELS study subjects enrolled in the PCPs, the 8.7% rate of nursing home residents for the Cape Breton PCP and the corresponding rate of 10.7% for the Colchester East Hants PCP were much lower than the 23.0% rate for all Nova Scotian residents. This is consistent with our study findings that nursing home residents have a lower rate of PCP enrolment. The Cape Breton indicator appears to be closer to the CCNS-algorithm derived measure (5.6% versus 5.0%) than is observed for Colchester East Hants (8.8% versus 5.3%).

In NS, there is a well-developed Department of Health and Wellness (DHW) database of assessments for home care and admission to a nursing home through the Single Entry Access (SEAscape) program. The single entry access program of the *Continuing Care unit manages a provincial database that includes data on the assessment of Nova Scotians for care in one's own home or a nursing home*²¹. These data follow accepted InterRAI²² and CIHI standards, and include symptom indicators. These data have been improving in completeness and quality over time, and *have been deemed of value for palliative and end of life studies*²³. The indication of approval for nursing home and home care, as well as the symptom indicator scales, can be used as indicators of need for supportive care. The provincial disease programs see the need for including *nursing home residents* in provincial palliative and end of life care surveillance. Nursing home residents are unlikely to be enrolled in palliative care programs, but a palliative approach to their care should be considered.

Both the PCPs and provincial disease programs would benefit from receiving an ongoing data feed from the DHW Continuing Care data. *The inclusion of data from this Continuing Care is advised for future studies of palliative care in NS.* In addition, ideally, the Business Intelligence, Analytics and Privacy (BIAP) and Continuing Care sections of the Nova Scotia DHW and the Vital Statistics division of Service Nova Scotia should work together to *develop one common and valid means of identifying nursing home residents, and nursing home as the place of death*, and this should be reconciled with Nova Scotia death certificate data. *The provincial disease programs should then be provided with these data fields: nursing home resident with dates of assessment, admission and discharge, and nursing home as place of*

²¹ On December 3, 2013, Peggy Dunbar was emailed the following description of the data available: "SEAscape is the main data collection database for Continuing Care. Its main purpose is to capture the RAI-HC assessments that we perform on clients that require Home Care and LTC services. We also use SEAscape to record all our intake and to create care plans for our clients to authorize services. SEAscape also records all the waitlist information for LTC and records the financial approvals and dates for LTC offers and acceptances. We have lots of data!

As for your questions on admission and discharge dates - we don't record the exact admission date to LTC but we do record the date of the offer and the date that the offer is accepted. This would be very close to admission date. Discharge date we would be able to produce."

²² There are three relevant InterRAI tools: home care, nursing home, and palliative care. The NS Seascapes database uses the InterRAI 'home care' tool for both home care and nursing home assessments. For many years, a small number of NS nursing homes have been using the InterRAI 'nursing home' tool that provides the opportunity to record admission and ongoing assessments in a format designed for nursing home residents. NS nursing homes do not have the staff, computers and training to routinely enter CIHI-advocated InterRAI nursing homes data. There is a third InterRAI tool for 'palliative care' that was purchased by NS DHW CC but may not as yet have been piloted.

²³ For further details, see pages 13-14 and Appendix I of: Report of Symptoms and Outcomes Measurement for End of Life Care in Nova Scotia, Canada (2012) at: http://www.dal.ca/content/dam/dalhousie/pdf/sites/nels/report_outcomesmeasurement2012.pdf

death. These data should also include the identification of who has been assessed and approved for nursing home placement but who was never admitted to a nursing home.

Cause of death on Vital Statistics death certificates

The accuracy of the cause of death²⁴ information on death certificates is very important for end of life studies using death certificates to define study subjects. On a death certificate, there can be up to 13 causes of death. The use of all causes of death, not just the main cause of death, is extremely important in that most people at end of life have more than one cause of death contributing to their functional decline.

Cancer as a cause of death has been shown to have high validity when compared to NS cancer registry data²⁵. This high validity was also observed in the 3x3 NELS study. Only 2.3% of 3x3 NELS study subjects with cancer as a cause of death were missing from the cancer registry. This 2.3% death-certificate-only (DCO) rate did not vary substantially by year. International standards for high quality cancer registries state that a DCO rate of 2-3% is expected since cancer is diagnosed at death for a small percentage of cases. A DCO rate of 0% indicates poor quality, usually due to the registry not carrying out a death clearance. The CCNS cancer registry has been in place for almost 50 years and thereby had the decades needed to attain complete case ascertainment.

The NSVS records did not have cancer as a cause of death for 27.9% of the persons enrolled in the cancer registry. This is not unexpected since many people diagnosed with an invasive cancer (and therefore enrolled in the cancer registry) do not die of their cancer. In other words, the cancer that was diagnosed and treated years ago, did not contribute to the person's death.

Diabetes and Cardiovascular disease. Persons who are dying of conditions other than cancer are increasingly being enrolled in PCPs. Therefore, it is timely for the CVHNS and DCPNS programs to be exploring the extent of need for palliative care for persons in their registries, and to examine the quality of data that could be available to them from NSVS records for this process. For both the CVHNS and DCPNS registries, much higher DCO rates were observed than was found for cancer: 47.9% for the CVHNS, and 44.6% for the DCPNS²⁶. As was expected with the development of a new disease registry, the DCO rates steadily dropped each year since the beginning of these registries about 15 years ago. By the end of the 3x3 NELS study period, these DCO rates were down to 36.5% for the cardiovascular registry and 43.0% for the diabetes registry²⁷. *High DCO rates for the diabetes and cardiovascular registries were expected given how cases were enrolled in these registries.*

DCPNS cases were enrolled primarily through referral to community-based education clinics. Therefore, persons diagnosed with diabetes in hospital or a nursing home and/or at

²⁴ The ninth edition of the International Classification of Disease (ICD) is used for 1995-1999 and the tenth edition from 2000 onwards.

²⁵ **Johnston GM**, Burge FI, Boyd CJ, MacIntyre MM (2001) End-of-Life Population Study Methods. **Canadian Journal of Public Health** 92(5):385-386

²⁶ International DCO rate standards for diabetes, cardiovascular, renal and other non-cancer disease registries have yet to be developed. Therefore, we do not know as yet what are the appropriate DCO rate benchmarks for chronic disease registries other than cancer.

²⁷ See slide 11 at: http://www.dal.ca/content/dam/dalhousie/pdf/sites/nels/slides_LethbridgeApr2012.pdf

an advanced stage of disease, when preventive education may be less relevant, were expected to be missing from the DCPNS registry. Persons with diabetes as a cause of death had more causes of death (4.2) on average than observed for all decedents (2.9)²⁸.

Since diabetes may be managed as a comorbidity by clinicians treating another condition, such as cardiovascular disease, we searched for diabetes cases in the other databases used in the 3x3 NELS study²⁹. Among the 10.7% of persons who had diabetes coded as one of their causes of death, 95.8% had the diagnosis of diabetes confirmed by linkage to another data source. In other words, when diabetes is listed as a cause of death on a death certificate, there is a very high probability that the decedent did have diabetes. Therefore, more complete case ascertainment would be possible if the diabetes program was provided with all persons with a NSVS death certificate with a cause of death of diabetes, as well as access to diabetes cases identified in the provincial cardiovascular, renal and cancer registries. The cancer registry does not as yet record comorbidities but it is recommended that comorbidities be recorded in the future since comorbidities can influence care plans, and cancer treatment can result in side effects that increase the risk of developing other conditions, e.g., diabetes can be a consequence of aggressive chemotherapy for cancer,

CVHNS cases are enrolled from inpatient hospital records. Therefore, cardiovascular cases treated out-of-hospital, including in nursing homes, are less likely to be registered. Once we can be assured that a disease registry has complete case ascertainment then the quality of the coding of cause of death on death certificates for these diseases can be more fully attained. In the meantime, the high validity of the cancer and diabetes causes of death prompt the decision to continue to use cause of death to plan for care at end of life.

Renal disease. While the NSRP did not have data available for the 3x3 NELS study, in recent years, it has developed an electronic registry that could be incorporated in 3x3 NELS type studies in future years to validate renal disease as a NSVS cause of death. In the meantime, 3x3 NELS study data were used to provide a report on renal cause of death³⁰. On average, 2 to 3 Nova Scotians die each day with renal disease on their death certificate. More than 850 persons died with renal disease in NS in 2009. In 2009, 10% of Nova Scotian decedents had renal disease as a cause of death; this percentage increased from 7% in 1996. Compared to other decedents, persons dying of renal disease are more likely to be older and male. Persons dying of renal disease have an average of four causes of death on their death certificates, which is greater than the average of less than three causes of death observed for all decedents. *The co-morbidities observed for renal decedents include cardiovascular disease (44.8%), diabetes (22.0%), cancer (16.9%), COPD (10.7%) and dementia/ Alzheimer's (7.0%). Persons dying of renal disease were identified in other provincial disease registries: cancer (37% of NS renal deaths, 2006-2009), cardiovascular (32% of 2009 renal deaths, steady increase from 15% in 1996), and diabetes (17% of 2009 renal deaths, projected to increase in the future).* Increasingly, persons dying of renal disease are also being seen in PCPs.

²⁸ See http://www.dal.ca/content/dam/dalhousie/pdf/sites/nels/poster_JewellLethbridgeJohnston.pdf

²⁹ Johnston G, Lethbridge L, Talbot P, Dunbar P, Jewell L, Henderson D, d'Intino AF, McIntyre P (2013) Importance of identifying persons with diabetes who could benefit from palliative care. Being submitted to **Canadian Journal of Diabetes**

³⁰ See http://www.dal.ca/content/dam/dalhousie/pdf/sites/nels/slides_LethbridgeApr2012Renal.pdf

*Chronic Obstructive Pulmonary Disease (COPD)*³¹ is of interest given that Graeme Rocker was a co-investigator on the NELS ICE grant and he developed the INSPIRED program³² in CDHA for persons at end of life with COPD to minimize their time in hospital and need for emergency department visits. *Among the 3x3 NELS study subjects, 11.5% had COPD as a cause of death but only 1.3% had COPD as an underlying cause of death. Among those with COPD as a cause of death, 36.0% were in the cancer registry, 29.2% in the cardiovascular registry, and 8.8% in the diabetes registry. These findings indicate that there could be merit for those planning for care at end of life for persons with a specific disease, for which there is no provincial registry, to work with the provincial disease programs to provide a complete picture of the palliative support needed and to coordinate care.*

*Dementia and Alzheimer's disease are the most rapidly increasing causes of death among PCP enrollees*³³. This is consistent with an aging population. Persons dying of *Parkinson's disease* had higher rates of Alzheimer's and dementia, but lower than expected rates of cancer³⁴. These findings again show that *persons at end of life have multi-morbidities that need to be considered to provide optimal palliative support*³⁵, especially as our population ages.

Enabling complete case ascertainment and being given access to all causes of death by the provincial disease registries is critically important for assessment of data quality and for developing a full understanding of the issues being addressed by persons at end of life. This need is urgent since people will increasingly have multi-morbidities at end of life as our population ages. *All provincial disease programs should be provided with access to all causes of death for all persons in their disease registries, and the opportunity provided to obtain DCO cases relevant to their disease focus.*

Palliative and End of Life Care Quality Indicators

*Quality indicators derived from administrative data are being used to examine adequacy in the provision of palliative care*³⁶. Two frequently used quality indicators are the rate of enrolment in a PCP, and the place of death³⁷. Time from PCP enrolment to death is also a quality indicator since a short time between enrolment and death is not optimal. Beyond this, equity in access to care at end of life needs to be assured to avoid inadequate care for some subpopulations. These quality indicators were produced from the 3x3 NELS data.

³¹ See http://www.dal.ca/content/dam/dalhousie/pdf/sites/nels/slides_LethbridgeFeb2013.pdf

³² Horton R, Rocker G, Dale A, Young J, Hernandez P, Sinuff T (2013) Implementing a palliative care trial in advanced COPD: A feasibility assessment. **Journal of Palliative Medicine** 16(1) : 67-73;

Rocker GM, Simpson AC, Young J, Horton R, Sinuff T, Demmons J, Donahue M, Hernandez P, Marciniuk D (2013) Opioid therapy for refractory dysnea in patients with advanced chronic obstructive disease: patients' experiences and outcomes. **CMAJ Open** E27-E36 .DOI:10.9778/cmajo.20120031

³³ http://www.dal.ca/content/dam/dalhousie/pdf/sites/nels/poster_JohnstonLethbridgeMcIntyreetal2012.pdf

³⁴ Lethbridge L, Johnston G, Turnbull G (2013) Planning for care for person's at end of life with Parkinson's disease using death certificate data. **Progress in Palliative Care** 21(3):140-145

³⁵ The diagnosis codes in the PCP databases were examined by comparison to disease codes in other 3x3 NELS databases. In summary, the PCP diagnoses are problematic. Therefore PCP diagnoses were not used to examine the validity of cause of death on NSVS death certificates.

³⁶ Steering Committee of Cancer Statistics (2010) **Canadian Cancer Statistics 2010**. "Special Topic: End of Life Care" Barbera L, Burge F, Dumont S, Fassbender K, Johnston G, Lau F Toronto: Canadian Cancer Society, 69-86

³⁷ While place of death has been widely used, a better measure is days in hospital in the last month of life.

Generation of this measure require linkages to the provincial hospital admissions file.

Lawson B, Burge FI (2010) Re-examining the definition of location of death in health services research. **Journal of Palliative Care** 26(3):202-4

In addition, *other indicators* of inadequate community-based care are *emergency department visits* and *long in-patient hospital stays*. Adequate access to medications for pain control indicates good end of life care. There are also *disease-specific indicators*, e.g. *support by the CCNS patient navigators*. *A five to ten year plan should be developed and resourced for the production of an enhanced set of indicators of quality care at end of life.*

Enrolment in a Palliative Care Program

PCP enrolment is accepted as an indicator of access to quality care at end of life³⁸. PCPs are designed to provide comprehensive, multidisciplinary symptom control and supportive care for persons at end of life and their families. Ideally, this includes information on allowing a natural death (AND), 24/7 advice and support, minimization of pain and adverse symptoms, and a holistic approach to maximize quality of life.

Historically, palliative care focused on persons with cancer. Compared to other geographic areas, the *rates of PCP enrolment for persons dying of cancer in NS have been relatively high at about 70%* in recent years and at least 60% for more than ten years³⁹. *Nursing home residents had considerably lower rates; this has not changed much over time.*

Increasingly, persons approaching end of life with conditions other than cancer are being enrolled in all three PCPs in the 3x3 NELS study. In 1995, about 5% of the PCP enrollees had a cardiovascular cause of death, and 2% diabetes. By 2009, almost 15% had cardiovascular cause of death, and almost 8% had diabetes. More than 10% in 2009 had renal disease. Colchester East Hants and Cape Breton have higher non-cancer rates than Capital Health.

Using Rosenwax et al⁴⁰ methods, *as a minimum, persons with these conditions could benefit from palliative support: cancer, heart failure, renal failure, COPD, Alzheimer's, Liver Failure, Parkinson's disease, Motor neuron disease, Huntington's disease, and HIV/AIDs.* 3x3 NELS show that *less than 50% of persons with these conditions listed on their death certificates are being seen by the PCPs.* When the maximal Rosenwax et al estimate is used⁴¹, *only about 30% of the persons dying in NS who could benefit from a palliative approach to their care were enrolled in PCP.* Rosenwax et al include a mid-range estimate but this requires hospital diagnosis data to operationalize.

Timely Palliative Care Program Enrolment

Wait times are critical. Timely enrolment in a PCP is another indicator of quality palliative care. A short time from PCP enrolment until death is not considered optimal. *The percentage of persons enrolled in a PCP within fourteen days of death indicates suboptimal support. Approximately 30% of persons dying of cancer are being enrolled in the last two weeks of their*

³⁸ 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

³⁹ See http://www.dal.ca/content/dam/dalhousie/pdf/sites/nels/poster_JohnstonLethbridgeMcIntyreetal2012.pdf

⁴⁰ Rosenwax, LK, Blackmore AM, Holman CDJ (2005) Estimating the Size of a Potential Palliative Care Population **Palliative Medicine** 19: 556-562.

⁴¹ All deaths except those during pregnancy or childbirth, originating during the perinatal period, or originating from injury, poisoning or other external causes (sudden death).

life⁴². Another concern is that some persons referred to a PCP die before being seen by PCP personnel. Therefore, development of a primary care palliative approach is advocated⁴³.

Note that while the term PCP enrolment is used, the situation is more complex than this term implies in that more than one date needs to be recorded. As a minimum, both referral and first assessment dates are needed. Reassessment and discharge dates should also be considered for inclusion. Some PCPs already have multiple dates recorded.

NELS ICE funding was used to pay for an analyst to produce all the 3x3 NELS stand findings to date, including times from PCP enrolment to death. However, NELS ICE funding has now ended. If new resources become available, an analyst with REB approval could use the 3x3 NELS dataset to generate predictors of short time from PCP enrolment to death, and descriptive statistics on the timing of PCP enrolment in relation to dates of registration in the disease programs. An early NELS study⁴⁴ demonstrated the value of using a data-mining technique called classification and regression tree (CART) analysis (also called recursive partitioning) to predict short time from PCP enrolment to death. Ideally, CART should be used for this proposed predictor analysis.

Place of Death (Hospital, Nursing Home, own home)

Numerous studies report that *people do not want to die in hospital if there is adequate community support*. However, the Canadian health system has been built largely on public funded hospital and physician care. An international ranking report states that Canada's major weakness in the delivery of palliative and end of life care is poor development and access to seamless community-based care⁴⁵. Hospital inpatient care is expensive, and not advisable for the majority of persons at end of life, the exception being the need for specialized palliative units for complex symptom management.

Not unlike other Canadian provinces, *NS has a relatively high (62.1%) rate of deaths in hospital*. There has been a slight decline from just less than 65% in 1995 to less than 60% in 2009 in hospital as the place of death. This decline is being seen for nursing home residents, especially in recent years; the rates of hospital death have declined from about 25% to 20%. Rates vary by cause of death. For example, averaged across 1996-2009, 77.2% of renal decedents in NS died in hospital.

The 3x3 NELS project used NSVS codes on the death certificates to identify place of death. If hospital discharge and admission (DAD) data were used, it is expected that the percentages would be approximately 10% lower since only inpatient deaths (i.e., excludes persons who die in the emergency department) are recorded as hospital deaths in DAD data.⁴⁶ Therefore, the *DAD, NSVS and continuing care data should be used together to create four measures of*

⁴² See slide 20 at: http://www.dal.ca/content/dam/dalhousie/pdf/sites/nels/slides_LethbridgeJun2012.pdf

⁴³Burge, F., Lawson, B., Mitchell, G. (2012) How to move to a palliative approach to care for people with multimorbidity. **BMJ**, 345: e6324. doi:10.1136/bmj.e6324

Shadd JD, Burge F, Stajduhar KI, Cohen SR, Kelley ML, Pesut B (2013) Defining and measuring a palliative approach in primary care. **Canadian Family Physician** 59 (Nov): 1149-1150

⁴⁴ Gao J, **Johnston GM**, Lavergne MR, McIntyre P (2011) Identifying population groups with low palliative care program enrolment using classification and regression tree analysis. **Journal of Palliative Care** 27(2): 98-106

⁴⁵ Ranking countries by quality of end of life care. (2010, July 14). **The Economist**. Retrieved from http://www.economist.com/node/16585127?story_id=16585127&fsrc=rss See Lien Foundation

⁴⁶ Neutel CI, Bishop ML, Samantha D. Harper SD, Gaudette LA (2005) Proportion of Cancer Deaths Occurring in Hospital, Canada 1994-2000. **Canadian Journal of Public Health** 96(4)264-8

place of death: i) died in hospital as an inpatient (ideally identifying palliative care, ICU, or other unit), ii) died in hospital (e.g. in emergency department) but not as an inpatient, and iii) died in own home which was not a nursing home, and iv) died in nursing home.

Variation by Socio-economic and Geographic factors

Multivariate analyses were carried out using 3x3 NELS data to understand socioeconomic and geographic predictors of the likelihood of receiving quality palliative care⁴⁷. Nursing home residents were removed since the nursing home postal code linked to census enumeration data would not provide valid measures of socioeconomic status. The *provincial disease programs could carry out ongoing postal code to census linkage for persons who are not nursing home residents to produce palliative care quality indicators by DHA, distance to care, and socioeconomic factors*, in addition to demographic factors.

In all PCPs, women were more likely to be enrolled in a PCP than men. In Capital Health, PCP enrolment was more probable for persons aged 50 to 64 than those who were younger or older; no statistically significant age gradient for PCP enrolment was observed in Colchester East Hants.

In Cape Breton, the PCP program was 5-6 times more likely to enrol an urban rather than a rural resident; this is consistent with PCP policies. In contrast, in Colchester East Hants, rural residents were more likely to be enrolled in the PCP. In all PCPs, persons living more than 50 km from the PCP were less likely to be enrolled.

The likelihood of persons at end of life in Capital Health being enrolled in a PCP was associated with economic and social deprivation. Also, in Capital Health, those living in neighbourhoods that were more socially deprived were more likely to die in hospital.

NELS researchers identified differing subpopulation needs for persons at end of life. Videos for the deaf community were developed⁴⁸. The needs of African Nova Scotians were studied⁴⁹, as well as Mi'kmaq ways to transition from this world^{50,51}. Cultural competence for Asian Indian immigrants was investigated⁵². Further learning and research is needed on these matters that span across the disease programs and DHAs.

⁴⁷ Lavergne R, Lethbridge L, **Johnston G** (2013) Palliative care program use and place of death in rural and urban contexts. In Oct 2013, submitted to **Journal of Palliative Medicine**

⁴⁸ <http://www.youtube.com/user/DeafPalliativeCare>

⁴⁹ Maddalena V, Bernard WT, Davis-Murdoch S, Smith D (2013) Awareness of palliative care and end-of-life options among African Canadians in Nova Scotia. **Journal of Transcultural Nursing**, 24(2): 144-52

⁵⁰ **Johnston G**, Vukic A, Parker S, (2013) Cultural understanding in the provision of supportive and palliative care: Perspectives in relation to an indigenous population. **BMJ Supportive and Palliative Care** 3:61-68

⁵¹ A database identifying aboriginal peoples in NS has been under development. Linkage to this database could be very informative, so long as information on people that have died have been obtained and retained in this new database.

⁵² Kanth F (2007) Cultural Competence in End of Life Care for Asian Indian Immigrants in Halifax.. BC NET Research Day, Vancouver, BC. See

http://www.dal.ca/content/dam/dalhousie/pdf/sites/nels/slides_KanthSep2006.pdfhttp://www.dal.ca/content/dam/dalhousie/pdf/sites/nels/slides_KanthSep2006.pdf

Opportunities for the Way Forward

All persons who could benefit from palliative support are not enrolled in a PCP. Furthermore, for many of those who are enrolled, the time between PCP enrolment and death is too short. From surveys around the world, the majority of persons want to die at home, but most die in hospital in Canada. This has led to national recommendations for improved advance care planning through new initiatives such as the Speak Up campaign⁵³, recommendations to expand primary care palliative support, and the need for population-based planning.

This report has demonstrated how a 3x3 NELS approach could enable this population-based planning to improve care at end of life in NS. Both the data quality assessment findings and the production of quality indicators have been informative. Throughout this report, opportunities for ways to move forward have been delineated.

The NS DHW has committed resources to the Maritime SPOR Support Unit (MSSU)⁵⁴ funded by the Strategy for Patient-Oriented Research (SPOR), which includes a collation of agencies and is lead Canadian Institutes of Health Research (CIHR). BIAP has recently renewed its multi-year agreement with Health Data NS (HDNS) for DAD, MSI Physician billings and Pharmacare data. BIAP is now working with MSSU and DHW partners to plan next steps in collaborating on approaches for operations and research in the years ahead to improve data and thereby health outcomes for Nova Scotians. A clear governance structure for decision-making, data access and transfer, and reporting is believed to be under development. It is assumed that through these developments, the provincial programs and others could plan to work together to build the next steps in the development of a surveillance database for care at end of life, modelled on the 3x3 NELS study.

The provincial disease programs are well positioned to partner in this process since they already have a mandate to provide guidelines and surveillance. They could be enabled to more readily identify those requiring palliative support. The 3x3 NELS data have been a rich source of insight for improving care in NS for those at end of life, as well as for research. *It is now time for this proven 3x3 NELS process to be formalized and further developed as an ongoing operational process*, and no longer be dependent on the uncertainties associated with independent researchers applying for research funding.

Concurrently, the 3x3 NELS data could continue to be used for further studies. Resources permitting, analyst(s) with Research Ethics Board (REB) approvals could carry out analyses to determine the value added of *probabilistic versus deterministic linkage* in relation to the 3x3 NELS study. Disease-specific studies could be carried out, e.g., to examine rates of disease associated with aggressive chemotherapy, other systemic therapy and radiation. Preliminary findings from British Columbia⁵⁵ indicate that cardiovascular rates were higher than expected among women survivors of breast cancer who have had aggressive oncology treatment. Also, plans are underway to use 3x3 NELS data to inform the expansion of the

⁵³ For more on the Speak Up campaign, see www.advancereplanning.ca

⁵⁴ For information on MSSU, see: <http://www.dal.ca/sites/cochrane/about-us/centres/maritime-spor-support-unit.html>

⁵⁵ Presented by Mary McBride in 2013 during a Canadian Council of Cancer Registries webinar

extended care paramedic role of Emergency Health Services in NS. Another step forward could be the design of a next study by building on what has been learned from 3x3 NELS⁵⁶.

A wide variety of other studies are needed and viable in linked administrative end of life care data become more readily available. A five to ten year plan should be developed, and resourced for the production of indicators of quality care at end of life. Beyond those reported from the 3x3 NELS data, there are additional indicators of the quality of care at end of life. Emergency department visits and long in-patient hospital stays are indicators of poor quality palliative care. Adequate access to medications for pain control is also an indicator of quality end of life care. There can be other and additional disease specific indicators.

While there is no provincial PCP database, through Research Ethics Board approved palliative and end of life care studies, CCNS has had access to PCP data and thus has some familiarity with these data. Also, a report⁵⁷ on how to improve PCP data in NS was prepared in 2012 at the request of the three PCPs in the 3x3 NELS study. It is timely for the all four provincial disease programs (CCNS, DCPNS, CVHNS, NSRP) to work collaboratively with the PCPs across the province, and the DHW, to develop province-wide PCP electronic data collection, storage, and analysis.

While some persons will favour developing one large data warehouse to house and process all NS electronic health data, I advocate grass-roots data development and quality control, along with enabled data linkage across databases using curated data practices. For this report, the term curated is used to mean that the linked health data have i) a gold stamp of approval, i.e., deemed of high quality by some authority, ii) rigorous methods to develop and maintain the data, iii) 'added value' of some specified type, iv) a data dictionary with "provenance", in other words, there is accurate, comprehensive, and easy-to-understand documentation of data fields with their coding, interpretation of codes, data sources, and changes over time in the data fields over the time period of the dataset, v) "curator(s)" who are person(s) available to explain data details, and vi) processes to provide wide access to methodologically qualified persons within clear ethical and data ownership stipulations

⁵⁶ For example, this next study might be called **4x5+ NELS** and again use administrative data linkage study. This could include **four** disease registries by including NSRP, i.e. the three disease programs involved in 3x3 NELS study: cancer, diabetes and cardiovascular, plus renal. It might be worthwhile trying to also add 1-2 more PCPs in other DHAs and the IWK (which includes children and youth across NS) beyond the three PCPs included in the 3x3 NELS study: Capital Health, Cape Breton, Colchester East Hants, Adding more PCPs depends on the availability of complete electronic PCP enrolments over a number of years. A check would need to be made with: Annapolis, South Shore, South West, Pictou, GASHA, and Cumberland. The 2008 report of PCP data availability by DHA prepared by Junaid Kapra for NELS ICE could be used as a guide for this step; it is available at: http://www.dal.ca/content/dam/dalhousie/pdf/sites/nels/surv_2008PCData.pdf. The aim might be for including a total of **five** PCPs in a next study. The addition of each dataset means a need to check the quality of the data, e.g. as was done for the Colchester East Hants PCP dataset by Lynn Lethbridge, and the Cape Breton PCP dataset by Martha Cox for the 3x3 NELS study. The study subjects could be all deaths in a set of more current years than in the 3x3 NELS study, e.g. 2006-2014 decedents as identified from NS Vital Statistics death certificates. While 2014 deaths are not available at this time, by the time a proposal is developed and approved, these deaths likely will likely be available. In addition, other databases could be considered for inclusion, hence the use of + in **4x5+** title e.g. i) emergency health services (paramedics/911), ii) SEAscape (Continuing care – nursing home and home care), iii) Prescription Monitoring Program, and iv) CCNS patient navigator.

⁵⁷ See the "Plan for Discussion: Palliative Care Database development in Nova Scotia" report at: http://www.dal.ca/content/dam/dalhousie/pdf/sites/nels/report_PCPdataplan2012.pdf

Development of a Dataset Enrollee File for End of Life (DEFEL) should be considered by the provincial disease programs to quickly identify which datasets actually have data on persons who have died. This could enable more efficient, timely and focused research and operations for end of life care multi-dataset surveillance and research projects for NS. DEFEL data may be sufficient in and of themselves for some studies. The DEFEL could also be used for identifying outcomes in studies unrelated to care of persons at end of life. The 3x3 NELS data dictionary⁵⁸ could be examined as a prototype to examine for building a provenance-driven data dictionary for DEFEL.

The provincial disease programs see the need to set consistent data standards and to monitor and enhance the quality of the data that will be used to produce palliative and end of life care quality indicators. CCNS is now in the process of adding hospital admission and separation data to its surveillance platform. The CVHNS already has data transfer from this source. The 3x3 NELS Data Field Dictionary can readily be adapted to provide infrastructure support for a curated palliative and end of life care linked dataset. Thus, these and other processes that could be underpinnings to end of life care surveillance already exist.

A 3x3 NELS approach to end of life care surveillance requires that study subjects be identified from NSVS death certificate records⁵⁹. All the disease programs have access to the NSVS death data, but they each have a separate arrangement with NSVS. A comprehensive and coordinated approach with access to improved NSVS data is needed

The disease programs are well positioned to work together to operationalize and maintain what has been developed through the 3x3 NELS research and to produce standardized population-based reports on need and quality indicators for palliative and end of life care. This assumes that they are provided with this expanded mandate and sufficient resources.

Conclusion

The 3x3 NELS study provided a rich and very successful learning experience on provincial disease program collaboration in NS, the assessment of data quality for monitoring care for persons at end of life, and the production of quality indicators to review the adequacy of palliative support across the province. To maximize the benefits from this work, a task, time and resource plan needs to be developed. This report was prepared to inform this next step forward.

Acknowledgement

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⁵⁸ Available at: <http://www.dal.ca/content/dam/dalhousie/pdf/sites/nels/3x3datadictionary.pdf>

⁵⁹ The disease programs operate provincial incident (new cases) registries. Incidence registries do not necessarily include all prevalent cases. For example, persons moving into NS who have had a past cancer diagnosis would not be included in the NS incident cancer registry. They would only be recorded as an incident case in the geographical area where they were diagnosed. This prevents double counting of cancer cases across Canada, and around the world. However, it means that if only provincial disease registry databases are used to identify persons prospectively who are approaching end of life, there would likely be under-reporting of those requiring palliative and end of life care. The use of NSVS data overcomes this problem in that includes all people who die, and thus may have required care at end life