

Research Protocol

Chronic Disease and Palliative Care Program Data Linkage and Analysis Project: The 3x3¹ Network for End of Life Study (NELS)

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Background

Health care near the end of life is becoming a priority in Nova Scotia and across the country. The increasing numbers of baby boomers entering their senior years are straining our health system and prompting an examination of service patterns and needs. A full investigation of end of life care to plan for quality end of life care goes beyond the baby boomers to include all people in the province of all ages: the elderly, adults of workforce age, young adults, teens, and children. National and provincial reports have documented the need for greater access to quality palliative and end of life care.

In the past, palliative care has focused on cancer and been more available in urban areas. Thus, there is a lack of end of life research today describing access to palliative care especially for persons with conditions other than cancer and for persons living in more rural areas. Effective policy depends on the availability of reliable data, sound analysis, and a clear and informed interpretation of the evidence. In this context, this research study is proposed with regard to palliative care and place of death for persons dying of chronic diseases in Nova Scotia using Nova Scotia Vital Statistics (NSVS) death certificates as the source of the study subjects. Place of death from death certificates has been used by other Canadian provinces (CIHI, 2007) and many countries in Europe (Cohen et al, 2007) as an important parameter of quality end of life care. Access to palliative care programs is another important quality indicator.

Literature Review

¹ This study involves three district health authority palliative care programs: Colchester East Hants, Capital Health, and Cape Breton, and three provincial chronic disease registries: Cancer, Cardiovascular, and Diabetes, to investigate end of life care for persons who died from 1995 onward.

Quality care at end of life. Research has shown a clear association between aging and declining health suggesting an increased need for health care services in later life. The mix of services required, however, depends on the characteristics and health status of the population. As individuals approach death, acuity and abilities will differ across individuals depending on their health conditions. Research has indicated that an individual's functional decline as death approaches varies across disease types leading to diverse requirements for end of life health care services (Fassbender et al, 2006). Lunney et al (2002, 2003) have suggested those dying of a terminal illness show a very rapid decline in functioning very near death while those with organ failure experience a more gradual decline accompanied by acute life threatening episodes. Cancer is the primary example used to represent a terminal disease decline. Advanced congestive heart failure is an example used of organ failure.

Beyond individual conditions, the presence of multiple diseases adds to the complexity of service need as the intermingling of conditions can accelerate or alter functional decline. Diabetes is an example of a disease that, when present as a co-morbidity, can influence care decisions. Seniors are more likely to be diagnosed with multiple conditions (Gorina et al, 2008) adding to the intricacies of service planning. Persons with Alzheimer's and dementia may not be ideal candidates for some treatment options available to others dying of cancer or congestive heart failure. In terms of medications, potential drug interactions for various diseases may alter preferred treatment choices. It is clear across all ages, co-morbidities can influence care provided. Research into the characteristics and disease profile of individuals near the end of life will help decision-makers propose efficient and effective policy.

To date, much of the palliative and end of life care research has focused on cancer. Quality indicators for care have been proposed and validated including access to a palliative care program (PCP) and having the option of dying at home rather than in hospital (Earle et al, 2004; Grunfeld et al, 2006, 2008; NELS ICE 2008). A recent literature review on access to palliative care services concludes that studies are needed to examine equity in care provision (Walshe et al, 2009). Studies are needed on the role of the PCP and place of death for persons with terminal disease.

There is a need for quality end of life care studies in predominantly rural District Health Authorities (DHA) in the province as previous PCP research has utilized information centred in the urban areas of Halifax and Cape Breton. Statistics show that about 45% of Nova Scotia's population lives in rural areas compared with a national rate of 20%². As such, important gaps exist in our understanding of palliative care in the province.

A variety of chronic diseases beyond cancer have a terminal phase including congestive heart failure, chronic obstructive pulmonary disease, renal failure, diabetes, Parkinson's disease, Alzheimer's disease, multiple sclerosis and cystic fibrosis. It is important to understand the occurrence of these conditions in order to plan for palliative care services. Also, analyzing multiple conditions enables researchers to more comprehensively track the interaction of conditions leading to death (Redelings et al, 2006, Wall et al 2005). A profile of the variations in patterns of end of life care will assist decision-makers both at the provincial and district level

Use of administrative data. Single-payer government-run health care systems in Canada have facilitated the development of administrative datasets which have been utilized for monitoring, surveillance, and research (Waien 2008, Gagnon et al 2006, Burge et al 2003). Using routinely-collected administrative data including disease registries has the advantage of a lower cost than primary collection. They represent well-defined populations, are generally fairly reliable for descriptive studies for planning purposes, and will continue to be available into the future. However, within the provinces, multiple departments and

² 2006 Census estimates. See CANSIM Table 153 0037.

organizations are responsible for a range of health care programs and databases. The result is a piecemeal collection of data and challenges for researchers attempting to collectively analyze available health information. The development of methods such as probabilistic record linkage has helped researchers more fully utilize information from combined datasets while maintaining patient confidentiality.

Linked administrative datasets have been used extensively in Nova Scotia to analyze issues surrounding end of life care for persons dying of cancer (Burge et al 2002, 2003, 2005, 2008; Committee of Canadian Cancer Society Research Institute 2010; Johnston et al 1998, 2001; Grunfeld et al 2007; NELS 2008; O'Brien et al 2007) and, to a limited extent, congestive heart failure (Burge et al 2002) as well as other chronic diseases (www.nels.dal.ca). Over the last decade, data from the PCPs in Capital Health (CH) and Cape Breton (CB) have been linked to multiple datasets including physician billings, hospital discharges, vital statistics and the registry of cancer patients in the province.

As the utilization of administrative data for research has increased, so has the focus on issues of data quality (Allan et al, 2005; Iezzoni 1997; Hilsenbeck 1990). Since administrative data are not collected for research purposes, the data files are not subject to the rigorous quality assurance protocols often used for surveys. Statistics Canada, for example, has developed a comprehensive Quality Assurance Framework which guides the management of data releases (Statistics Canada, 2002)³. Manual checks such as chart abstractions have been used to validate administrative data (Grunfeld et al, 2006) but such measures can be costly and there are less time-intensive data quality assessment procedures available when utilizing administrative data. Standard quality control checks within individual datasets include scanning for duplicate records, data completeness, and data field accuracy. The ability to link multiple datasets provides a valuable opportunity to further validate data fields across data sources. Data quality assessments of hospital and physician data (Roos et al, 1989) as well as registry data (Hilsenbeck, 1990; Johnston et al 2001b) have been undertaken through electronic file linkages. Validation across multiple sources can help determine the extent to which individuals are receiving care but are missing from data files in contrast to not adequately accessing the health care system. A comprehensive analysis of available data can help to ascertain where gaps exist in recording and monitoring across administrative spheres and facilitate collaboration in working towards overcoming barriers in access to care.

Nova Scotia administrative sources data include disease registry information for several chronic diseases. The cancer registry maintained by Cancer Care Nova Scotia (CCNS) has been used extensively for research purposes including linkages to other administrative data (Burge et al, 2008, O'Brien et al 2007, Grunfeld et al 2006). From these studies, indications are that approximately 80% of adults dying of cancer are seen by a PCP in both the CH and CB districts, and the majority of decedents die in hospital. Anecdotally, we know that in more rural areas and increasingly in all areas, persons diagnosed with other chronic conditions are being seen by PCPs. In the rural areas, the rates of dying in hospital may be even higher than in urban areas and this is a concern. Further analysis which includes an examination and linkage of additional datasets will enhance and expand upon these results.

Study Context

Within the province of Nova Scotia, PCPs are administered separately through the DHAs with each developing its own database. This has led to variations in content and recording methods (Kapra, 2008). There is no central provincial PCP database. To analyze access to PCP in the province, therefore, means data must be added one DHA at a time. Prior to incorporating a PCP database that has not been previously used in a linked research dataset, the first step is to examine the quality of the data so as to ascertain the reliability prior to the use for statistical reporting. As noted above, in previous studies, the CH and CB palliative care data have been linked to NSVS and other administrative data. This study is the first time

³ See Beland (2002) for a description of the procedures used for the Canadian Community Health Survey.

that Colchester East Hants Health Authority Palliative Care Service (CEHHA PCS) data will be added to the data linkage.

An examination of the Kapra PCP report shows that the CEHHA PCS has many years of data that are comparable to that used from the CH and CB PCP databases. However, an important potential difference in patient clientele has emerged from discussions. The CH and CB DHAs have major oncology centres and up to 2005 their PCP programs have had 90% or more of their patients dying of cancer. A recent audit by Anne Frances d'Intino, a CB PCP physician, shows that for 2009, there has been a steady and substantial shift: 2/3's of the patients were cancer, while 1/3 were noncancer. The numbers of persons with cancer have increased slightly over time. However, the major reason for an annual increase in caseload is an increase in noncancer patients. The CH PCP has also seen an increase in the percentage of noncancer cases reaching 25% in 2009/10. In contrast, the CEHHA PCS serves a clientele that may well be up to 50% noncancer. This may reflect both the increasing trend for PCPs to serve more than cancer patients and/or a pattern of practice in rural areas that do not have a major oncology treatment centre.

The CEHHA PCS has maintained a comprehensive ACCESS database of palliative care patients since the mid 1990's. Information collected includes referral, registration, and discharge information. Such a comprehensive database in electronic form provides the opportunity to analyze the characteristics of individuals receiving palliative care outside of Halifax and Cape Breton. The inclusion of personal identifiers including the provincial Health Card Number, name, and birth date allows for probabilistic linkages enabling external validation of data fields and a more in-depth analysis of the health profile of palliative care patients in the district.

The DCPNS and CVHNS maintain province-wide disease registries for surveillance purposes. These programs aim to include in their registries individuals diagnosed with each disease in the province. Information from the DCPNS registry is used to influence program delivery, operations, and disease management decisions. The CVHNS registry is based on hospital admission and discharge information. Electronic records from the diabetes registry are available since 1995 while the cardiovascular program includes individuals since 1997. The availability of these longitudinal data, linked to PCP and other administrative databases, provides an opportunity to analyze services received by patients with cardiovascular disease and diabetes near the end of life. Linkage of disease registry diagnoses to Nova Scotia Vital Statistics (NSVS) causes of death can be used for diagnosis validation studies (Johnston et al, 2001).

The Vital Statistics data file is a valuable source of information for researchers. The Statistics Act requires registration for all deaths in the province increasing the reliability of capturing the full population. Included in the death certificate is cause of death information. Since many individuals have multiple conditions at death, there can be up to 13 causes of death listed. It is feasible to link death certificate records with disease registry and PCP data generating a rich data source with which to understand disease progression and patterns of end of life care. Co-morbidities can influence end of life care considerably. A fall or an accident, for example, can introduce new medications and/or increase the risk of an earlier than expected death. Also, infections, falls and accidents can greatly increase the chance of an in-hospital death and decrease the likelihood of PCP enrollment, key explanatory variables in this study. It is important to control for these external factors that may influence outcomes. As a result, all causes of death from the Vital Statistics file are required including fall, accidents and infections. An analysis of disease associations can assist in resource planning and disease management for end of life care.

For this research, it is proposed that disease registry, PCP, and death certificate data be utilized. It is important from both a data quality and analysis perspective to include all these sources. The aim of registries is to capture specific information on individuals with that particular disease. Some patients deemed to be terminally ill will enroll in a PCP while others will not. There may be those who are enrolled

in a PCP due to a particular disease who do not appear in a disease registry. For example, it is known that cancer registries include ‘death certificate only’ (DCO) cases. The addition of the diabetes and cardiovascular registries as well as the PCP data from Colchester East Hants in this new study will help to further our understanding in terms of both quality of data and provision of health services. The short title of this study is 3x3 NELS since data are from three disease registries (cancer, cardiovascular, diabetes) and three PCPs: Capital Health, Cape Breton, Colchester) linked to NSVS deaths.

Once data quality has been assessed, a profile of PCP use and place of death over time, by causes of death, DHA, and age of decedents at death can be developed. This will be timely given that the development of a Canadian Institute for Health Information (CIHI) report of end of life care in Atlantic Canada is in progress. The Atlantic report is expected to parallel a Western Canada report (CIHI, 2007). The Atlantic CIHI report is not expected to include PCP access as an indicator of end of life care because these data are not available in provincial databases in the Atlantic provinces. PCP use is known to be very important but reports investigating PCP access have largely only been available to date from research studies.

The Network for End of Life Studies (NELS) has received a Canadian Institutes for Health Research (CIHR) Interdisciplinary Capacity Enhancement (ICE) grant to build team and research capacity and create new knowledge around end of life issues. This ICE grant is to move end of life research beyond cancer to include other chronic diseases and investigate the needs of vulnerable populations including those in rural areas. Further information on NELS ICE is available at www.nels.dal.ca.

NELS ICE analysts have been analyzing NSVS data and have produced reports on deaths for various chronic diseases (congestive heart failure, renal disease, diabetes, cancer, chronic obstructive pulmonary disease, Alzheimer’s and dementia, Parkinson’s disease and multiple sclerosis) including the likelihood of dying in hospital. Other indicators of care at end of life for persons with a range of chronic diseases cannot be obtained without linkage of NSVS data to administrative databases.

It is increasingly being recognized that end of life care for many chronic diseases and population groups requires greater attention. This 3x3 NELS study aims to help meet this need.

Research Questions

Two research questions are the focus of this 3x3 NELS project:

1. What is the reliability and validity of the diagnoses and other variables in disease registry and palliative care administrative data sources to be used for new end of life studies?
2. To what extent are people with various chronic diseases
 - a) being seen by a PCP, and
 - b) differing in their place of death (hospital, nursing home, own home), and
 - c) differing in health care use by PCP access?

METHODS

Subject Selection

The study population is all Nova Scotia residents who died in Nova Scotia from 1995 to 2009 according to Nova Scotia Vital Statistics. There are approximately 8,000 deaths each year in the province for a total across the 15 years of 120,000 decedents. Residents of NS who die outside of the province will be excluded from the population as any palliative care services received by these individuals cannot be ascertained from NS administrative data.

Data Sources

There are seven administrative database sources for this study and one Statistics Canada Census file:

- 1 – Nova Scotia Vital Statistics (NSVS) death certificate data
- 2 – Cancer Care Nova Scotia (CCNS) Cancer Registry
- 3 - Cardiovascular Health Nova Scotia (CVHNS) Cardiovascular Registry.
- 4 - Diabetes Care Program of Nova Scotia (DCPNS) Diabetes Registry
- 5 - Capital Health (CH) Integrated Palliative Care Service PCP patient enrollment file,
- 6 - Cape Breton (CB) Palliative Care Program PCP patient enrollment file, and
- 7 - Colchester East Hants Health Authority (CEHHA) PCP patient enrollment file
- 8 – Statistics Canada 2006 Community Profile Census data

Probabilistic Record Linkage by the SEU Analyst

In order to construct the 3x3 NELS study dataset, the seven administrative data sources will be linked at an individual person level. If a unique identifier such as a provincial health care number (HCN) was available for all study subjects in all the databases, deterministic linkages could be used to construct a complete dataset. While HCN is recorded in each administrative dataset, HCNs are missing for over 10% of the NSVS records and are also missing on some records in the disease registry and palliative care program datasets. Also, previous experience indicates that there will be data entry error leading to incorrect HCNs being assigned. Therefore, to obtain a high quality 3x3 NELS study dataset, probabilistic record linkage is required. This process uses multiple identifiers and weighting scores of agreement and disagreement between records to compensate for missing and inaccurate HCNs (Qayad and Zhang, 2009). This linkage will be carried out by a SEU analyst who has considerable experience with the probabilistic record linkage of NSVS death files to cancer registry cases. Decedents from the NSVS files will be matched with cases from the disease registries and PCP databases.

As mentioned, cancer registry data has previously been linked to NSVS death certificate and PCP data within the SEU system to study end of life care issues. DCPNS and CVHNS registry data, however, have not been used for this purpose. This project involves these datasets being linked by a SEU analyst at CCNS in a two-stage linking procedure. Records from both the DCPNS and CVHNS registries will be transferred securely to the SEU analyst containing only the data fields required for the probabilistic linkage (i.e., individual identifiers). The SEU analyst will identify the study subjects (decedents) and assign a unique 3x3 NELS study ID for each study subject. Identifiers will then be returned to the respective DCPNS and CVHNS programs along with the assigned 3x3 NELS study identifiers, and confirmed dates of death for the study subjects. The respective DCPNS and CVHNS analysts will then extract the study analysis variables for each study subject from their respective registries and attach the 3x3 NELS identifiers. The study analysis variables with 3x3 NELS identifiers will be transferred securely by the DCPNS and CVNS analysts to the NELS study analyst. Through this procedure, the SEU linkage analyst will have access to the DCPNS and CVHNS identifiers, but not their 3x3 NELS study analysis variables; the NELS analyst will have access to their study analysis variables, but not DCPNS and CVHNS record identifiers.

The SEU probabilistic linkage analyst requires access to the unencrypted HCNs. Probabilistic linkage involves utilizing identifying information to weight scores of agreement to determine matches. As noted, HCNs can be missing or assigned incorrectly due to data entry error. The probabilistic linkage software accounts for digit reversal and other typical recording discrepancies. If the HCNs are encrypted, this critically important benefit of probabilistic linkage will be lost since the encrypted HCN with a small error in one dataset will differ from the encryption of the HCN without error and correct record matches will be missed. To obtain the highest quality dataset for analysis, original HCNs are required for this project.

Figure 1 outlines the data flow and linking procedures to construct the final dataset for analysis. Table 1 indicates the variables that will be utilized for the probabilistic linkage. Identifiers are not the same in all datasets. All identifier information available from each source will be used to determine record matches.

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Figure 1: Data Development for the 3x3 NELS Study

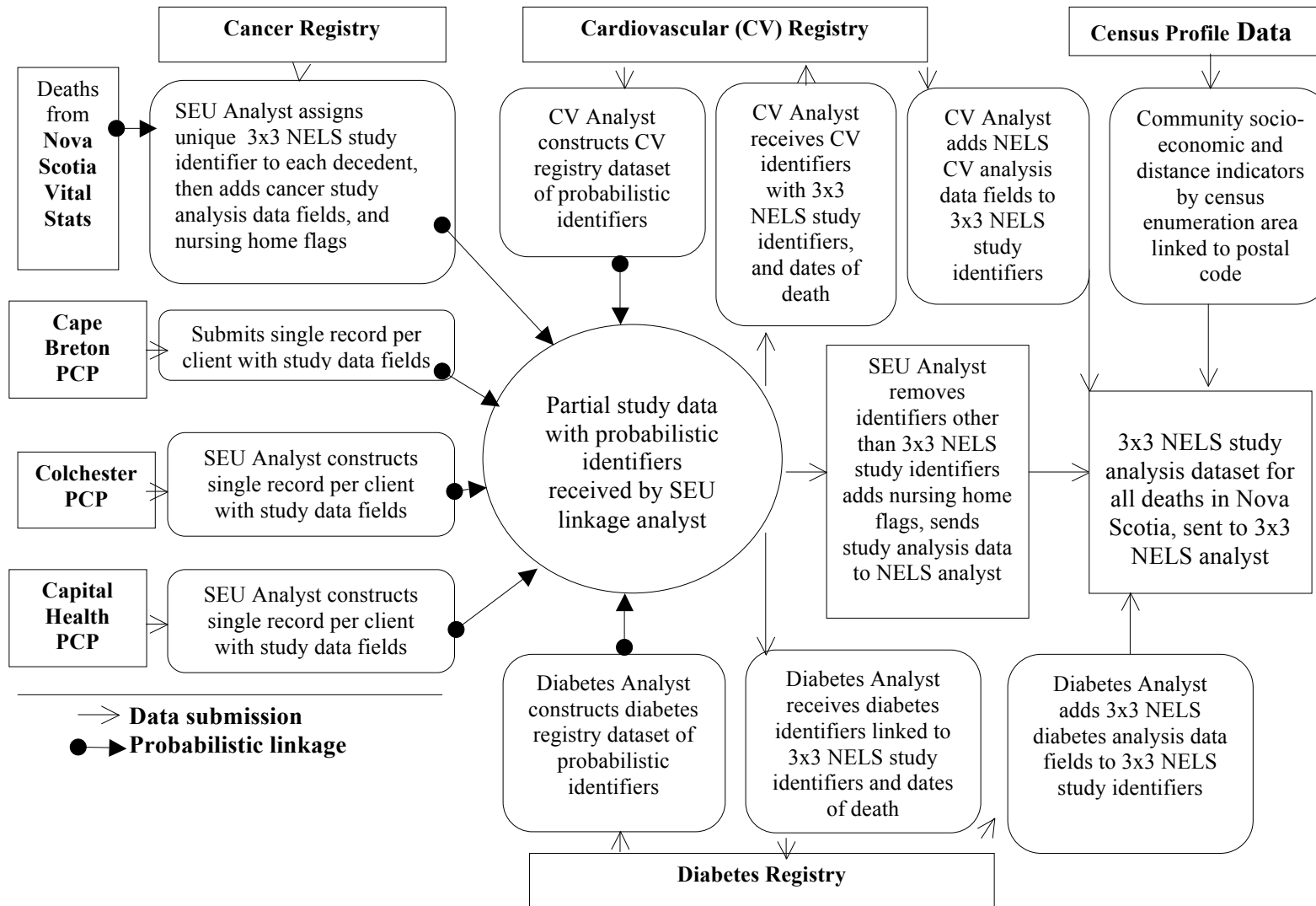


Table 1: Variables from death certificates, the cancer, diabetes and cardiovascular registries, and the Capital Health, Cape Breton and Colchester Palliative Care Programs (PCP) that are required for Probabilistic Record Linkage by the SEU Analyst

Nova Scotia Vital Statistics	Cancer Registry	Cardiovascular Registry	Diabetes Registry	Capital Health PCP	Cape Breton PCP	Colchester PCP
HCN	HCN	HCN	HCN	HCN	HCN	HCN
All names	All names	All names	-	All names	All names	All names
Birth maiden name	Birth maiden name	-	-	-	-	-
Sex	Sex	Sex	Sex	Sex	Sex	Sex
Date of birth	Date of birth	Date of birth	Date of birth	Date of birth	Date of birth	Date of birth
Date of death	Date of death, or date last alive	Date of death or date last alive	Date of death or date last alive	Date of death or date last alive	Date of death, or date last alive	Date of death, or date last alive
Hospital code	Hospital code	Hospital code	-	-	-	-
Postal code, county of residence	Postal code, county, DHA	In-hospital death Postal code, county, DHA	Postal code, place table, county, DHA	Postal codes	Postal codes	Postal codes

Probabilistic linkage software (LinkageWiz) will be used to construct the study dataset and to generate data quality assessment reports that will be shared with the respective data providers. For this 3x3 NELS study, the NSVS death certificate data are considered the ‘gold standard’ in terms of recording deaths in the province. It is possible that the PCP and disease registries may be missing deaths recorded in NSVS, and conversely, occasionally may contain deaths missed in NSVS. As such, records from the disease registry and PCP programs for all living or deceased persons will be included in the probabilistic linkage to ensure all individuals who died as indicated by the NSVS records are contained in the 3x3 NELS analysis dataset, and the completeness of the recording of deaths determined in all datasets. Individuals from the DCPNS registry who are very unlikely to require palliative care in the time frame of this study will be excluded since this study focuses on end of life care. Thus, DCPNS registrants diagnosed with pre-diabetes and gestational diabetes will be excluded.

The first probabilistic record linkage step is to check for and reconcile any duplicate cases identified within the PCP and disease registry files. From previous experience, the rates of duplicates are expected to be low for the cancer registry and the CH and CB PCPs. The CH and CB PCP datasets have been used previously for end of life with cancer studies. These data will be transferred directly to the SEU analyst, as in the past, for this check to be carried out. The duplicate record rates are unknown for the Colchester PCP and the diabetes registry but are assumed to be minimal. The cardiovascular registry is event (hospital admission) based, not case (client, patient) based so that database is expected to require considerable duplicate case resolution. Individuals may be legitimately included in the CVHNS database multiple times for repeat hospital admissions and with multiple cardiovascular diagnoses. Record linkage to create the 3x3 NELS study analysis dataset will be highly problematic if duplicate resolution is not carried out prior to the other probabilistic record linkage steps.

After the NSVS-cancer linkage is carried out, probabilistic linkages to the cardiovascular registry and the three PCP databases will be carried out as in Figure 1 using the variables given in Table 1. Health card numbers (HCNs) that are missing from the NSVS⁴ records will be replaced by HCNs available from the cancer and cardiovascular registry and then used to assist in a more complete linkage of the study decedents to the diabetes registry. The diabetes registry lacks first and last names and therefore is the registry most adversely affected by the missing health card numbers in the NSVS data. It is expected the last registry database to be linked will be the diabetes registry since it has the fewest individual identifiers available. To the extent possible, postal codes missing from NSVS⁴ will be backfilled from the disease registries and PCP databases so that the distance, and socio-economic data used for the study analysis will be as complete as possible.

Access to individual identifiers will be required from all seven administrative database sources to carry out the probabilistic data linkage. As indicated in Table 1, these identifiers include health card number, first name, last name, date of birth, date of death, last known date alive, hospital ID, in-hospital death, and postal code of residence. A file translating the individual identifiers to new unique 3x3 NELS study numbers will be retained by the SEU probabilistic linkage analyst in case data quality issues require investigation during the study data analyses. Any data quality issues that surface will be sent back to the originating data source for reconciliation.

Development of Nursing Home Resident and Place of Death Indicators

Nursing home residency has been shown to be an important factor in end of life care provision (O’Brien et al, 2007). Place of death has been used as an indicator of the quality of end of life care. For previous end of life care research, SEU developed an algorithm to determine whether individuals were nursing home

⁴ The optimal process would be for the NSVS to backfill missing health card numbers and postal codes by linkage with the provincial health card number database.

residents, and whether their place of death was a nursing home. The construction of the two nursing home indicators involves the comparison of the individual's place of residence and place of death addresses in NSVS records to the addresses of publicly funded (provincial and federal) long-term care facilities across the province. The nursing home resident and nursing home as place of death variables will be generated by the SEU linkage analyst using NSVS address information. A nursing home resident will be defined as having a nursing home address as either place of residence or place of death. Past use of this variable in our end of life studies has shown that there are people recorded as a NSVS death with a personal home address and a nursing home as place of death; these persons will be labeled as nursing home residents for the 3x3 NELS study. A nursing home indicator is also included in the NSVS death certificate information but has not been previously used for research purposes. For this study, a comparison will be conducted to assess the validity of the NSVS nursing home indicator to the SEU created nursing home indicators. Time permitting, a comparison will also be made to the nursing home as place of discharge in the cardiovascular registry databases and with PCP indicators of nursing home residency.

Analyses of the 3x3 NELS Study Data

Table 2 shows the variables which will be included in the 3x3 NELS study analysis dataset for use by the NELS analyst for data quality assessment between databases and to investigate patterns of end of life care. Table 3 summarizes the variables which will be utilized to examine end of life care issues.

Assessment of Cardiovascular and Diabetes Registry Diagnoses compared to NSVS Causes of Death

All causes of death are a critical component of this study. Johnston et al (2001b) validated the cancer causes of death in Nova Scotia. This 3x3 NELS study will carry out parallel analyses to assess the validity and reliability of the diabetes and cardiovascular diseases recorded as causes of death on NSVS records through comparison with the cardiovascular and diabetes registry records. The proportion of individuals who died according to the disease registries but do not have that disease as a cause of death will be calculated as well as the reverse situation of a cardiovascular or diabetes cause of death for persons in NSVS records who do not appear in the respective disease registries. An analysis of causes of death for cancer registry patients who die of cancer and other causes will also be carried out for CCNS surveillance and monitoring purposes. These analyses will be stratified by attendant type: Coroner (medical examiner) or other (attending physician) completing the death certificate. Disease associations will be analyzed utilizing all causes of death and all disease registry diagnoses as individuals can potentially be diagnosed with multiple conditions all of which can affect their end of life service requirements. The diagnoses in the PCP databases will also be available for parallel data quality checks, and will be compared to NSVS and disease registry data as time permits. ICD disease code groupings will be adapted as needed from those developed by Alison Zwaagstra for NELS to reconcile any differences with the disease coding of the diabetes and cardiovascular registries, and the PCP databases.

Hospital as place of death in NSVS will be compared to in-hospital death from the cardiovascular registry. The cardiovascular in-hospital death indicator comes from hospital discharge abstract data. In the past across Canada, the hospital and VS data vary in the percentage of hospital deaths as a result of differences in coding deaths in the emergency department and other factors (Neutel et al, 2005).

Colchester East Hants Health Authority PCP Data Quality Assessment

Unlike the Capital Health and Cape Breton PCP files, Colchester PCP data have not been used previously by SEU CCNS for research. It is important, therefore, to assess the quality of the Colchester PCP data which will include calculation of rates of missing values as well as out of range, inconsistent and implausible values within the database. In addition, an external validation will be conducted through a comparison of the dates and causes of death in the NSVS and Colchester PCP databases.

Study Data Analysis to investigate Patterns of End of Life Care

Data fields in Table 2 will be used to create the study variables including those shown in Table 3. The study variable development will employ the methods developed in previous NELS studies.⁵ The NSVS deaths linked to the registries will provide the study population representing the entire province. The proportion of persons dying in hospital or a nursing home versus their own home will be calculated for all Nova Scotia decedents and compared across disease types and health districts with standard chi-squared and t-tests utilized to test for statistical significance. Place of death across the Nova Scotia decedent study population will be examined and compared across disease types, age groups, and geographic grouping of DHAs, as an indicator of quality care near the end of life. A descriptive profile of those who died with cancer, diabetes, and/or cardiovascular disease will be generated.

For the three districts with PCP data available for this study, further analysis of end of life health care use will be conducted. The proportion of PCP enrollments will be measured and compared across disease types and other covariates. PCP enrollment includes both referral and registration. The proportion of persons referred who were never registered, and the wait time from referral to registration, will be computed. Length of time between disease diagnosis and death will be analyzed with comparisons between those who were enrolled in a PCP and those who were not. A profile comparing individuals across districts in their receipt of palliative care will be prepared. Most individuals registered with each PCP will be living within the corresponding DHA. As such, analysis of PCP programs will focus on the Capital Health, Cape Breton and Colchester East Hants catchment areas. However, receipt of services outside of one's DHA of residence will also be investigated, for example to what extent are Colchester residents served by Capital Health, and are people who are more distant from both PCPs but living with one of these DHAs being underserved?

The PCP analyses will be carried out in the context of and in dialogue with the management of each PCP. For example, in the Capital Health PCP, distance from the decedents' residence to the PCP will need to stratify for West Hants from 2005/6 onward since at that point in time a full time nurse and part time physician were assigned to provide local coverage, rather than being dependent on Halifax-based consultations. After the end of the study time period, in August 2010, the Eastern Shore (Tri-facilities) initiated a similar distance program with one nurse and a part time physician providing local coverage.

Multivariate analysis will allow for comparisons across groups controlling for other characteristics such as age and distance to care as well as help determine statistically significant associations. Logistic regression will be used to investigate factors associated with quality care variables. For the full study population, associations with place of death and time between disease diagnosis and death will be examined. PCP enrollment rates, time from PCP referral until death, and time between PCP assessment/visit and death will be analyzed for the subpopulation of the three DHAs with PCP data in the study. Classification and regression tree analyses may be employed to identify subpopulations which are most vulnerable to lack of service access. Independent variables will include age group at death, sex, causes of death, DHA of residence and nursing home residence.

⁵ Derived variables include age, time from PCP enrollment to death, nursing home resident, place of death (hospital, nursing home, own home), time from diagnosis to death, palliative radiation therapy indicator, medical oncology consultation, and socioeconomic and distance measures. Details of these methods are at: <http://www.cancercare.ns.ca/site-cc/media/cancercare/DetailedMethods.pdf> and in our published papers.

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Table 2: NSVS, Disease Registry and PCP Data fields to be used as or developed into variables for 3x3 NELS Study Analysis

Nova Scotia Vital Statistics	Cancer Registry	Cardiovascular Registry	Diabetes Registry	Capital Health PCP	Cape Breton PCP	Colchester PCP
Sex Date of birth Date of death Addresses of residence and death ¹ NSVS Nursing home flag Causes of death Attendant type Postal code of residence at death ² , DHA	Dates of cancer diagnoses, medical oncology consults, and palliative radiotherapy (RT) consults and treatment from palliative RT flag, number of fractions at last treatment and time from RT to death	Dates of hospital admissions Admission diagnoses Discharge diagnoses Indicators of: Hyperlipidemia Diabetes Hypertension Previous diagnoses Discharge to nursing home	Dates of diabetes diagnoses Dates of registration Dates of clinic visits Type of diabetes Indicators: Thyroid, PVD, CVD, hypertension, CAD, dyslipidemia	Referral date(s) Registration date(s) Discharge date, if any Main diagnosis Comorbidities	Referral date(s) Registration date(s) Discharge date, if any Main diagnosis Comorbidities	Referral date(s) Registration date(s) Discharge date, if any Disease coding Other variables ²
<p>1 Full street address of residence and of death is required for the SEU Analyst to create the validated SEU nursing home resident and nursing home as place of death indicators.</p> <p>2 Postal code of residence at death is linked to census enumeration area to create socioeconomic and distance measures. If postal code is missing from the NSVS record, postal code will be backfilled from disease registry or PCP records. If DHA is not available directly from NSVS records, the best available source including postal code and county look up tables will be used.</p> <p>3 After data quality check, other variables in the Colchester PCP registration file deemed suitable for analysis</p>						

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Table 3: Study Analysis Variables Obtained or Derived from Data Fields in Databases

Nova Scotia Vital Statistics	Cancer Registry	Cardiovascular Registry	Diabetes Registry	Capital Health PCP	Cape Breton PCP	Colchester PCP	Census Profile Data⁴
Sex Age at death Place of death ¹ Nursing home resident indicators	Time from diagnosis to death	Time from diagnosis to death	Time from diagnosis to death	PCP referral and registration	PCP referral and registration	PCP referral and registration	Distance from residence to PCP ⁵
Causes of death ² Attendant type DHA, county	Consults ³ in last nine months of life	Died in/out of hospital	Time from registration to death	Time from first/last referral to first/last registration	Time from first/last referral to first/last registration	Time from first/last referral to first/last registration	Community socio economic variables ⁵
	Received palliative radiotherapy	Discharged to nursing home or not	Time from clinic visits to death	Time from first /last registration to death	Time from first /last registration to death	Time from first /last registration to death	

¹ Hospital, nursing home, own home
² An all causes classification will be based on the taxonomy developed by Alison Zwaagstra and adapted to the classifications used in the disease registry and PCP databases once they become known and validated during the work of this project
³ Medical oncology, radiotherapy
⁴ 2006 Census information will be linked by census dissemination area to six digit postal code using Health Canada methods
⁵ Postal codes that are missing from the NSVS records will be replaced by the last postal codes available in the cancer, cardiovascular and diabetes registries to enable the development of district health authority (DHA), distance and community socio-economic indicators with fewer missing values.

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The study time line is provided in Figure 2. CIHR funding to NELS ICE ends in 2011. Therefore, the Study Analyst funded by NELS ICE is not available to work on this study after 2011.

Figure 2: Study Time Line

<i>NELS Study Analyst</i>	Protocol and REB preparation			Add distance and SES measures and prepare other study variables. Analyze study data and prepare reports, publications presentations of findings	
<i>SEU Probabilistic Linkage Analyst</i>		Link cancer registry, PCP to VS data. Create 3x3 NELS study ID numbers, and nursing home variables	Send diabetes/ cardiovascular identifiers with 3x3 NELS IDs to registry analysts	Send linked NSVS, cancer and PCP data, with nursing home indicators, to NELS analyst	
<i>Diabetes/ Cardiovascular Registry Analysts</i>		Prepare identifier data files; send to SEU analyst	Prepare study data with 3x3 NELS IDs; send to NELS analyst	Receive linkage quality reports from SEU analyst, and NSVS disease code validation from NELS analyst	
	2010	Winter 2011		Spring/Summer/Fall 2011	

DATA CONFIDENTIALITY, ETHICS AND STUDY FUNDING

Data Confidentiality Processes

NELS ICE processes for security and access will be followed. See Appendix A for the NELS ICE data policy statement. NELS ICE staff employment contracts include a data privacy and confidentiality agreement.

Data quality assessment, data set development and analyses will be carried out on a password-protected computer housed in Dr Grace Johnston’s office (room 568) in the Bethune Building where the NELS analyst is located. The NELS Study Analyst is Lynn Lethbridge. Her computer and shared drive are supported by Capital Health’s IT department which has extensive data security. Data is stored and backed up on a secure drive that is only accessible to NELS staff. The NELS analyst will have access to analytic data only. She will not have access to any individual identifiers from any of the seven datasets that will be linked to create the study dataset.

The SEU Record Linkage Analyst carrying out the probabilistic record linkage will be Ron Dewar. He will have access to individual identifiers of the study subjects since this is the only way that this linkage process can be carried out to create the 3x3 NELS study dataset. The SEU linkage analyst is employed by CCNS. In his employment position, he has access to cancer registry, NSVS deaths, and PCP data including identifiers for record linkage and surveillance reporting. Therefore, he will create and provide to the NELS analyst the 3x3 NELS study data fields extracted from the cancer, NSVS, and PCP databases with all identifiers from these source databases removed and replaced with unique 3x3 NELS study numbers.

For this 3x3 NELS study, the SEU analyst will create the unique 3x3 NELS study subject numbers, and build and retain a file of these unique 3x3 NELS study numbers linked to the identifiers from the source

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databases for each study subject. This individual identifier dataset will only be accessed for approved data quality audit purposes and only if data quality problems are identified and there is no other means for resolving data integrity problems. The data quality problems will be handled only by the custodians of the originating dataset(s).

Since the SEU analyst does not have access to DCPNS and CVHNS databases in his SEU analyst employee position, a two-stage process will be used to identify the study subjects in the DCPNS and CVHNS registries, and then to provide NELS study data to the NELS analyst. The SEU Linkage Analyst will be provided with the identifiers of persons in the DCPNS and CVHNS registries, but will not have access to the health information of these persons in the DCPNS and CVHNS registries. After the 3x3 NELS study subjects are determined by the SEU analyst through linkage to NSVS records, their identifiers will be returned to the DCPNS and CVHNS analysts with the assigned unique 3x3 study numbers.

In a totally separate step, the 3x3 NELS study data fields required by the 3x3 NELS analyst will be prepared by DCPNS and CVHNS registry analysts linked to the unique 3x3 NELS study identifiers. These study data will be sent by the DCPNS and CVHNS analysts to the NELS study analyst only with all DCPNS and CVHNS identifiers removed. In this way, the SEU linkage analyst will not have access to DCPNS and CVHNS registry health data on their clients, and the NELS analyst will not have access to the identifiers in the disease registries or other source databases.

To ensure the confidentiality, security and integrity of the files, all data linkages will be performed only by authorized personnel. Access will be governed by the contractual agreements of the data providers.

The dataset will be stored on a NELS shared drive for a minimum of seven years. The Canadian Institutes of Health Research (CIHR) is the research grant funder for NELS ICE. As of September 2007, the CIHR “Policy on Access to Research Outputs” (page 5, item 5) requires that “grant recipients retain original data sets arising from CIHR-funded research for a minimum of five years after the end of the grant.”

We will adhere to all the requirements of the Tri-Council policies on secondary use of data, a requirement of CIHR funding, and Capital Health IT and disease registry data safeguards and security requirements as well as those of the data providers. The study dataset will be analyzed exclusively on location in the NELS office (room 568) of the Bethune. Only those who are authorized through the REB processes will have access to this data. Remote access will not be granted.

Ethical review of benefits and potential harms

Research Ethics Board (REB) approval will be requested from the Capital Health, Cape Breton and Colchester East Hants Health Authority (CEHHA). No work on this project will begin until these REB approvals are received. Letters of approval from the data providers are required for these REB applications.

NELS ICE personnel had numerous meetings in 2010 with CCNS, DCPNS and CVHNS so that these programs can fully understand and have input into the research that is being proposed. The NELS ICE Principal Investigators (PIs) and analyst traveled to Truro on March 23 2010 to meet with the Manager and Medical Director of the CEHHA PCS regarding this study, again to enable full disclosure and discussion of this study. On July 14 2010, the NELS ICE PI and analyst met with the NSVS director and analyst to discuss this study in person. In the summer of 2010, the NELS ICE PI communicated with a CB PCP palliative care physician. In September 2010, the NELS ICE PI met with the medical director of the CH PCP.

The benefit of this study is acquiring an improved understanding of the issues surrounding end of life care for Nova Scotians dying of chronic disease. This project is in accord with the emerging focus on chronic disease management which goes beyond the historic disease silo focus. The study is now logistically more viable given that the Department of Health within the last year has located the provincial chronic disease programs (cancer, cardiac, diabetes) in the same location – 5th floor of the Bethune Building at the VG Site of Capital Health. Furthermore, the Diabetes Care Program of NS and Cardiovascular Health NS now have access to an epidemiologist, Dr Jennifer Payne, to advise on analyses of the cardiac and diabetes disease programs' data. The chronic disease programs have a mandate from the Nova Scotia Department of Health to work together. This 3x3 NELS study is a first major collaborative data project among these provincial chronic disease programs.

This study goes beyond previous reports focusing on cancer through the inclusion of diabetes and cardiovascular data. This study goes beyond examining individual databases in isolation to examine decedent profiles across a set of databases using comparable measurements. This study will provide findings beyond those in surveillance reports that focus on end of life care (NELS ICE, 2008; proposed Atlantic CIHI report) by incorporating diabetes and cardiovascular registry data as well as the CEHHA PCS data. Knowledge translation from this research will inform planning and policies to improve the provision of quality care for persons dying of chronic diseases.

A potential harm would be compromised patient privacy/confidentiality. However, state of the art safeguards are in place to protect subject privacy. We will adhere to the CIHR, data providers, Capital Health IT, CCNS, NELS ICE, DCPNS, CVHNS and PCPs data security, access and privacy standards.

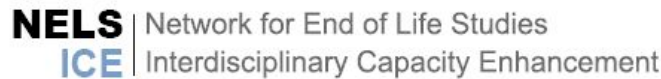
We will use standard scientific methodologies for the development and use of secondary health administrative databases. There are no unique or new ethical issues in our research.

Thus, the considerable benefits from this research are much greater than the potential harms which are deemed minimal in studies using the analysis of secondary data.

Study Funding

This study is supported by 'in-kind' contributions for data extraction from the disease registries and palliative care programs in return for the analyses and the reports produced by the NELS ICE staff. Support will be provided from the NELS ICE grant for the time of Lynn Lethbridge and Nicole McQuinn. The time of Ron Dewar for the probabilistic record linkage will be provided mainly in-kind by CCNS with partial payment of this cost from NELS ICE. The time of the diabetes and cardiovascular analysts to prepare their data files will be provided in-kind by DCPNS and CVHNS, as will be the data from NSVS and the PCPs.

Appendix A



Data Privacy, Access and Retention Policy

I. Introduction

The Network for End of Life Studies (NELS) is a group of researchers from the Faculties of Medicine and Health Professions at Dalhousie University, the Capital District Health Authority, the IWK Health Centre, and Cancer Care Nova Scotia. NELS has received funding from the Canadian Institutes of Health Research (CIHR) through a strategic initiative grant: “Interdisciplinary Capacity Enhancement (ICE) Reducing Health Disparities and Promoting Equity for Vulnerable Populations” (2006-2011).¹ The primary goal of NELS ICE is to improve the quality of end of life care for persons with terminal illness. In working toward this goal, NELS obtains administrative data from various organizations, as well as data collected from other CIHR funded grants and other sources. This data is analyzed by NELS ICE and other research or operations staff to produce research findings provide evidence to guide service planning and policy development for end of life care in Nova Scotia.

Each research project using personal information requires a detailed plan in writing that is submitted to the NELS ICE Management Committee or associated NELS grant principal investigator, the data provider and a Research Ethics Board for approval. All NELS ICE investigators, staff, trainees and students involved with data analysis must adhere to the data access policies and confidentiality agreements of the organizations from which data is received and through which the study is approved. Safeguards for protecting confidential information are outlined below.

Since the objective of the work funded by an ICE grant is to collaboratively build capacity, it is implicit in the nature of this work that there will be new developments over time. New developments are a marker of success of ICE funding. Thus, it is implicit that this Data Privacy, Access, and Retention Policy will continue to develop over time. However, adherence to best practices, provincial and national legislation and standards, and collaboration with key stakeholders will remain as basic tenets.

II. Definitions

“Privacy” means the right of individuals to determine when, how and to what extent they share information about themselves with others.²

“Confidentiality” means the obligation of an organization or custodian to protect the information entrusted to it and not misuse or wrongfully disclose it.²

“Security” means the process of protecting information by assessing threats and risks to that information and implementing the procedures and systems to restrict access and maintain the integrity of that information.²

“Personal information” means recorded information about an identifiable individual, including

- (i) the individual's name, address or telephone number,
- (ii) the individual's race, national or ethnic origin, colour, or religious or political beliefs or associations,
- (iii) the individual's age, sex, sexual orientation, marital status or family status,
- (iv) an identifying number, symbol or other particular assigned to the individual,
- (v) the individual's fingerprints, blood type or inheritable characteristics,
- (vi) information about the individual's health-care history, including a physical or mental disability,
- (vii) information about the individual's educational, financial, criminal or employment history,
- (viii) anyone else's opinions about the individual; and,
- (ix) the individual's personal views or opinions, except if they are about someone else.³

III. Privacy Legislation and Guidelines

NELS ICE operates under the terms of the following privacy legislation and guidelines:

- *Personal Information Protection and Electronic Documents Act* (Federal)⁴
- *Freedom of Information and Protection of Privacy (FOIPOP) Act* (Provincial)³
- *Personal Health Information Act* (Provincial Discussion Paper)⁵
- Tri-Council Policy Statement “Ethical Conduct for Research Involving Humans”⁶
- Canadian Standards Association’s Model Code for the Protection of Personal Information (see schedule 1 of *Personal Information Protection and Electronic Documents Act*)⁴
- Pan-Canadian Health Information Privacy and Confidentiality Framework²
- CIHR Best Practices for Protecting Privacy in Health Research⁷
- Canadian Health Information Management Association Professional Practice Brief - Health Data Access, Use and Control for Secondary Uses⁸

IV. Description of NELS ICE Surveillance Data and Activities

NELS ICE is building a dataset of Nova Scotia residents who died on or after January 1, 1998, in order to evaluate the end of life care being provided to this population. Study subjects are identified from Nova Scotia Vital Statistics. Dataset development involves the linkage of data from Nova Scotia Vital Statistics and/or data from disease registries (e.g. Nova Scotia Cancer Registry) to data from other sources including: Palliative Care Program databases, Continuing Care database (SEAscape), Pharmacare, narcotics triplicate billing, physician billing claims, and the Canadian Institute for Health Information’s (CIHI) Discharge Abstract Database (DAD).

Personal identifiers including health card number, first and last name, date of birth and date of death may be obtained by NELS ICE for data linkage activities. Probabilistic record linkage using software such as Linkagewiz⁹ will be used to obtain optimal linkages, unless it is clear that deterministic methods are available that will provide as good or better linkages. Before analysis commences, any information that can be used to identify the individual will be removed and replaced with a unique study ID number. In a separate and secure data file that is only accessible by two NELS ICE personnel and not other NELS ICE trainees or researchers, the unique study numbers will be linked to the original personal identifiers so that if the need arises data checks can

be made by chart audit or other data quality review process under the direction of or by NELS ICE staff.

The dataset for analysis will contain personal information such as age, sex, place of residence at death, postal code, diagnoses and health service information; without this information it is not possible to describe the care provided and whether care is equitable (i.e. across sexes, for different age groups, rural/urban, etc.). Reports and journal articles by NELS ICE will only contain aggregate-level data with cell counts of five or more.

When NELS ICE investigators are funded for other research studies and work with additional investigators, the variables collected will differ. However, the principles of data privacy, access and retention policy for person-specific study data will remain the same. Examples of such studies include the palliative care costing studies led by Dr Serge Dumont funded by CIHR.

V. Safeguards for Protecting Confidential Information

To ensure the confidentiality and security of NELS ICE data files, the following administrative, physical and technical safeguards are employed. Parallel conditions will be in place for other NELS research.

Administrative:

- NELS ICE activities are governed by the contractual agreements with data providers.
- NELS ICE staff sign a confidentiality agreement as a condition of employment (see Appendix). NELS ICE staff acknowledges that breaches are grounds for dismissal and possible legal action.
- Staff and trainees receive training on the importance of maintaining the privacy and confidentiality of personal information. This includes the online Introductory Tutorial for the Tri-Council Policy Statement offered by the Interagency Advisory Panel on Research Ethics (PRE).¹⁰
- All staff and trainees are required to have a good understanding of the “NELS ICE Data Privacy, Access and Retention Policy”. This policy and other key privacy-related documents are available on the NELS ICE space on Blackboard Learning System (BLS).
- NELS ICE data cleaning, data set development, linkage and analysis that use Nova Scotia Vital Statistics records to identify the study subjects (CIHR grant # HOA-80067) are performed by NELS ICE authorized personnel only in Room 568 of the Bethune Building. Remote data access is not granted.
- Since the NELS ICE office is located within the Surveillance and Epidemiology Unit (SEU) at Cancer Care Nova Scotia, requests for new staff and trainees to have access to this office must be submitted to the SEU Director for approval.
- When individuals without authority to access confidential information are present in the office, a NELS ICE staff member must accompany them or ensure that confidential information has been secured.
- Data providers and the Research Ethics Board will be informed when investigators, post doctoral fellows, clinical trainees, graduate students or other new staff join the research team and require access to NELS ICE data.

Physical:

- Access to the NELS ICE office is by key and it is a requirement that this office remain locked when not in use. NELS ICE staff will adhere to the same data access arrangements that are in place at SEU for provincial cancer registry data.

Technical:

- The Bethune Building is located at the VG site of the QEII Health Sciences Centre and is part of the Capital District Health Authority (CDHA). All computer equipment in the NELS ICE office is supported by the CDHA IT department. NELS ICE staff and trainees using CDHA computer equipment are required to follow CDHA IT policies. These can be found within the administrative policies section on the CDHA Intranet.
- Computers in the NELS ICE office are only accessible with a CDHA user name and password. Passwords must conform to CDHA standards and be changed regularly. They are never shared. All staff must log off the CDHA network at the end of each day.
- Data files are password protected and stored on a secure folder on the Cancer Care Nova Scotia shared network drive. This folder can only be accessed by NELS ICE personnel.

Data cleaning, data set development, linkage and analysis for data sets that developed and/or analyses via funds from another research grant or funding source will be governed by the terms and conditions of the relevant grant. The specific personnel, data location and processes will differ from NELS ICE specifics noted above but equally rigorous the principles of data privacy, access and retention policy for person-specific study data will be in place and all relevant Research Ethics Board approvals and conditions will be met.

Retention of Personal Data

Personal data obtained by NELS ICE will be retained as long as they are needed to fulfill the research objectives.⁷ CIHR requires that grant recipients retain original data sets from CIHR-funded research whether published or not for a minimum of five years after the end of the grant.¹¹ Once the retention period has passed and the data set is no longer needed to fulfill research requirements, the data set will be securely destroyed. CDHA IT services staff will be consulted when data destruction is required.

REVIEWED by NELS ICE Management Committee: November 7, 2008

REVISED: December 5, 2008, August 2009

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**Appendix
NELS ICE
Pledge of Confidentiality**

As a condition of employment, NELS ICE requires a signed agreement from all staff and trainees with access to NELS ICE data. Data providers who release data files to NELS ICE may require separate confidentiality pledges or agreements to be signed.

I have been given and read the NELS ICE Privacy Policy, and I fully understand this policy and how it applies to the NELS ICE work I will be doing. I understand that anything I learn about an individual's personal information or other sensitive information in the course of my work, whether through conversation, processing data or other methods is confidential. I will not discuss it other than for work-related purposes. I will not release it except when authorized and following procedures approved by the NELS ICE Management Committee including adherence to the NELS ICE Privacy Policy. I acknowledge that any breach of confidentiality or inappropriate use of personal information obtained through the workplace may result in disciplinary action.

Signed: _____
Employee

Signed: _____
Witness

Print name: _____

Print name: _____

Date: _____

Date: _____

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