

Plan for Discussion: Palliative Care Database development in Nova Scotia¹

September 25, 2012

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¹ You may share this report with palliative care programs, others in Nova Scotia District Health Authorities, and others interested in the ideas herein. The goal is to enable further discussion on the ideas being proposed.

A comprehensive review has not been carried out. Therefore, some statements may not be accurate, up-to-date, or complete. Furthermore, systems and ideas continue to evolve. Input is greatly appreciated to try to attain a clear understanding of the complex situation regarding Nova Scotia Palliative Care Program (PCP) database development. Please send comments to Grace.Johnston@dal.ca

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Executive Summary

This report proposes ideas for discussion of electronic data base development in Nova Scotia to track the care of persons at end of life who would benefit from palliative support. It is based on the author's understanding of data being collected electronically by three palliative care programs and provincial databases; therefore, it has a limited perspective.

This report is a base for discussion and critique. Hopefully, it will help lead to the emergence of leadership for future database development to serve persons at end of life, their families and care providers in the years ahead.

Premises of this report include i) Leadership from and knowledge exchange with (Palliative Care Program) PCPs is vital, ii) Data on care provided by PCPs is integral, iii) Linkage across care provider and sector databases is beneficial, iv) Existing databases should be incorporated as much as possible, v) Development should not be locked into existing practices and should be able to adapt over time, vi) Future web portal data entry and retrieval through electronic hand-held devices is assumed, and viii) Development of a Nova Scotia population based palliative registry for early identification and tracking of needs and care is advisable.

Ideas for PCPs to move forward include i) Development and updating of a PCP data dictionary for each District Health Authority ideally moving toward a common PCP data dictionary, ii) Importing data from other existing high quality electronic databases, iii) Requiring data entry of critical data elements, enabling data quality checking, and using drop-down menus, iv) Supporting real time, direct electronic data entry and retrieval by care providers, v) Ensuring correct patient identifiers, vi) Incorporating dates of referral, assessment and discharge as well as death clearance, viii) Including other key data field such as case coordinator, next of kin, community pharmacist, and Advance Care Plan with information on the Compassionate Care Benefit and Emergency Health Service 24/7 support, and ix) Using multiple screens or fields to show transitions in care locations, diagnoses, symptoms and medications.

In the years ahead, the goal is for care providers as well as persons with advanced chronic diseases and their families to have ready access to quality information for optimal care provision. Since management tends to follow measurement, much needed policy development, planning and advocacy will hopefully emerge. Ongoing engagement in research and education is advised.

Introduction

The Network for End of Life Studies (NELS) is a team of researchers in Nova Scotia (NS) who are working to enhance interdisciplinary research capacity through collaborations aimed at improving end of life care. NELS received funding from the Canadian Institutes of Health Research (CIHR) through a multi-year (2006-2013) Interdisciplinary Capacity Enhancement (ICE) grant to help build research capacity with a focus on vulnerable populations. Grace Johnston is the Principal Investigator for NELS ICE. The goal of this ICE grant is to improve care for persons at end of life by enhancing interdisciplinary research capacity. The specific objectives of the NELS ICE were to:

- Develop a system that will enhance identification and surveillance of populations that are vulnerable at end of life.
- Design and conduct pilot studies to facilitate the development of research proposals to examine and address vulnerability and inequity in the provision of quality end of life care.
- Engage in knowledge translation to inform decision-makers, health professionals and researchers on the provision of end of life care in vulnerable populations.
- Further build an interdisciplinary team of researchers, trainees, health professionals and community partners.

Two NELS ICE surveillance reports were released in 2008². This was followed by the production of a series of NELS newsletters³ and a Report of Symptoms and Outcomes Measurement for End of Life Care in NS in 2012. In parallel two additional reports using NS data on end of life care have been reproduced⁴.

One aspect of NELS ICE was the development of a new linked database called 3x3 NELS. In May 2012 in Halifax, Lynn Lethbridge, NELS ICE analyst, presented preliminary 3x3 NELS findings (see Appendix A) to persons from the palliative care programs (PCP) in the three District health Authorities (DHA) in NS which have more than ten years of electronic data of patient registrations: Capital Health (CH), Cape Breton (CB) and Colchester East Hants (CEH). Data from these three PCPs were included in the 3x3 NELS linked dataset.

At this May 2012 meeting, David Henderson (CEH) asked Grace Johnston to prepare a report that could be used by PCPs in NS for discussion on further development of electronic palliative care databases which could be used across NS. Anne Frances d'Intino (CB), Paul MacIntyre (CH) and Mark Scales (CEH) were also in attendance and supported this idea.

² See: <http://nels.schoolofhealthservicesadministration.dal.ca/pdfs/Listening%20to%20Stakeholders%20Report.pdf>
<http://nels.schoolofhealthservicesadministration.dal.ca/pdfs/End%20of%20Life%20Care%20in%20Nova%20Scotia%20Surveillance%20Report.pdf>

³ See NELS News at: <http://nels.schoolofhealthservicesadministration.dal.ca/nelsnews.html>

⁴ Steering Committee of Cancer Statistics (2010) Canadian Cancer Statistics 2010. "Special Topic: End of Life Care" by Barbera L, Burge F, Dumont S, Fassbender K, Johnston G, Lau F Toronto: Canadian Cancer Society, pages 69-86

Canadian Institute for Health Information (CIHI) (2011) Health Care use at the End of Life in Atlantic Canada. CIHI Atlantic: St John's, Newfoundland

Purpose

This report proposes ideas for discussion on further electronic data base development in NS to track the care of persons at end of life⁵ who would benefit from a palliative approach⁶ to their care. Key premises in the development of this report include:

- Leadership from and knowledge exchange with PCPs is vital
- Data on care provided by PCPs is integral
- Since end of life care includes but is not limited to care provided directly by PCP staff, database development should be set up with linkage across care provider databases in mind. This might be a repository fed by the databases, which could be queried.
- Since new databases take years and considerable resources to develop, existing databases should be incorporated as much as possible
- Development should be based on ‘best-guesses’ on future service delivery and information technology developments, should not be locked-in to existing practices, and should be able to adapt to change over time
- Data development should assume that there will be web portal data entry and data retrieval in the future through mobile devices, lap-tops in places of care, and internet access
- Hospital-based data systems are improving over time and need to be incorporated into a plan for improved palliative data collection primarily to demonstrate a shift over the years ahead from hospital to integrated community based palliative support for persons at end of life
- The Gold Standards Framework (GSF) developed in the United Kingdom and the British Columbia primary care Practice Support Program (PSP) algorithm for end of life care should be used to guide developments for a palliative approach to primary care in Nova Scotia
- Since both GSF and PSP are grounded in the development of a population based palliative registry that extends beyond PCP programs, earlier assessment and data tracking over time and place should be planned for NS

This report is based on the author’s current understanding and experiences with data being collected electronically in PCPs, and on data being collected or under development in NS, combined with a vision for optimal end of life care in the future. Totally new options for palliative care data collection are not the focus of this report. ICE funding for NELS will end shortly and so NELS ICE personnel cannot play a long term key leadership role. Also, the NELS mandate relates to developing research to improve the situation for persons at end of life. Beyond the influence of research, NELS does not have a leadership practice mandate. Therefore, leadership for PCP database development in NS must come from elsewhere.

⁵ For a description of end of life care, see page 2 of the NELS ICE 2012 “Report of Symptoms and Outcomes Measurement for End of Life Care in Nova Scotia”

⁶ In this report, the term “palliative approach” is used to mean care provided by formal palliative care programs in each DHA and at the IWK Health Centre for children and youth, as well as out-of-hospital palliative support provided in other ways and locations, e.g. home care including the Victorian Order of Nurses, long term care facilities, primary care by family physicians and collaborative teams, emergency health services, community pharmacists, and provincial chronic disease programs including those for cancer, renal disease, cardiovascular disease, and diabetes, and the CH INSPIRED program for persons with advanced chronic obstructive pulmonary disease (COPD).

Context

Palliative care is underdeveloped and uneven in access in NS, across Canada and elsewhere. Across Canada, access to adequate integrated community-based care is known to be particularly problematic⁷ and there is pressure for those at end of life to receive their care in the community rather than at a hospital as an inpatient or in the emergency department. Concurrently, the baby boomers are aging and this will further increase demand at a time when both federal and provincial funding for health care is being curtailed. Historically, providing palliative care focused on cancer but increasingly many other chronic conditions with an end of life phase are receiving attention. As these changes occur, there is increasing use of the terms such as palliative ‘approach’ or ‘philosophy’ to reflect palliative and end of life support for persons who receive care beyond delivery in a formal palliative care service.

Data Base Development associated with Palliative End of Life Care

In NS, there is no province-wide PCP database. There is no standard across PCPs for data fields to be entered or in software to be used. Three of the nine DHAs in NS have had a PCP electronic database of patients for more than ten years: CH, CB, and CEH. PCPs in other DHAs have an electronic database for recent years only, or rely on paper records.⁸ The IWK Health Centre PCP in Halifax has an electronic database for children and youth in NS and other provinces in their catchment area. While critically important, PCPs only provide part of the care and data for persons at end of life.⁹

Starting in 2009?, for two to three years, under the leadership of Heather MacDonald, the Department of Health and Wellness (DOHW) worked toward improving PCP data collection. Kevin Durhan¹⁰ was involved initially in supporting this work at DOHW. Kevin had previously worked with the InterRAI SEAscape database. PCPs in DHAs outside of CH¹¹ were being encouraged to begin using **Meditech** for PCP scheduling since this software was already available in their DHAs. In 2011, pilot testing of PCP

⁷ Ranking countries by quality of end of life care. **The Economist**. July 14, 2010
http://www.economist.com/node/16585127?story_id=16585127&fsrc=rss

⁸ Junaid Kapra (2008) **Palliative Care Program Data in District Health Authorities 1-7 in Nova Scotia**. NELS ICE: Halifax at: <http://nels.schoolofhealthservicesadministration.dal.ca/pdfs/p1/2008%20PCData.pdf>

⁹ Lavergne R, Johnston GM, Gao J, Dumont S, Burge F (2011) Exploring generalizability in a study of costs for community-based palliative care. **Journal of Pain and Symptom Management** 41(4): 779-787

¹⁰ Kevin left the DOHW in 2012 for a private sector position

¹¹ CH uses STAR as its ADT system and a combination of Pathways Health Care Scheduling (PHS) and OPIS (Cancer Care application) for scheduling patient appointments in their DHA, not Meditech. The PCP at CH has its own PCP database which was built in house and received information from the ADT system. As of July 1 2011, the CH PCP data entry was moved from a stand-alone ZIM-based system to the CCASPER application. The historic CH ZIM PCP data have not been imported into CASPER. The CASPER-based system imports patients registered to the PCP demographics using STAR on an ongoing basis.

Meditech commenced at least in the CB PCP with support from HITS at the DOHW. There is some interest by some DHAs in including more data fields in a PCP database than are in Meditech.

Since 2003, the DOHW Continuing Care branch has used and supported the provincial **InterRAI home care** electronic database for recording information on persons in the province being assessed for home care and/or long term care facility placement through the Single Entry Access (SEAscape) service. Thus, a proportion of persons at end of life have records in this database. The DOHW purchased and had planned to pilot test the use of the **InterRAI palliative care** database a few years ago but this has not as yet occurred.¹² InterRAI palliative care had the support of Heather MacDonald. There is no provincial electronic database of clients in long term care facilities in NS, just the assessment for nursing home placement through SEAscape.

Apparently, many years ago, responsibility for palliative care was located in Continuing Care. During the first part of Heather's time at DOHW, she reported through Acute and Tertiary Care. However, part way through, she and palliative care were moved to Primary Care. Currently and in the foreseeable future, Primary Care is swamped with many demands and changes. So, there is little apparent focus on palliative and end of life care. However, family physicians are being encouraged to use electronic health record systems. The "Better Care Sooner" initiative at the DOHW is working on changes that relate to palliative care including an extended role of the paramedic being developed by the Emergency Health Services (EHS). EHS has a well developed database on their clients and services they provide.

There are two province-wide medications databases being supported by DOHW: 1) the **Prescription Monitoring Program (PMP)** database and 2) Pharmacare. The PMP has a comprehensive database of all prescriptions for narcotics outside of hospital in the province from 2005 onward. It is real time and has the capacity for real time alerts to physicians and pharmacists. In contrast, Pharmacare only includes prescriptions for persons 65 years and over who have enrolled in Pharmacare and are purchasing provincially approved drugs through Pharmacare, as well as for prescriptions being paid by the DOHW persons on social assistance. The design and development of a new provincial **Drug Information Symptoms (DIS)** database is underway and is expected to be operational in 2015.

For fifteen years, Cancer Care Nova Scotia (CCNS) has had responsibility for planning and providing guidelines across the continuum of care for persons with cancer; this includes supportive care. CCNS operates a **registry** of all persons with cancer, as well as CCNS has distress screening and patient navigator initiatives, both of which have their own patient/client databases. The Diabetes Care Program NS and Cardiovascular Health NS also have provincial mandates to guide in the development and monitoring of adherence to standards across the care continuum, and they have patient/client **registries** for their respective diseases for this purpose. The NS Renal Program has a parallel mandate and this program is in the midst of developing a renal registry. While there is not a NS Chronic Obstructive Pulmonary Disease (COPD) program, in CH, there is an INSPIRED program with a database of community care for COPD patients. The CH/ Dalhousie Geriatrics program is encouraging the use of PATH for assessing and recording the assessment of elderly persons in the community.

¹² From communication with Joanne Boudreau in relation to her presentation at the February 29, 2012 workshop which led to the Report of Symptoms and Outcomes Measurement for End of Life Care. Joanne retired from DOHW in the Spring of 2012.

Improving and Standardizing Palliative Care Program Data Fields

In the past ten years or more, there have been initiatives in Canada and elsewhere to develop a minimum dataset for palliative care. This work has not lead to consensus but is very time consuming. Therefore, this is not the process which I would advise for palliative care data development in NS. Rather, I would advise the review, adaptation and augmentation of data already being collected or being planned for care by the range of agencies and sectors providing palliative support to persons at end of life. That said, as PCPs move toward improving data for the patients they serve, based on experience reviewing the CH, CB and CEH databases, the following are some recommendations for moving forward.

1. Development and ongoing updating of a *data dictionary* is essential for training of data entry staff and being able to appropriately interpret reports from the PCP database. NELS ICE analysts have prepared and provided reports to the CEH and CB PCPs which could be revised for this purpose. Mary Eileen MacPhail is developing a data dictionary for the CH PCP database that is now operational through CASPER. Reviewing and comparing these documents is a substitute for a starting-from-scratch discussion of a minimum data set for a PCP. The PCP in each DHA should have an up-to-date PCP data dictionary and the PCPs across the DHAs should ideally move toward agreement on a common PCP data dictionary.
2. *As much as possible, import data* from other existing high quality electronic databases such as Meditech scheduling and/or the provincial Medical Services Insurance (MSI) health card number (HCN) database. This should include death clearance directly with NS Vital Statistics or indirectly through the MSI HCN, Meditech in DHAs 1-8, or STAR in CH. Death clearance is the process of searching for and adding accurate date, cause and location of death. Electronically importing quality data can help ensure the quality and completeness of PCP data and reduce PCP data entry costs. Relationships and processes will need to be developed to reconcile differences between databases and over time to improve the efficiency of processes.
3. Data entry software should be set to *require* data entry of critical data elements. *Data quality* checking, processes and reporting is encouraged¹³.
4. *Drop down menus & check boxes* should be used as much as possible with limited use of free text to help ensure accuracy in data input. All dates should be in three separate fields in standard format ideally using drop down menus.
5. *As much as possible, support real time, direct electronic data entry and retrieval by care providers* through mobile devices and/or lap top computers. This will reduce data entry clerk time, improve the accuracy and timeliness of data entry, and make the database much more useful for clinical care delivery. This is now being done by some CH PCP nurses.

¹³ Canadian Institute for Health Information (CIHI) (2009) **The CIHI Data Quality Framework** at: http://www.cihi.ca/CIHI-ext-portal/pdf/internet/DATA_QUALITY_FRAMEWORK_2009_EN

6. Since it is critical that records fully and correctly identify patients, and to ensure correct linkages over time within the PCP database and with records beyond the PCP database are complete and accurate, the entry of correct patient identifiers is critical. Therefore, as much as possible, the following data elements should be extracted electronically from other databases or otherwise be recorded for each patient and should be mandatory. The underlined data elements are very important to record for all persons. Data entry clerk should have immediate access to the NS MSI HCN database to look up missing required patient identifiers, and ideally in real time extract and verify these fields from NS MSI to improve both accuracy and efficiency of data entry.
 - Formal title: Doctor, Rev, Sister
 - Legal first name
 - Last name
 - Middle name/initial
 - Nick name or Preferred name if different from First name
 - Maiden/birth/previous surname(s)
 - Health Card Number (HCN) and exception flag indicating a province/HCN other than NS, and other numbers or persons not in the NS MSI database
 - Date of birth (software can automatically generate age based on date of birth and current date)
 - Sex: Male or Female
 - Current full street address in set of standard fields for place of residence including postal code
 - Recent past full street addresses including postal codes
 - Mailing address if different from street address

7. PCP admission and discharge scheduling¹⁴ is essential to record for all patient referrals to the PCP. For example, consider including these fields:
 - Referral date
 - Referral source – drop down menu of Family Physician, Long Term Care facility¹⁵, NS Home Care, Specialist by Selected Types (e.g. Emergency, ICU, Oncology, Geriatric, Pediatric ...), Other, with free text for typing in name
 - Date first seen/assessed by PCP staff¹⁶
 - PCP assessor - drop down menu of PCP Physician by name, PCP nurse, ..

¹⁴ Automated real time data entry of these fields into the PCP database is advised

¹⁵ Much work is needed to standardize definition and types of long term care facilities. Until a better system is set up, recommend the list of NS nursing homes receiving DOHW funds which is available on DOHW website: http://www.gov.ns.ca/health/ccs/pubs/approved_facilities/Dir_approved_facilities_NH.pdf

¹⁶ Variations exist between palliative care programs on what assessment/ first visit date is entered. For example, the CB PCP records two dates. The first is the date when the triage nurse sees the patient; a bench mark maximum of 48 hours after referral has been set and is monitored to ensure timely triage. The second date is the date when the physician assessed the patient. For a date of assessment/first visit field to be meaningful for comparisons across PCPs of wait times, rates of referred patients who are not assessed, etc, common definitions across PCPs must be developed and used. In the meantime, so long as the definition is clear within each PCP, the data is interpretable within the PCP and comparisons among PCPs will need to keep the varied definitions in mind and make crude adjustments for the differences in definitions.

- Date Discharged
 - Readmission Date
 - Date of Death (DOD) and flag indicating data source¹⁷
8. Other key data field to enter are:
- Case Coordinator¹⁸
 - Next of Kin and contact Information
 - Community Pharmacist (for provincially funded reconciliation of drugs to help plan for medication changes¹⁹ and consideration of the Provincial Palliative Care medication program)
 - Advance Care Plan (consider items such as the following):
 - Tissue donation discussion
 - Preferred location for the majority of palliative care
 - Preferred location of death
 - Allow a Natural Death (AND) (use this term rather than Do Not Resuscitate (DNR))
 - Date AND directive was signed
 - Compassionate Care Benefit info provided to family
 - Plan for an expected death at home has been reviewed with the family²⁰
 - EHS ECP 24/7 support arranged²¹
 - Nutrition plan
 - Spiritual Care

Use drop down menus as much as possible with Other option with text field

9. Multiple data entry screens are needed for each of the following:
- Care Locations and contact information

¹⁷ Flag codes: 0= PCP data entry for PCP care; 1= obtained from or validated through NS MSI database which should be set up so PCP database is automatically updated as soon as DOD is entered into NS MSI database. Should ideally be process whereby PCP data entry clerk can immediately contact NS MSI when there is a difference in date of death, place of residence, or other information to get differences resolved

¹⁸ The author's vision is that there will be only one case coordinator who operates across all locations and forms of care for persons at end of life. This is idealistic at this point in time in that, for example, a continuing care coordinator may oversee VON involvement and a Palliative Care Consult Nurses (PCN) may be the case manager in relation to care from the DHA's PCP. Until there is seamless, patient-centred care across health sectors, an interim solution could be to have data fields for multiple case coordinators listed by type of health sector. Another approach might be to name a lead sector and thereby case manager, with other sector managers listed. The goal would be that the person at end of life and his/her family would only need to connect with one person who would coordinate and monitor appropriate care across sectors.

¹⁹ Maddison A, Fisher J, Johnston G (2011) Preventive medications at end of life. **Progress in Palliative Care** 19(1): 15-21

²⁰ For example, plan for family to call funeral director, not 911, when death occurs. There is no need for a physician to pronounce death or for a coroner to visit the home when a registered palliative care patient has died.

²¹ See Report of Symptoms and Outcomes Measurement for End of Life Care in NS (2012) or contact Dr Andrew Travers at Emergency Health Services for NS

- Relevant Diagnoses using drop down menus or ICD²² codes ideally extracted from another electronic data sources such as pathology and diagnostic imaging, hospital admission/discharge, and physician billing, to the extent they are now or they become available
 - ESAS or other symptom assessment²³ at time of admission and periodically thereafter
 - Medications: Developed in collaboration with NS Prescription Monitoring Program (and over time with the new DIS provincial drug data base) with real time multi-way data feeds also with community pharmacist and family physician
10. Data entry and retrieval personnel as well as information technology staff are very important players in these developments. They should be at-the-table and actively engaged in ideas for PCP data development. Opportunities for their ongoing education and development are advised.

Beyond the above, ten year goals for all PCPs in NS should ideally include:

1. Ready access for persons with advanced (life threatening, life limiting) chronic diseases and their families to a quality web-based approach for symptom assessment (such as ESAS) and checking (ideally with auto reporting to care providers and flags for intervention priority), and to review and make changes to a person's advance care plan. Examples of useful patient websites include Virtual Hospice at <http://www.virtualhospice.ca/>, Mayo Clinic at <http://www.mayoclinic.com/>, and Caring Bridge to communicate with loved ones at www.caringbridge.org/. There should be coordination with the provincial telecare (811) information available to patients and families.
2. PCP personnel engagement in data analysis and reporting and local PCP-driven research projects²⁴ so they can be more able to engage in formed dialogue as changes occur and serve as training sites for students in health professions and retraining/upgrading continuing education.

Recommendations

1. Wide NS PCP cross-sector discussion and critique of this report is needed
2. Given that strong DOHW leadership for palliative care development is not readily obvious, PCP leadership should develop and share a strategic plan for database development for palliative care across the province. Ideally, this strategic planning process should include key stakeholders from a range of sectors²⁵ and be used as the basis for discussion and advocacy with DOHW²⁶.

²² The International Classification of Diseases (ICD) is the accepted standard for recording diseases. See: <http://www.who.int/classifications/icd/en/>

²³ Report of Symptoms and Outcomes Measurement for End of Life Care in Nova Scotia (2012)

²⁴ See papers published by Amy Abernathy and others to aid in this process

²⁵ Persons and agencies to include in this strategic planning process are proposed as follows: Carolyn Marshall (Health Association of Nova Scotia), Dr Andrew Travers (Emergency Health Services), someone from Victorian Order of Nurses, Catherine MacPherson (Decision Support, Shannex), Dr Ingrid Sketris (Dalhousie College of Pharmacy), Susan MacNeil (Nova Scotia Renal Program), Maureen MacIntyre (Cancer Care Nova Scotia), Dr Carman
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3. Concurrently, PCPs in all DHAs should
 - a. maintain existing electronic databases,
 - b. opportunistically improve their electronic data collection in the directions of this report, a PCP-led strategic plan, and directions in their DHA, and
 - c. take advantage of opportunities that may arise formally or informally to learn more about possibilities and best practices for data collection and use. In particular, a focus on symptom and outcome assessment²⁷ and performance indicators is advised.

4. To the greatest extent possible, PCPs and others engaged in providing a palliative approach to care should participate in research and evaluation opportunities as well as university, college and high school student mentorship to aid in learning new and worthwhile approaches for care provision and the use of information technology, reflect on practice, explore innovations, and enable change. The way of the future will be very different than past practices.

Conclusion

Palliative care programs and the use of a formalized palliative approach in a range of locations of care is relatively new in terms of the development of medicine and health systems. Thus, there are no widely accepted standards and models for the development of appropriate patient-based databases. Furthermore, the recent and future evolution of information technology (IT) products and processes in NS means that change will be ever-present in the years ahead. That said, this is a time of opportunity for PCPs to become informed about and work with emerging IT systems using a vision for a comprehensive population-based, linked data systems platform for early identification and real-time tracking and enabling of care provision and other supports for persons at end of life, their families and care providers. This report provides a scan of ideas for discussion and consideration. My dream is that this report will trigger reflection and innovation leading to NS in five to ten years having databases for persons at end of life which are among the best in the world. Timely, accurate, relevant, user-friendly, cross-sector/service, state-of-the-art information can greatly improve access and equity in palliative support. This is particularly important given the steadily increasing complex and expensive demands for the care of persons with advanced chronic conditions which will be occurring in the years ahead.

Gaicomantonio (Cancer Care Nova Scotia), Bev Lawson (Dalhousie Family Medicine), Mary Eileen MacPhail (Clinical Informatics Coordinator, Capital Health), Dr Paul McIntyre and Peter MacDougall (PCP, Capital Health), Dr Anne Frances d'Intinio (CB PCP), Mark Scales (CEH PCP) with Dr David Henderson (CEH PCP) as Chair.

²⁶ DOHW and other persons who should be considered for involvement in a review of this plan include: Susan Lowe (Decision Support), Emily Somers (Better Care Sooner), Dawn Frail (DIS), Jill Casey (Decision Support), Ian Bower (Primary Care), Gail Sloane (Chronic Disease Management Coordinator), Dr Rick Gibson and Lynn Edwards (CH Primary Care), Paula English (Acute and Tertiary Care), Katherine Fraser, Alison Shea (Data privacy officer), person from Continuing Care's Single Entry Access (SEA)scape. These persons may lead to other persons.

²⁷ See 2012 NELS ICE "Report of Symptoms and Outcomes Measurement for End of Life Care in Nova Scotia"

Appendix A: Palliative Care Program data from 3x3 NELS Linked Dataset

**Chronic Disease and Palliative Care Program Data Linkage and Analysis Project:
The 3x3 Network for End of Life Study (NELS)**

Palliative Care Programs

Grace Johnston
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June, 2012

NELS Network for End of Life Studies
ICE Interdisciplinary Capacity Enhancement

Background

- It is increasingly being recognized that end of life (EOL) care requires greater attention
- Evidenced-based decision making requires reliable data
- Much of the research on EOL care has focused on cancer
 - Other diseases have a terminal phase
 - The occurrence of co-morbidities can affect service requirements
- Linked administrative datasets are a valuable tool to study EOL care issues

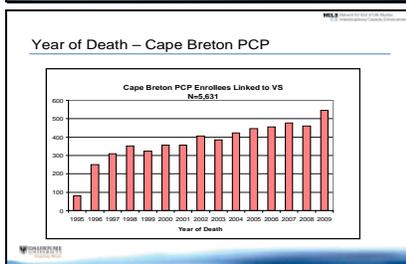
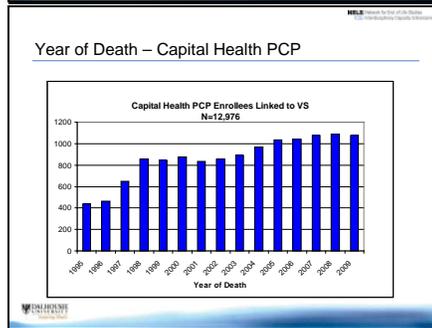
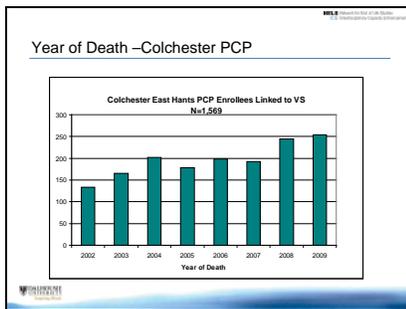
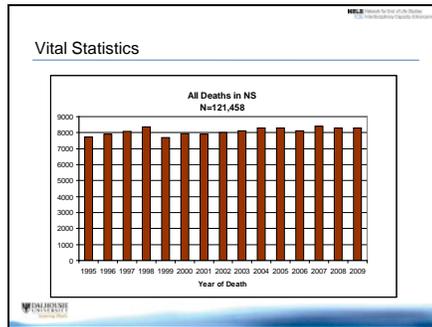
Since PCPs in NS are located in District Health Authorities (DHAs), each has its own administration and its own data. The only PCP data available for the 3x3 NELS project were from Capital Health, Cape Breton, and Colchester East Hants.

Note: the 5.1% missing postal codes refers to the percentage of all deaths over the 1995-2009 period.

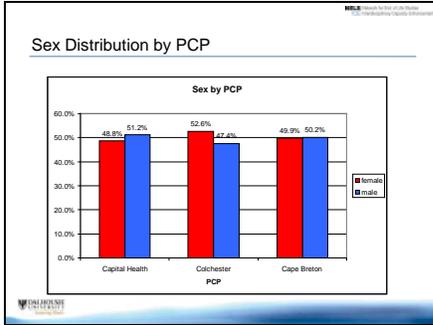
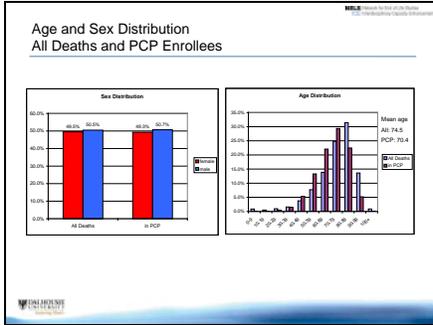
Data Sources

- Link data from 3 disease registries and 3 Palliative Care Programs to Vital Statistics Death Certificate data
- Registry data:
 - Cancer
 - Diabetes
 - Cardiovascular
- Palliative Care Program (PCP) data
 - Capital Health
 - Cape Breton
 - Colchester
- Probabilistic data linkage

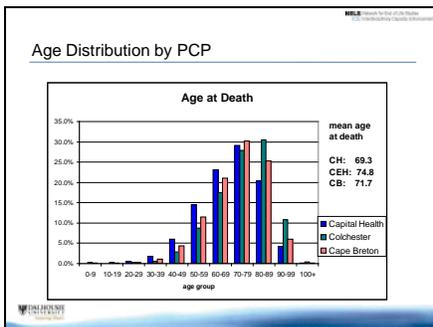
Note: as seen in a later slide, Capital Health PCP enrollees can reside in areas outside of the Capital Health DHA. The slides here refer to all enrollees no matter where the individual resided.



Cape Breton PCP began in 1988 but entry of referrals in electronic database began in 1995 which explains small number in 1995



PCP enrollees are younger than all who died. Average age for all deaths is 74.5 years and for PCP 70.4. Modal age for all deaths is 80-89: 31.4%. Modal age for PCP 70-79: 29.4%. Colchester East Hants enrollees are oldest with an average age of 74.8. Modal age group is 80-89 compared to 70-79 for Capital Health and Cape Breton.



Where Do PCP Enrollees Reside?

- Residential Postal Code information used to determine resident DHA
- Postal Code information obtained from VS
 - If missing, other data sources used where available
- Missing/Invalid Postal Code information
 - 1.6% of all PCP Enrollees

1.6% missing or invalid postal codes refers to percentage of PCP enrollees. Earlier slide indicates 5.1% for all deaths in province.

Residential DHA by PCP

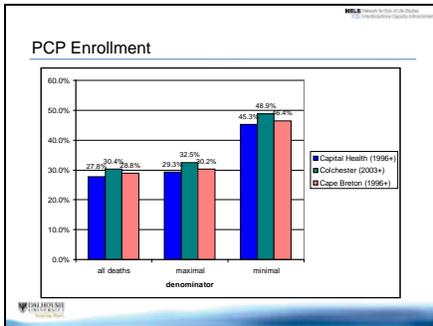
	Capital Health	Colchester	Cape Breton
South Shore	3.45%	0.13%	0.05%
South West	2.27%	0.19%	0.02%
Annapolis Valley	2.79%	0.45%	0.00%
Colchester East Hants	4.62%	90.70%	0.04%
Cumberland	1.20%	2.82%	0.02%
Pictou	1.55%	1.28%	0.05%
Guysborough/Antigonish	1.64%	0.26%	2.21%
Cape Breton	1.62%	0.13%	97.35%
Capital	80.86%	4.04%	0.27%

PCP Enrollment

- Percentage of deaths enrolled in PCPs
- District Health Authority population
 - All deaths
 - Conditions which could potentially benefit from PCP (Rosenwax et al*)
 - Maximal Estimate: all deaths except pregnancy-related and sudden deaths
 - Minimal Estimate: 10 conditions
- Limited years
 - Capital Health: 1996-2009
 - Colchester East Hants: 2003-2009
 - Cape Breton: 1996-2009

* Source: Rosenwax, LK, Blackmore AM, Holman CDJ (2005) Estimating the Size of a Potential Palliative Care Population. Palliative Medicine 19: 566-572.

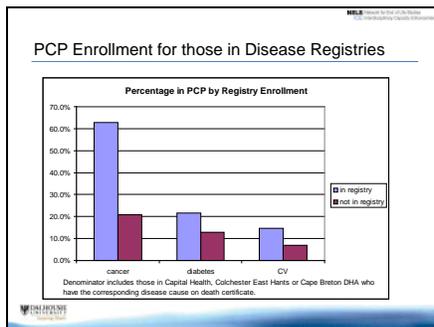
Minimal conditions which could potentially benefit from palliative care are cancer, heart failure, renal failure, COPD, Alzheimer's, Liver Failure, Parkinson's disease, Motor neuron disease, Huntington's disease, HIV/AIDs.



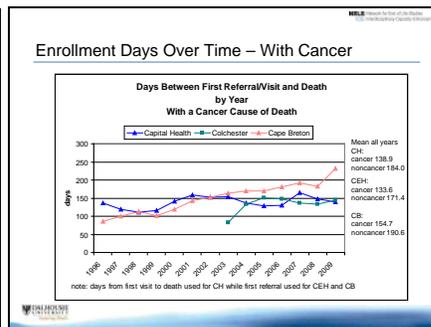
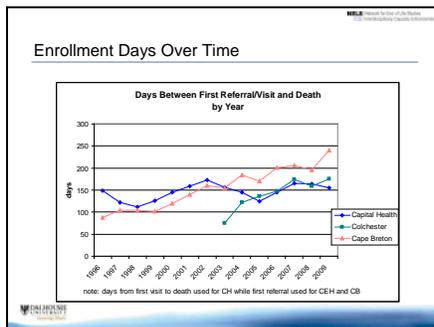
Maximal estimate is all deaths EXCEPT those during pregnancy or childbirth or perinatal period, or from injury, poisoning or other external causes, i.e., sudden death.

Rosenwax et al includes a mid-range estimate which requires hospital diagnosis data to operationalize. PCP enrollment is shown above compared to three different populations: First as a percentage of all deaths in each DHA. CEH was highest percentage at 30.4%. Next, compared to Rosenwax's maximal population which could benefit, since there is only a small percentage of deaths excluded (5%), enrollment is about 2% higher than for all deaths. Finally, compared to those who had died from one of 10 minimal conditions which could benefit from PCP, the percentage of persons being seen by a PCP were: 48.9% enrollment in Colchester, 46.4% in Cape Breton, and 45.3% in Capital Health.

The slide below on the left shows that of those in NS **cancer registry** and with cancer as a cause of death, 62.8% were enrolled in a PCP; in contrast, of the 3% not in the registry with a cancer cause of death (e.g. cancer was a clinical diagnosis of advanced disease for an elderly nursing home resident, or person may have been diagnosed out-of- province but died in NS), 20.9% were enrolled in a PCP. Of those in NS **diabetes registry** and with diabetes cause of death, 21.7% were enrolled in a PCP; those not in NS diabetes registry had a 13% PCP enrollment rate. Of those in NS **cardiovascular disease (CVD) registry** with a CVD cause of death, 14.7% were enrolled in a PCP; those not in CVD registry had a 7.1% PCP enrollment rate. In summary, a **higher percentage of persons who died were enrolled in a PCP if they were registered in their respective disease registry.**



- ### Enrollment Days
- Days enrolled in PCP
 - Used as a quality care indicator
 - First referral date until death used for Colchester and Cape Breton
 - First PCP visit until death used for Capital Health
 - 1996-2004 > 90% have missing value for referral date
 - Mean days between first referral and first visit for Capital Health where both dates are non-missing (2005-2009):
 - 4.39 days when referral date is not the same as the first visit date
 - 40.5% had the same referral and first visit date



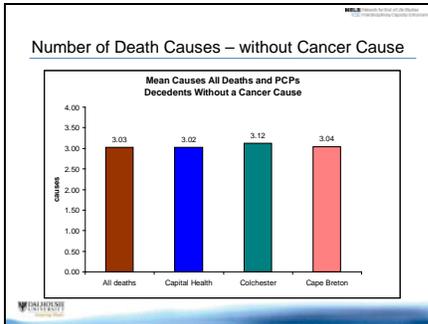
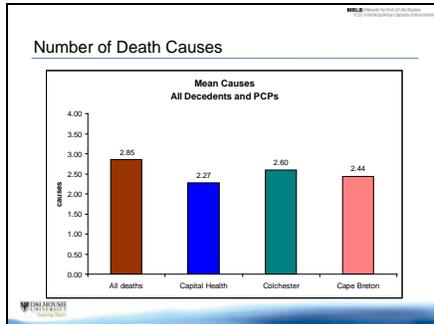
Literature indicates those with cancer have a shorter PCP time enrolled in a PCP compared to those without cancer. Mean days enrolled suggest enrollees for three PCPs have similar patterns. Days are longer for those with a non-cancer cause of death. Increasing time enrolled is similar in two slides above because cancer is predominate in PCPs.

Slide at left below shows another quality indicator: % enrolled close to death. Enrollment near death may indicate less optimal care. CEH shows highest percentage enrolled near death calculated using within 1 or 2 weeks of death. For individuals enrolled in more than 1 PCP, earliest enrolment/visit date was used.

Time from Palliative Care Enrollment to Death

Days	Palliative Care Program				
	Capital Health (2005-2009)		Colchester East Hants (2002-2009)		Cape Breton (1996-2009)
	first referral	first visit	first referral	first visit	first referral
≤7 days	19.2%	20.7%	22.6%	23.5%	20.4%
≤14 days	28.7%	30.2%	31.2%	32.5%	28.8%

- ### Causes of Death
- All causes of death from death certificate utilized
 - Can be up to 13 causes of death listed
 - Disease types were identified through ICD coding used on the death certificate



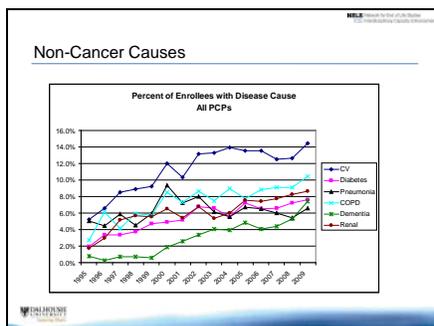
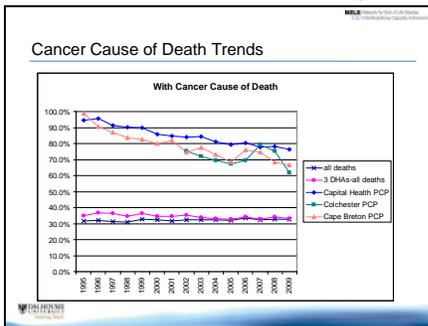
Cancer dominates PCP

enrollment, and percent with cancer varies by PCP. Those with cancer listed as cause of death are less likely to have other causes listed. For those WITHOUT cancer listed as a cause on the death certificate, there is less variation in mean number of causes. Colchester has highest average number of causes of death; age is likely a factor. Colchester has older enrollees who likely often have more co-morbidities.

Cause of Death Frequencies

Program	All Deaths	CH	CEH	CB	All PCPs
Cancer	32.2%	83.6%	70.9%	76.5%	80.5%
Cardiovascular Disease	31.6%	10.1%	16.4%	14.0%	11.8%
Diabetes	10.6%	4.9%	8.6%	7.5%	5.9%
Pneumonia	11.7%	6.2%	8.2%	6.2%	6.3%
COPD	11.5%	6.3%	11.9%	10.4%	7.9%
Dementia/Alzheimer's	10.2%	2.6%	7.6%	4.4%	3.5%
Renal	8.8%	6.6%	6.7%	6.5%	6.5%
observations	121,458	12,076	1569	5631	19,835

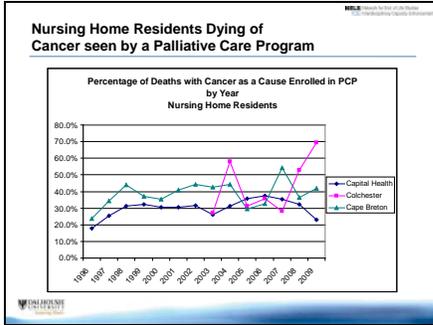
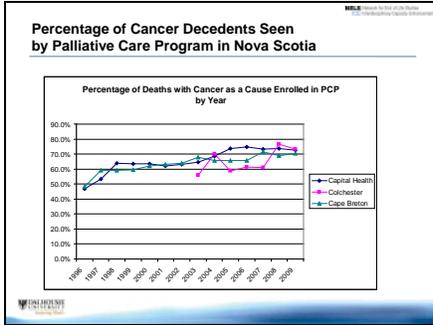
* Categories are not mutually exclusive.



Trends

Average Annual Change in Percent of Enrollees with Disease Cause All PCPs	Value
Cancer	-1.57%
Cardiovascular Disease	0.58%
Diabetes	0.36%
Pneumonia	0.07%
COPD	0.41%
Dementia/Alzheimer's	0.45%
Renal	0.37%

Over 30% of deaths had cancer as cause; consistent over time. Similarly, 33-35% of those who died in any of 3 PCP DHAs had cancer as cause. In PCPs, decreasing % of enrollees dying of cancer. While percent of enrollees with Cancer cause is falling. % PCP enrollees with other causes increasing, particularly dementia.



Decrease in % of PCP

enrollees with cancer does not mean decreasing % of individuals with cancer enrolling in palliative care programs; 65-70% of those with cancer were enrolled in PCP. % of individuals with cancer who enrolled in PCP is increasing in each of the DHAs. However, plateauing in more recent years, particularly in Capital Health. For those in nursing home, increase in those with cancer enrolling in a PCP is not clear.

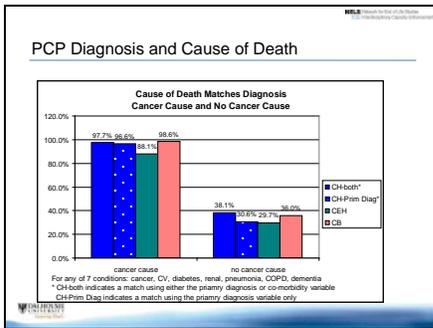
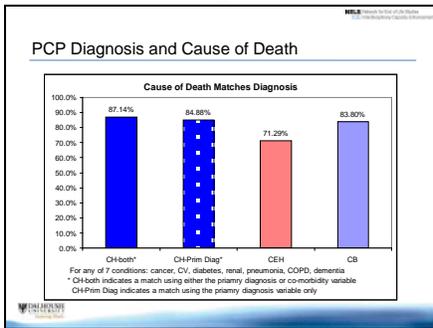
- ### Palliative Care Programs Diagnosis Data
- Capital Health PCP uses ICD-9 codings (as is used on the death certificates)
 - Two variables available to indicate health condition
 - Primary Diagnosis
 - Comorbidity
 - Colchester East Hants and Cape Breton PCPs utilize free text to indicate diagnosis
 - The program searches the diagnoses variables for a list of words and phrases to indicate the various diseases.
 - There could be multiple conditions listed

PCP Diagnoses Frequencies

Program	CH		CEH	CB
	Primary Diagnosis or co-morbidity	Primary diagnosis	Diagnosis	Diagnosis
Cancer	85.9%	84.3%	63.9%	78.2%
Cardiovascular Disease	6.8%	2.5%	2.5%	3.5%
Diabetes	5.1%	2.5%	0.13%	0.23%
Pneumonia	0.90%	0.47%	1.2%	0.60%
COPD	5.3%	1.6%	4.1%	4.6%
Dementia/Alzheimer's	2.3%	0.82%	2.4%	2.1%
Renal	3.3%	1.8%	4.9%	4.6%
Observations	12,976	12,976	1,569	5,631

Note: Categories are not mutually exclusive
Other conditions not listed due to small numbers

Diagnoses are also in PCP data. Two variables in CH: primary diagnosis and co-morbidities; both entered using ICD coding. In CEH and CB, only one diagnosis entered as free text. Most have cancer diagnosis. CH highest at 85.9%; CEH is lowest. PCP diagnosis patterns similar to those from cause of death.

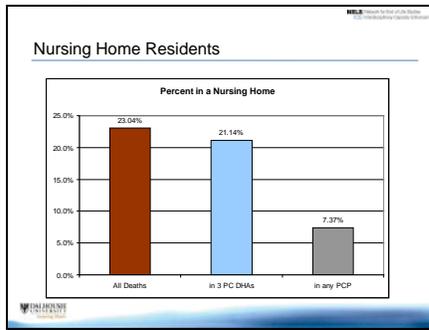


Comparing diagnoses in PCP to cause of death gives validation measure. CH has highest agreement. Stratified by cancer or not shows

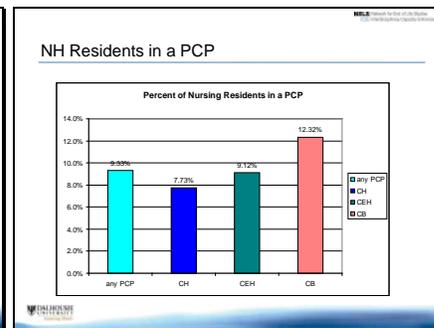
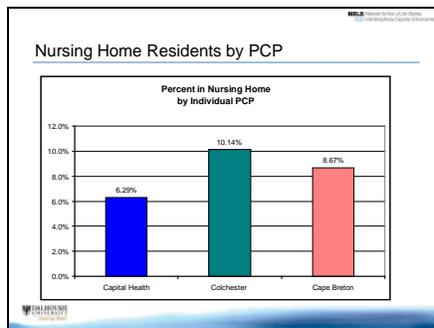
match is much higher for cancer. CB has highest match for cancer and CH for non-cancer.

Nursing Home Residents and PCPs

- 9 indicators of residence in a nursing home in 3x3 data
 - 2 from VS data
 - 2 using CCNS algorithm using address information
 - 2 from cardiovascular registry
 - 2 from Cape Breton PCP data
 - 1 from Colchester PCP data
- The time period and populations covered varies across indicators
- The 2 CCNS variables cover the entire study period and population



Those in nursing homes are less likely to be enrolled in PCP. Of those enrolled in PCP, only 7.4% resided in a nursing home compared with 23% of all deaths. % of nursing home residents enrolled in each PCP are: 6.3% in CH, 10.1% in CEH, 8.7% in CB. Among nursing home residents, % enrolled in a PCP are 9.3% overall with variation by PCP: In CH: 7.7%; In CEH 9.1%; In CB 12.3%.

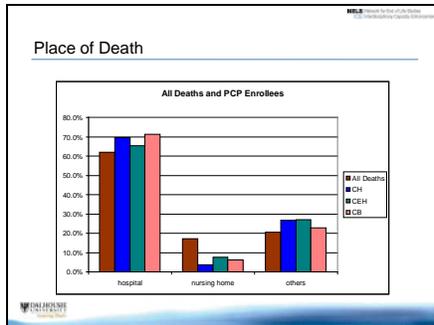


Place of Death

- Location of death is an indicator of quality care near the end of life
- Most patients prefer to die at home
- An algorithm developed by CCNS is used to determine place of death
- Variable constructed indicates if the death occurred in hospital, nursing home or "other"

Place of Death

- "place of death" is distinguished from "location of care" in the last weeks of life
- Decedents may be admitted to the hospital in the last few days of life
- In recent work, researchers have measured the location of care in the last weeks of life
- Further data linkages to the 3x3 NELS data are required to explore location of care during end of life
 - e.g. hospital admission/discharge data



Thank you for your attention!

Higher % of deaths in hospital for PCP enrollees compared with all deaths may reflect that those admitted to hospital receive PCP referral at that time. As shown in previous slides, those enrolled in PCP were less likely to reside in a nursing home and, therefore, less likely to die in one.