Palliative Care Program Data in Nova Scotia

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March 21, 2016

Please cite as: Lethbridge L, Johnston G (2016) Palliative Care Program Data in Nova Scotia.
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This report is posted at: www.dal.ca/nels

Support was provided by the 'Supportive care for women with advanced breast cancer' (ABC-SC) project that was funded by a Breast Cancer Society of Canada / QEII Foundation Award for Breast Cancer Research through the Beatrice Hunter Cancer Research Institute.

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Executive Summary

Provincial and national reports indicate that there are as yet few standardized metrics on access and quality of palliative care. Within this context, Nova Scotia (NS) has been a leader in publishing research on palliative care program (PCP) enrollment rates, and along with national agencies, has reported on the use of various forms of health care for persons at end of life. However, our NS PCP reports have data only up to 2009. So, it is time to assess what PCP data are now available in electronic form for the production of relevant PCP metrics in the future.

Basic data recorded for each patient seen by a PCP are personal identifiers (name, address, date of birth, provincial health card number) as well as the date of referral to the PCP and date of first visit by the PCP team. This report shows that these basic PCP data may be available in electronic retrievable form for all persons referred to any of the ten PCPs in NS from stand-alone PCP databases or via Meditech. In other words, for 100% of the NS population, it appears possible to report important metrics such as i) percent of patients referred to a PCP who were seen by the PCP, and ii) among those seen, the average and range of times between referral and being seen/assessed. Comparisons across PCPs could be made. The first full year of electronic data available varies by PCP from 1996 for Capital Health to 2015 for Pictou.

PCPs are able to record their patients' dates of death, but these dates are incomplete. Linkage of PCP data to Vital Statistics (VS) deaths either directly from VS or via the provincial health card number database would allow the reporting of more metrics including number of people enrolled in a PCP as a percentage of deaths in the geographic area, timing of PCP care before death, and location of death (home, hospital, long term care facility). Of the 8,815 deaths in NS VS in 2013, 58% died in hospital though the percentage of deaths in each district varies.

The data collected varies by PCP and are not standardized. However, palliative care metrics could be reported if VS deaths are used to retrospectively identify persons at end of life and linked to basic electronic PCP data and other NS administrative data, e.g., hospitalizations, continuing care (SEAscape), physician billing claims, emergency department visits, emergency health services (paramedic/ambulance), and narcotics prescription monitoring database. Resultant metrics could include the use of acute and emergency services prior to death, and the percent receiving some forms of home visits in the last weeks of life. Also, given the decision of the Supreme Court of Canada on February 2015, metrics for physician assisted death (PAD) including associations between PAD and the various forms of palliative care are likely to be examined.

Patient preferences, goals of care, and symptom assessment are largely lacking in electronic form. With concerted effort, they could be developed by the PCPs. For population-wide and more immediate metrics, these data will need to be generated in another form, e.g., a mortality follow-back survey of the next of kin. In the longer term, it is hoped that standardized data collection and sharing across care settings will occur. This report is one step toward helping NS prepare to provide metrics on a palliative approach to care that are likely to be expected by the public and governments, and can enable research to improve palliative care.

Background

Palliative and end of life care is available across Nova Scotia (NS) through programs administratively organized by the former District Health Authorities (DHAs) as shown in Figure 1. Each palliative care program (PCP) developed uniquely in terms of service management and provision. Thus, variations in data availability for planning and research also exist.

Findings from PCP data were first published for Capital Health in 1998[1]. PCP data from Cape Breton were added and also published[2]. Having an electronic patient database available enabled patient and caregiver recruitment for costing[3] and other studies. Reports have been generated on how to improve data quality and accessibility[4].

In March of 2008, a report by the Network for End of Life Studies (NELS)[5] provided an inventory of PCP data in the seven DHAs beyond Capital Health and Cape Breton. This report enabled new research and the publication of results[6] that included Colchester East Hants, as well as Capital

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

[2] Maddison AR, Asada Y, Burge F, Johnston G, Urquhart R (2012) Inequalities in end-of-life care for colorectal cancer patients in Nova Scotia, Canada. Journal of Palliative Care 28(2):90-96

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

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

Burge FI, Lawson B, Critchley P, Maxwell D. (2005) Transitions in care during the end of life: changes experienced following enrolment in a comprehensive palliative care program. BMC Palliative Care 4(1):3

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

[3] Dumont S, Jacobs P, Turcotte V, Turcotte S, Johnston G (2015) Palliative care costs in Canada: A descriptive comparison of studies of urban and rural patients near end of life. Palliative Medicine Published online first DOI: 10.1177/0269216315583620

Dumont S, Jacobs P, Turcotte V, Turcotte S, Johnston G (2014) Distribution and sharing of palliative care costs in rural areas of Canada. Journal of Palliative Care 30(2):90-98

Dumont S, Jacobs P, Fassbender K et al. (2009) Costs associated with resource utilization during the palliative phase of care: A Canadian perspective. Pallitat Med 23(8):708–717

[4] Johnston G, Lethbridge L (2014) Lessons Learned and Opportunities for Palliative Care Programs from the 3x3 NELS Study. Dalhousie University, Halifax, Nova Scotia. Available at: http://www.dal.ca/content/dam/dalhousie/pdf/sites/nels/2014%20February%20Lessons%20Learned%20and%20Opportunities%20Report.pdf

Johnston G (2012) Palliative Care Database Development in Nova Scotia. . Network for End of Life Studies, Dalhousie University, Halifax, Nova Scotia. Available at: http://www.dal.ca/content/dam/dalhousie/pdf/sites/nels/report_PCPdataplan2012.pdf

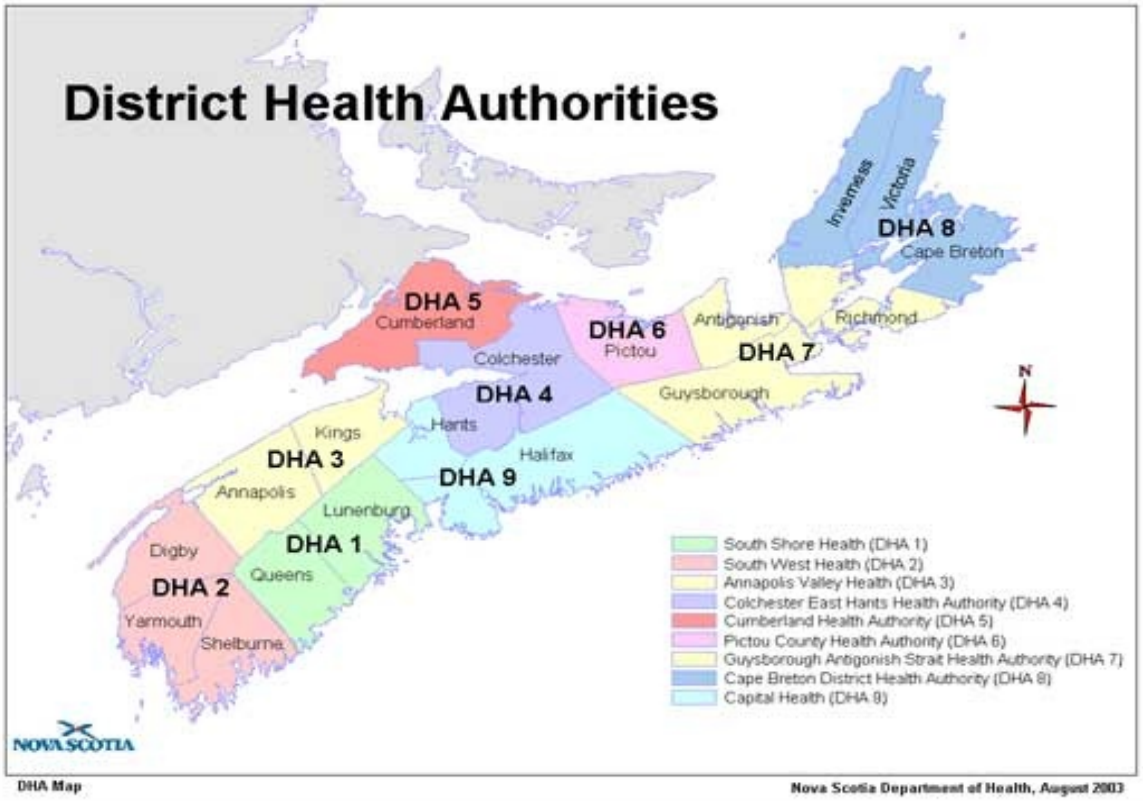
Network for End of Life Studies (2012) Report of Symptoms and Outcomes Measurement for End of Life Care in Nova Scotia, Canada. Available at: http://www.dal.ca/content/dam/dalhousie/pdf/sites/nels/report_outcomesmeasurement2012.pdf

[5] Kapra (2008) Palliative Care Program Data in District Health Authorities 1 to 7 in Nova Scotia Available at: http://www.dal.ca/content/dam/dalhousie/pdf/sites/nels/surv_2008PCData.pdf

[6] Johnston G, Lethbridge L, Talbot P, Dunbar P, Jewell L, Henderson D, d'Intino AF, McIntyre P (2015) Importance of identifying persons with diabetes who could benefit from palliative care. Canadian Journal of Diabetes 39(1):29-35.

Health and Cape Breton, PCP data up to 2009. It is now time to ascertain whether electronic patient-specific PCP data from other districts in the province have become available for more recent years.

Figure 1: Map of District Health Authorities (DHA) by County[7]



Funding and related projects: Two weeks of staff salary support was provided by the 'Supportive care for women with advanced breast cancer' (ABC-SC) project funded by a Breast Cancer Society of Canada / QEII Foundation Award through the Beatrice Hunter Cancer Research Institute. The ABC-SC project enabled research to improve supportive care for women with advanced breast cancer. We published a paper on comorbidities and care for persons dying of breast cancer using data from 1995 to 2009 from three PCPs[8]. After reviewing

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Lavergne MR, Lethbridge L, Johnston G, Henderson D, d'Intino AF, McIntyre P (2015) Examining palliative care program use and place of death in rural and urban contexts: A Canadian population-based study using linked data. Rural and Remote Health 15:3134 Online at http://www.rrh.org.au

[7] Retrieved January 16 2016 from: https://search.yahoo.com/yhs/search?p=Nova+Scotia+DHA&ei=UTF-8&hspart=mozilla&hsimp=yhs-001

[8] Johnston G, Urquhart R, Lethbridge L, MacIntyre M (2015) Increasing our understanding of dying of breast cancer: comorbidities and care. Progress in Palliative Care, Advance publication online: 26 Dec 2015 10.1080/09699260.2015.1108638

palliative care literature to identify quality indicators[9], Cancer Care Nova Scotia has been examining the feasibility of extracting some priority indicators from hospital and ambulatory databases linked to cancer data and 2010-2012 Vital Statistics (VS) deaths.

The literature review showed that access to a PCP is an important palliative care quality indicator. However, the Cancer Care Nova Scotia quality indicator feasibility project does not include PCP data since prior research indicated feasibility for 65% of Nova Scotians (those living in Capital Health, Cape Breton or Colchester East Hants). The Canadian Institutes of Health Research (CIHR) funded NELS to study quality indicators in available electronic PCP data from 1995-2009, but these findings are no longer current and our health system has been changing. Therefore, the 2008 NELS report on PCP data availability needs to be updated so researchers and others will know what electronic PCP data are available, particularly from 2010 onward.

Purposes: This report 1) updates the 2008 PCP data report, and 2) informs researchers and others on electronic PCP patient data availability in NS.

Context: While there is coverage for PCP across the entire province, there is variation in the level and types of services available. Each PCP was developed based on local circumstances which has impacted the resources and training available as well as data collection across the PCPs in the province

Care for individuals near the end of life is a complex issue for families, clinicians and policy-makers. As with other aspects of the health care system, it is essential that decision-makers utilize robust evidence to develop effective policies. Reliable data are necessary for generating evidence and aiding in policy and program development. Administrative data have been an important resource in health care research as they are routinely collected and population-based. Administrative data are particularly valuable in end of life and palliative care research given the inherent emotional and ethical challenges of collecting new primary data through interviews.

PCP data can be combined and linked to other administrative data to generate reliable evidence if there is a clear understanding of when information is comparable and of high quality. Availability and exchange of information can also facilitate cooperation and encourage PCP administrators to learn from the experiences of programs in other areas.

When utilizing administrative data for operations and research purposes, care must be taken to ensure data quality. Data entry errors can occur especially if there are no rigorous checking and quality improvement processes. What is equally important is content knowledge. There is a

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

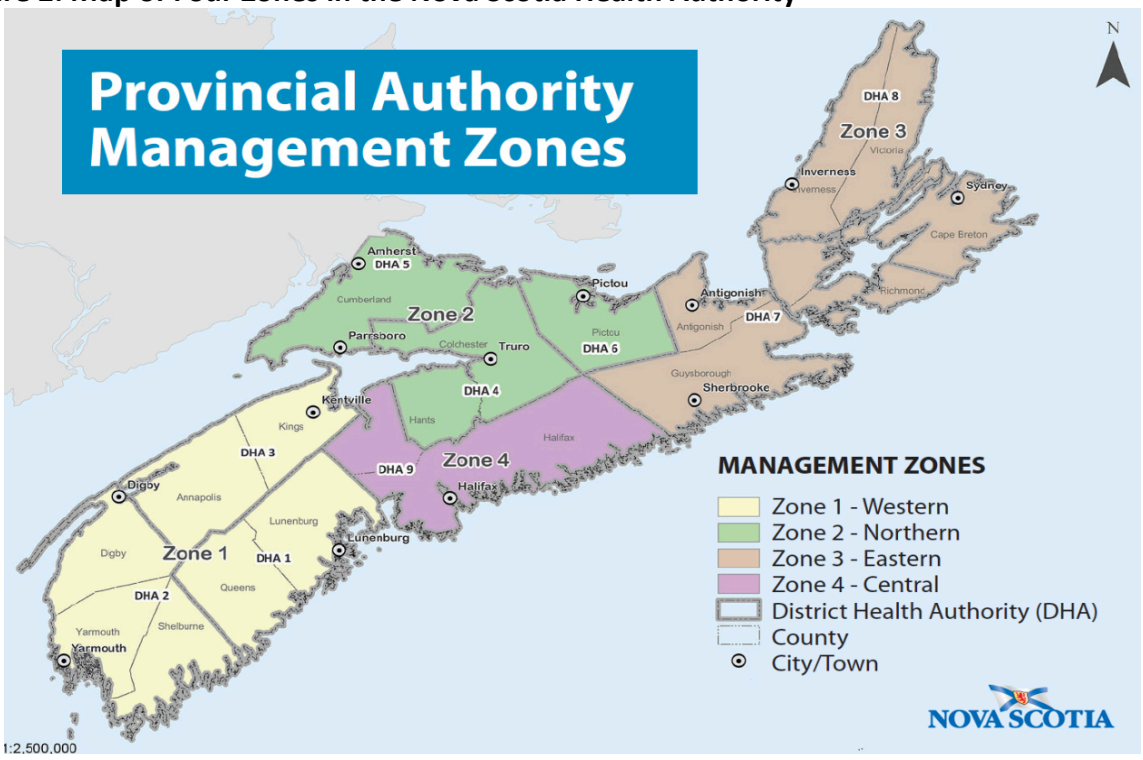
Grunfeld E, Lethbridge L, Dewar R, Lawson B, Paszat LF, Johnston G, Burge F, McIntyre P, Earle CC. (2006) Towards using administrative databases to measure population-based indicators of quality end-of-life care: testing the methodology. Palliative Medicine 20:769-777

need for a clear understanding of the information that is available. Documentation of data elements over time is paramount but this task is often not a priority for PCP data administrators. Documentation is particularly beneficial when a program is not administered centrally across an entire province or country.

A helpful description of data sources includes whether data are collected in electronic form, population coverage, a history of the data collection, a list of the data fields along with the values that can be recorded in each data field, and information on the validity and quality of the data. Contact information of individuals who are able to answer any inquiries with respect to the data is also very useful.

In NS, PCPs were administered separately across nine districts plus a program at the IWK Health Centre for children and youth under the age of 18. Even though in 2015, the province combined the DHAs into a single Nova Scotia Heath Authority plus the IWK, this report uses the DHA names as the PCPs established under the old system remain in place administratively as of early 2016. The Nova Scotia Health Authority is organized into four zones[10] that to some extent combine and follow the old DHA boundaries (Figure 2).

Figure 2: Map of Four Zones in the Nova Scotia Health Authority



[10] NHSA **Northern Zone** includes East Hants, and the counties of Colchester, Cumberland and Pictou.
Western Zone includes Annapolis, Kings, Digby, Yarmouth, Shelbourne, Queens, Lunenburg.
Eastern Zone includes Cape Breton, Inverness, Victoria, Richmond, Guysborough, Antigonish.
Central Zone includes the county of Halifax (except IWK), and township of West Hants.

Approach and Rationale

A list of PCP managers for the nine DHAs and IWK was provided by Cheryl Tschupruk, Provincial Palliative Care Coordinator. PCP managers were contacted by Lynn Lethbridge (LL) in September 2015 to survey them to gain a better understanding of availability of current, usable PCP data. When possible, telephone interviews were scheduled to understand the differences in data collection and accessibility. LL sent an outline of questions before the interview that resulted in additional individuals with content expertise joining the call in some cases. LL then prepared a first draft of this report. LL had carried out the data quality assessment for the Colchester East Hants PCP data so was familiar with PCP data. In December 2015, Grace Johnston followed up with the PCPs in all DHAs that had not yet responded to LL's requests, and completed this report. The report is to be posted on NELS website (www.dal.ca/nels) and provided to researchers, stakeholders and decision makers.

For each PCP, there are two sub-sections (Data and Context) in the Results section of this report. The Data sub-section is a summary of information provided by the PCP, unless indicated otherwise. If the PCP did not provide Context information for this report, the Context sub-section is from website information. Appendix 1 lists people who contributed to this report.

Table 1 summarizes the districts that have data in electronic form and indicates the first full year for which they have electronic data for each person seen by their PCP. Electronic storage of data in a format that is easily accessible by statistical software (i.e., not on paper or in PDF form) is required for efficient data analysis. A very **basic electronic PCP patient database would include the personal identifiers** for accurate linkage to other administrative databases **as well as the date of referral and date first seen/assessed**. It appears that this basic data set can be obtained through a stand-alone electronic PCP database, or Meditech[11] for three districts. For each of the nine districts and the IWK in 2013, Table 1 also includes the number of deaths in the district, this number as a percent of all deaths in NS, and the percent of hospital deaths[12].

Tables 2-9 show details on patient related information. Since Colchester East Hants data were studied (including preparation of a data quality report) and used previously, and we were informed that the Colchester East Hants database had not changed since then, an interview on details for this report was not carried out for this report. Cape Breton's PCP data was also used previously but their data platform has changed substantially, so an interview was carried out. In 2011, the PCP database for Capital Health was converted into the Ccasper database; its data dictionary is in Appendix 3.

Table 2 lists information about the patient/client. The Health Card Number (HCN) is a unique identifier for all individuals with NS publicly funded medical insurance. This variable enables the

[11] This report lacks a comprehensive understanding of Meditech. It is hospital-based and used for admission and scheduling across Nova Scotia, except in Capital Health.

[12] Calculations were made using county count data in the NS VS annual report on page 30, and page 45 for IWK, accessed January 25, 2015 at: http://novascotia.ca/sns/pdf/ans-vstat-2013-annual-report.pdf

linkage of the PCP data to other health databases such as VS death records, as well as hospital and other health utilization data. It is also used to check for duplicate patient records. If HCNs are found to be incomplete, inaccurate or missing, in either or both the PCP database and the database to which the PCP data are to be linked, then probabilistic record linkage software and other personal identifiers including first and last name, full date of birth, and postal code of residence become critically important for accurate record linkage.

Table 3 lists data fields on referral and discharge dates, place and reason, as well as physician contact information, and other dates. Clarity in the definition and consistency in use and coding of the various dates across the PCPs is needed. Dates of referral and first assessed are extremely important in studies of timeliness of access to care, a key measure of quality care. In our PCP studies to date, the basic PCP variables used were personal identifiers for accurate patient linkage, plus the referral and assessment dates. Discharge and readmission dates were also included in analyses. From these data, metrics can be computed such as i) percent of patients referred to a PCP who were seen by the PCP, and ii) among those seen, the average and range of times between referral and being seen/assessed. Comparisons across PCPs could also be made.

PCPs are able to record their patients' dates of death, but the dates are often incomplete. However, PCPs with direct access to the provincial HCN database may be able to fill this void. Automated linkage of PCP data to VS deaths either directly from VS or via the provincial HCN database would allow the reporting of more metrics including the number of people enrolled in a PCP as a percentage of deaths in the geographic area, timing of PCP care before death, and location of death (home, hospital, long term care (LTC) facility). For more than a year, funeral home directors[13] have been completing and submitting death certificates electronically to VS, and so theoretically at least, timely access to these data should be possible.

VS causes of death are not available for a year or more after the death since physicians manually complete and submit this information to VS, and then it needs to be coded using the International Classification of Diseases and entered electronically. For Nova Scotia as a whole, over 9,000 deaths per year are expected, given that the Statistics Canada total of 9,152 deaths from the sum of the quarterly counts for 2014[14].

Table 4 has information collected on the caregiver and family. Table 5 lists data fields related to social supports. Table 6 provides information on advance care planning and death. Table 7 lists data collected on the palliative care team members involved in the care/support of the patient and/or family.

[13] The role of the funeral director in completing and submitting personal identifier death certificate information to NS VS is at: http://www.novascotia.ca/sns/access/vitalstats/funeral-directors.asp

[14] Statistics Canada report of deaths in Nova Scotia by year as of January 15, 2016 at: http://www5.statcan.gc.ca/cansim/a26

Table 8 identifies the data fields related to palliative care assessment, clinical and medication information including symptom assessment and diagnoses. Our work to date indicates that the diagnoses codes in PCPs are often not standardized or reliable. Medical records training of data entry staff could improve the accuracy, or these data can be imported from other more reliable sources. Capital Health was a leader in creating and using a look-up table for entering diagnoses using ICD-9CM (International Classification of Diseases) for the primary and multiple secondary diagnoses for each patient. Including symptom assessment is deemed critically important for the assessment of quality care, but rarely reported. Table 9 has other data fields identified and added at the time of the interviews for this report.

The Results section of this report begins with the three PCP districts that now have their own electronic patient database to collect palliative care information: Cumberland, South Shore and Annapolis Valley. Cumberland is in the new Northern Zone; South Shore and Annapolis Valley in the Western Zone.

This is followed by information on the three PCPs that have not developed their own PCP database: South West, Pictou County, and Guysborough Antigonish Strait. Their electronic patient data collection has advanced from their situation in the 2008 NELS report in that they all now use Meditech for electronic patient registration. Heather MacDonald encouraged the use of Meditech for PCP patient registration when she was the provincial palliative care coordinator in 2010/11. Each of these three PCPs is in a different zone of the new Nova Scotia Health Authority: South West in Western Zone, Pictou County in Northern Zone, and Guysborough Antigonish Strait in Eastern Zone.

IWK PCP data are then described. Lastly, we recap the status of the three PCP districts for which data have been previously published data: Colchester East Hants (which is in Northern Zone), Cape Breton (in Eastern Zone), and Capital Health (now called Central Zone).

Results

There is no one accepted format for a PCP database for use across the province. The Central Zone database appears the most comprehensive in that it includes the ability to record details on transitions in places of care. However, it imports data from hospital data systems that are not available in other Nova Scotia Health Authority zones. Informally, our impression is that the Cape Breton PCP has played a strong leadership role in recent years in the development and collection of PCP data.

All ten NS PCPs now have electronic patient data that could potentially be used. This means it may be feasible to analyse PCP data for 100% of the NS population. Hopefully, this will be useful

in the production of metrics for the accountability pillar described in the 2014 provincial Integrated Palliative Care strategy[15].

There is variability in the number of years of PCP data that are available. The range in the first full calendar year of PCP patient data is from 1996 for Capital Health to 2013 for South West (Table 1). There is also variability in the number of deaths (proxy for palliative care need) in each district. The percent dying in hospital was 58% for NS, varying by district from 55% to 63% in 2013.

Cumberland

Data: The Cumberland PCP (in the Northern Zone) maintains a database in MS Excel with consistent data since 2007. There are 'bits and pieces' of information from 2000-2006 however these data are incomplete in terms of tracking individuals. There are a minimal number of variables, but include the essential variables of HCN, demographics, and service dates, along with provider identification, date and location of death and diagnosis.

Context: Early in 2000, through support from a Federal Health Transitions Fund, a formalized team was established for Cumberland, Colchester East Hants, Pictou and Prince Edward Island to provide coordinated PCP[16]. With the establishment of DHAs later in 2000[17], the three NS DHAs each went its own way. The Cumberland PCP started with staff at two sites and now has dedicated nursing services at five sites across Cumberland county. Currently, there are 5 nurses (3.2 FTEs), 1 physician and full administrative services. The program also consults with a social worker and community services. Nurses provide both community and facility-based services (we assume that this likely means hospital, but might include LTC facilities) that facilitates transition between the two. Recently, the Cumberland PCP consulted with Cape Breton PCP to try and follow their model.

South Shore

Data: The South Shore PCP (in the Western Zone) maintains an electronic database in MS Access with complete and consistent data beginning in 2010. HCN is included as well as demographic information, dates of referral and consultation, clinical and service information as well as the date of death. Additional information from the Meditech and Continuing Care SEAscape applications is also available. Finally, there is an Excel file of active patients containing

[15] Source: "Integrated Palliative Care: Planning for Action in Nova Scotia" May 2014 available at http://novascotia.ca/dhw/palliativecare/ Accessed December 17, 2015

[16] Burge F, Canning K, Cummings I, Dukeshire S, McKim A, Rowswell C, et al. A rural palliative home care model: the development and evaluation of an integrated palliative care program in Nova Scotia and Prince Edward Island. Truro, Nova Scotia; 2001. Available at: http://www.novascotia.ca/dhw/publications/palliative_care.pdf accessed February 12, 2016

[17] Health Authorities Act at http://nslegislature.ca/legc/bills/58th_1st/3rd_read/b034.htm accessed Feb 12, 2016.

supplementary data; however, these records are deleted once the individuals are deceased and so would not be available for analysis.

Context: The South Shore PCP is based at the Fishermen's Memorial Hospital, Lunenburg with satellite offices located at the South Shore Regional Hospital in Bridgewater and Queens General Hospital in Liverpool. Palliative care in the district began as a grassroots initiative in the mid 1980s including both professionals and volunteers with funding provided through community interest. Following recognition that palliative care services needed to be more organized, the Department of Health approved a PCP for Lunenburg and Queen's Counties in 1993. The focus of the program was a combination of facility and community support. Initially, there was funding for a 0.5 FTE coordinator and 1.5 FTE nursing positions. As of 2015, the team consists of a manager, a physician, 4.8 FTE nursing positions, a social worker, a navigator, casual administrative support and 27 volunteers.

A gap in support for the PCP has been a need for more administrative assistance. Currently, help is borrowed from other programs and services. Another area of concern is that there are no designated beds or inpatient units resulting in a scattered bed approach. There are plans to expand services to nine LTC facilities in 2016.

Annapolis Valley

Data: The Annapolis Valley PCP (in the Western Zone) has maintained an accessible database using MS Access since 2009. It includes the patient's name, HCN, date of birth, what priority code they have been assigned (see Appendix 2, Patient Classification Criteria), their civic address, phone number, who their main contact is, unit number (if they have one), diagnosis, date of and referral source, Family Physician, do not resuscitate order (DNR, yes or no), geographic district, palliative care team member assigned, whether or not they are a Continuing Care client and a section for notes, date of death, location of death and preferred location of death. Unfortunately, the current procedure for generating reports from this tool is labour intensive. Tables 4-9 identify what is captured in the Annapolis Valley PCP database, as well as by tools used during the assessment. Whether the data fields from these tools are in electronic form is unclear as yet.

In Meditech, only the first community visit for PCP patients is registered. There is no flag in Meditech to indicate that a client was seen by the PCP team. For Continuing Care patients, SEAscape is available to the PCP team to view and document in continuation notes if necessary.

Context[18]: Patient dignity and comfort are at the core of the philosophy at the Annapolis Valley PCP. Direct assistance to patients and families is offered as well as support and education to help health care providers develop skills in palliative care.

[18] http://www.avdha.nshealth.ca/program-service/palliative-care-services

Consultations and services are provided in the community and at five health facilities in the region: Annapolis Community Health Collaborative Emergency Centre, Eastern Kings Memorial Community Health Centre, Western Kings Memorial Health Centre, Valley Regional Health Centre, and Soldiers Memorial Health Centre. Three of these facilities have inpatient beds, but there are only two designated "palliative care beds" in the district, those being at the Collaborative Emergency Centre. These beds are supported by the Annapolis Community Health Foundation. All other inpatient palliative care patients are in beds throughout the district, with various levels of resources and space available to them and their families.

The Annapolis Valley PCP team consists of a part time manager and admin support, 3 Consult Nurses and 1.5 Physicians. Primary care involvement is encouraged whenever possible. Seniors Living Independently with Community Supports (LINCS)[19] may provide the client with occupational therapy and physiotherapy. Patients in hospital may access spiritual care and social work. Patient care is available in the home and LTC facilities. The PCP is not often asked to be involved with patients in LTC, but do when asked.

The Annapolis Valley PCP team of physicians and nurses has strong partnerships with Primary Care, Victorian Order of Nurses (VON), Continuing Care, Cancer Care Nova Scotia, LTC personnel, and community groups. Patients in the community seen by the PCP team are strongly encouraged to accept VON support, as they are accessible to the client and family 24/7 in contrast to the PCP team who are available 8-4, 5 days a week. The PCP has rounds every Monday morning to discuss patients in the community and in hospital. VON, Continuing Care and some acute care staff join briefly to ensure good communication regarding the patients' needs and goals of care.

Patients in the community have a "white binder or traveling chart" to facilitate communication. All disciplines in the client's circle of care are encouraged to read and/or write in the chart. All of the notes are on carbon copy paper to facilitate information sharing and maintenance of documentation. An electronic file is also maintained so all members of the team can access the client file if need be. PCP team members are also able to access the client's Continuing Care SEAscape file and patient information via Share and Meditech.

VON continues to maintain a separate chart, although they are hopeful that this may change in the future in an effort to decrease duplication and confusion, both for the care providers and the client and family. Recognizing the need for educational support with patients and their families as well as with the multidisciplinary team, Annapolis Valley PCP offers Frontline Education annually, provides learning opportunities for the public and professionals on Advance Care Planning, Death Cafes and specific education for acute care, Emergency Health Services, LTC, VON, Continuing Care and Primary Care; two continuing medical education sessions were held in 2015. Organizing and providing education and support has become a very real challenge for team members who are trying to remain accessible and supportive in two counties with a population that has a high percentage of seniors and chronic disease.

[19] http://www.avdha.nshealth.ca/program-service/seniors-lincs

The Annapolis Valley PCP caseload has risen by approximately 50% in the last year, thus sustainability is a concern. They have been focusing on changing the perception of the PCP team from being viewed as a "taking over" team to a "multidisciplinary shared care model". Moving toward earlier intervention and supporting care providers, both professional and nonprofessional, while ensuring quality care is available, is a "big ask" for a very small team.

South West

Data: Since April 2012, South West PCP (in the Western Zone) has registered their patients in Meditech. Patients can be identified in Meditech; there is a data field or flag in Meditech that indicates the person is a South West PCP patient. A file that lists information on all South West PCP patients can be exported to an Excel, Access or other database for use in research or operational studies.

One record per patent can be provided for at least the following data fields: provincial health card number (HCN), first and last names, date of birth (day month year), and address including postal code. Dates of referral to the PCP and date first seen/assessed can be reported. Thus, South West in effect has the equivalent of a basic PCP database, just that it is under Meditech, rather than the PCP control, and the South West PCP does not add any information specific to palliative care. South West is not included in Tables 2-9. This appears to be much the same situation as for (see below).

Context[20]: The South West PCP is dedicated to providing a tailored plan of care based on choices of individuals and their families. The program offers services at three hospitals: Digby Hospital, Yarmouth Regional and Roseway Hospital in Shelburne, as well at home and in LTC facilities. The palliative team is comprised of a physician, nurses, social workers, administrative staff and volunteers. The team works closely with primary care providers, hospital nurses, nutritionists, pharmacists, physiotherapists, and occupational therapists, and a spiritual advisor to provide patient-centred support.

Pictou

Data: PCP patients in Pictou PCP (in the Northern Zone) are registered electronically in Meditech. We were told that the Pictou PCP began using Meditech about 2 years ago, and so we assume electronic data are available for full calendar years beginning in 2015 for purposes of completing Table 1, even though 2014 may also be complete. Only the data fields checked in Table 2 are electronically available via Meditech. Data fields checked in Tables 3-8 are in paper file only (not electronic) and may be incomplete. Data collected manually are put in an Excel spreadsheet. For purposes of this report, it is assumed that the data available for Pictou PCP are much the same as for South West and Guysborough Antigonish Strait, as described below.

[20] Source: http://www.swndha.nshealth.ca/pages/palliativecare.htm

Context: The Pictou county PCP offers pain and symptom management, emotional, spiritual and home support as well as bereavement follow-up using a holistic, comprehensive approach. A palliative care unit is located at the Aberdeen Hospital with community-base services offered at home.

Guysborough Antigonish Strait

Data: The Guysborough Antigonish Strait hospital (in the Eastern Zone) uses Meditech. Since 2010, a program in Meditech called Community Wide Scheduling (CWS)[21] has been used to schedule and track patient appointments. PCP patients are not flagged in Meditech. However, the PCP can search for their patients in Meditech to identify their other hospital-based visits and to check details of their PCP enrollment.

The nurse consultants keep track of their appointments each day on paper[22]. The PCP secretary inputs that information into CWS. CWS can be used to schedule home, hospital, clinic or LTC visits. Patient demographics are printed after the visit is registered by the PCP staff. Using Meditech visits and information from the nurses' reports, PCP staff enter information into Excel[23] and send to the Guysborough Antigonish Strait accounting/finance office.

There are a couple of different personal identifiers that can be used when entering a PCP patient into Meditech: patient's hospital specific patient number or Health Card Number (HCN). The HCN is more commonly used because information and appointments are entered for five different hospitals; HCN is universal across them. Information to complete Tables 2-9 for the Guysborough Antigonish Strait PCP was not provided.

Some information in Meditech that relate directly to palliative care are the Palliative Performance Scale (PPS) and Edmonton Symptom Assessment Scale (ESAS) assessments at baseline, preferred place of care at end of life, referral source, and distress symptoms on

[21] Guysborough Antigonish Strait PCP is able to use CWS to print custom reports with the patient's hospital number (ST#), appointment type, date referral received, palliative performance scale (PPS) on referral, preferred place of death (when recorded), closed status, date closed, place of death, and date of death.

[22] The Guysborough Antigonish Strait PCP nurses use a triage system (on paper) to schedule their visits and organize workloads weekly. Information is gathered on non-registered contacts (workload not directly related to a registered visit). Level 1: Requires frequent contact for continuous monitoring of symptoms during dying phase (usually daily contact). Level 2: Changing condition, not actively dying, but may be experiencing a crisis or interventions required to stabilize (2-5 calls/visits week). Level 3: Stable with actual problems or care breakdown (1-2 calls/visits per week). Level 4: Stable with greater risk for problems or care breakdown (call or visit every 1-2 weeks). Level 5: Adequate symptom management; disease stable (monitor every 2-4 weeks). Level 6: Cancer Support. Level 7: Registered, not followed (these are usually discharged and re admitted if condition changes).

[23] Scheduled visits: inpatient, client hospital clinic, visits-face to face-resident, visits-face to face-service recipient, not uniquely identified, visits-face to face-outpatient/client (community), visits telephone, non registered contacts, new referrals-inpatient, new referrals-outpatient/client (hospital clinic), new referrals-resident, new referrals-outpatient/client (community), active carryovers-inpatient, active carryovers-outpatient/client (hospital clinic), active carryovers-resident, active carryovers-outpatient/ client (community), education to health professional and community (minutes), deaths, volunteer hours.

admission. These data fields are manually extracted from patient charts and entered into Meditech.

When a patient is first registered into the PCP, a paper sheet called a 'Palliative Care Referral Form' gets printed off and placed in the front of the patient's chart. It has the patient's hospital number[24] and provincial HCN, along with the patient's name, address and next of kin (NOK). When a patient dies or is discharged information collected on the sheet gets entered electronically into CWS. The paper copy of the form is kept in their records. From the 'Palliative Care Referral Form', date referred to the PCP, date of death, and where the death occurred are entered. Most records are now kept electronically. Some data that may not be directly related to the patient is hand written.

Through the EMR (Electronic Medical Record)[25] part of Meditech, the PCP nurse consultant has access to the patient's demographics, NOK, and clinical or service information at any of their five facilities. The EMR is for in-hospital charting only. If the patient's death occurred in the hospital, the nurses would have access to that information. If a patient's death occurs at home, that information wouldn't necessarily be noted in the EMR. The form of the EMR is not clear as yet nor were we able to find out for this report whether the EMR has exportable data fields readily-usable for electronic data analysis.

Another source used by PCP staff to find patient information is SHARE, which might be a portal with limited clinical data available to health care professionals across the province. Through SHARE, the PCP can access reports from hospitals in Halifax, Sydney and throughout Guysborough Antigonish Strait.

*Contex**t***[26]: Within Guysborough Antigonish Strait, St Martha's Regional Hospital PCP provides a hospital-based, scattered bed program[27] and community-based outreach clinic services. Nurse consultants work with the cancer support clinic, Nova Scotia Health Authority Cancer Patient Navigators within each district, and at-home oncology consultation. Volunteers assist in homes, LTC facilities and hospitals. Bereavement support is also available.

IWK

Data: The IWK PCP began in 1995 with data available since mid-1998. The first full year of data begins in 1999 and is continually updated as patients are enrolled. The database is entered and maintained in MS Access. Information collected includes HCN, demographics, referral, consult

[24] ST# is the facility unit number: ST-St. Martha's, SM-St. Mary's, SR-Strait Richmond, EM-Eastern Memorial, GM-Guysborough Memorial. It is a unique identifier for the patient record in that facility. It is used in Meditech as well.
[25] The EMR contains electronic demographics which export/transfer to CWS (Community Wide Scheduling). At this time, only physician visits are dictated into the EMR. Nurses and Social Work keep paper charts. Their visits are entered electronically but no notes attached to visits other than physicians.
[26] Source: http://nshpca.ca/wp-content/uploads/2014/03/NSHPC-Services-Directory-January-2013.pdf
[27] What is meant by a "scattered bed program" has not been clarified for this report.

and enrollment dates, and diagnosis. The bereavement section contains date and location of death as well as an indicator of whether the patient/family wishes were met.

Context[28]: The Pediatric Palliative Care Service at the IWK Health Centre oversees policies and provides end of life care for children and their families throughout the Maritime provinces. Most patients are 0-18 years of age although some are in their early 20s when they have conditions that are considered to be "child or youth" diseases. The program offers services within the IWK facility as well as at home and in communities across the region. The program uses an integrated approach working directly with the patient, family, caregivers, clinicians, other allied health professionals and volunteers. It aims to provide enhanced quality of life; facilitate communication and continuity of care; provide emotional social, spiritual, and bereavement services; and support research leading to the best possible care. Currently there is 1.0 FTE physician, 2.0 FTE Clinical Nurse Specialists (1.0 [29]temporary full-time for 1 year term beginning Feb 2016), 0.5 FTE Bereavement Coordinator, and 1.0 FTE Administrative Assistant.

Colchester East Hants

Data: The Colchester East Hants PCP (in the Northern Zone) maintains an MS Access database of patients administered jointly by the District Palliative Care Services and the Social Work Department. Entry is initiated when an individual is referred to the program and information is continually updated. Individuals remain in the dataset after death or discharge for other reasons.

A data quality report completed by the NELS team in 2011 indicated that a broad range of information is collected by the Colchester East Hants PCP. The PCP database was deemed to be of high quality with minimal missing values and general consistency over time. Although the database was created in 1997, there are very few entries until 2002 so we deemed this as the first year of reliable data. The database contains HCN, patient demographics, and dates for referral, first visit, discharge and death. Clinical information includes the number of visits by health care providers and primary diagnosis. The place of death is also recorded. Consultation with the Colchester East Hants PCP Manager in the fall of 2015 confirmed that the database continues to be updated with no changes in variables collected since the 2011 Colchester East Hants data quality report was prepared.

Context[30]: The Colchester East Hants PCP vision is to lead in hospice palliative services and education. The goal is to provide a broad range of care through an integrated team system. There is currently a dedicated unit at the Colchester East Hants Heath Centre, consultation services at the Lillian Fraser Memorial Hospital as well as a community-based home and LTC consult team. Nurses work both in facilities and communities and are part of a team that

[28] Source: http://www.iwk.nshealth.ca/childrens-health/services/#/childrens-health/services/pediatric-palliative-care-service

[29] Clarification is needed on whether this is an extra 1.0 FTE or one of the two clinical nurse specialists.

[30] Source: http://www.cehha.nshealth.ca/services/pallative.htm

includes a physician, a pharmacist, a social worker, home care workers, hospice, VON and pastoral care.

Cape Breton

Data: The Cape Breton PCP (in the Eastern Zone) began a data entry system in MS Access in 1992 but relatively few individuals were entered. It wasn't until 1996 when the database began to include most/all who enrolled each year. In 2011, a data quality report was prepared by NELS staff. In December 2014, a new electronic database management system was launched. As a result, administrators have much more flexibility in terms of generating reports as well as fewer instances of system crashes. For example, the patients' preferred place of death is now recorded and compared to actual location. The IT team was able to import all previous years of data into the new system preserving the historical integrity. Consistent data are available from 1997 onwards. Key variables include HCN, patient demographics, next of kin, service dates, date and location of death as well as diagnosis. Data from the Meditech system are also available.

Context: The Cape Breton PCP has a relatively large geographical area covering the entire island. There is a nine-bed palliative care unit located at the Cape Breton Regional Hospital in Sydney but community-based services are delivered to those outside of the municipality. Over the years, the program has evolved into a system in which the PCP team works closely with the primary care physicians and nurse practitioners. Some palliative care duties have been taken on by primary providers, strengthening continuity of care for patients. However, some providers do not feel comfortable undertaking end of life care responsibilities leading to variations in the main source of care for patients within the program. Early intervention is a goal of the program but resources are limited.

Capital Health

Data: The Capital Health PCP (in Central Zone) database dates from 1984. It was initially developed by the chaplain at the old Halifax Infirmary. Data were collected only sporadically and inconsistently until PCP personnel dedicated specifically to data entry were provided starting in January 1987. In 1987, David Maxwell developed a ZIM database to replace the initial database and keep the historic data. Therefore the first complete year of data entry was 1988. Further development of the database occurred several times over the succeeding 23 years, with the incorporation of both additional data fields and additional tables, for example, details of survivors of decedents. In about 1996, a WIN-PC database was developed and the data in ZIM database imported. The data fields that were included on WIN-PC are listed in Tables 2-9 under the column "CH". In April 2011, the WIN-PC database was replaced by a Ccasper database. The data dictionary for the new Ccasper database is in Appendix 3. Since we know more about the Capital Health data prior to April 2011, that is the focus of much of the following. While the new Ccasper database appears very similar, a few possible differences are noted at the end of this section.

Data integrity was enforced at the level of data entry by the extensive use of field masking, validation of date sequencing, and restricted values linked to look-up tables to enforce entry of only valid codes. A single primary and unlimited number of secondary diagnoses[31] were recorded using the International Classification of Diseases, 9th Edition (ICD-9) coding system via a look-up table with the ICD-9-CM codes. In the 3x3 NELS data analysis[32], Capital Health PCP diagnoses had a higher level of consistency and accuracy in diagnoses than the free text diagnosis entry used by the Colchester East Hants and Cape Breton PCPs. Beyond better accuracy, the use of ICD coding also resulted in less complicated programming.

Date of admission to the service, i.e., first visit, was recorded over time. From May 1, 2004 onward, date of receipt of referral, as well as referring service and physician, were recorded. Reason for referral was recorded and included "pain control" and "other symptoms" as well as other reasons.

A number of patients were referred to the PCP for consultation, but not actually admitted to the service. These patients were recorded in the database, but distinguishable by referring to their "transitions" history. Capital Health recorded all "transitions" (movements from one care setting to another) with dates. Transitions recorded the "component" of the program caring for the patient in each care setting (PCP nurses, VON, family doctor, etc.) and permitted determination of time spent in hospital and in other settings. In cases where the patient was in a nursing home, the specific nursing home was listed using a lookup table to help ensure data integrity.

Date and place of death are also in the database. Semi-automated[33] record linkage with VS deaths was established to permit periodic death clearance. There was a field to record patients' preferred place to die, but the information was not collected by the clinicians because they said patients' desires fluctuated. A report was routinely generated for one of the primary care practices alerting them to the palliative care of patients in their practice. We do not know the current status of these processes.

Records for 17,557 patients were collected in WIN-PC up to April 2011, when Win-PC was replaced with a new database, Ccasper. When Ccasper became operational, all Win PC ZIM tables were moved into a separate SQL-server database. Unlike Meditech, Capital Health PCP

[31] The primary and secondary diagnoses in Win PC represent the diagnoses responsible for admission to the PCP. These were frequently different from either the diagnosis recorded on hospital admission, or the diagnosis recorded on the death certificate as the cause of death.

[32] Information on the 3x3 NELS project is at: http://www.dal.ca/sites/nels/research/3x3.html

[33] Death clearance in Win PC used a composite key to identify probable matches between Win PC and the VS death files. Each match was reviewed manually for confirmation. If confirmed, the program wrote the death date into the Win PC record, and moved to the next record. It was felt that, with the secondary human review of each record, reasonable certainty of data quality was attained.

data are ODBC[34] database standards compliant. This process made it easier for Capital Health IT staff to access the PCP data and retain the historic Capital Health PCP data for access as needed. Ccasper is managed by the Capital Health IT department; Ashraf Iqbal can answer many data questions, point you in the right direction, or direct you to his manager. For a full understanding of the historic Capital Health PCP, contact Dr. David Maxwell[35].

It appears that anyone wanting to track trends over time that cross the year 2011 may need to request data up to and including 2011 from the Capital Health Win PC data archived in the SQL server database, as well as from the Ccasper PCP database for years 2011 onward.

The first full calendar year for Capital Health PCP data in Ccasper is 2012. Since the Capital Health PCP Ccasper data dictionary is in Appendix 3, and the data fields entered may be quite similar to the WIN PC data, Ccasper is not included in Tables 2-9 of this report. A cursory examination indicates that the Ccasper database may have an added a module to capture clinical records. Unfortunately, unlike the WIN PC database, it appears as though only one diagnosis is recorded plus cancer metastases in free text form. Given the increasing attention on multi-morbidities in an aging population, the omission of the recording other diagnoses responsible for the PCP admission is unfortunate.

Context[36]: The Capital Health PCP offers an integrated care service that includes clinical, social, emotional, spiritual support as well as occupational therapy, physiotherapy, social work, music therapy, and bereavement support. Care is provided both in hospitals and at home with informal caregivers and family doctors consulted throughout. The main goal is to offer comfort and symptom relief while maintaining patient dignity.

Discussion

This report on PCP data in NS is timely given the release of the Canadian Hospice Care Association report in March 2015 called "The way forward national framework: a road map for an integrated palliative approach to care"[37] and in January 2016 of the Canadian Cancer Society report called "Right to care: Palliative care for all Canadians" [38]. The report states that there are serious gaps in our knowledge of palliative care because available data are incomplete,

[34] ODBC is a database standard that is familiar to experts in database management. It stands for Open Data Base Connectivity, and means that it is possible to connect to data tables in one database, e.g., Zim, using a different database engine, e.g., Oracle or SQL Server. Meditech is not ODBC compliant.

[35] David Maxwell is a retired Emergency Medicine physician who can be reached at David.Maxwell@Dal.Ca

[36] Source: http://www.cdha.nshealth.ca/palliative-care

[37] Available at: http://www.hpcintegration.ca/media/60044/TWF-framework-doc-Eng-2015-final-April1.pdf

[38] Released January 12, 2016, and available at: http://www.cancer.ca/~/media/cancer.ca/CW/get%20involved/take%20action/Palliative-care-report-2016-EN.pdf?la=en

inconsistent in their method of data collection, and lack common definitions[39]. Some indicators of palliative care noted in the report as being important to provide include:

- number of people receiving palliative care as a percent of deaths in the geographic area,
- percent that die before receiving care,
- wait time for palliative care,
- number of palliative care beds and staffing,
- percent receiving home visits in last weeks of life,
- percent with no assessments in last weeks of life,
- location of death, and
- use of acute and emergency services prior to death[40].

Some, but not all, of these indicators would be available from NS PCP data alone. Others would require linkage to other administrative care, e.g. VS deaths, hospitalizations, physician claims, emergency department admissions, etc.

While analyses can now be carried out to provide some metrics on PCP enrollment across NS, this does not mean that this would be an easy or quick task to accomplish. The PCPs do not typically have the time or expertise to extract and produce analytics. For research and province-wide metrics calculation, analysis is likely best carried out at one central location. However, grass-roots involvement in metrics development and reporting is also very important[41]. Furthermore, potential negative unintended consequences such as these[42] need to be avoided:

- tunnel visions leading to neglect of important aspects of quality care that are not measured,
- failure to investigate potential inequities that systematically disadvantage some groups of people,
- bullying or intimidating staff and/or managers to attain targets or adjust data reporting to achieve metrics rather than improve care,
- erosion of the intrinsic motivation of palliative care providers to learn and continuing to improve their delivery of high quality state-of-the-art palliative support,
- removing incentives for further improvement by implying that meeting targets is good enough,
- gaming the metrics system by distorting the process of care or reporting in order to meet targets, and

[39] Canadian Cancer Society (2016) Right to care: Palliative care for all Canadians, page 20, at http://www.cancer.ca/~/media/cancer.ca/CW/get%20involved/take%20action/Palliative-care-report-2016-EN.pdf?la=en

[40] Canadian Cancer Society (2016) Right to care: Palliative care for all Canadians, page 20, at http://www.cancer.ca/~/media/cancer.ca/CW/get%20involved/take%20action/Palliative-care-report-2016-EN.pdf?la=en

[41] Hsien Seow (undated) Re-thinking palliative care in the community: a change guide. Retrieved on February 12, 2016 from: http://palliativecareinnovation.com/thechangeguide/

[42] DrFoster.com (2015) Uses and abuses of performance data in healthcare, page 19. Retrieved on February 12, 2016 from http://www.drfoster.com/wp-content/uploads/2015/04/Uses-and-abuses-of-performance-data-April-2015-FINAL-DIGITAL-with-cover1.pdf

- obfuscating or otherwise avoid reporting data that indicate underperformance rather than fixing the problems.

While the next section focuses on centralized data collection, local data entry, analysis, and reporting are very important for local quality improvement, to be able to inform province-wide metrics development to attain relevancy and validity, and for local care providers and managers to critically analyze centrally produced reports.

Proposed approach to Nova Scotia centralized palliative care metrics development: From previous experience, it is likely that an experienced analyst[43] who understands database creation and extraction as well as data quality assessment would need to physically go to each of the ten PCPs and speak to the PCP manager and data entry staff as well as IT staff maintaining the database. This analyst is likely to need to work directly with these people to extract the PCP data for analysis. It is probably easiest and ultimately most accurate for one analyst to extract all the PCP data from each district, and carefully examine each PCP database. From our experience, there can be an incomplete understanding of the PCP data by the PCP health care providers and managers, for example, due to changes over time and change in staff. Also, for the most part, there are few if any data dictionaries and limited if any training of data entry staff. This analyst should not totally rely on statements in this report but should verify any information to be used since this report may not always accurately or fully reflect what is the actual practice. Also, changes in data entry and archiving can occur after this report is completed. Hence dialogue is critical amongst the experienced and skilled analyst(s) assigned with this task and various PCP and IT staff.

Once the analyst has the extracted PCP data, data quality assessment is advised, prior to the use of the data for metrics creation. Missing data are common. Data fields may have text rather than easily quantifiable data. Interpretation of codes can be problematic. Checks should be made for duplicate patient entries, and for missing patients (e.g. check for major variations in enrollment over time) as well as 'dummy' patients that may have been created to test the system but which have not been removed. The critical variables will be personal identifiers (HCN; first, last and other names/initials; date of birth; date of death if available; address and especially 6-digit postal code) for linking to VS deaths and other administrative data. Reliance on HCN as the only variable for data linkage is not advised since the quality and completeness of the HCNs is not known and the VS deaths may have missing HCNs if death data are obtained directly from VS. Probabilistic record linkage is optimal and therefore advised until such time as accurate and complete HCNs are assured in both datasets to be linked.

For analysis, dates need to be checked for consistency in the order of day, month and year, and the use of dummy numbers for missing date information. Checks should be made in sequencing of dates, e.g. referral happens before date seen, and both of these dates should occur before death date. Some PCPs may discharge a patient and then could enrol the patient later if the

[43] Ron Dewar, an analyst at cancer Care Nova Scotia who is planning to retire at the end of March 2016, has been the key 'guru' over the past twenty years in helping with an understanding death data, extracting PCP data, record linkage and analytic methods.

patient is again served by the PCP. The analyst needs to understand whether the PCP uses this practice, and if so, how the coding is done, and clarify how the analysis will be done, e.g. first enrolment, or last enrolment, or both. The analyst needs to be experienced and skilled in the ways that dates can be recorded and errors that can occur in various types of databases.

Hopefully, the analyst will create a data dictionary and frequency counts for the PCP data. Then, the analyst should personally discuss these findings with the manager, data entry staff, clinicians providing data, and any relevant IT staff in each PCP to ensure a solid understanding of the data before metrics are reported. This takes time, but creates a solid base of credibility and a base for ongoing and efficient further analysis. Also, if data fields are not being used, the data are not accurate, or lack efficient coding (e.g. drop down menus are much better than free text; data entry checks are important for ensuring completeness and correct sequencing of numbers), the PCP database should be refined to be more efficient and contain data with greater accuracy.

Diagnoses are likely not complete and fully accurate or clear so analysis of that variable is not usually advised; instead, use of all VS causes of death is advised since ICD coding is used, and these diagnoses codes have been widely used elsewhere for these types of analyses. Furthermore, a VS cause of death is available for all those who die, enabling comparisons between those who receive and do not receive a service. Use of only the first VS cause of death is not advised since that will lead to under-reporting of non-cancer conditions that could be a key reason for a PCP visit. Also, using only the first cause does not reveal the complexity of multi-morbidity in this population. While the reliability of causes of death has been challenged in various studies, we have shown that VS data have adequate validity[44] for the metrics proposed herein.

Symptom data are important but not frequently reported using a standardized form and a validated tool for all Nova Scotians at end of life in all their settings of care[45]. Goals of care and advance care planning information are also important to know, but are likely unavailable for much of the province in electronic form.

Limitations of this report: While research and operations reporting of recent PCP use appears viable for the province, feasibility and data quality need to be ascertained especially for data that had not previously been used for metrics reporting outside of the PCP. This task is well beyond of the scope of this report. A thorough investigation is expected to identify further limitations and errors in interpretation and other inaccuracies in this overview report. Another limitation is that even though Tables 2-9 may indicate the same type of information is included

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

Johnston G, Lethbridge L, Talbot P, Dunbar P, Jewell L, Henderson D, d'Intino AF, McIntyre P (2015) Importance of identifying persons with diabetes who could benefit from palliative care. Canadian Journal of Diabetes 39(1):29-35.

[45] Network for End of Life Studies (2012) Report of Symptoms and Outcomes Measurement for End of Life Care in Nova Scotia, Canada. Available at:
http://www.dal.ca/content/dam/dalhousie/pdf/sites/nels/report_outcomesmeasurement2012.pdf

by two or more PCPs, this does not mean that the definition of the terms were interpreted in the same way or that the same reporting categories were used.

This report does not advise on what data should be recorded electronically for all persons who could benefit from palliative support. Another limitation is that the Contexts sections in the Results could be more fully described or reported in a common table, e.g., see Figure 1 in the Lavergne at al (2015) paper[46] that summarizes and compares Capital Health, Cape Breton and Colchester East Hants.

Ideas for the Future: As the 2014 provincial Integrated Palliative Care strategy[47] indicates, the focus in the future will be on developing palliative primary care and integrating across the various community care providers of palliative support. Therefore, Figure 3 was developed for this report. It provides a schematic of proposed real-time electronic data flow to generate quality care indicator reports for the provision of palliative support across the health system. It includes NS's primary healthcare information management (PHIM).[48]

Figure 4 is also included. It proposes reporting by the disease and other province-wide programs of the Nova Scotia Health Authority that have a mandate that includes palliative care. However, these programs do not have the means to identify palliative patients in real time their databases. Programs that can or could readily identify their palliative patients in real-time are listed in the first column of Figure 3, not in Figure 4.

Beyond PCP and other electronic health administrative record data, there are other ways to collect data to complement access to administrative data, such as a Mortality Follow-back Survey (MFB)[49]. With support from the ABC-SC project, a plan to move the MFB survey from research into ongoing practice has been developed[50].

[46] Lavergne MR, Lethbridge L, Johnston G, Henderson D, d'Intino AF, McIntyre P (2015) Examining palliative care program use and place of death in rural and urban contexts: A Canadian population-based study using linked data. Rural and Remote Health 15:3134 Online at http://www.rrh.org.au

[47] Source: http://novascotia.ca/dhw/palliativecare/

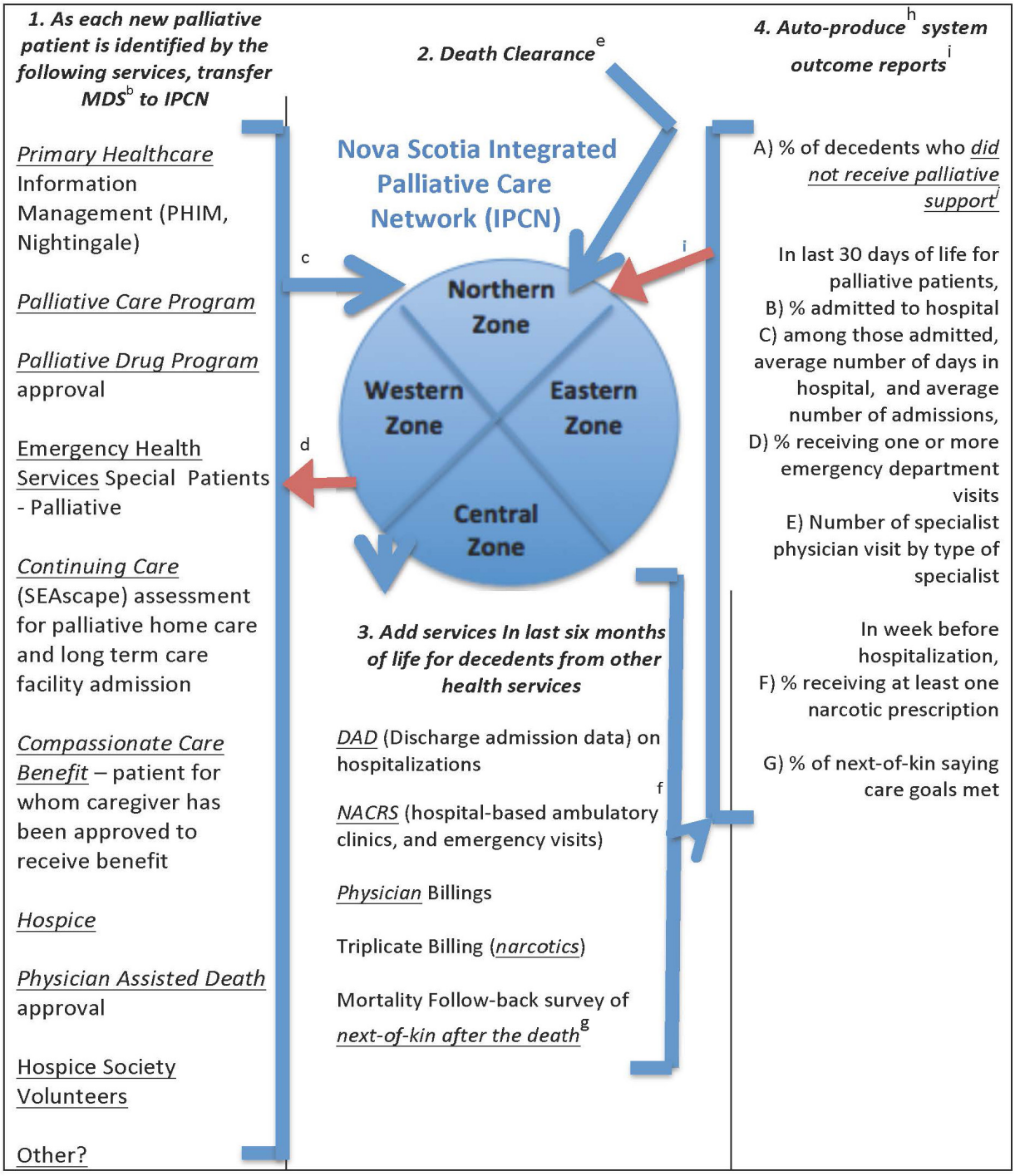
[48] Source: http://novascotia.ca/dhw/ehealth/emr/

[49] Burge F, Lawson B, Johnston G, Asada Y, McIntyre P, Grunfeld E, Flowerdew G (2015) Preferred and actual location of death: What factors enable a preferred home death? Journal of Palliative Medicine In press

Burge F, Lawson B, Johnston G, Asada Y, McIntyre P, Grunfeld E, Flowerdew G (2014) Bereaved family member perceptions of patient-focused family-centred care in the last 30 days of life using a mortality follow-back survey: Does location matter? BMC Palliative Care. 13:25-39 doi:10.1186/1472-684X-13-25 open access at: http://www.biomedcentral.com/content/pdf/1472-684X-13-25.pdf

[50] Loney E, Lawson B (2015) An ongoing, province-wide patient-focused, family centred quality measurement strategy for the experience of end-of-life care from the perspective of the bereaved family member caregiver. Network for End of Life Studies, Dalhousie University, Halifax, Nova Scotia. Available at: http://www.dal.ca/content/dam/dalhousie/pdf/sites/nels/2015%20June%20EOL%20Care%20Quality%20Measurement%20Strategy%20online%20version%20update.pdf

Figure 3: Proposed[51] real time data transfer plan to generate system level palliative care metrics for review and action by the Nova Scotia Integrated Palliative Care Network[a] (IPCN)



Alphabetic (rather than numeric) footnote citations for Figure 3 are all in one footnote on the next page[52].

[51] Metrics generation is to be operational by 2020.
Remaining footnotes for this figure (which are alphabetic rather than numeric) are on the next page.

Given the decision of the Supreme Court of Canada in 2015, the federal and provincial governments will be required to provide physician assisted death by mid 2016. Details of how this will occur are not known at the time of this report being finalized. However, it is assumed that physician assisted death requests and occurrences will likely be recorded and analyzed in and of themselves, but also probably in relation to access to palliative care services. Future PCP and other palliative care data development should consider this development.

NS's "One Patient One Record" initiative was designed to increase efficiency and access to information across the health system for both patients and their health care provider teams[53]. A pilot with Relay Health has been operational for some family physician practices in the province. This electronic health record is unique in many ways including patient access to their diagnostic and other records, ability of patients to add information to their records (e.g. hopefully on their goals of care, symptoms, etc.), and the ability for two-way email consultation. The status of this or a similar project should be considered in the design of palliative care electronic record transfer system for the province, particularly, the direct and immediate access of all health records to the patient and the two-way real time communication

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[52] The label "Integrated Palliative Cate Network" (IPCN) was created based on direction advised in the "Integrated Palliative Care: Planning for Action in Nova Scotia" report at:
http://novascotia.ca/dhw/palliativecare/documents/Integrated-Palliative-Care-Strategy.pdf

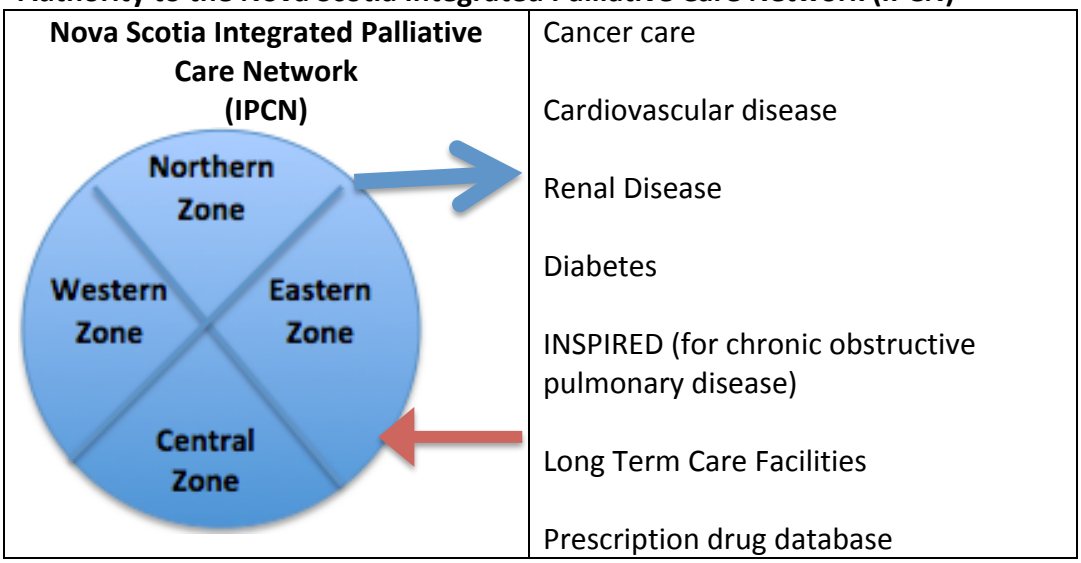
a. MDS means Minimum Data Set. As stated in the Limitations section of this report, this report does not include a recommendation on the MDS, beyond implying that it would include the basic electronic data described herein as personal identifiers and dates of referral and assessment. The MDS might include a few more variables, if found to be essential to do so.
b. All care providers that have an electronic real time database of patients and can identify which patients are palliative, would automatically and immediately send notification to the IPCN of the referral and first visit along with the MDS for any new palliative patient.
c. Automatically and immediately, the IPCN would notify all other palliative care providers in the first column of this table of a new palliative patient in the province, so that care and reporting can be integrated across palliative care providers.
d. Death clearance would be carried out by access to Vital Statistics deaths from on-line funeral director registration of deaths, or from the provincial heath card number database. Care providers who have provided care would immediately be notified of a death. Also, deaths in a selected time period (e.g. year, ever three months) would be the population base reported on for many of the metrics. Some metrics would be reported for a time period (e.g., week, month) before death.
e. IPCN would ensure linkage of deaths to a variety of administrative databases occurs on a regular basis, and the automatic production of a variety of palliative care metrics.
f. A mortality follow-back survey of next-of-kin should be launched and include permission to link to health administrative data. Not all next-of-kin will complete this survey. Therefore, metrics from this survey will be for a representative sample but not all deaths in the province.
g. Ongoing quality metrics should be automatically and efficiently produced and provided to stakeholders. Some new metrics can be produced from time to time as needed. However, most new metrics development should begin as a research study.
h. The metrics in this third column are only a sample of possible metrics to provide readers with a few concrete examples to better understand this figure. The actual list of metrics that should be produced should be decided by the provincial Palliative Care Evaluation and Monitoring Working Group and/or the IPCN.

[53] Mary Russell, Nova Scotia Department of Health and Wellness, personal communication, Oct 8, 2015

capability. This would mean reduced waiting on phones and for the office to open since the system would be accessible 24/7.

This report will hopefully serve to provide an overall impression of NS PCP data availability in NS. However, it should not be used as a definitive or detailed source of information since this report is likely to contain inaccuracies and misunderstandings. From years of working with PCP data, we have seen that initial impressions can differ from the actual situation when further investigated. There tends to be a substantial learning curve for all involved. Sometimes things are better than they seem at first, sometimes worse. Regardless, we have seen steady progress over time in PCP data access and quality in NS.

Figure 4: Proposed data transfer plan[54] for disease programs within the Nova Scotia Health Authority to the Nova Scotia Integrated Palliative Care Network (IPCN)



Recommendations

For a report to be worthwhile, action must follow. Hence, two key recommendations are presented for considerations as the next steps to be accomplished.

[54] Nova Scotia Health Authority disease and other programs are to generate specific system level palliative care (PC) metrics (to be determined) routinely e.g. quarterly (four times a year) for the IPCN. Thereby, the IPCN would have a more comprehensive picture of care being provided. This is proposed to be operational by 2020.

The Zones (or networks or clusters within zones) would identify the persons receiving a palliative approach to their care along with the start date for their palliative care (PC), and provide this to the Nova Scotia Health Authority disease and other programs.

The disease and other programs would then identify active and palliative care that they are providing to these PC patients, e.g. patient navigation, education, ambulatory services, etc. to the NHSA palliative patient population.

If any of these programs has the means to identify PC patients in real time and then provide care for them, then the program should be removed from this Figure, and be added to the first column of Figure 3.

1. Using consistent definitions and data fields, all NS PCPs report and compare across PCPs on these metrics:
i) number of patients seen each year divided by number of VS deaths in the PCPs geographic area to get a crude indicator of access,
ii) percent of patients referred to the PCP but not seen,
iii) among those seen, average and range of time between referral and being seen, and
iv) completeness of:
a) HCN, since HCN is very important for accurate linkage to other administrative data, and
b) 6-digit postal code, since this is needed to ascertain the correct district of residence, and for creation of socioeconomic indicators by linkage to census data.

2. The Nova Scotia Health Authority work with all community-based palliative care providers (PCPs, primary care, home care, LTC, Emergency Health Services, etc.) toward standardizing symptom and other palliative care data reporting across all palliative care providers, and enable data access across providers to reduce the need for patients and families to repeat information. This will improve the accuracy, completeness and currency of information in records.

Readers of this report are likely to have their own recommendations for moving forward and these should also be considered.

Conclusions

Basic electronic patient PCP data (i.e., personal identifiers and referral/seen dates) appear to be available via stand-alone databases and/or Meditech in the ten PCPs, in other words, for 100% of the NS population. Therefore, important metrics can be provided, e.g. percent of patients referred but not seen, and among those that were seen, the average and range of time between referral and being seen/assessed. Comparisons across PCPs could also be made.

Many more palliative care metrics could be reported if the available basic electronic PCP data are linked to other NS administrative data, e.g., hospitalizations, continuing care (SEAscape), physician billing claims, emergency department visits, emergency health services (paramedic/ ambulance), and the narcotics prescription monitoring database. Resultant metrics could include the use of acute and emergency services prior to death, and the percent receiving some forms of home visits in the last weeks of life.

Patient preferences, goals of care, and symptom assessment are largely lacking in electronic form. With concerted effort, they could be developed by the PCPs. For population-wide and more immediate metrics, these data will need to be generated in another form, e.g., a mortality follow-back survey of the next of kin. In the longer term, it is hoped that standardized data collection and sharing across care settings will occur. This report is one step toward helping NS prepare to provide PCP metrics that are likely to be expected by the public and governments, and can enable research to improve palliative care.

Tables

Table 1: Palliative care program (PCP) electronic data availability

Descriptor	PCP data available for a next study			Meditech only			IWK Child/ Youth	PCP quality indicators have been published		
	CU[1]	**SS**[2]	**AV**[3]	**SW**[4]	**PI**[5]	**GA**[6]		**CEH**[7]	**CB**[8]	**CH**[9,10]
First full calendar year[11]	2007	2010	2009	2013	2015	2011	1999	2002	1999	1988
Deaths in 2013[12]	411	713	823	686	469	390[13]	43[14]	925[15]	1490[16]	2,908[17]
Percent of 8,815 deaths in 2013 in NS	4.7%	8.1%	9.3%	7.8%	5.3%	4.4%	0.5%	10.5%	16.9%	33.0%
Percent deaths in hospital in 2013	61%	58%	55%	61%	63%	57%	-	59%	62%	56%

1. CU is Cumberland; contiguous with Cumberland county.
2. SS is South Shore; includes Lunenburg and Queens counties.
3. AV is Annapolis Valley; includes Annapolis and Kings counties.
4. SW is South West; includes Yarmouth, Digby and Shelburne counties.
5. PI is Pictou; contiguous with Pictou county.
6. GA is Guysborough Antigonish Strait
7. CEH is Colchester East Hants
8. CB is Cape Breton
9. CH is the original Capital Health ZIM PCP database designed and managed by David Maxwell.
10. Appendix 3 is the data dictionary for the Ccasper database that became operational in Apr 2011.
11. Year is first full calendar year of data that is complete and linkable to other data sources by using HCN and other personal identifiers.
12. From Nova Scotia annual Vital Statistics report on January 15, 2015 at: http://novascotia.ca/sns/pdf/ans-vstat-2013-annual-report.pdf
    These data were only available by county, not by DHA. Therefore, grouped counties as reported below are reported in Table 1 last three rows, rather than actual DHA areas.
13. For the numeric findings in this column, Guysborough Antigonish Strait includes Guysborough, Antigonish and Richmond counties. Unlike the actual DHA, does not include part of Inverness county as in map in Figure 1.
14. For ages 0-14 only. The 43 deaths for those aged 0-14 are also reported in their respective districts in this table (not mutually exclusive). There were 27 deaths in NS in 2013 among those ages 15-19.
15. For the numeric findings in this column, Colchester East Hants includes Colchester and Hants counties. Unlike the actual DHA (see map in Figure 1), West Hants is included.
16. For the numeric findings in this column, Cape Breton includes Cape Breton, Inverness and Victoria counties. Unlike actual DHA (see map in Figure 1), all of Inverness is included; part is not in GA.
17. For the numeric findings in this column, Capital Health includes Halifax county only. Unlike the actual DHA, does not include West Hants as in map in Figure 1. West Hants is included in Colchester East Hants in this table.

Table 2[1]: Patient/client personal identifiers and other descriptors

	CU	SS	AV	SW	PI[2]	GA	IWK	CEH	CB	CH
Personal Identifiers for Record Linkage										
Last Name	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
First Name	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Initial						Y	Y		Y	
Birth Date	Y		Y	Y	Y	Y	Y		Y	Y
Health Card Number	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Other client information										
NSCC Number						Y*				Y[3]
Unit Number			Y			Y			Y	Y
Sex	Y	Y			Y	Y	Y	Y	Y	Y
Religion					Y		Y		Y	Y
Clergy										
Ethnicity							Y			
Spoken Language										
Marital Status					Y					Y
Living Arrangements					Y					
Resident Type					Y					
Occupation										
Private Health Insurer					Y					Y
Other medication coverage/assistance					Y					
Patient Location (Hospital/Home)		Y	Y		Y	Y			Y	Y
Hospital Choice					Y					
Pharmacy/Drug Store					Y					
Address	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
City/Town/County	Y	Y	Y		Y	Y	Y	Y	Y	Y
Province	Y	Y	Y		Y	Y	Y	Y	Y	Y
Postal Code	Y	Y		Y	Y	Y	Y	Y	Y	Y
Communication (Phone/Fax)	Y					Y	Y	Y	Y	Y

1. See footnotes to Table 1 for explanations of district letters at the top of each column
2. Information for Pictou County PCP is in electronic form via Meditech for data fields checked in this table only
3. If patient was treated at NSCC. (Not all patients were)

Table 3[1]: Referral/discharge and Physician contact information

	CU	SS	AV	SW	PI[2]	GA	IWK	CEH	CB	CH
Referral										
Referral Date	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Referred by	Y	Y	Y		Y			Y	Y	Y
Reason for referral	Y	Y	Y		Y		Y		Y	Y
Place of referral	Y				Y			Y	Y	Y
Enrollment date	Y	Y					Y	Y	Y	Y
Institution			Y		Y			Y	Y	Y
Unit									Y	Y
Initial Assessment Date	Y	Y	Y	Y	Y			Y		Y
Referred to		Y	Y		Y					Y
Referring Site	Y	Y						Y	Y	Y
Referring Service	Y							Y	Y	Y
Date Consult Received	Y	Y	Y		Y		Y	Y		Y
Admission date	Y	Y	Y		Y	Y	Y	Y		Y
Type										
Reason			Y				Y			Y
Discharge date	Y	Y	Y					Y		Y
Place discharged to			Y			Y				Y
Physician			Y		Y					
Name(s)	Y						Y	Y	Y	Y
Specialty								Y	Y	Y
Phone/Fax			Y					Y	Y	Y

1. See footnotes to Tables 1 and 2 for explanations of district letters at the top of each column and details in table.
2. Data fields checked for Pictou County PCP is manual (not in electronic form) in this and all subsequent tables, and may be collected inconsistently.

Table 4[1]: Family and caregiver

	CU	SS	AV	SW	PI[2]	GA	IWK	CEH	CB	CH
Next of Kin										
Name		Y	Y			Y	Y		Y	Y[3]
Relationship			Y			Y	Y		Y	Y
Address			Y			Y	Y		Y	Y
City/Town						Y	Y		Y	Y
Province						Y	Y		Y	Y
Postal Code						Y	Y		Y	Y
Phone			Y				Y		Y	Y
Significant Caregiver										
Name			Y				Y		Y	Y
Address							Y		Y	Y
City/Town							Y		Y	Y
Relationship							Y			Y
Province							Y		Y	Y
Postal Code							Y		Y	Y
Phone			Y				Y		Y	Y
Occupation										
Employment Current Status										
Compassionate Care Benefits										
Health Status										
Others Caregivers			Y							
Emergency/ Support Contacts										
Name					Y		Y		Y	Y
Relationship					Y		Y		Y	Y
Address					Y		Y		Y	Y
Phone					Y		Y		Y	Y

1. See footnotes to Tables 1 and 2 for explanations of district letters at the top of each column and details in table.
2. Data fields checked for Pictou County PCP is manual (not in electronic form) in this and all subsequent tables, and may be collected inconsistently.
3. Multiple survivors, (in addition to Next of Kin) also captured

Table 5[1]: Social supports

	CU	SS	AV	SW	PI[2]	GA	IWK	CEH	CB	CH
Number of children			Y		Y					
Patient/Family Coping and Support			Y							
Financial Concerns			Y							
Main Concerns of Patient			Y							
Main Concerns of Family			Y							
Patient support needs			Y		Y					
Caregiver support needs			Y							
Children's needs			Y							
Religious/Spiritual practices			Y				Y			
Religious/Spiritual guidance/ support requirement			Y				Y			
Emotional needs			Y							

1. and 2. See under Table 6

Table 6[1]: Advance care planning and death

	CU	SS	AV	SW	PI[2]	GA	IWK	CEH	CB	CH
Advance Care Planning										
Patients wishes on care setting			Y							Y[3]
Family wishes on care setting			Y							
Advanced Directive			Y		Y					
DNR order information					Y					
Personal Care Power of Attorney										
Power of Attorney for Finances										
Patient wishes on resuscitation			Y							
Family wishes on resuscitation										
Patient /family funeral wishes			Y							
Funeral Home Name			Y							
Death/Bereavement										
Date of Death	Y	Y	Y		Y		Y	Y	Y	Y
Time of Death							Y			
Location of death	Y	Y	Y				Y	Y	Y	Y
Patient /family death wish captured?			Y				Y			
Patient /Family wishes Kept							Y			
Bereavement Details		Y					Y			Y

1. See footnotes to Tables 1 and 2 for explanations of district letters at the top of each column and details in table.
2. Data fields checked for Pictou County PCP is manual (not in electronic form) in this and all subsequent tables, and may be collected inconsistently.
3. This field was extant, but not consistently filled in.

Table 7[1]: Palliative Care Program team

	CU	SS	AV	SW	PI[2]	GA	IWK	CEH	CB	CH
Care Coordinator					Y		Y			Y
Social Worker		Y					Y			Y
Home Support			Y		Y					Y
Private Nursing Agency			Y		Y					Y
Volunteer Information		Y								Y

1. and 2. See under Table 8

Table 8[1]: Palliative Care assessment, clinical and medication information

	CU	SS	AV	SW	PI[2]	GA	IWK	CEH	CB	CH
Palliative Care Assessment										
Palliative Performance Scale			Y			Y				
Pain Assessment Tool			Y							
Symptom Assessment			Y			Y				
Clinical Information										
Diagnosis	Y	Y	Y		Y	Y	Y	Y	Y	Y
Metastases			Y				Y		Y	Y
Other Diagnosis			Y				Y		Y	Y
Date of Diagnosis			Y							Y
Health history			Y		Y		Y			
Diagnosis known by Patient/Family			Y		Y		Y			
Prognosis known by Patient/Family			Y				Y			
Radiation/Chemotherapy			Y		Y		Y			
Surgery			Y		Y		Y			
ARO (Antibiotic Resistance) Screening							Y			
Medical Equipment in use/needed			Y							
Medication and Drugs										
Medication Name			Y				Y			
Dosage, Route Frequency			Y				Y			
Knowledge/Teaching required			Y							
Administration required										
Payment (Self, Insurance, NRHB, Others)			Y							
Drug Allergies/Sensitivity			Y				Y			

1. See footnotes to Tables 1 and 2 for explanations of district letters at the top of each column and details in table.
2. Data fields checked for Pictou County PCP is manual (not in electronic form), and may be collected inconsistently.

Table 9[1]: Other data fields identified and added at interview

	CU	SS	AV	SW	PI	GA	IWK	CEH	CB	CH
Triage		Y	Y							Y
RN Name	Y		Y					Y		Y
Organ/tissue donor			Y				Y			
CPR administered			Y				Y			
In a clinical trial			Y				Y			Y

1. See footnotes to Tables 1 and 2 for explanations of district letters at the top of each column and details in table.

Appendix 1: Persons contacted who provided information for this Report

We gratefully acknowledge the assistance of the following people in providing information and editing.

South Shore: Janet Carver (janet.carver@nshealth.ca)

Cumberland: Terri-Lynn Smith (Terri-Lynn.Smith@nshealth.ca)

Colchester East Hants: Mark Scales (mark.scales@nshealth.ca)

Cape Breton: Lynette Sawchuk (lynette.sawchuk@nshealth.ca)

IWK: Krista Rigby (Krista.Rigby@iwk.nshealth.ca) and Shauna Wilcox (shauna.wilcox@iwk.nshealth.ca)

South West: Nicole Boudreau (NicoleE.Boudreau@nshealth.ca) and Kim Miller

Pictou County: Jane Jordan (Jane.jordan@nshealth.ca)

Annapolis Valley: Fern Brydon (Fern.Brydon@nshealth.ca)

Guysborough Antigonish Richmond Strait (GASHA): Charlene Porter (Charlene.porter@nshealth.ca)

Central Zone: David Maxwell (David.Maxwell@Dal.Ca) who designed and operated the original Capital Health Win PC database using ZIM software from 1996 to 2011.

Paul McIntyre for providing the Casper data dictionary in Appendix 3.

Jill Petrella, Manager of Quality and Cancer Site Teams, Cancer Care Nova Scotia, for her careful proofreading

Appendix 2: Annapolis Valley Palliative Care Patient Classification Criteria

1) Highest Needs Patients :

- Patients who are considered to be actively dying, especially those at home
- Inpatients (unless in ALC – then may be lower priority)
- Patients who have difficulty with pain and symptom management, patients who require frequent medication changes or frequent medical/nursing assessments and interventions
- Patients and family members whose emotional, spiritual, social, and practical needs require frequent medical/nursing/social work/volunteer assessments and interventions
- Families experiencing caregiver stress; caregiver at risk for burnout or ineffective coping; or patient alone – no caregiver available
- Patients/family who indicate difficulty accepting the diagnosis or prognosis

  Frequency of Contact for **Highest Needs Patients** (Red List):
  - Requires **one or more contacts per week**
  - Requires frequent home visits

2) Medium Needs Patients :

- Patients, whose pain and symptoms are relatively stable, require regularly scheduled, but frequent follow-up
- Patients and family members who have adequate support
- Patients and family members who report adequate understanding of illness, prognosis and treatment plan
- Patients whose prognosis indicates a change in the level of care is anticipated.

  Frequency of Contact for **Medium needs Patients** (Yellow List):
  - Requires contact once **every two weeks**
  - Home visits as needed.

3) Lowest Needs Patients :

- Patient's pain and symptoms are stable.
- Patients and family members have need for less frequent involvement from the Palliative Care Team
- There is no indication of imminent change in the patient's level of care
- There are adequate resources; a good support network, and the patient and family members have a good understanding of the plans for care

  Frequency of contact for **Lowest Needs Patients** (Green List):
  - Requires contact **once per month**
  - Requires home visit only once every three months

4) Hold

- Patients who are in another facility outside the district
- Patient's request
- Remission of disease

5) Recently Deceased (4-6 weeks):

6) Discharge Criteria:

- If everything is found to be satisfactory with no active issues for an extended period, then the nurse will discuss with the patient/family and if agreed, then the patient will be discharged from the service
- Family physician will be notified

7) Deceased

Jan 2010

Provided on December 31, 2015 by Fern Brydon, Manager of Hospice, Palliative and Continuing Care, Eastern Kings Memorial Health Centre

Appendix 3

Ccasper Palliative Care

Project Name: Ccasper Palliative Care
Department: Palliative Care
Last Updated: Oct 23, 2012
Author: Mary Eileen MacPhail
Project Manager(s): Michael Thibodeau
Project Analyst: Clay Pye
Executive Sponsor: Peter MacDougall, Dr. Paul MacIntyre
Project Department Owner: Peter MacDougall

Overview of the Ccasper Implementation for Palliative Care.

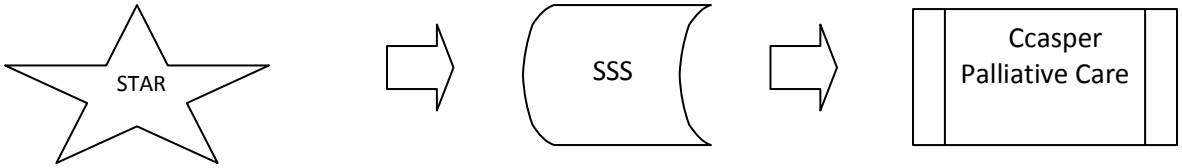
Provided by and used with the permission of Dr. Paul McIntyre, Head, Palliative Medicine, Central Zone, Nova Scotia Health Authority, on February 11, 2016

Table of Contents

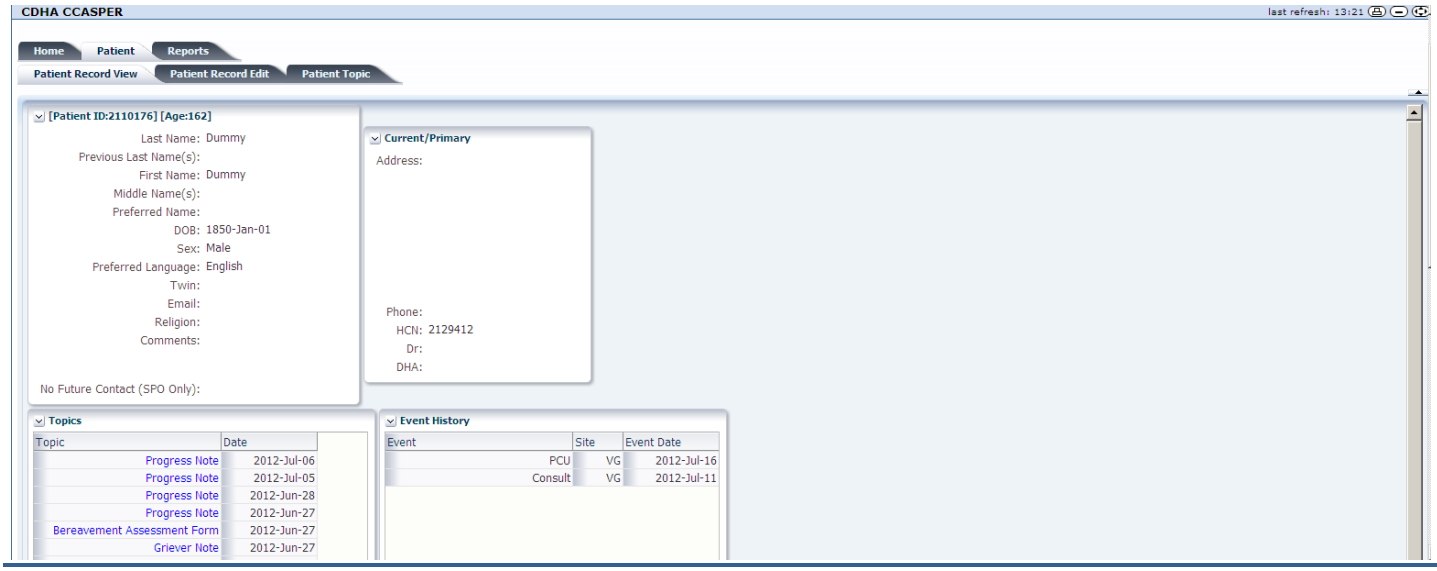
Ccasper Palliative Care

Ccasper is a web-based application accessible through Capital Health's Clinical Portal. Only approved users can gain access to it. It is a role-based application meaning the clinician's particular role determines what components the clinician will have access to. Ccasper was developed to replace the ZIM database.

Ccasper receives Admission/Discharge/Transfer (ADT) information from the enterprise system STAR via STAR Sequel Server (SSS). SSS has a real-time HL7 interface with STAR. Ccasper retrieves information from SSS hourly. Retrieving the patient information relies on codes entered during the STAR registration. To be included as a Palliative Care patient a Patient Data Form must be completed.



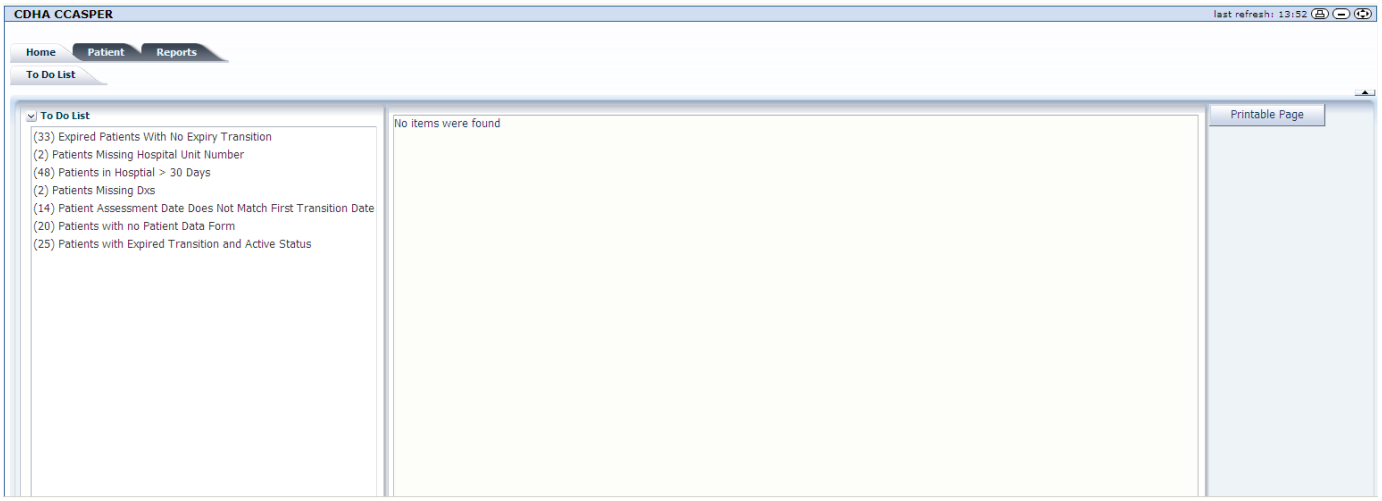
Opening View



- The opening page defaults tot eh Patient/Patient Record View tabs.
- Other available tabs include: Home, reports, Patient Recode Edit and Patent Topic.
- Selections shown in **blue** indicate links to previous documentation. Click the link to view.
- If the Topics list is empty, this is a new patient with no documentation in Ccasper.

Home Tab

This page shows the “To Do List” that allows end users to follow up on required tasks.



To Do List

Expired Patients with No Expiry Transition

List of Palliative Care patients that are expired in STAR and the message has passed to Ccasper via SSS that do not have an Expired transition in the Ccasper system:

Data Displayed:

- Hospital Unit Number
- Name
- Date of Death

Patients Missing Hospital Unit Number

List of Palliative Care patients in the Ccasper system, which have no Hospital Unit Number recorded:

Data Displayed:

- Name

Patients in Hospital >30 Days

List of Palliative Care patients that have been in hospital longer than 30 days:

Data Displayed:

- Hospital Unit Number
- Name

Patients Missing Dxs

List of Palliative Care patients that have no Diagnosis entered:

Data Displayed:

- Hospital Unit Number
- Name

Patient Assessment Date Does Not Match First Transition Date

In the Ccasper system, the first transition should match the Palliative Care patient's assessment date. This is a list of Palliative Care patient's that have Assessment Date and First Transition Date that do not match:

Data Displayed:

- Hospital Unit Number
- Name
- Assessment Date
- First Transition Date

Patients with no Patient Data Form (PDF)

Displays a list of Palliative Care patients with no PDF completed. For patient's to be included in the Palliative Care program count, they must have a completed PDF:

Data Displayed:

- Hospital Unit Number
- Name

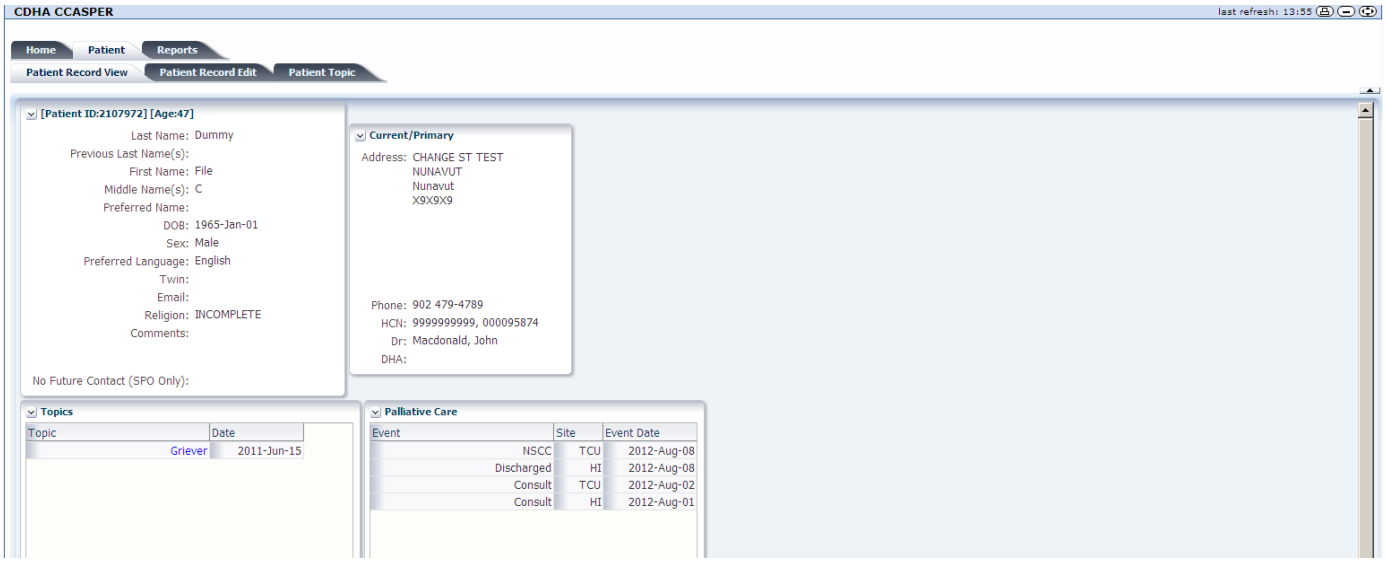
Patients with expired Transition and Active Status

Displays a list of Palliative Care patients that have an expired transition but are still active in the system. When Patient's are expired in STAR, this message is sent to SSS. SSS updates Ccasper on an hourly basis. The STAR message will trigger a change in status from Active to Deceased. If there is an expired transition and an active status, STAR must be updated to reflect the new status of the patient. See appendix for process flow chart.

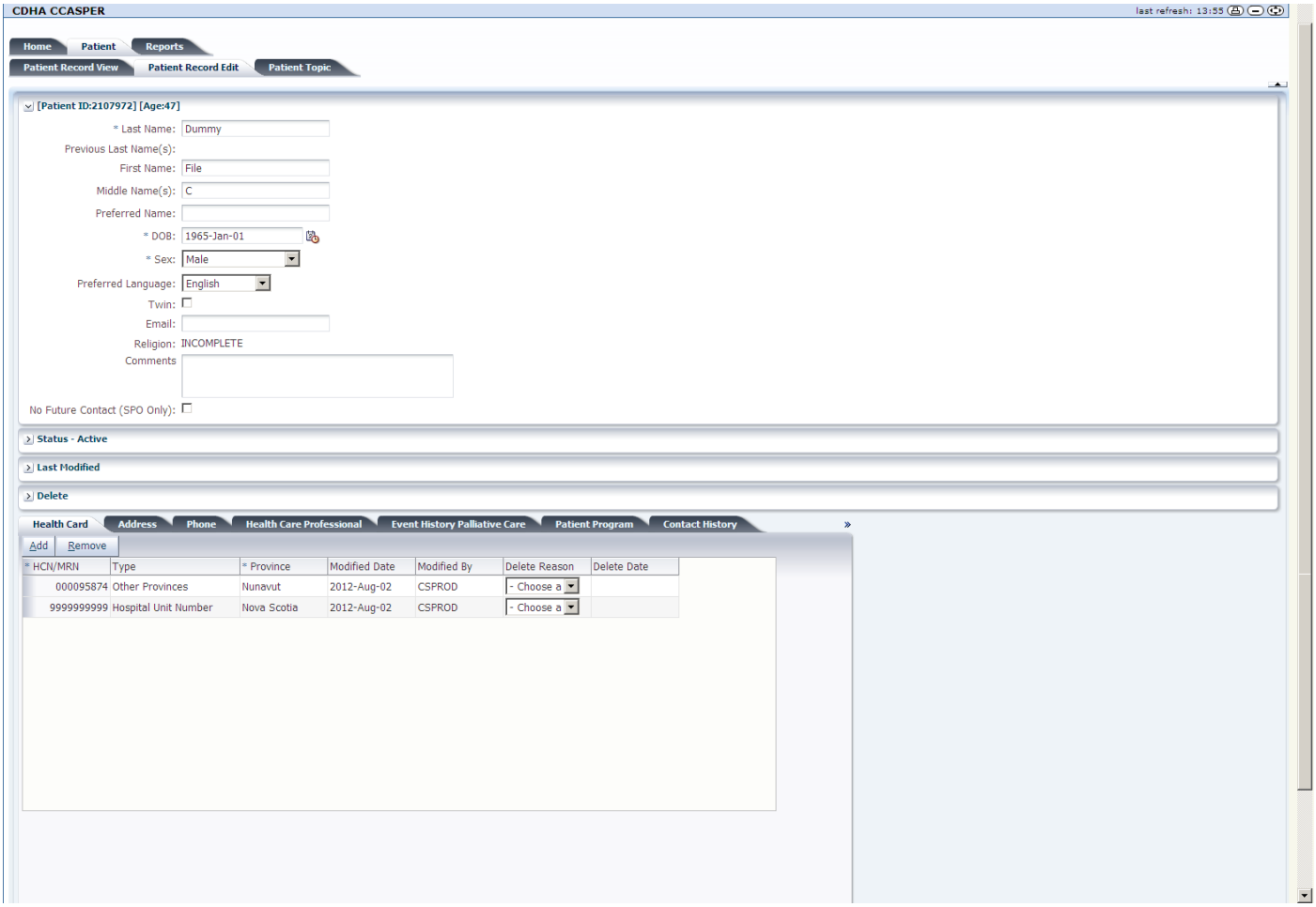
Data Displayed:

- Hospital Unit Number
- Name
- Transition Date
- Patient Tab

Patient Tab



Patient Record Edit



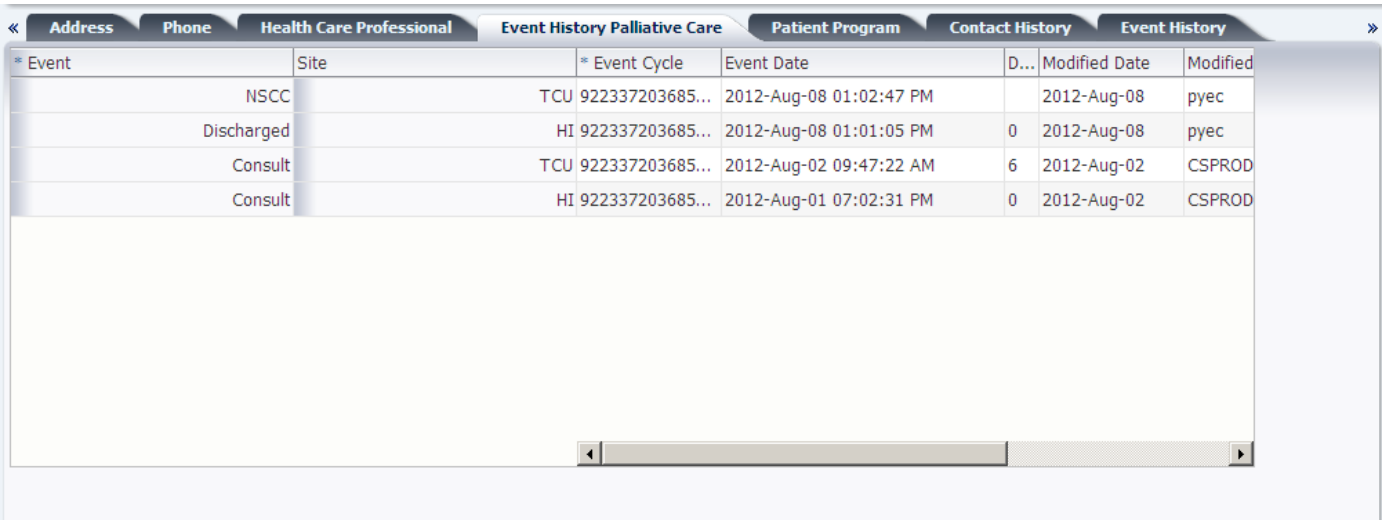
- Allows editing of the data displayed on the Patient Data View tab.
- Mandatory fields at identified with an asterisk *

Patient Record Edit

Field Name	Type	Comment
Last Name	Free Text	Mandatory Field, Comes from *SSS, editable
Previous Last Name(s)	Free Text	No text box if not applicable
First Name	Free Text	Comes from *SSS, editable
Middle Name (s)	Free Text	Comes from *SSS, editable
Preferred Name	Free Text	
DOB	Date Field	Mandatory Field, Comes from *SSS, editable
Sex	Drop Down	Mandatory Field, Comes from *SSS, editable Options: Female, Male Unknown
Preferred Language	Drop Down	Options: English, French, Arabic, Unknown

Twin	Check box	Not used
Email	Free text	Not used
Religion	Display	Comes from *SSS, not editable
Comments	Display	Not used
No Future Contact (SPO Only)	Display	Not used
Current/Primary		
Address	Display	Comes from *SSS, not editable Address line1, Address line 2, City, Province, Postal Code
Phone	Display	Comes from *SSS, not editable
HCN	Display	Comes from *SSS, not editable Stores both HCN and MRN
Dr:	Display	Comes from *SSS, not editable Primary Care Physician
DHA	Display	Comes from *SSS, not editable

Event History Palliative Care (Transitions)



Event History Palliative Care

Field Name	Type	Comment
Event*	Drop down	Both PRI & CONS, Cobequid Clinic, Consult, Discharged, Expired, NSCC, PC O/S, PCU, PRI. Team
Site	Drop Down	ABBIE LANE, CAMP HILL, DGH, EASTERN SHORE, HANTS COMM., HI, HOME, MUSQ. VALLEY, NON-CDHA, NS HOSP, NURSING HOME, OTHER HOSP, REHAB, TCU, TWIN OAKS, VG, VMB

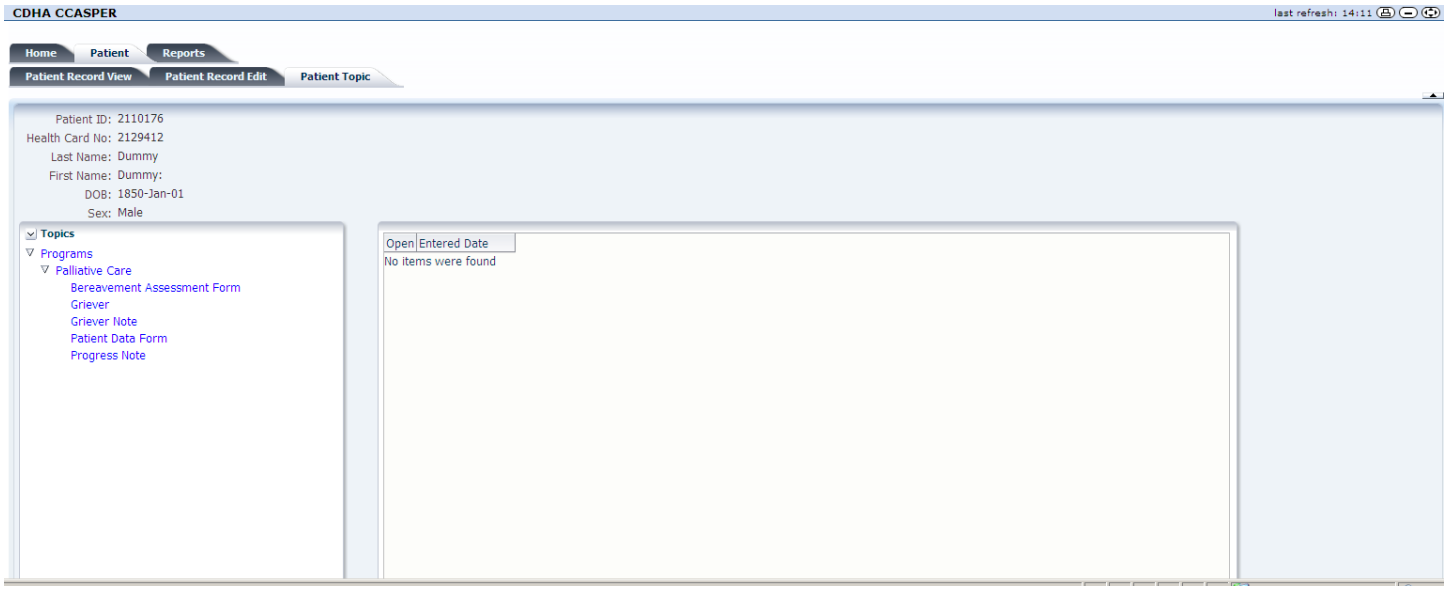
Event Cycle	N/A	Not used, cannot be deleted or hidden
Event Date	Auto fill	Year/Month/Date & time (hour:month:second) of entry
Duration	Auto fill	Calculated from one event to the next
Modified Date	Auto fill	Year/Month/Date of entry
Modified by	Auto fill	User name
Delete Reason	Drop Down	Duplicate, Entered on wrong patient, Error Correct
Delete Date	Auto fill	Year/Month/Date of entry

***Complete list of Event (Transitions) History options**

Transition Events

Option	Definition – Patient followed by	Site
Both PRI & CONS	Patient followed by Primary Provider and Palliative Consult Team.	Any site location
Cobequid Clinic	Patient followed by Palliative Cobequid Clinic	Home
Consult	Patient followed by palliative consult team	Any site location
Discharged	Patient has been discharged from the Palliative Care Program	Home or NON CDHA
Expired	Patient has expired	Site where patient expired
NSCC	Patient followed by palliative clinic held in the Nova Scotia Cancer Centre	Home
PC O/S	Patient admitted to palliative care off-service (no beds on 5A or 7A, bed on another unit in VG)	VG
PCU	Patient admitted to palliative care unit (5A or 7A)	VG
PRI. Team	Patient followed by primary provider (i.e. family doctor or specialist) that is able to call covering palliative physician	Home

Patient Topic Tab



Bereavement Assessment Form

Field Name	Type	Comment
Entered Date:	Date	Auto fills with *save*
Family/Bereaved Reactions during Patient's Illness:	Free text	Small text box
Family/Bereaved Reactions At Time Of Death:	Free text	Small text box
Further Comments:	Free text	Large text box
Name	Free text	Mandatory field, name of person who has completed the assessment
Position	Free text	Mandatory field, position (RN/ MD) of person who has complet
Team Site	Drop down	QEII, DGH, Eastern Shore
Delete		
Delete Reason	Drop down	Options: Duplicate, Entered on Wrong Individual, Error Correct
Delete Date:	Date field	Auto fills with *save*
Delete User:	Date filed	Auto fills with *save*

Grievers are place in the Bereavement program by one of two triggers – the patient has an expired transition or STAR via SSS sends an update to the patient record indicating the patient has expired. There are 4 letters that are sent to the grievers at 1, 4, 8 and 12 month intervals. The system generates the letters on Monday morning and emails them in PDF form to the Bereavement Coordinator. The letters are formatted to include the mailing address formatted for a windowed envelope.

Griever

Field Name	Type	Comment
Entered Date:	Date	Auto fills with *save*
Next Of Kin:	Check box	Check box selected if Griever information from STAR
Salutation:	Drop Down	Mr., Mrs., Dr, Ms
First Name :	Free text	
Last Name:	Free text	
Address Line 1:	Free text	
Address Line 2:	Free text	
City:	Free text	
Province:	Drop Down	List of Provinces and Territories plus “Other” option
Postal Code:	Free text	
Phone	Free text	
Alternate Phone:	Free text	
Relationship	Drop down	Aunt, Brother, Common Law, Cousin, Daughter, Ex-spouse, Father, Foster Parent, Friend, Grandfather, Grandmother, Guardian, Husband, Legal Guardian, Mother, Nephew, Niece, No Next of Kin, Other, Self, Sister, Son, Spouse/Partner, Uncle, Unknown, Wife
Send Letters:	Drop down	Yes, No – default Yes
Phone Contact:	Drop down	Yes, No – default Yes
No Contact:	Drop down	Yes, No
Home Visits:	Free text	
Grief Group:	Drop down	Dynamic table – grows as groups are added by Bereavement Coordinator.
One-on-One counseling:	Drop down	Yes, No
Best Time to Call:	Drop down	Daytime, Evening, Anytime
Children under 18 in home:	Drop down	Yes, No
Contact Details		10 occurrences available
Phone	Check box	
Counseling	Check box	
Date	Date field	Calendar to select date or type *(yyyy-mon-dd eg; 2012- Jul-30)*
Note	Free text	

Notes		
1st Month Letter	Date field	Date entered by system when letter is sent to griever
4th rd Month Letter	Date field	Date entered by system when letter is sent to griever
8th Month Letter	Date field	Date entered by system when letter is sent to griever
12th Month Letter	Date field	Date entered by system when letter is sent to griever
Delete		
Delete Reason	Drop down	Options: Duplicate, Entered on Wrong Individual, Error Correct
Delete Date:	Date field	Auto fills with *save*
Delete User:	Date filed	Auto fills with *save*

Griever Note

Field Name	Type	Comment
Entered Date:	Date	Auto fills with *save*
Griever Name:	Free text	Mandatory field
Note:	Free text	
Delete		
Delete Reason	Drop down	Options: Duplicate, Entered on Wrong Individual, Error Correct
Delete Date:	Date field	Auto fills with *save*
Delete User:	Date filed	Auto fills with *save*

Patient Data Form

Field Name	Type	Comment
Entered Date:	Date field	Auto fills with *save (yyyy-mon-dd eg; 2012- Jul- 30)*
Date Consult Received:	Date field	Calendar to select date or type *(yyyy-mm-dd e.g.; 2012- Jul-30)*
Urgent:	Drop down	Options: Yes, No
Assessment Date:	Date field	Calendar to select date or type *(yyyy-mm-dd e.g.; 2012- Jul-30)*
Referred To:	Drop down	Options: Cobequid Clinic, NSCC, In-Patient Consult, Home Consult, In-Patient Unit, Primary Team
NSCC Number:	Free text	
Marital Status:	Drop down	Options: Common Law, Divorced, Married, Separated, Single, Unknown, Widowed
Primary Diagnosis	Drop down	See Appendix for complete list
Date Diagnosed	Date field	Calendar to select date or type *(yyyy-mm-dd e.g.; 2012- Jul-30)*
Metastases (if cancer):	Free text	
Other Conditions:		Able to select multiple

CHF	Check Box	
Depression	Check Box	
Liver	Check Box	
COPD	Check Box	
Diabetes	Check Box	
IHD	Check Box	
HTN	Check Box	
Renal	Check Box	
Details	Free text	
Other	Free text	
Consult Nurse	Drop down	Options: list of PC RN names, plus MD Only
Home Consult Nurse	Drop down	Options: list of PC RN names
Patient in Nursing Home	Drop down	Options: Yes, No
Nursing Home	Drop down	See Appendix for full list
Documentation Verified By:	Drop down	Options: list of PC RN names
Delete		
Delete Reason	Drop down	Options: Duplicate, Entered on Wrong Individual, Error Correct
Delete Date:	Date field	Auto fills with *save*
Delete User:	Date filed	Auto fills with *save*

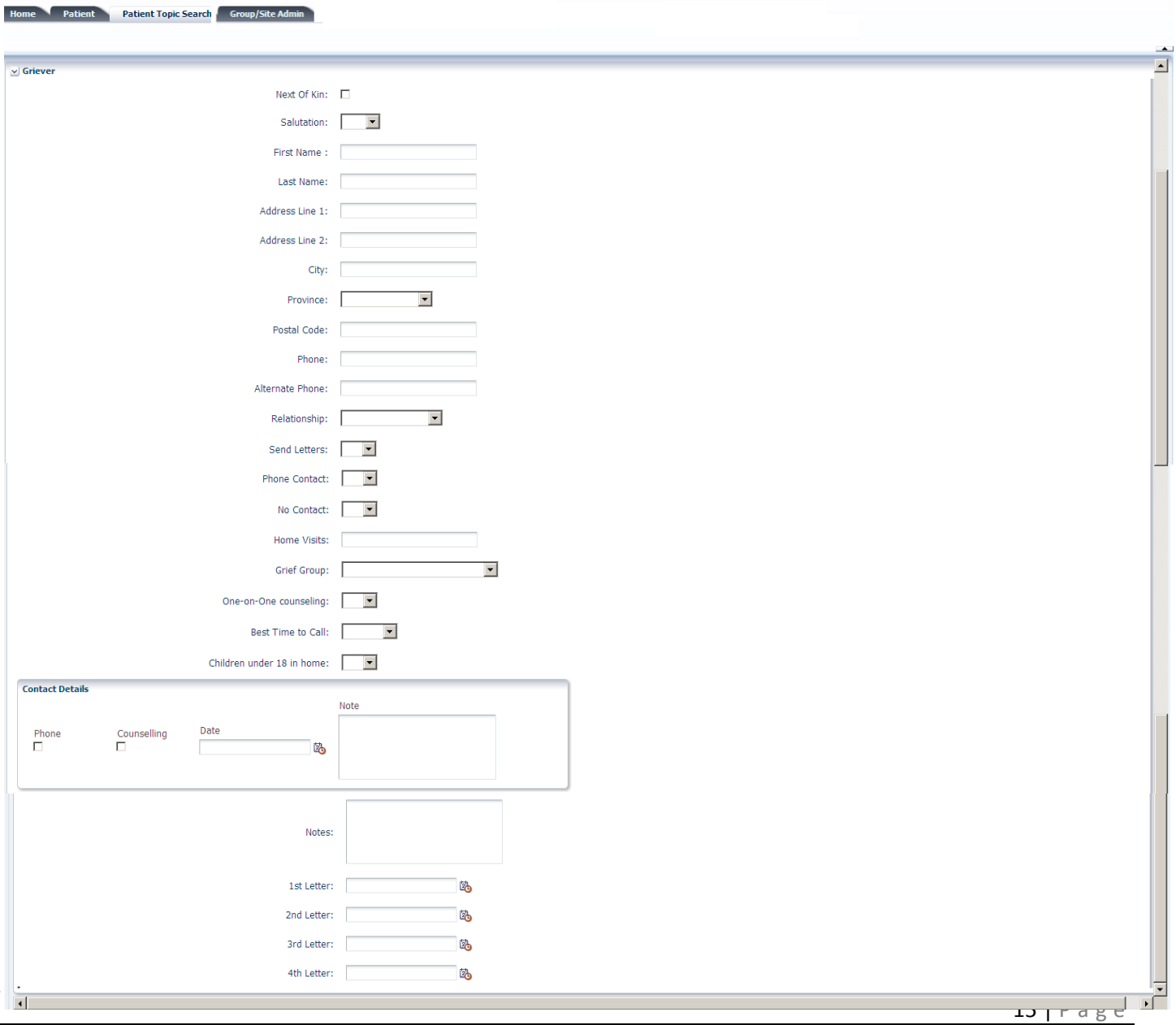
Progress Note

Field Name	Type	Comment
Entered Date:	Date	Auto fills with *save*
Account Number	Free text	Mandatory field
Pain	Drop Down	Options: None, Mild, Moderate, Severe
Range 1-10: __/10	Free text	
Symptoms	Drop Down	Options: None, Mild, Moderate, Severe
Anxious/worried:	Drop Down	Options: No, Sometime, Most of time, All of the time
Family Anxious	Drop Down	Options: No, Sometime, Most of time, Yes preoccupied
Communication	Drop Down	Options: Full information, Info not understood, Likes more info, Very little given
Share Feelings	Drop Down	Options: Yes, Most of time, Sometimes, Not at all
Depressed	Drop Down	Options: No, Sometimes, Most of time, All of the time
Feel good about self	Drop Down	Options: Yes, Most of time, Sometimes, Not at all
Waiting for Services	Drop Down	Options: No, Yes not a problem, Yes problematic
Practical matters	Drop Down	Options: Affairs, Being addressed, Not addressed
Narrative Note	Free text	
Medication review	Radial	Options: Yes, No, Unknown

	buttons	
Last BM:	Date	Calendar to select date or type *(yyyy-mm-dd e.g.; 2012- Jul-30)*
PPS %	Drop Down	Options: 10,20,30,40,50,60,70,80,90,100
PPS Direction	Drop Down	Options: Increased, Decreased, Equal
Pall Prognostic Index __/15:	Free text	
Cognition	Drop Down	Options: Normal, Abnormal
Preferences:		
DNR	Radial Buttons	Options: Yes, No, Unknown
Preferred place of care/death:	Drop Down	Options: Home, Hospital, Other
Other	Free text	
Personal Directive	Radial Buttons	Options: Yes, No, Unknown
Proxy	Free text	
Cornea donor:	Radial Buttons	Options: Yes, No, Unknown
Enhanced PC Home Care	Radial Buttons	Options: Yes, No, Unknown
Level of Care (if change in health status):	Drop Down	Options: Investigate/Treat, Comfortable Death
DX/MSI Code (MD only):	Free text	
Assessment/Plan:	Free text	
Completed By:	Drop Down	Options: List of PC RN
Delete		
Delete Reason	Drop down	Options: Duplicate, Entered on Wrong Individual, Error Correct
Delete Date:	Date field	Auto fills with *save*
Delete User:	Date filed	Auto fills with *save*

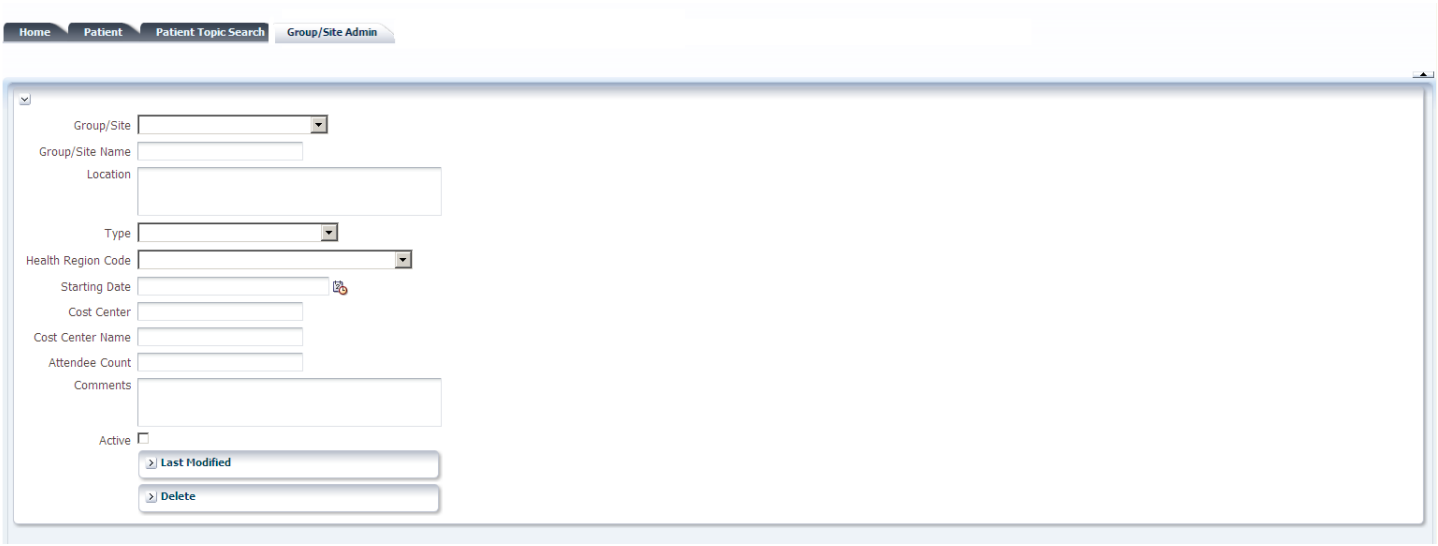
Patient Topic Search Tab

This tab is available to the Bereavement Coordinator of the Palliative Care Program only.
It allows the Bereavement Coordinator to search by griever rather than patient. It also record when the system has generate Bereavement letter to send to grievers.



Group/Site Admin Tab

This tab is available to the Bereavement Coordinator of the Palliative Care Program only. It is used to create and track Griever Groups.

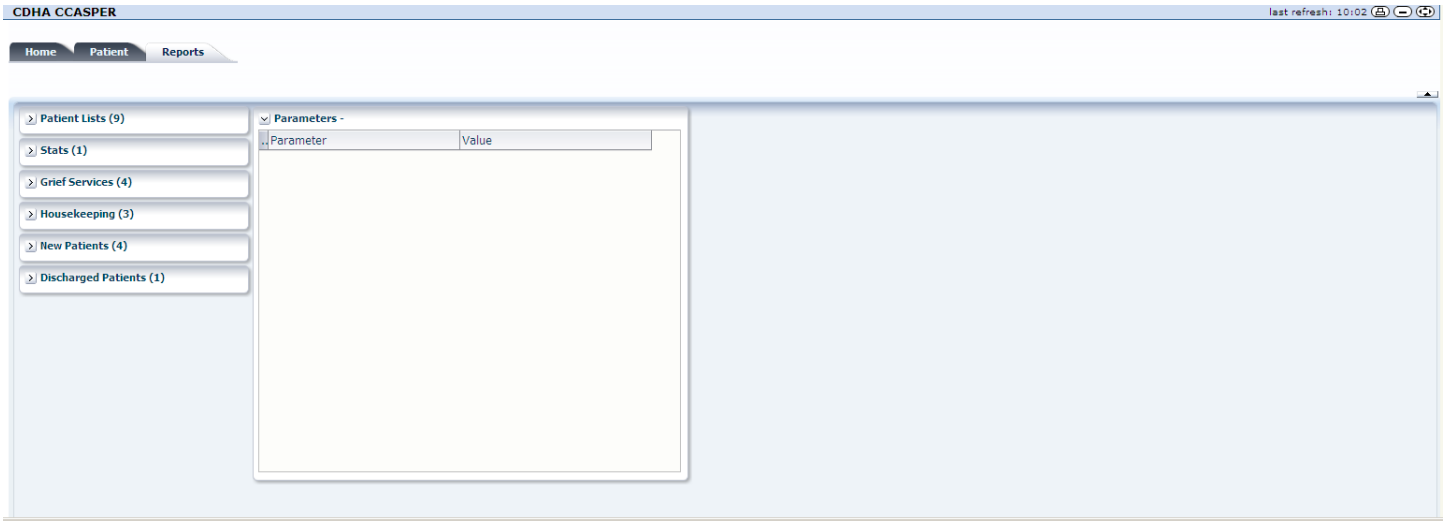


Group/Site Admin

Field Name	Type	Comment
Group/Site	Drop Down	Not a required field
Group/Site Name	Free text	Enter Group name
Location:	Free text	Enter a location for the Group
Type	Drop Down	Grievers Group
Health Region Code	Drop Down	Not a required field
Starting Date	Date	Year/Month/Date & time (hour:month:second) of entry
Cost Center	Free Text	Not a required field
Cost Center Name	Free Text	Not a required field
Attendee Count	Free Text	Number of people who attended the group
Comments	Free Text	
Active	Check box	

Last Modified			
Modified Date:	Date Field	Auto fills with *save*	Auto fi
Modified By:	Auto fill	Auto fills with *save* with user id	
Delete			
Delete Reason	Drop down	Options: Duplicate, Entered on Wrong Individual, Error Correct	
Delete Date:	Date field	Auto fills with *save*	
Delete User:	Date filed	Auto fills with *save*	

Reports Tab



Patient Lists

Rpt – Patients in Hospital

A list of Palliative Care patients in the Ccasper system currently admitted to hospital.

Data Displayed:

Facility;

Name

PID (Ccasper assigned number

Hospital Unit Number

Admitted Date

Consult RN

Rpt – Home Support Patients – Alphabetic

An alphabetic list of Palliative Care patients in the Ccasper system being followed by a Home Consult Team

Data Displayed:

Name

Hospital Unit Number

Phone

HSN (Home Service Nurse)

Rpt – Home Support Patients – by Nurse

A complete list of Palliative Care patients in the Ccasper system filtered by Nurse being followed by a Home Consult Team

Data Displayed:
- Name
- Hospital Unit Number
- Phone
- HSN (Home Service Nurse)
- Team

Rpt – Home Support Patients – by Individual Nurse

A list filtered by Nurse of Palliative Care patients in the Ccasper system being followed by a Home Consult Nurse

Data Displayed:
- Name
- Hospital Unit Number
- Phone
- HSN (Home Service Nurse)
- Team

Rpt -Home Support Patients – Doctors

A list of Palliative Care patients in the Ccasper system being followed by a Home Support

Data Displayed:
- Name
- Health Card Number
- Primary Diagnosis

Rpt - Home Support Patients between Two Dates

A list of Palliative Care patients in the Ccasper system being followed by a Home Support Nurse, between two dates:

Parameters entered are Report Start Date and Report End Date.

Data Displayed:
- Name
- Health Card Number
- PID (Ccasper generated number)
- Palliative Care Physician

Rpt- Discharged Patients in CDHA

A list of Palliative Care patients in the Ccasper system discharged in CH's ADT system (STAR)

Parameters entered are Report Start Date and Report End Date.

Data Displayed:
- Name
- MRN (Medical Record Number)
- NSCC# (Nova Scotia Cancer Care Number)
- Discharged Date

Rpt - Deaths

A list of deceased Palliative Care patients in the Ccasper system:

Parameters entered are Report Start Date and Report End Date.
Data Displayed:
Name
NSCC# (Nova Scotia Cancer Care Number)
Unit # (MRN)
Date

Rpt - Patient Family Contact by Nurse

A list of Palliative Care patients in the Ccasper system, by Nurse (HSN): This report is printed weekly for each nurse to capture calls and visits made to the patient each week. This information is then entered into CH ADT system STAR as check-ins against a series visit.

Parameter selected from a drop down list of HSN names.
Data Displayed:
Unit Number
Patient's Name

Stats

Rpt - Stats for Any Period (With Previous Year)

Parameters entered are Report Start Date and Report End Date.
Data Displayed:
New Consults to Service
New Consults to:
In-Patient Consult
Home Support
In-Patient Unit
NSCC Clinic
Cobequid Clinic
Primary Team
New In-Pt Consults Came From:
VG
HI
Other QE-II Sites
DGH
Tri-Facilities
Musquodoboit Valley Memorial
Eastern Shore Memorial
Twin Oaks
Hants Community Hospital
NS Hospital and Other Hospitals
Response Times to New Referrals
Number of Urgent Referrals
Average Response Time
Minimum Response Time
Maximum Response Time
Percent over Target (2 Days)
Number of Non Urgent Referrals
Average Response Time
Minimum Response Time
Maximum Response Time

Percent over Target (7 Days)
Referrals with No Urgency Recorded
Hospital Consultations – Total Patient Days in Period
VG (Excel. PC Unit and PC O/S)
HI
VMB
Abbie Lane
Rehab
Total Hospital Days All QE-II (Excl. PCU)
DGH
Hants Community
Eastern Shore
Musquodoboit Valley
Twin Oaks
Hospital Consultations – Average Daily Census
VG
HI
VMB
Abbie Lane
Rehab
Average Daily Census All QE-II (Excl. PCU)
DGH
Hants Community
Eastern Shore
Musquodoboit Valley
Twin Oaks
Palliative Care Unit & Off-Service
No. of Pts. Admitted
Total Patient Days for Period
Average Daily Census
Average Length of Stay
No. of Pts. Discharged Alive
%of Discharges Discharged Alive
Number of Patients Off-Service
Total Patient Days off Service

Deaths

Total Deaths in Period (Where Known)
Died in Palliative Care Unit
Died in VG (Excl. PCU)
Died in HI
Died in other QEII- Site
Died in DGH
Died in Tri-Facilities
Died in Eastern Shore
Died in Musquodoboit Valley
Died in Twin Oaks
Died in Hants Community Hospital
Died in Other Hospital
All Hospital Deaths
Died in Nursing Home
Deaths in Locations Other Than Above

Home Support (Incl. Active Nursing Home Pts)
New Entries to Home Support
(Incl. existing PC pts new to HS component)
Average Daily Home (Active) Census
NSCC Patients
New Referrals to NSCC in Period
Average Daily NSCC Census
Grief Program
Total Number of Grievers Followed in Period
Number of Non-Palliative Care Grievers
Counseling
Number of Direct Contacts with Grievers
Group Counseling
"Griever-Sessions" in Period
(Number of Grievers times Session)

Grief Services

Rpt – Grief Program Activity Report

QEII Grief Program Statistical Report
Parameters entered are Report Start Date and Report End Date.
Data Displayed:
Number of Grievers followed in Period:
Number of NON – Palliative Care Grievers followed in Period:
Individual Counseling
Number of direct contacts with grievers
Group Counseling
"Griever-Sessions" in Period
(Number of Grievers times sessions)

Rpt – Current Active Grievers

Currently 'Active 'Grievers (Associated with PC)
Data Displayed:
Name
Phone
Last Contact Date

Rpt – Current Active Grievers Non-Pal

Currently 'Active 'Grievers (NOT Associated with PC)
Data Displayed:
Name
Phone
Last Contact Date

Rpt – Patients with Expired Transitions and Active Status

Patients remain active in the Ccasper Palliative Care System until an expired message is received from STAR via SSS. This report identifies patients that have an Expired transition, but remain active in Ccasper and require follow-up.

Data Displayed:

- Hospital Unit Number
- Patient Name
- Transition Date

Housekeeping

RPT- Pts in Hospital >30 Days

Identifies patient who have been in Hospital over 30 Days

Data Displayed:

- Name
- Unit #
- Admitted
- Place
- Service

RPT- Patients Missing Diagnosis

Identifies patient who do not have a diagnosis entered:

Data Displayed:

- Name
- Unit #
- Referred
- Diagnosed (null)

RPT – Missing and Erroneous Data

Identifies patients with no Transitions Entered, Patients with no Patient Data Form completed and Patients with Transition(s) after Expiration Transition:

Data Displayed:

- Name
- HUN

Expired Patients with no Expiry Transition

Data Displayed:

- Name
- HUN
- Date of Death

Patient Assessment Date does not match first Transition Date

Data Displayed:

- Name
- HUN
- Assessment Date

First Transition Date

New Patients

Rpt – Geographic Origin

Number of new patients between dates entered, by region.
Parameters entered are Report Start Date and Report End Date.

Data Displayed:

District
Postal Code
Region
Number

Rpt – Geographic Origin by District County

Number of new patients between dates entered, by district.
Parameters entered are Report Start Date and Report End Date.

Data Displayed:

District
County
Total

Rpt- Diagnosis and Age Distribution

New patients referred to Palliative Care
Parameters entered are Report Start Date and Report End Date.

Data Displayed:

Primary Diagnosis
Number

Sorted by Age and Sex

Data Displayed:

Age 20 to 29; Sex and Total
Age 30 to 39; Sex and Total
Age 40 to 49; Sex and Total
Age 50 to 59; Sex and Total
Age 60 to 69; Sex and Total
Age 70 to 79; Sex and Total
Age 80 to 89; Sex and Total
Age 90 to 99; Sex and Total

Rpt – Response Times

This report displays Urgent referral response time.
Parameters entered are Report Start Date and Report End Date. The report calculates average response for Urgent patient referrals and the percentage of Urgent referrals seen within target (2 days).

Data Displayed:

PID (Ccasper assigned number)
Name
Referred to
Received

Response

Discharged Patients

Rpt-length of Stay by Setting

Length of stay for patients discharged from listed setting. Calculate the average length of stay per setting.
Parameters entered are Report Start Date and Report End Date.

Data Displayed:

Setting

Stay Range

Stay Range Count

Appendix

SSS Data Elements received by Ccasper Palliative Care

Field Name	Details
Health Care Number	HCN VARCHAR2(50 BYTE),
Last Name	LNAME VARCHAR2(20 BYTE),
First Name	FNAME VARCHAR2(20 BYTE),
Middle Name	MNAME VARCHAR2(20 BYTE),
Date of Birth	DOB DATE,
Gender	GENDER VARCHAR2(1 BYTE),
HCN Effective Date	HCN_EFFECTIVE_DATE DATE,
HCN Expiry Date	HCN_EXP_DATE DATE,
HCN Province Code	HCN_PROV_CD VARCHAR2(2 BYTE),
Address line 1	ALINE1 VARCHAR2(30 BYTE),
Address line 2	ALINE2 VARCHAR2(30 BYTE),
City	CITY VARCHAR2(30 BYTE),
Province	PROV VARCHAR2(2 BYTE),
Postal Code	POSTAL VARCHAR2(6 BYTE),
Home Phone	PHONE1 VARCHAR2(20 BYTE),
Alt Phone	PHONE2 VARCHAR2(20 BYTE),
Medical Record Number	MRN NUMBER(20),
Religion	RELIGION_CD CHAR(3 BYTE),
Family Physician PMB	FAM_PHY_CD NUMBER(10),
Date if Death	PATIENT_EXPIRED_DT DATE,
Residence Code	RES_CD VARCHAR2(10 BYTE),
Next of Kin Relation	NOK1_REL_CD CHAR(1 BYTE),
Next of Kin Last Name	NOK1_LAST_NAME VARCHAR2(100 BYTE),
Next of Kin First Name	NOK1_FIRST_NAME VARCHAR2(100 BYTE),

Next of Kin Address Line	NOK1_ADDR_1 VARCHAR2(100 BYTE),
Next of Kin Address Line	NOK1_ADDR_2 VARCHAR2(100 BYTE),
Next of Kin City	NOK1_CITY VARCHAR2(100 BYTE),
Next of Kin Province	NOK1_PROV_CD CHAR(2 BYTE),
Next of Kin Postal Code	NOK1_POSTAL VARCHAR2(100 BYTE),
Next of Kin Country	NOK1_COUNTRY_CD CHAR(2 BYTE),
Next of Kin Phone	NOK1_PHONE1 VARCHAR2(100 BYTE),
Next of Kin Phone	NOK1_PHONE2 VARCHAR2(100 BYTE),
Next of Kin 2 Relation	NOK2_REL_CD CHAR(1 BYTE),
Next of Kin 2 Last Name	NOK2_LAST_NAME VARCHAR2(100 BYTE),
Next of Kin 2 First Name	NOK2_FIRST_NAME VARCHAR2(100 BYTE),
Next of Kin 2 Address Line 1	NOK2_ADDR_1 VARCHAR2(100 BYTE),
Next of Kin 2 Address Line 2	NOK2_ADDR_2 VARCHAR2(100 BYTE),
Next of Kin 2 City	NOK2_CITY VARCHAR2(100 BYTE),
Next of Kin 2 Province	NOK2_PROV_CD CHAR(2 BYTE),
Next of Kin 2 Postal Code	NOK2_POSTAL VARCHAR2(100 BYTE),
Next of Kin 2 Country	NOK2_COUNTRY_CD CHAR(2 BYTE),
Next of Kin 2 Phone	NOK2_PHONE1 VARCHAR2(100 BYTE),
Next of Kin 2 Phone	NOK2_PHONE2 VARCHAR2(100 BYTE