# Palliative Care Program Data in District Health Authorities 1 to 7 in Nova Scotia

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in collaboration with
Cancer Care Nova Scotia (CCNS), and
Nova Scotia Hospice Palliative Care Association (NSHPCA)

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NELS ICE | Network for End of Life Studies
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## Background

The importance of reliable information for palliative care programs (PCPs) and management of related services is irrefutable. The Nova Scotia Hospice Palliative Care Association (NSHPCA) has been working on measures to support palliative care in Nova Scotia with uniformly reliable information from all the District Health Authorities (DHAs). A province wide approach is being advocated to structure a minimum data set (MDS) for Nova Scotia. Minimum data sets by definition include standardized data which is accurate, reliable and practical to collect. There are variations across Canada in the data collected by palliative care programs (Kuziemsky & Lau, 2008). In Nova Scotia, as one step towards this goal, this report provides a work-in-progress inventory of information being collected for palliative care patients by the DHAs 1 to 7.

The Network for End of Life Studies (NELS) Interdisciplinary Capacity Enhancement (ICE) team has been funded by the Canadian Institutes for Health Research (CIHR) to build research capacity to improve access to palliative and end of life care for vulnerable populations at end of life (www.nels.dal.ca). One goal of NELS ICE is to examine access to care in rural, as well as urban, areas in Nova Scotia to identify differences observed (Burge et al 2005b).

NELS ICE researchers have been collaborating with the Capital Health Integrated Palliative Care Service (CH IPCS) on research projects for more than a decade, and with the Cape Breton Palliative Care Program (CB PCP) in recent years. CH IPCS and CB PCP have electronic databases of patient information since 1988 for CH, and since 1996 for CB. However, CH and industrial CB comprise the two largely urban areas in Nova Scotia and so there is a need to learn more about PCP databases that cover smaller urban and the majority of rural residents in the province.

The CH and CB PCP data linked to cancer deaths and other health services data were analyzed to produce papers (Burge et al 2008 2005a 2002a; Grunfeld et al 2006; Johnston et al 2001 1998; O'Brien et al 2007) and presentations including meetings of NSHPCA (Burge & Johnston 2002b) and Cancer Care Nova Scotia (CCNS) (Johnston 2006). New studies have commenced with the IWK Health Centre palliative care program (ICE project 6), and Colchester East Hants Health Authority on costing palliative care (Dumont et al 2008-2010).

## Objectives

The purpose of this report is to provide a work-in-progress inventory of datasets used for palliative care by the seven DHAs outside Capital Health and Cape Breton (Figure 1). The primary NELS ICE objective is to determine to what extent comparable electronic palliative data exists in the seven more rural DHAs. Ideally, this report will also be useful to others to support ongoing discussions on moving toward a common standardized data set for PCPs across Nova Scotia.

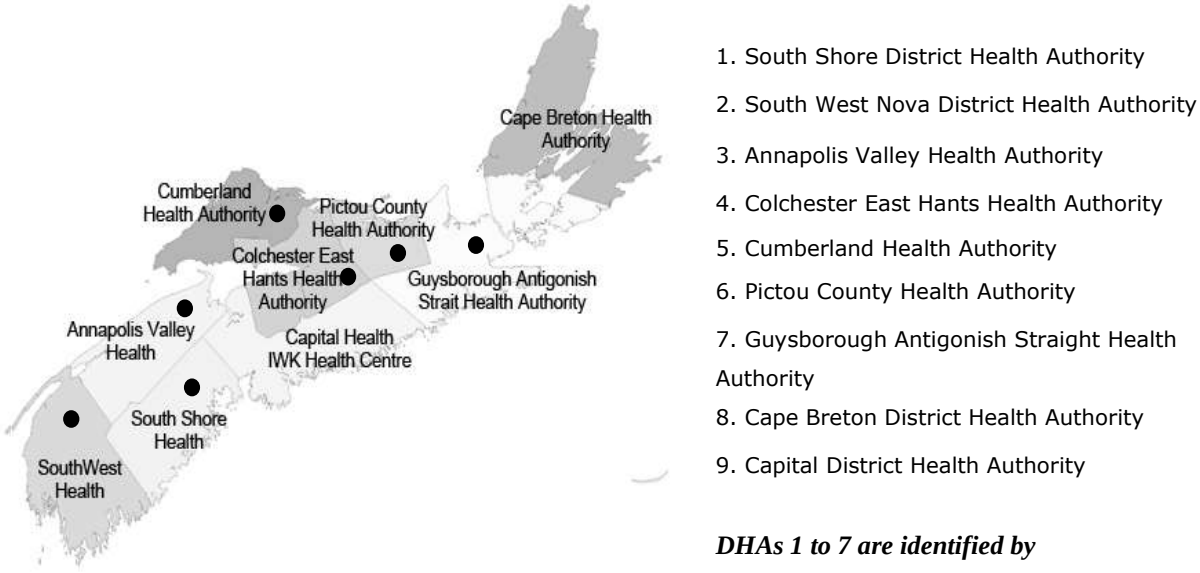



**Figure 1 : District Health Authorities in Nova Scotia**

## Methods

With advice and support from Judy Simpson, who was the Palliative and Supportive Care Coordinator, Cancer Care Nova Scotia (CCNS), key persons responsible for palliative care in the seven DHAs were approached by Junaid Kapra from October 2007 to March 2008 for the information used to prepare the results reported herein. The information was obtained by telephone interviews and copies of intake forms used by the DHAs as well as the reports generated from the palliative care records that were made available to him. In April 2008, this report was circulated to the NSHPCA, PCP contacts in the seven DHAs, and Cancer Care Nova Scotia (CCNS), and staff at the Department of Health (DOH) to verify the information reported herein and to discuss next steps. The report was also made available to the NELS ICE team.

## Results

PCP patient specific data available in DHAs 1 to 7 is summarized in Table 1 as provided in early 2008. Only two DHAs, Annapolis Valley and Colchester East Hants had PCP based Microsoft Access databases. Cumberland had a database which is in very early stages of development so the PCP data is mostly paper based. DHAs with electronic databases do not enter all the information in their PCP paper based records into their electronic database. Annapolis Valley enters primarily demographic information in it database (Appendix A). Colchester East Hants has a more comprehensive database including bereavement details, discharge and referral information (Appendix B). In this report, data elements from the paper based records are included for all DHAs, noting the differences in record type wherever possible.

| Database Descriptors | South Shore Health Authority | South West Health Authority | Annapolis Valley Health Authority | Colchester East Hants Health Authority | Cumberland Health Authority | Pictou County Health Authority | Guysborough Antigonish Strait Health Authority |
|---|---|---|---|---|---|---|---|
| **Time period** | 10 yrs | 2 | 1.5 yrs | 15 yrs | 5 yrs | 8 yrs | 15 yrs |
| **Patient admissions per year** | 70 | 225 | 55-60 | 80-90 | 203 | 103 | 55-60/month |
| **Population of DHA** | 60, 000 | 61,000 | 89,000 | 73,000 | 32,400 | 50,000 | 50,000 |
| **Record Type** | Paper | Database | Database | Database | Paper | Paper | Paper |

**Table 1 : Palliative Care Program information in the seven DHAs as provided in early 2008**

### Personal Information

Personal data recorded for each palliative care patient identifies the patient uniquely and provides basic demographic information about the patient, such as patient's usual address and personal information which may be of interest to the palliative care program. Most of these data items are collected routinely from the patient or care-giver at initial registration. In general paper based records in the DHAs were found to be more comprehensive than databases. Key data elements in this category can be grouped as under:

**Patient Identifiers** : Health Card Number
NSCC Number
Unit Number
Patient's full name (First Name, Last Name)

**Demographic Information** : Sex (Male, Female)

| | | |
|---|---|---|
| | | Date of birth |
| | | Ethnicity |
| | | Religion |
| | | Preferred language |
| | | Living Arrangements |
| | | Residence type (home, group home, long term care facility) |
| | | Marital Status (Married, Divorced, Single, Widowed, ) |
| | | Occupation |
| **Administrative Information** | **:** | Private Health Insurer |
| | | Medication coverage/assistance |
| | | Patient Location (Hospital/Home) |
| | | Hospital Choice |
| | | Pharmacy/Drug Store |
| | | Family Doctor |
| **Patient's Communication** | **:** | Address |
| | | City/Town/County |
| | | Province |
| | | Postal Code |
| | | Communication (Phone, Fax) |

Almost all these data elements are captured consistently by the DHAs with some minor differences. Table 2 provides a comparison of these data elements as captured by the DHAs. A unit number is assigned upon registering a patient for the first time in the program. The provincial health card number serves as a reference for records at a provincial level. All DHAs except Cumberland also record the Nova Scotia Cancer Centre (NSCC) number. Cumberland refers some cases to Moncton, New Brunswick for care and consequently uses their number. Referral date of the patient is captured and discussed within the referral information section.

Ethnicity, religion and language preferences are not captured uniformly by all the DHAs. Some DHAs record the "resident type" to specify the location of the patient at the time of care such as home, group home, long term care facility, etc. This along with the "living arrangement" element serves to indicate the need for special measures for access or support for the patient.

All DHAs record patient address at the time of intake only and do not differentiate between the usual or permanent and most recent or temporary address, if any, of the patient. The latter may change several times during the care, while the patient's usual address normally

remains the same throughout. The granularity of the records differs among DHAs with some recording geographic elements such as district, city/town and county separately.

The electronic databases capture basic patient information for statistical reports. For example, while religion, patient occupation and pharmacy are captured in the paper based record in Colchester East Hants, there are no corresponding fields in the electronic database (Appendix A). The database for Annapolis Valley has no fields for sex, marital status, resident type and other administrative information (Appendix B).

## Support/Informal Caregiver

Support and informal care information is primarily demographic and contact details. Some DHAs capture information which can be used to assess the type of support and level of contact provided to the patient. Key data elements in this category are grouped as:

| | | |
|---|---|---|
| **Other Significant Caregiver** | **:** | Name |
| | | Relationship |
| | | Address (City/Town, Province) |
| | | Postal Code |
| | | Phone |
| | | Name |
| | | Relationship |
| | | Address (City/Town, Province) |
| | | Postal Code |
| | | Phone |
| **Next of Kin Information** | **:** | Occupation |
| | | Current Employment Status |
| | | Compassionate Care Benefits |
| | | Health Status |
| | | Name |
| | | Relationship |
| **Emergency/Support Contacts** | **:** | Address |
| | | Phone |
| | | Physician Name(s) |
| **Physician Information** | **:** | Specialty |
| | | Phone/Fax |

| Variable | South Shore Health Authority | South West Health Authority | Annapolis Valley Health Authority | Colchester East Hants Health Authority | Cumberland Health Authority | Pictou County Health Authority | Guysborough Antigonish Strait Health Authority |
|---|---|---|---|---|---|---|---|
| Client Information | | | | | | | |
| Last Name | Y | Y | Y | Y | Y | Y | Y |
| First Name | Y | Y | Y | Y | Y | Y | Y |
| Initial | Y | Y | Y | Y | | Y | Y |
| Birth Date | Y | Y | Y | Y | Y | Y | Y |
| Health Card Number | Y | Y | Y | Y | Y | Y | Y |
| NSCC Number | Y | Y | Y | | Y | Y | N |
| Unit Number | Y | Y | Y | Y | Y | sometimes | Y |
| Sex | Y | Y | Y | Y | Y | Y | Y |
| Religion | Y | Y | Y | Y (optional) | Y | Y | Y |
| Clergy | Y | Y | | Y (optional) | Y | Y | Y |
| Ethnicity | | Y | | | N | N | Y |
| Spoken Language | | Y | Y | | N | N | Y |
| Marital Status | Y | Y | Y | Y | Y | Y | Y |
| Living Arrangements | Y | Y | Y | Y | Y | Y | Y |
| Resident Type | | Y | Y | Y | | Y | Y |
| Occupation | Y | Y | Y | Y | N | N | Y |
| Private Health Insurer | Y | Y | Y | Y | Y | Y | Y |
| Other medication coverage/assistance | Y | Y | Y | Y | Y | Y | Y |
| Patient Location (Hospital/Home) | Y | Y | Y | Y | | Y | Y |
| Hospital Choice | Y | Y | Y | Y | | Y | Y |
| Pharmacy/Drug Store | Y | Y | Y | Y | Y | Y | Y |
| Client Address | | | | | | | |
| Address | Y | Y | Y | Y | Y | Y | Y |
| City/Town/County | | Y | Y | Y | Y | Y | Y |
| Province | | | Y | Y | Y | | Y |
| Postal Code | Y | Y | Y | Y | Y | | Y |
| Communication (Phone/Fax) | Y | | Y | Y | Y | Y | N |

Legend: Y: Information is collected N: Information is not collected

**Table 2 : Comparison of Personal Patient Information captured by DHA 1 to 7**

Table 3 provides a comparison of the support or informal caregiver information elements captured by DHAs 1 to 7. Some DHAs, e.g., Cumberland, do not differentiate between next of kin and significant caregiver while Colchester East Hants and South Shore capture emergency contact information. There are no fields to indicate the role these contracts, e.g., willingness of next of kin to act as significant care provider or as an emergency contact person. Information about occupation, income and health status of the significant caregiver provides a potential indication of care available to the patient but is not captured by all the DHAs.

Information about attending physicians/specialists is captured by almost all the DHAs. Some DHAs, e.g., Cumberland, do not differentiate between this information and family doctor.

## Referral / Discharge Information

Referral/discharge information can be sued to monitor and review referral patterns. Data elements in this category are determined by the method for handling referrals to palliative care. Thus, they are not necessarily confined to registering of the patient at the first referral. The information is collected at different times throughout the course of palliative care. The DHAs show a wide variation in captured data elements in this category. The key data elements are:

| | | |
|---|---|---|
| **Referral Information** | **:** | Referral Date |
| | | Referred by |
| | | Reason for referral |
| | | Place of referral |
| **Service Information** | **:** | Institution |
| | | Unit |
| | | Initial Assessment Date |
| | | Referred to |
| | | Referring Site |
| | | Referring Service |
| | | Date Consult Received |
| | | Admission date |
| | | Type of Service |
| | | Reason |
| **Discharge Information** | **:** | Discharge date |
| | | Place discharged to |

| Variable | South Shore Health Authority | South West Health Authority | Annapolis Valley Health Authority | Colchester East Hants Health Authority | Cumberland Health Authority | Pictou County Health Authority | Guysborough Antigonish Strait Health Authority |
|---|---|---|---|---|---|---|---|
| Next of Kin Information | | | | | | | |
| Name | Y | Y | Y | Y | Y | | Y |
| Relationship | Y | Y | Y | Y | Y | | Y |
| Address | Y | Y | | Y | N | | Y |
| City/Town | | | | Y | N | | Y |
| Province | | | | Y | N | | Y |
| Postal Code | Y | | | Y | N | | Y |
| Phone | Y | Y | Y | Y | Y | | Y |
| Significant Caregiver | | | | | | | |
| Name | Y | Y | Y | Y | N | | Y |
| Address | | | | Y | N | | Y |
| City/Town | | | | Y | N | | Y |
| Relationship | | Y | Y | Y | N | | Y |
| Province | | | | Y | N | | Y |
| Postal Code | | | | Y | N | | Y |
| Phone | | | Y | Y | N | | Y |
| Occupation | Y | Y | | | N | | Y |
| Current Employment Status | Y | Y | Y | | N | | Y |
| Compassionate Care Benefits | Y | Y | Y | | N | | Y |
| Health Status | Y | Y | Y | | N | | Y |
| Others involved in Care | | Y | Y | | N | | Y |
| Emergency/Support Contacts | | | | | | | |
| Name | | Y | Y | | Y | Y | Y |
| Relationship | | Y | Y | | Y | Y | Y |
| Address | | Y | | | N | Y | Y |
| Phone | | Y | Y | | | Y | Y |
| Physician Information | | | | | | | |
| Physician Name (s) | Y | Y | Y | Y | Y | Y | Y |
| Specialty | Y | Y | Y | Y | | | Y |
| Phone/Fax | Y | Y | Y | Y | N | | Y |

Legend: Y: Information is collected N: Information is not collected

**Table 3 : Comparison of Support or Informal Caregiver Information Captured by DHAs 1 to 7**

Table 4 provides a comparison of referral, service and discharge information captured by DHAs 1 to 7. While the referral date is recorded by all DHAs, the date of initial assessment is captured by only some DHAs. Time between date of referral and commencement of service can be an important indicator for a palliative care program. Contact details for the referral source are not captured by any DHA. Data elements such as whether the referral actually resulted in a service being provided or 'service could not be provided' and 'when the service was initiated' are not recorded. It is not clear if a patient discharged from palliative care and requires care again at a later date is considered a new referral as there is no data element to track the referral sequence. There seems to be no system to link the referral data set to services provided as a result of that referral. A palliative care case can receive multiple services determined either at the time of initial referral or subsequently in the course of their care. Discharge information, including date discharged and place of discharged is captured by only some DHAs.

## Social History

A major goal of palliative care is to achieve the best quality of life for patients and their families. This requires care of their physical, emotional, psychosocial and spiritual needs. It thus becomes imperative that data sets for palliative care include information that can be used to effectively address these issues. Almost all the DHAs have policies to address this aspect of palliative care. The key data elements in this category include:

| | | |
|---|---|---|
| **Social Information** | : | Number of children |
| | | Patient/Family Coping and Support |
| | | Financial Concerns |
| | | Main Concerns of the Patient |
| | | Main Concerns of Family |
| | | Patient support needs |
| | | Caregiver support needs |
| | | Children's needs |
| | | Religious/Spiritual practices |
| | | Religious/Spiritual guidance/support requirement |
| | | Emotional needs |

| Variable | South Shore Health Authority | South West Health Authority | Annapolis Valley Health Authority | Colchester East Hants Health Authority | Cumberland Health Authority | Pictou County Health Authority | Guysborough Antigonish Strait Health Authority |
|---|---|---|---|---|---|---|---|
| Referral/Discharge Information | | | | | | | |
| Referral Date | Y | Y | Y | Y | Y | Y | Y |
| Referred by | Y | | Y | Y | Y | Y | Y |
| Reason for referral | | Y | Y | Y | Y | Y | Y |
| Place of referral | | | | Y | N | Y | Y |
| Institution | | | | Y | N | Y | Y |
| Unit | | | | Y | N | N | Y |
| Initial Assessment Date | | | | Y | Y | Y | Y |
| Referred to | | | | | | | Y |
| Referring Site | | | | | | Y | Y |
| Referring Service | | | | | | | Y |
| Date Consult Received | | | | Y | | N | Y |
| Admission date | | | | Y | | N | N |
| Type | | | | Y | | Y | Y |
| Reason | | | | Y | | | N |
| Discharge date | | | | Y | Y | Y | Y |
| Place discharged to | | | | Y | Y | | Y |

Legend: Y : information is collected N : Information is not collected

**Table 4 : Comparison of Referral/Service/Discharge information captured by the DHAs 1-7**

Most of the social information included in palliative care records by DHAs 1-7 are captured in descriptive text format and are non- standardized. Colchester East Hants, Annapolis Valley and Cumberland do not capture these fields in their electronic databases.

## Advanced Care Planning

Capturing advanced care planning decisions is an important requisite for a palliative care dataset. This planning may involve the immediate family of the person receiving palliative care. Advanced care planning may include an advanced directive with informed consent or a Do Not Resuscitate (DNR) order. In almost all DHAs DNR information is captured separately and may include information such as the location of the DNR document. Most DHAs collect this

| | | |
|---|---|---|
| **Death Information** | **:** | Patients wishes regarding care setting |
| | | Family wishes regarding care setting |
| | | Advanced Directive |
| | | DNR order information |
| | | Power of Attorney for Personal Care |
| | | Power of Attorney for Finances |
| | | Patient wishes regarding resuscitation |
| | | Family wishes regarding resuscitation |
| | | Patient /family wishes regarding funeral |
| | | Funeral Home Name |

information with minor differences. Key data elements are above

## Death/Bereavement Support Information

Information about bereavement, if captured, helps with the management of resources of the palliative care program. In most palliative datasets, the death/bereavement information is linked to data of the deceased patient. There is wide variation in the data elements captured for this category by the DHAs. The key data elements in this category can be grouped as:

| | | |
|---|---|---|
| **Death Information** | **:** | Date of Death |
| | | Time of Death |
| | | Location of death |
| **Bereavement Information** | **:** | Patient /family death wish captured? |
| | | Patient /Family wishes Kept |
| | | Bereavement Details |

The amount and type of bereavement information captured varies among each of the DHAs (Table 5). Colchester East Hants has a separate table to capture details such as memorial service, record of visits, calls made and letters sent.

### Palliative Care Assessment

Palliative care assessment tools provide a means for appraisal of the impact of interventions at the end of life. The tools used by the DHAs fall under three broad groups: Pain Assessment Tool, Palliative Performance Scale (Appendix C) and Symptom Assessment System (Appendix D). Although there is a broad consensus on using standardized validated tools for assessment, a variety of tools are used by the DHAs. For example, while most DHAs use the Edmonton Symptom Assessment System, Annapolis Valley uses a Modified Memorial Symptom Assessment tool (Appendix E).

### Clinical and Medication/Drug Information

All DHAs collect clinical information about palliative care cases although the level of detail shows considerable variation. Guysborough Antigonish Strait has the most detailed clinical information component and includes elements such as antibiotic resistant organism (ARO) screening and medical equipment in use/needed. None of the other DHAs surveyed capture ARO screening. Date of diagnosis, co-morbidities and previous health history elements are not recorded consistently by all the DHAs. On the other hand, treatment modalities such as radiation/chemotherapy are recorded by most DHAs. Medication/drug information data elements are captured in a remarkably standardized format by all the DHAs.

| Variable | South Shore Health Authority | South West Health Authority | Annapolis Valley Health Authority | Colchester East Hants Health Authority | Cumberland Health Authority | Pictou County Health Authority | Guysborough Antigonish Strait Health Authority |
|---|---|---|---|---|---|---|---|
| Social History/Information | | | | | | | |
| Number of children | | Y | | Y | N | | Y |
| Patient/Family Coping and Support | | Y | | Y | Y | | Y |
| Financial Concerns | | Y | Y | Y | Y | | Y |
| Main Concerns of the Patient | | Y | Y | Y | Y | | Y |
| Main Concerns of Family | | Y | Y | Y | Y | | Y |
| Patient support needs | | Y | | Y | Y | | Y |
| Caregiver support needs | | Y | | Y | Y | | Y |
| Children's needs | | Y | | Y | Y | | Y |
| Religious/Spiritual practices | | Y | Y | Y | | | Y |
| Religious/Spiritual guidance/support requirement | | Y | Y | Y | | | Y |
| Emotional needs | | Y | Y | Y | Y | | Y |
| Advanced Care Planning | | | | | | | |
| Patients wishes regarding care setting | Y | Y | Y | Y | | Y | Y |
| Family wishes regarding care setting | Y | Y | Y | Y | | | Y |
| Advanced Directive | Y | Y | Y | Y | N | | Y |
| DNR order information | Y | Y | Y | Y | Y | | Y |
| Power of Attorney for Personal Care | | Y | Y | Y | Y | | Y |
| Power of Attorney for Finances | | Y | Y | Y | Y | | Y |
| Patient wishes regarding resuscitation | Y | Y | Y | Y | | | Y |
| Family wishes regarding resuscitation | Y | Y | Y | Y | | | Y |
| Patient /family wishes regarding funeral | | Y | | Y | N | | Sometimes |
| Funeral Home Name | Y | | | Y | Y | | Sometimes |
| Death/Bereavement Information | | | | | | | |
| Date of Death | | | Y | Y | Y | | Y |
| Time of Death | | | | | N | | N |
| Location of death | | | Y | Y | Y | | Y |
| Patient /family death wish captured? | | Y | Y | Y | | | N |
| Patient /Family wishes Kept | | | | | | | N |
| Bereavement Details | | | | Y | N | | Y |

Legend : Y : Information is collected N : Information is not collected

**Table 5 : Comparison of Social, Death/Bereavement and Advanced Care Planning Data elements captured by DHAs 1 to 7**

### Palliative Care Team Information

Most DHAs record the staff members of the support team. The members which may be recorded include:

- Care Coordinator
- Social Worker
- Home Support
- Private Nursing Agency
- Volunteer Information
- Cancer Society

Detailed information about each is lacking in all DHAs (Table 6). It is not clear how multiple team members in a particular group are recorded.

## Statistical Reporting

South Shore District Health Authority's monthly statistical reporting is provided in Appendix F. It is assumed that there is further information on PCP reporting in the DHAs but that this information was not available to the lead author at the time of the release of this report.

The assistance of numerous people in the DHAs associated with the palliative care programs is gratefully acknowledged. See Appendix G for DHA informants/contributors to this report.

| Variable | South Shore Health Authority | South West Health Authority | Annapolis Valley Health Authority | Colchester East Hants Health Authority | Cumberland Health Authority | Pictou County Health Authority | Guysborough Antigonish Strait Health Authority |
|---|---|---|---|---|---|---|---|
| Palliative Care Assessment | | | | | | | |
| Palliative Performance Scale | | Y | Y | | N | | Y |
| Pain Assessment Tool | | Y | Y | Y | Y | | Y |
| Symptom Assessment System | | Y | Y | Y | Y | | Y |
| Clinical Information | | | | | | | |
| Diagnosis | Y | Y | Y | Y | Y | | Y |
| Metastases | | Y | Y | Y | N | | Y |
| Other Diagnosis | | | Y | | Y | | Y |
| Date of Diagnosis | | Y | | Y | N | | Y |
| Health history | | | Y | Y | | | Y |
| Diagnosis known by Patient/Family | | Y | Y | Y | N | | Y |
| Prognosis known by Patient/Family | | Y | Y | Y | N | | N |
| Radiation/Chemotherapy | | Y | Y | Y | Y | | Y |
| Surgery | | Y | | Y | Y | | Y |
| ARO (Antibiotic Resistance) Screening | | | | | N | | Y |
| Medical Equipment in use/needed | | | | | Y | | Y |
| Medication and Drug Information | | | | | | | |
| Medication Name | | Y | Y | Y | Y | | Y |
| Dosage, Route Frequency | | Y | Y | Y | Y | | Y |
| Knowledge/Teaching requirement | | Y | Y | Y | Y | | Y |
| Administration requirements | | Y | Y | Y | Y | | Y |
| Payment (Self, Insurance, NRHB, Others) | | Y | Y | Y | | | Y |
| Drug Allergies/Sensitivity | | Y | Y | Y | Y | | Y |
| Palliative Care Team Information | | | | | | | |
| Care Coordinator | | Y | Y | Y | Y | | Y |
| Social Worker | | Y | Y | Y (inpatient) | Y | | Y |
| Home Support | | Y | Y | Y | | | Y |
| Private Nursing Agency | | Y | Y | Y | N | | N/A |
| Volunteer Information | | Y | Y | Y | N | | Y |
| Cancer Society | | Y | | Y | | | Y |

Legend : Y : Information is collected N : Information is not collected

**Table 6: Comparison of Palliative Care Assessment, Clinical , Medication and Palliative Care Team Information data elements captured by DHA 1 to 7**

## Conclusion

There are variations in the type of records available and the methods used by the DHAs to record information about palliative care. In most cases, paper records are supplemented by administrative databases. In DHAs 1 to 7 in Nova Scotia with standalone electronic databases for palliative care, only a basic dataset is recorded. This report does not compare the palliative care data in DHAs 1 to 7 to the data being collected by Cape Breton, Capital Health and the IWK Health Centre but this could be a useful in the future.

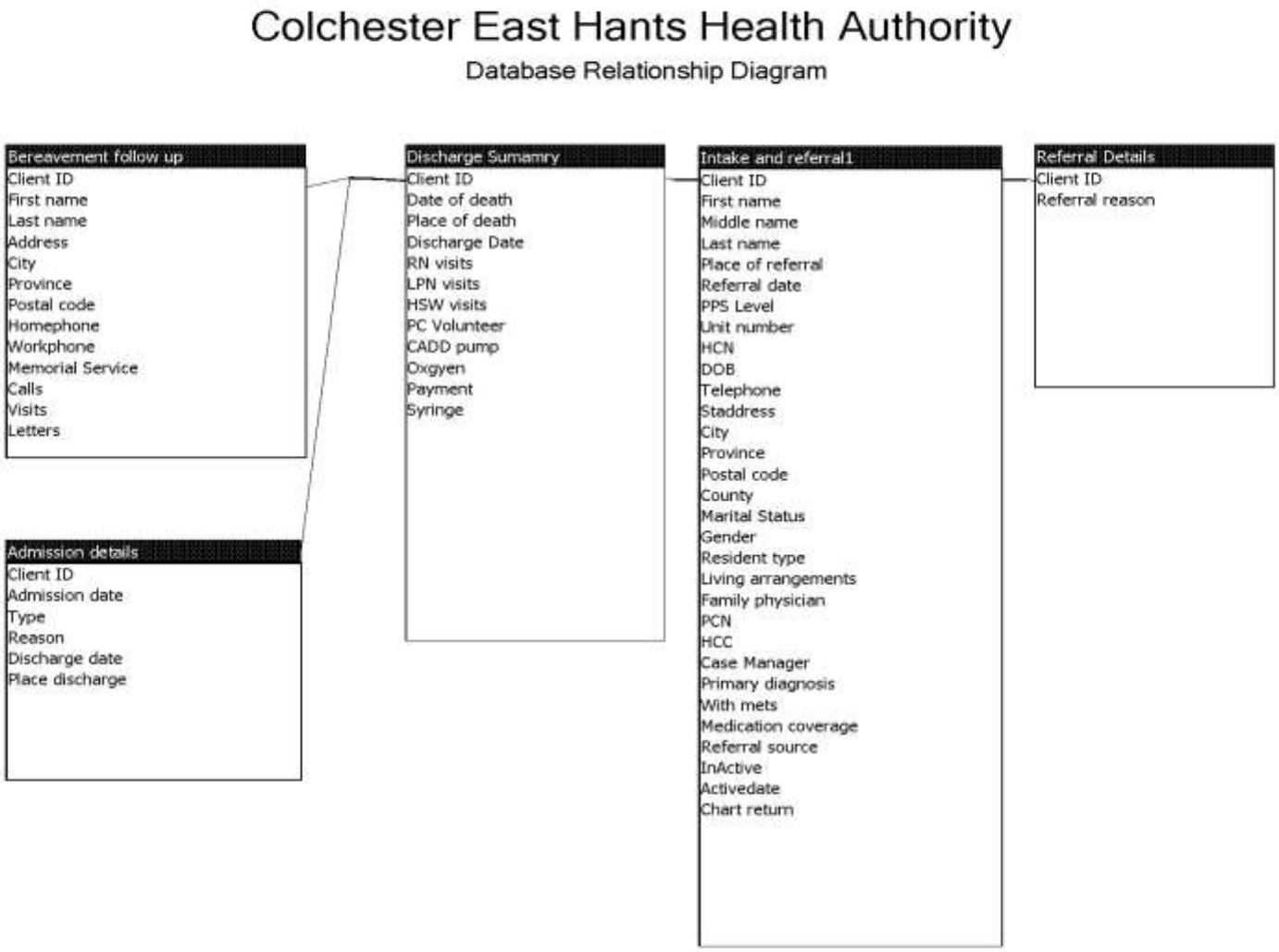
A typical palliative dataset needs to capture data across the spectrum of services used by those individuals receiving palliative care. This may include patient registration, inpatient, outpatient, hospital support services, bereavement, home care, family support, voluntary services, psychosocial and spiritual care. Since the palliative care patient can utilize a service multiple times and moves across various services, there is a need to capture elements which track these events. For effective use of information, data needs to be standardized, accurate and readily available. In this regard, electronic systems for palliative care information management are invaluable. In countries such as the United States (Connor, Tecca, Lund-Person & Teno, 2004) and Australia (Jellie & Shaw, 1999), much work has been done in defining and implementing standardized methodologies for data collection in palliative care. A useful review of palliative care program data in selected urban regions in Canada has been carried out (Kuziemsky, & Lau, 2008). In Nova Scotia, it would be useful to move toward a consensus on a minimum data set with data definitions of key data palliative care fields. Many of the critical data items are already recorded in one way or another by the majority of the DHAs. The introduction of a standardized minimum data set for all palliative care programs across the province would improve data consistency and allow for more reliable comparison of data between the DHAs.

The Network for End of Life Studies (NELS) Interdisciplinary Capacity Enhancement (ICE) team funded by the Canadian Institutes for Health Research has a mandate to develop palliative and end of life care research (www. nels.dal.ca). This report helps identify which DHAs have data that could allow them to potentially partner with researchers in the future for surveillance and research studies, given appropriate approvals. The NELS ICE team also hopes that this work-in-progress report will help a range of other stakeholders interested in further development of palliative care program data in Nova Scotia.

## Appendix A: Annapolis Valley Health Database Table

| |
|---|
| C-Date |
| Death |
| LOC |
| P Code |
| Priority |
| Location |
| FirstName |
| LastName |
| Address |
| HomePhone |
| Main Contact |
| DOB |
| MSI Number |
| Referred |
| Consult |
| Diagnoses |
| Family Doctor |
| C-Loc |
| CPR |
| C-by |
| Team |
| Date Ref |
| Unit. |
| Notes |

## Appendix B: Colchester East Hants Health Authority Database Relationship Diagram



## Appendix C: Palliative Performance Scale

| PPS Level | Ambulation | Activity & Evidence of Disease | Self-Care | Intake | Conscious Level |
|---|---|---|---|---|---|
| 100% | Full | Normal activity & work No evidence of disease | Full | Normal | Full |
| 90% | Full | Normal activity & work Some evidence of disease | Full | Normal | Full |
| 80% | Full | Normal activity with Effort Some evidence of disease | Full | Normal or reduced | Full |
| 70% | Reduced | Unable Normal Job/Work Significant disease | Full | Normal or reduced | Full |
| 60% | Reduced | Unable hobby/house work Significant disease | Occasional assistance necessary | Normal or reduced | Full or Confusion |
| 50% | Mainly Sit/Lie | Unable to do any work Extensive disease | Considerable assistance required | Normal or reduced | Full or Confusion |
| 40% | Mainly in Bed | Unable to do most activity Extensive disease | Mainly assistance | Normal or reduced | Full or Drowsy +/- Confusion |
| 30% | Totally Bed Bound | Unable to do any activity Extensive disease | Total Care | Normal or reduced | Full or Drowsy +/- Confusion |
| 20% | Totally Bed Bound | Unable to do any activity Extensive disease | Total Care | Minimal to sips | Full or Drowsy +/- Confusion |
| 10% | Totally Bed Bound | Unable to do any activity Extensive disease | Total Care | Mouth care only | Drowsy or Coma +/- Confusion |
| 0% | Death | --- | | | - |

## Appendix D: Edmonton Symptom Assessment System

### Numerical Scale

**Please circle the number that best describes:**

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| No pain | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst possible pain |
| Not tired | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst possible tiredness |
| Not nauseated | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst possible nausea |
| Not depressed | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst possible depression |
| Not anxious | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst possible anxiety |
| Not drowsy | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst possible drowsiness |
| Best appetite | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst possible appetite |
| Best feeling of wellbeing | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst possible feeling of wellbeing |
| No shortness of breath | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst possible shortness of breath |
| Other problem | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | |

Patient's Name _____

Date _____ Time _____

Complete by *(check one)*

- ☐ Patient
- ☐ Caregiver
- ☐ Caregiver assisted

***BODY DIAGRAM ON REVERSE SIDE***

## Appendix E: Modified Memorial Symptom Assessment Scale

| MODIFIED* MEMORIAL SYMPTOM ASSESSMENT SCALE | | | | | |
|---|---|---|---|---|---|
| **NAME:** | | **DATE:** | | | |
| How Often Do You Have It?: | 1 = Rarely, 2 = Occasionally, 3 = Often, 4 = Always | | | | |
| How Severe Is It Usually?: | 1 = Slight, 2 = Moderate, 3 = Severe, 4 = Very Severe | | | | |
| How Much Does it Distress/Bother You? | 0 = Not at all, 1 = A Little Bit, 2 = Somewhat, 3 = Quite, 4 = Very Much | | | | |
| **Symptom** | **None** | **How Often** | **How Severe** | **Distress** | **Notes** |
| **PAIN:** | | | | | |
| **GI:** | | | | | |
| Dry Mouth | | | | | |
| Mouth Sores | | | | | |
| Lack of appetite | | | | | |
| Weight loss | | | | | |
| Change in food taste | | | | | |
| Difficulty swallowing | | | | | |
| Nausea | | | | | |
| Vomiting | | | | | |
| Feeling bloated | | | | | |
| Diarrhea | | | | | |
| Constipation | | | | | |
| **Respiratory:** | | | | | |
| Cough | | | | | |
| Dyspnea | | | | | |
| **Constitutional:** | | | | | |
| Difficulty sleeping | | | | | |
| Feeling drowsy | | | | | |
| Lack of energy | | | | | |
| Muscle weakness | | | | | |
| **Appearance:** | | | | | |
| "I don't look like myself" | | | | | |
| Changes in skin | | | | | |
| Hair loss | | | | | |
| Swelling of arms and legs | | | | | |
| **Neurological:** | | | | | |
| Confusion | | | | | |
| Dizziness | | | | | |
| Itching | | | | | |
| Numbness/tingling in hands/feet | | | | | |
| Problems with urination | | | | | |
| Sweats | | | | | |
| **Emotional:** | | | | | |
| Difficulty concentrating | | | | | |
| Feeling irritable | | | | | |
| Feeling nervous | | | | | |
| Feeling sad | | | | | |
| Problems: sexual interest/activity | | | | | |
| Worrying | | | | | |
| **Other:** | | | | | |
| | | | | | |
| *Modified from Memorial Symptom Assessment scale for use in Annapolis Valley Health | | | | | |

## Appendix F: Monthly Palliative Care Statistics Captured by South Shore Health Authority

**New Referrals**

- Inpatient (Patient in Local Hospital)
- Outpatient

**Source of Referral**

- Hospital Staff/Volunteer/Patient Navigator
- Physicians
- HCNS / VON / HAS / LTC / Private Agency
- Patient / Family Member / Friend
- Other Palliative Care Programs

**Patient Follow-Up**

- Inpatient Hospital Visit
- Outpatient Home Visit / DVA
- Outpatient Clinic Visit
- Patient / Family Contact
- Team Member Contact (PC Consult Team / Volunteer)
- Resource Contact (Hospital / Community Physician)

**Location of Patient Death**

- Hospital (Local / Halifax)
- Home / DVA / Boarding Home

**File Closed**

- Discharge from Service

**Bereavement Caseload Information**

- New Referrals

## Appendix G: District Health Authority Informants to This Report

Janet Carver
Manager of Palliative Care Services, South Shore Health (DHA 1)

Nancy Castlebury
Manager of Palliative and Supportive Care Services, South West Health (DHA2)

Shelagh Campbell-Palmer
District Palliative Care Manager, Annapolis Valley Health (DHA 3)

Mark Scales
Manager of Palliative Care, Colchester East Hants Palliative Care (DHA 4)

Carolyn Atkinson, and Robin Latta
Palliative Medicine Physician, and Acting Manager, Cumberland Health (DHA 5)

Debbie Williams
Palliative Care Co-ordinator, Pictou County Health Palliative Care Program, (DHA 6)

Lynn MacDonald
Manager Palliative and Supportive Care Services, Guysborough, Antigonish Strait Health Authority (DHA 7)

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