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Context

Nova Scotia had 8029 deaths in 2006, of which, 30% were cancer, 9% chronic ischemic heart disease, 6% stroke, and 5% chronic obstructive pulmonary disease.

The province has nine district health authorities (DHAs), each with its own Palliative Care Program (PCP). Children's palliative care is focused at the IWK Health Centre. Nova Scotia now has a provincial Palliative Care Coordinator.

Consistency in data elements collected by the PCPs is lacking. Introducing a standardized minimum data set (MDS) for all PCPs will enhance palliative and end of life (EOL) care surveillance and research.

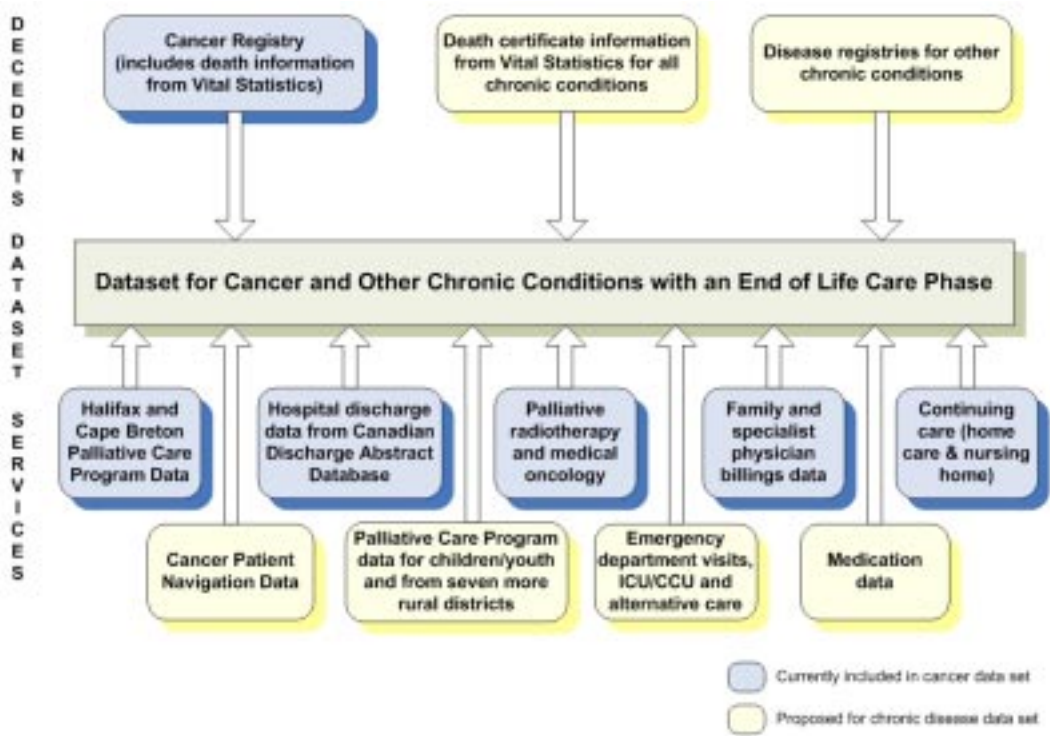
Purpose

Enable discussion to identify the key data elements necessary to monitor and improve service delivery.

Plan development of a MDS for palliative and EOL care funded¹ research.

¹ Canadian Institutes of Health Research (CIHR) Strategic Initiative: Reducing Health Disparities and Promoting Equity for Vulnerable Populations ICE Grant, 2006-11 (App# HOA-80067)

Data Linkages for Retrospective Studies of Equity in Access to Quality Care



Challenges

To make further progress toward the MDS, the following challenges need to be addressed:

- Time, resources, and negotiations are needed to develop province-wide PCP and EOL data.
- Canadian Council on Health Services Accreditation (CCHSA) standards are being introduced for PCPs requiring new data in five areas:
 - Client/family service goals
 - Service availability
 - Continuity of care
 - Symptom management
 - Family/caregiver satisfaction

Definitions

PCP data set: Patient specific data (e.g. demographic, clinical characteristics, and service provision) used to support PCP activities in each DHA.

EOL data set: PCP data linked to Vital Statistics (VS) deaths and other administrative data available in the province of Nova Scotia. EOL data has been used to assess various forms of care provided in the last months of life for persons dying of cancer.

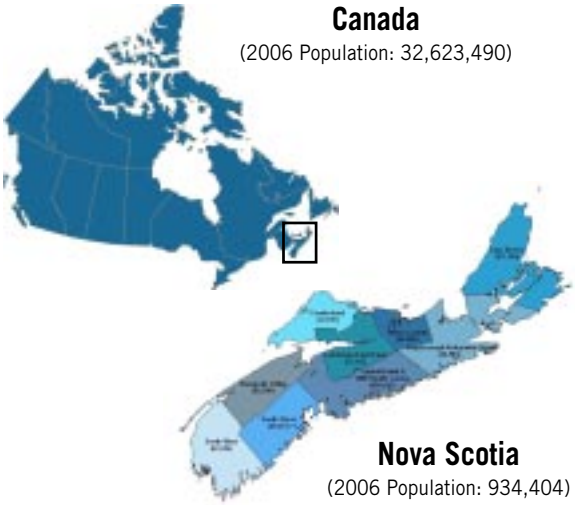
Methods

Compared PCP data for two largely urban DHAs (Capital Health and Cape Breton) which represent 57% of the provincial population.

Completed a survey of PCP data collected in the other seven DHAs.

Examined child and youth EOL data available at the IWK Health Centre.

Used cancer as a model to plan an EOL data set for chronic disease by linking VS and PCP data to other administrative data.



Identifiers for Record Linkage

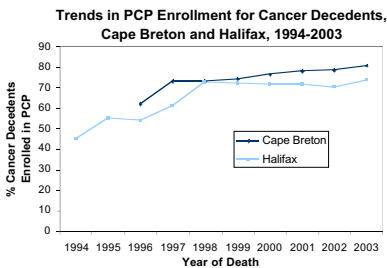
- Provincial health card number
- Nova Scotia Cancer Centre number
- First and last name
- Date of birth

Identifiers used vary depending on agency policies, need for encryption, and their completeness and accuracy.

Some Data Elements Available for Analyses

- Sex, and age at death
- Date of death
- Immediate and underlying causes of death (International Classification of Disease codes)
- Location of death (hospital, nursing home, home)
- Postal code of residence (for creation of community socioeconomic status and cultural predictors)
- PCP referral and assessment dates
- Hospital days, and physician visits

Data Reporting Example



Conclusions

Progress is being made in Nova Scotia on PCP and EOL linked data set development. Some indicators for measuring access to EOL care are available and have been published. Further MDS development is underway to address DHA reporting requirements and to enhance research capacity.

Acknowledgements

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