

# **Toward a Population-based Approach in End-of-life Care Surveillance**

## **Oral Presentation for the CAHSPR 2012 Conference**

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### **Objectives**

This project was funded by the Canadian Partnership Against Cancer to establish a Hospice Palliative End-of-life (HPEOL) Care Surveillance Team Network. Its purpose was to improve the quality/use of existing electronic data sources to better understand terminally ill cancer patients in their final year of life with non-cancer as comparison.

### **Approach**

The HPEOL Network created an early design for a Web-based EOL care surveillance system. Using a 'flagging' process, anonymized datasets on cancer and non-cancer palliative patients and those who died in 2008/09 were extracted from Network members. These included the six BC Health Authorities, Edmonton Palliative Care Program, and Yukon Department of Health. The Australian palliative approach was adapted as the conceptual model according to the datasets available. Common data elements were defined then mapped to local datasets to create a common HPEOL dataset. Information products were created as online reports. Members engaged in knowledge translation (KT) throughout the project.

### **Results**

The outputs included five innovations that could advance EOL care surveillance in Canada. These are: (a) a set of common definitions to describe the palliative population including diagnosis, care/death locations and type of services received; (b) 24 flags in the existing datasets that could identify palliative patients including those unknown to the palliative care programs; (c) a method to extract/map local datasets into the common HPEOL dataset; (d) a set of information products in the form of epidemiologic, service use and quality reports such as admission to different locations in final year before death and their lengths of stay; (e) recommendations to improve the quality/use of existing HPEOL datasets. Independent evaluation showed Network members were highly satisfied with the integrated KT effort and outputs.

### **Conclusion**

The modified Australian model, common definitions/dataset and information products from this project were well received by the HPEOL Network members. There are still major data quality and linkage issues that require further work. The project has recently been extended and may evolve into a pan-Canadian EOL care surveillance reporting system.