

## **Regional Palliative Care Program Newsletter**

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### **The Drive for a National Palliative Care Database.**

The Edmonton Regional Palliative Care Program has an extensive database that has been in evolution for approximately ten years. Originally it was designed for the tertiary palliative care unit at the Edmonton General Hospital, but now has evolved to collect palliative care data on patients seen by the program throughout the city. This includes the tertiary palliative care unit, the palliative care hospice units, and consultations in the acute care setting and the community. Information collected includes a variety of socio-demographic data, as well as the standard assessments used in our region including the Edmonton Symptom Assessment System, the Mini-Mental State Examination, the Edmonton Staging System for Cancer Pain, the Palliative Performance Scale, and the CAGE screening questions for alcohol use. This information has been extremely useful on a day to day basis for clinical care, as well as having applications for teaching, prospective and retrospective research, and administrative planning and reporting to our supervising bureaucracy (1, 2). While we continue to fine tune and improve the quality of the information we collect, we are challenged and assisted by evolving technology and legislation. Our program has been a leader in collecting this clinical information, and now other palliative care programs across the country have developed an increasing interest in this area and we are challenged to consider how our local database might fit into a national palliative care database.

Surveillance has been identified as a priority area by the National Action Committee for Palliative Care (3) and the Cancer Control Strategy for Cancer Control (4). More recently, a surveillance steering committee was established which resulted in a proposal to create a national palliative care database (5). This proposal is based on a conceptual framework called CaPDN (Canadian Palliative Data network). "CaPDN is based on a coordinated data warehouse concept, where participating centres across Canada would share a subset of their palliative data with others on a regular basis via one or more data warehouses. Three levels of data sharing are expected: clinical data from local practices, regional program and service delivery data..." (6) This is not the first attempt to create such a database. In 1997 Health Canada assembled a national care database consisting of data over a three-year time period (1993-97) contributed by six palliative care programs (7).

A national database is needed in response to numerous recommendations to alter organization and financing of palliative care programs plus implementation of changes in clinical practice (8, 9, 10). Surveillance and the construction of a national database could be used by decision makers to assess the performance of these changes. In fact, surveillance is defined as "the tracking and forecasting of any health event or health determinant through the collection of data, and its integration, analysis and interpretation into surveillance products, and the dissemination of those surveillance

products to those who need to know.” (11) Decision makers (or “those who need to know”) include clinicians, program managers, medical directors, regional health authorities and ministries of health.

Canada is not unique in constructing a national palliative care database and is therefore in a position to learn from the experience of others. The United Kingdom (12), Australia (13), Ireland (14) and Finland (15) have varying experience in implementing palliative surveillance systems. There are numerous frameworks developed to improve health system performance in general that can be applied to palliative care.

Although Health Canada has taken the initiative, there is little evidence to suggest that a theoretical framework or process from these other initiatives have been taken into account. Rather, the process consists of constructing a minimum data set based on availability (rather than need) for data. Furthermore, the role of several key organizations is yet to be determined. These include CIHI (Canadian Institute for Health Information), CHPCA (Canadian Hospice Palliative Care Association), and Statistics Canada.

Finally, there are several other practical considerations in constructing a national database. They include quality, confidentiality, definition of palliative care and property rights. In Canada, as elsewhere, data quality issues arise in the lack of manpower and tradition with respect to medical record keeping for services delivered in a community setting. The second issue of confidentiality is a concern in light of increased ethical standards and introduction of health privacy legislation. Thirdly, consensus on the definition of palliative care drives a variety of program designs, and together with the variability of palliative care delivery, makes the comparison and interpretation of data between centers challenging. Finally, who owns the data and how is the data to be used? Can it be used for research for example?

Despite these limitations, the need for a national database is great and many of the leading centers are willing to make the data available. Whether good intentions are sufficient to overcome any limitations remains to be seen. More importantly, will this effort lead to better evidence, better allocation of resources and clinical decisions?

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