

Working Group on Surveillance Terms of Reference

Scope

Issues related to the development of systems for surveillance of end-of-life and palliative care.

Mandate

The Surveillance Working Group will promote, facilitate and coordinate implementation activities, including possibly:

- an inventory and analysis of existing databases that could contribute to a national surveillance initiative;
- the identification of pertinent performance measures/evaluation indicators; an environmental scan to look at current activities and future directions for palliative care and end-of-life care surveillance;
- consideration given to how ethical, spiritual and cultural dimensions of end-of-life care can be included in the paradigm of surveillance;
- based on ongoing surveillance pilot projects and the other above activities, identify a core data set and method/approach to data collection.

Membership

The Working Group will consist of no more than 10 members including 2 co-chairs, to be appointed by Health Canada. The members will represent organizations and associations and will be chosen for their experience and expertise and the resources they can bring to the table. Other expertise may be brought to the table periodically, as needed.

Potential members: Members drawn from the existing surveillance network created by Health Canada; Canadian Institutes of Health Information, Statistics Canada; Regional Health Authorities, various provincial cancer agencies; Canadian Hospice Palliative Care Association, Canadian Society of Palliative Care Physicians, Canadian Bioethics Society, and Canadian Association for Pastoral Practice and Education.

Responsibilities of Members

- \$ Attend all meetings
- \$ Consult with their respective networks
- \$ Bring resources to the table (e.g. expertise, experience, financial as applicable)
- \$ Coordinate efforts among themselves
- \$ Communicate with one another and with their organization(s)
- \$ Establish linkages with broader stakeholder networks
- \$ Initiate activities at the organizational level
- \$ Co-chairs are required to provide a progress report to the Coordinating Group by end of November 2003. This report will include suggestions for future directions for end-of-life care

initiatives in Canada, relative to their theme or issue area.

Budget

Health Canada will support up to two face-to-face Working Group meetings per year, as well as teleconferences as needed. Members' travel and accommodation expenses will be reimbursed according to Treasury Board guidelines. Given the voluntary nature of the involvement in the Working Group, no honoraria will be paid to members.

Timeframe

The Working Group will be put in place until March 31, 2004. The Working Group will assess future direction at that time.