# Surveillance Report and Systems Development Meeting

An Interdisciplinary Capacity Enhancement Project for

The Network for End of Life Studies

January 17, 2007



## Agenda

- Welcome and Introductions
- Overview
  - Purpose of the work today
  - What is surveillance?
- Current Status and Desired Directions
  - Equity measures
  - Vulnerable populations
  - National surveillance
  - CHPCA
  - Accreditation
  - Quality Indicators in Breast Cancer
  - Primary Care
  - Beyond cancer

- Break
- Small groups
- Report back
- Next steps



## **The Driving Demographics**

	2006	2031
Canadian Population	32 Million	40 Million
Per cent Canadian population 65+	13 %	25%
Number of 65+	4 Million	10 Million
Number 65+ dying	160,000	400,000
(approx 70% all deaths)		



## **Context for and Purpose of Today's Meeting**

- ICE Background:
  - ► Special CIHR call for research on vulnerable populations
  - Some definitions
  - ▶ Where we've been
  - ▶ Where we're going



## **ICE-NELS**

- Specific call by CIHR
- Goal is to create research capacity in studying vulnerable populations (ICE)
- Our additional goal is to grow this capacity in end of life care research (NELS)
- Graduate students
- Eight projects
  - Surveillance report development is one
- Knowledge translation goal



## **Some Definitions**

- Vulnerable: At risk because of age, sex, socioeconomic or ethnocultural status (a starting point)
- Health Disparities (inequalities): Variations in health achievements of individuals and groups
- Health Inequity: avoidable and unfair health inequalities
  - Vertical: lack of preferential treatment for those in greater need
  - ► Horizontal: treatment variation for those with equal need



#### **More Definitions**

- Quality of care: The degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge. (IOM 1996)
- Surveillance: The ongoing, systematic collection, analysis, interpretation, and dissemination of data regarding a health-related event for use in public health action to reduce morbidity and mortality and to improve health. (CDC 2001)



## Two Issues of Focus

- Surveillance of end of life care
- As considered in the light of various "vulnerable" populations



## **Indicators and Quality Measurement**

- Health indicators are standardized measures by which to compare health status and health system performance and characteristics among different jurisdictions in Canada. (CIHI)
- Varying conceptual frameworks:
  - ▶ Donabedian: structure, process, outcomes
  - ► Logic Models: inputs, outputs and outcomes
  - Maxwell (and LuAnn Aday et al): effectiveness, efficiency, equity, acceptability, appropriateness, and accessibility



#### **Surveillance**

- Can have multiple purposes
- Measure burden of disease (dying)
- Measure populations at risk
- Measure trends
- Measure structures, processes and outcomes

- Improve quality of care
- Reduce inequalities
- Support decision-making
- Facilitate resource allocation



## To date

- Focus has been on health services
  - Receipt of palliative care, palliative radiation, home visits by family physicians, hospitalizations, emergency dept visits, home care, nursing homes
- And "some" outcomes
  - ▶ Location of death, time spent at home
- And predictors of these by certain characteristics
  - ► Age, sex, geography, tumor type, socioeconomic status, etc as measures of inequality



#### Desire to move on

- Broaden health service use descriptors
- Add health outcomes (e.g. symptoms, satisfaction)
- Broaden definitions of "vulnerable" populations
- Move to inequity
- Beyond cancer
- Beyond adults



#### Presenters' task

## Using a particular theme area

- Consider what they'd like to have in surveillance capability in 2011
- Consider intermediate goals
- Consider what we could do now
- Consider what a sustainable surveillance report would require



## Presenters' Topics: Current Activities for Inclusion and Discussion

- Equity measures
- Vulnerable populations
- National surveillance
- CHPCA
- Accreditation
- Quality Indicators in Breast Cancer
- Primary Care
- Beyond cancer

