Need for a comprehensive model of palliative support and end of life care in Nova Scotia

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Provincial Cancer Network Meeting

Concurrent Session:

Exploring a Model of Palliative Support for Persons with Advanced Cancer

April 20, 2012

NELS ICE | Network for End of Life Studies
Interdisciplinary Capacity Enhancement

Outline

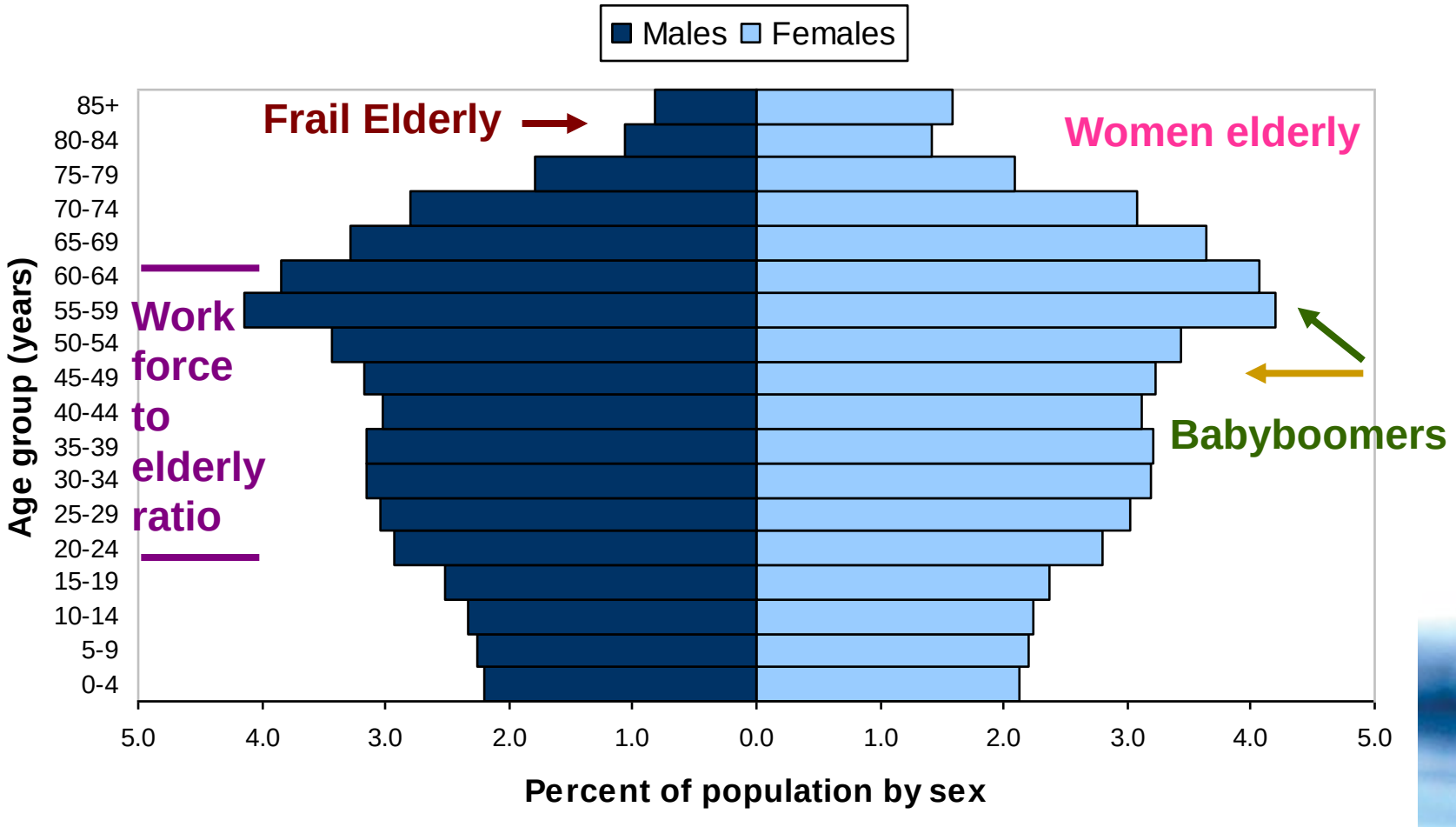
- Demographics and risk of death
- Health services in an historical context
- Conceptualizations of palliative and end of life care
- Context of NELS research knowledge exchange
- Insights into situation for persons living with cancer in Nova Scotia
- Purposes of today's concurrent session

Impact of aging population, increasing and inevitable risk of death with age, and resource implications

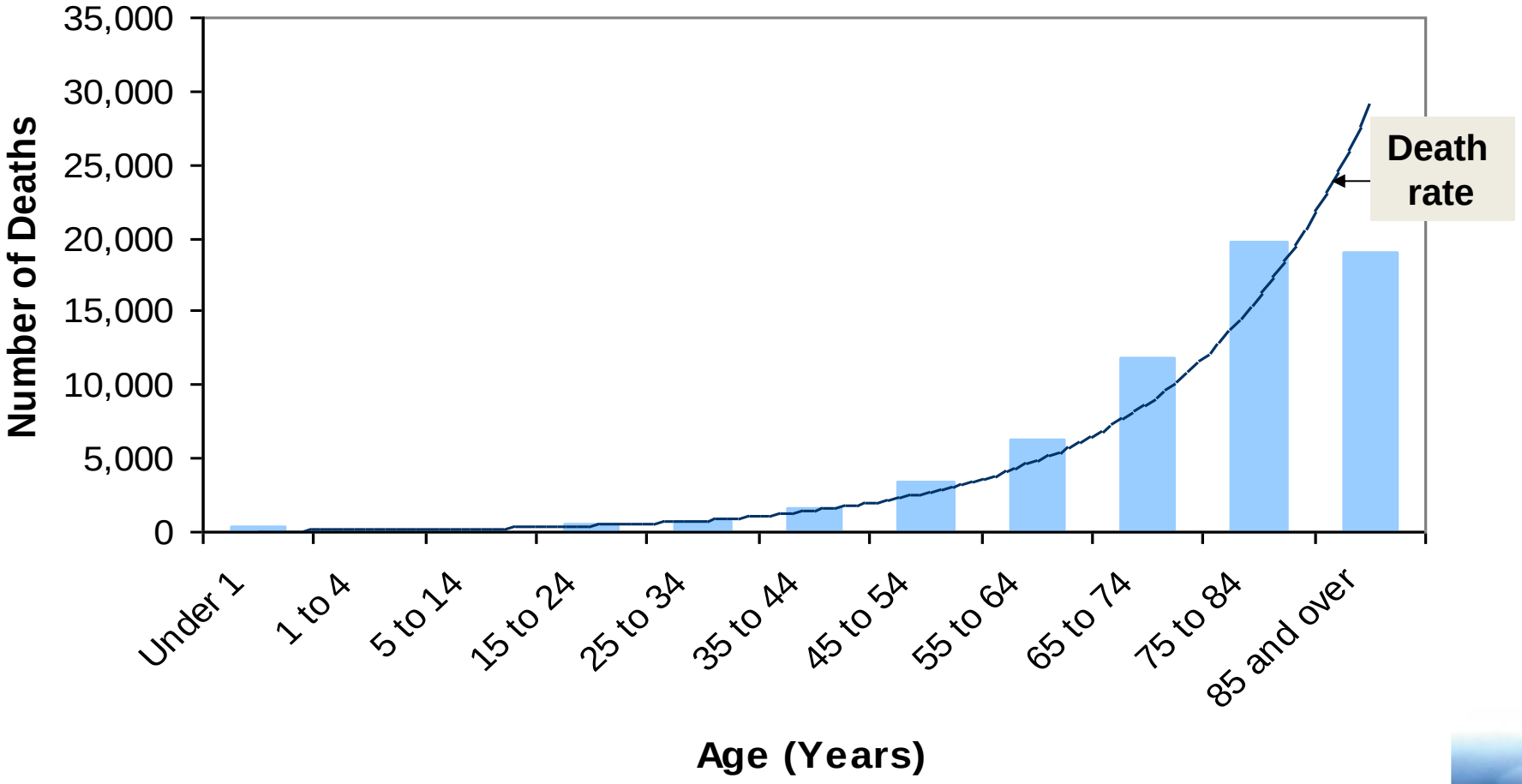
Aging of the Population

Population pyramid, by five year age categories, Nova Scotia, 2001

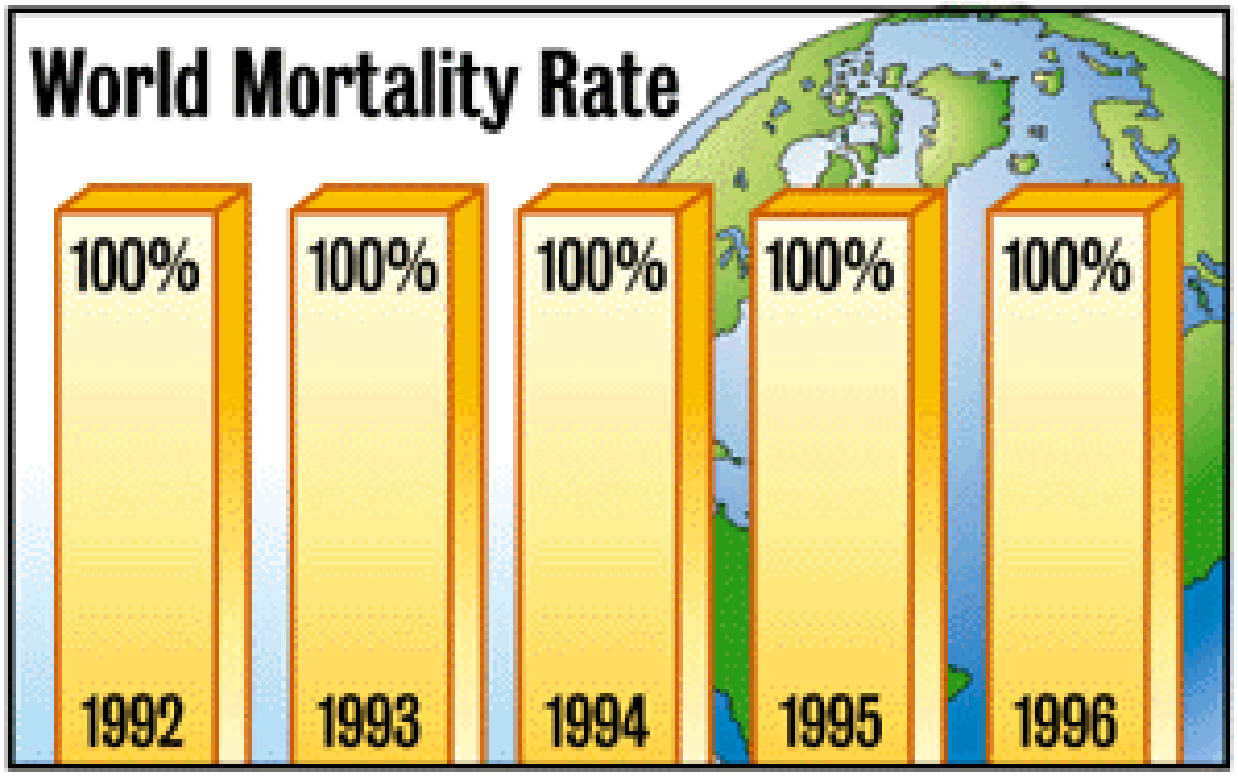
Population pyramid, by five year age categories, Nova Scotia, 2020



Nova Scotia Deaths by Age, 1998 - 2005



What is the likelihood that we will die?

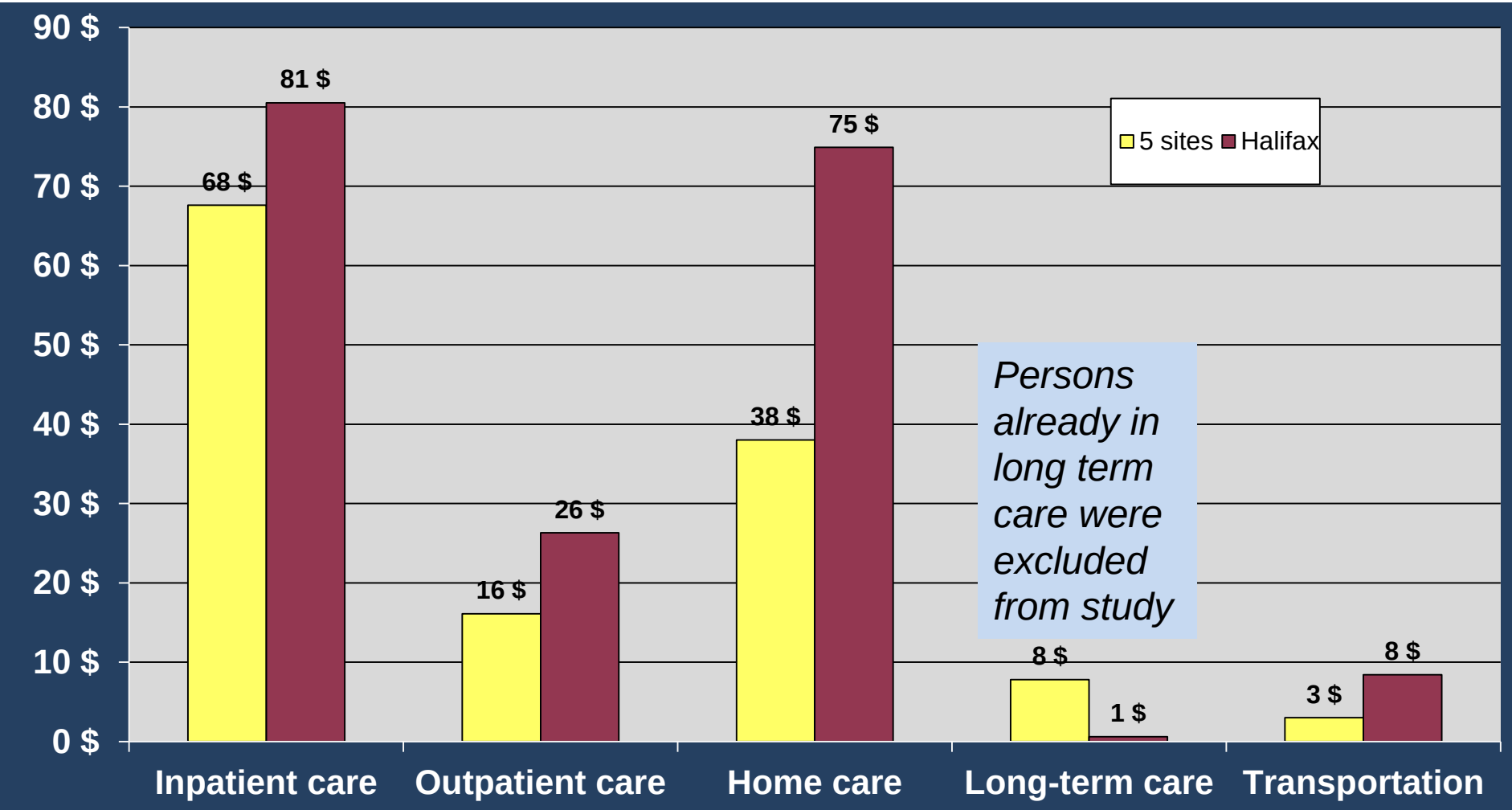


Avoidance of discussion of death and dying – someone else's issue.

Consider the language we use: "if" we die versus "when" we die.

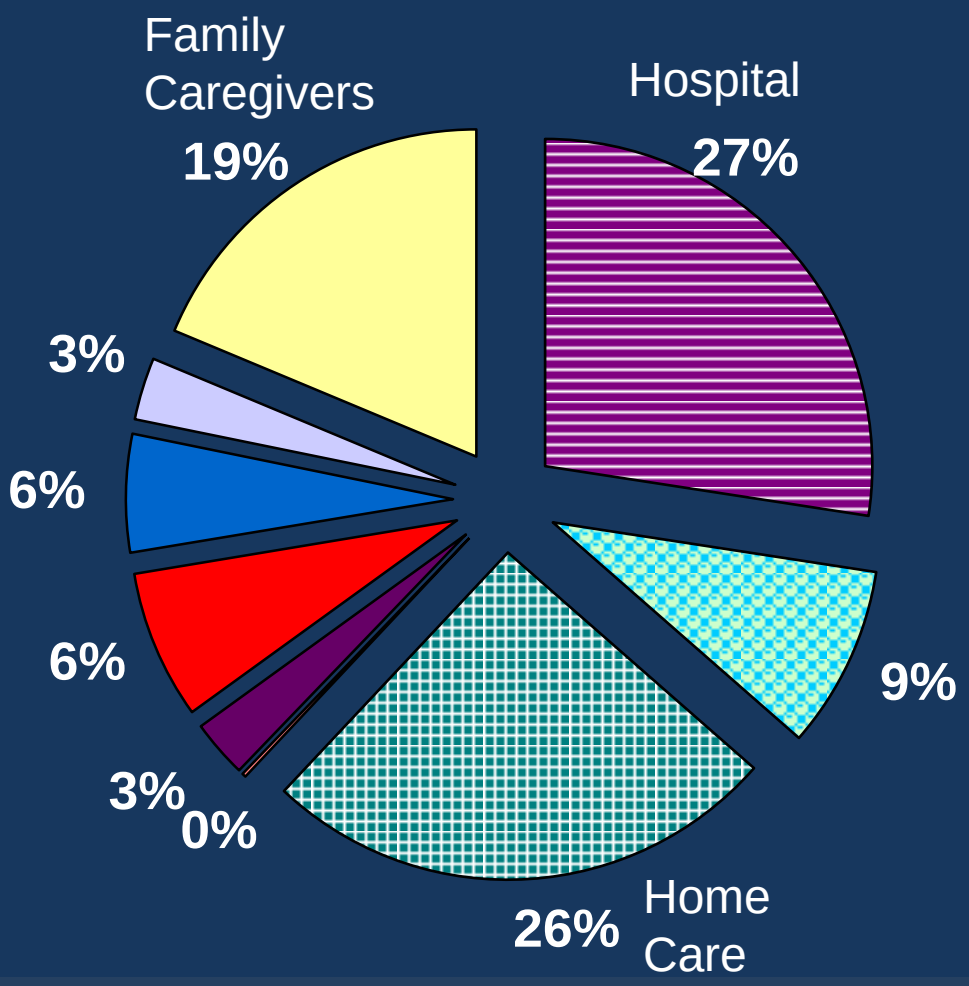
Need public health and societal shift in thinking which encompasses new information technology, transformation in primary and community health, in context of comprehensive collaborative chronic disease management

Mean daily costs per palliative care patient



Preliminary findings from 2009 presentation by Serge Dumont. Findings now published as: Dumont S, Jacobs P, Fassbender K et al. (2009) Costs associated with resource utilization during the palliative phase of care: A Canadian perspective. Palliative Medicine 23(8):708–717

Cost distribution for palliative care patients



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Health services context

Brief Historical Context - Canada

Health is a **provincial** not a federal responsibility: BNA Act

Post WW II – in 1950's built hospitals

1960's – Canada-wide **hospital insurance**

1970's – Canada-wide **physician insurance added**

Led to Canada Health Act; Recent Health Accord discussions

Concurrently, palliative medicine began. Dr Balfour Mont in Montreal after studying hospice care with Dame Cicely Sanders in UK. In Canada became physician and hospital based where costs of services were publicly funded. For decades, palliative care had cancer focus and urban-based champions.

Out-of-hospital , community-based health care is underdeveloped in Canada

Ranking countries by quality of end of life care. (2010, July 14). *The Economist*. Retrieved from http://www.economist.com/node/16585127?story_id=16585127&fsrc=rss Lien Foundation.

Palliative care problems are known

Since mid 1990's, Sharon Carstairs and other Canadian reports show:

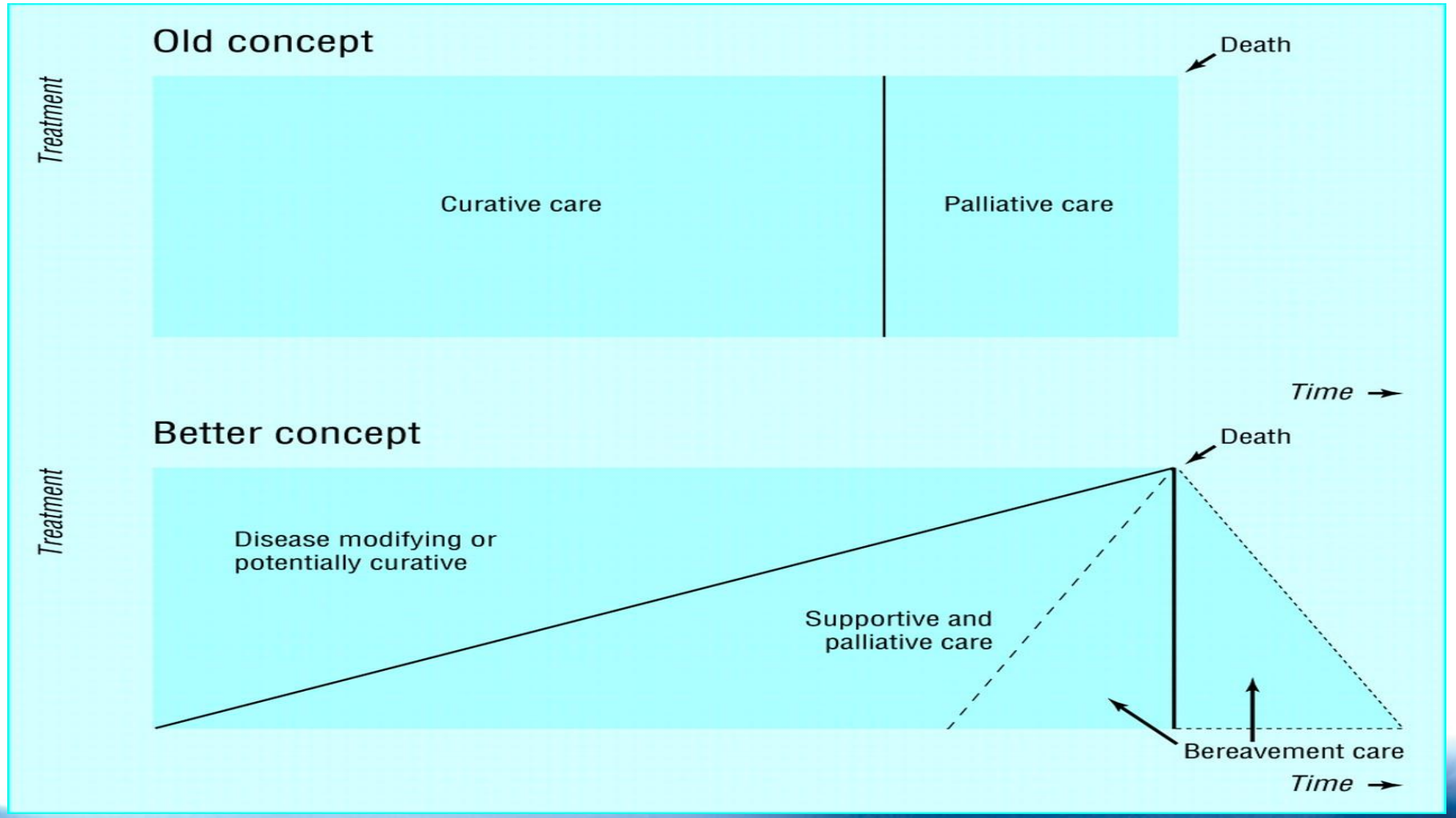
- societal and professional avoidance of death and dying
- inadequate access to care
- underdeveloped palliative care
- lack and challenges in communication
- poor **continuity and coordination of care across providers and in transitions in care location**
- lack of central **leadership and vision**; improved by local champions
- care and planning of **care is often in disease 'silos' but people at end of life usually have more than one condition**
- quality of care and need for care and accreditation standards
- limited research and surveillance data

Definitions and conceptualizations of palliative and end of life care

Palliative “Care” versus “Approach”

End of life care is all health care in the last weeks, months (or years) of life

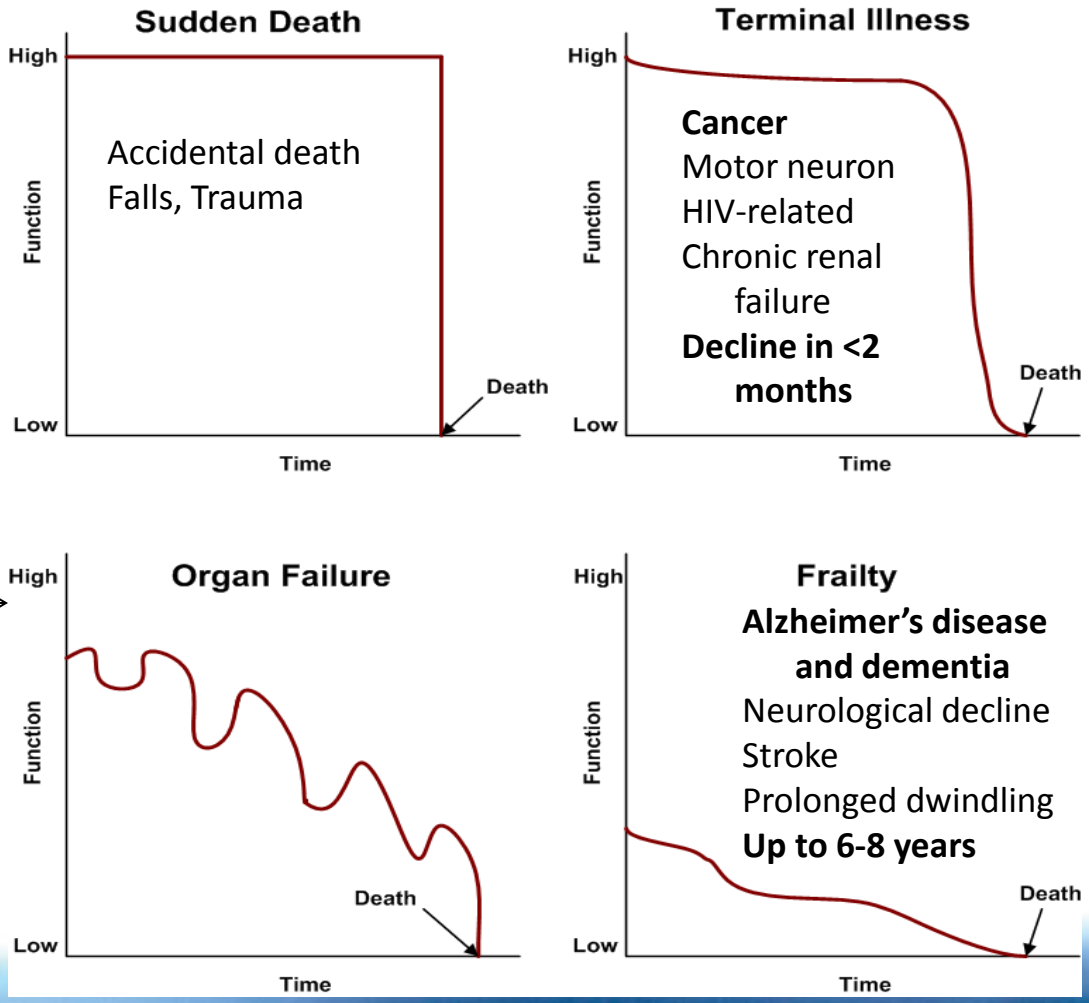
Palliative Care



Reference: Murray, S. A et al. **BMJ** 2005;330:1007-1011

End of Life Trajectories

Lunney JR, Lynn J, Foley DJ, Lipson S, Guralnik JM. Patterns of functional decline at end of life. *JAMA.* **2003**; 289:2387-2392.

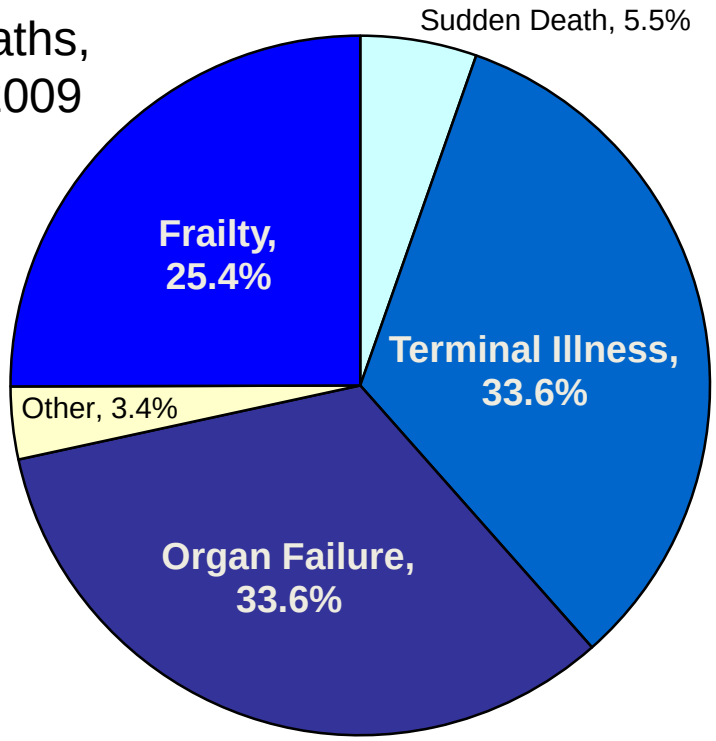


Trajectories Distribution

95% of people die of a life threatening disease with end of life stage

They access many services: nursing home, home care, specialty chronic disease care, diagnostic testing, primary care, inpatient hospital, emergency department, palliative care, …

Nova Scotia deaths, all ages, 1995-2009



Population priorities in context of U.S. Institute of Medicine's quality goals

Divides population into eight groups: 1) in good health, 2) maternal/child, 3) with an acute illness, 4) stable chronic conditions 5) serious but stable disability, 6) **failing health near death**, 7) **advanced organ system failure**, 8) **long-term frailty with failing health**.

Definitions of optimal health and priorities for services.

Framework to plan resources, care arrangements, and service delivery.

Joanne Lynn, BM Straube, KM Bell, SF Jencks, RT Kambic (2007) Using population segmentation to provide better health care for all: The "**Bridges to Health**" model. *The Millbank Quarterly, 85*(2), 185-208

Gold Standards Framework in UK

International best practice standard

Covers all places of care

Continuing to evolve

http://www.goldstandardsframework.org.uk/

Key issues: **When is the beginning of end of life time period? And, how to transition into end of life care**

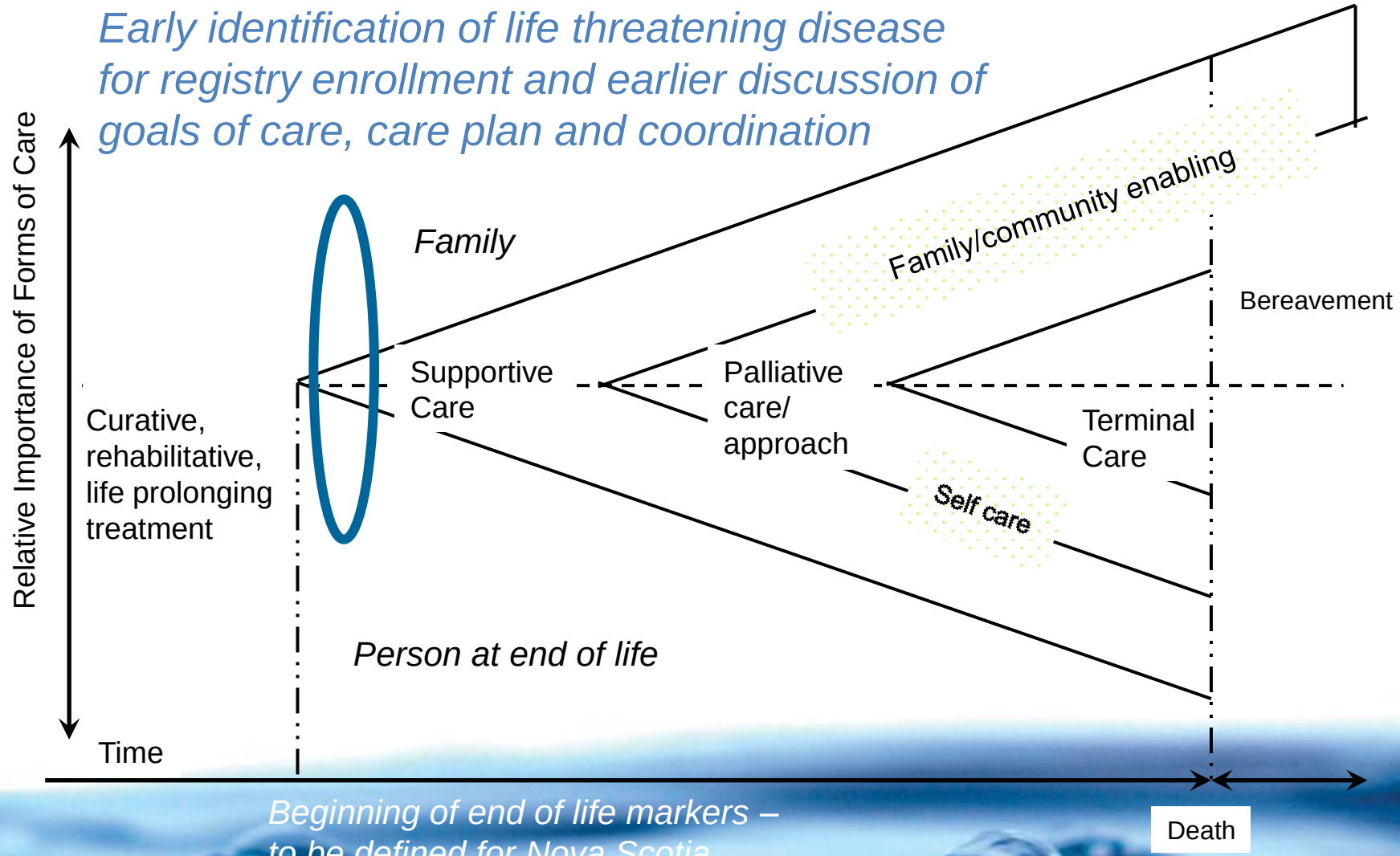
Primary care is a focus for training and audit

Registry of persons at end of life is a key component

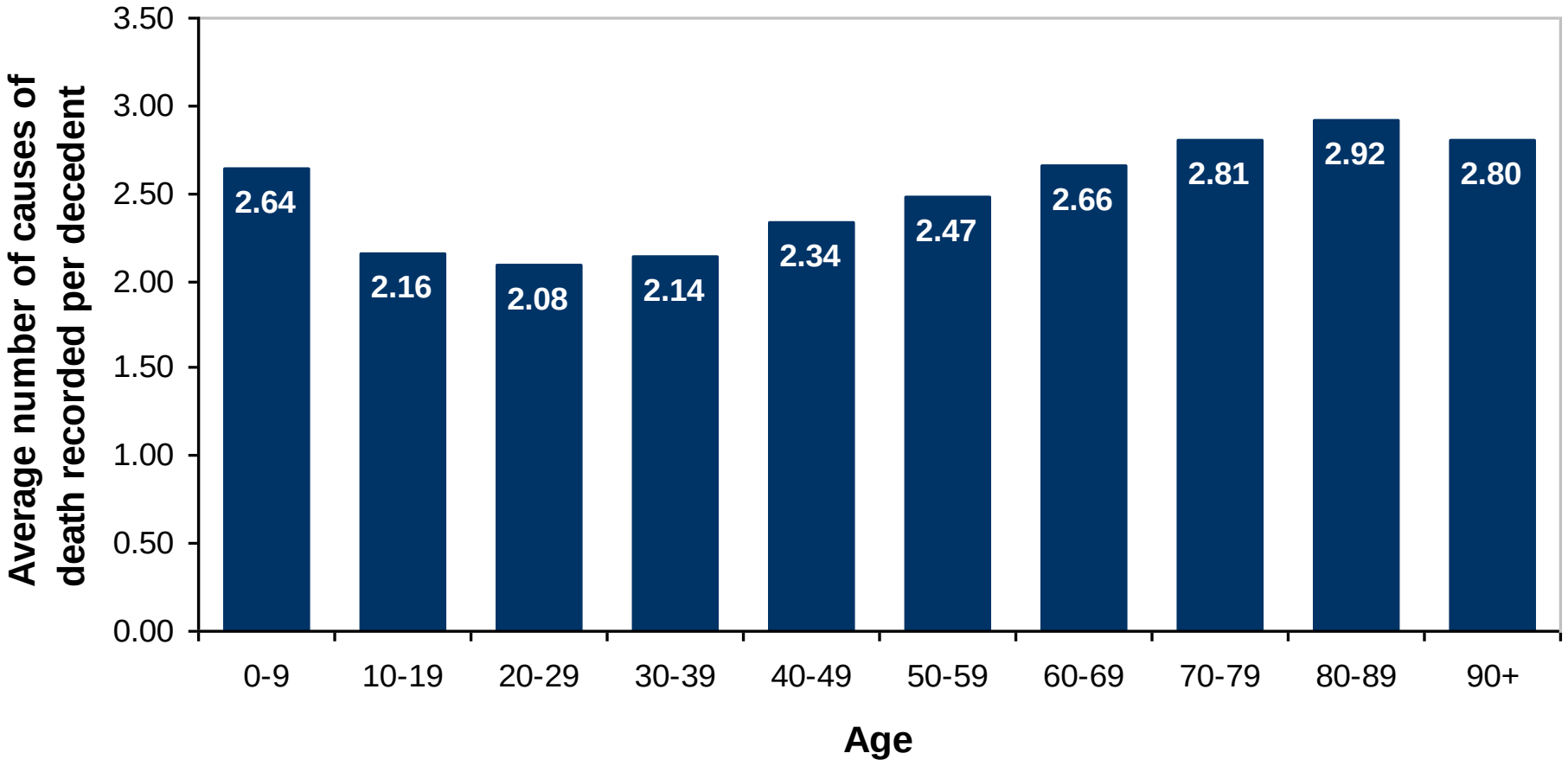
http://www.goldstandardsframework.org.uk/Resources/Gold%20Standards%20Framework/PDF%20Documents/QIP%20Flyer%20Oct10%20v%2023.pdf

Creation of an end of life care registry

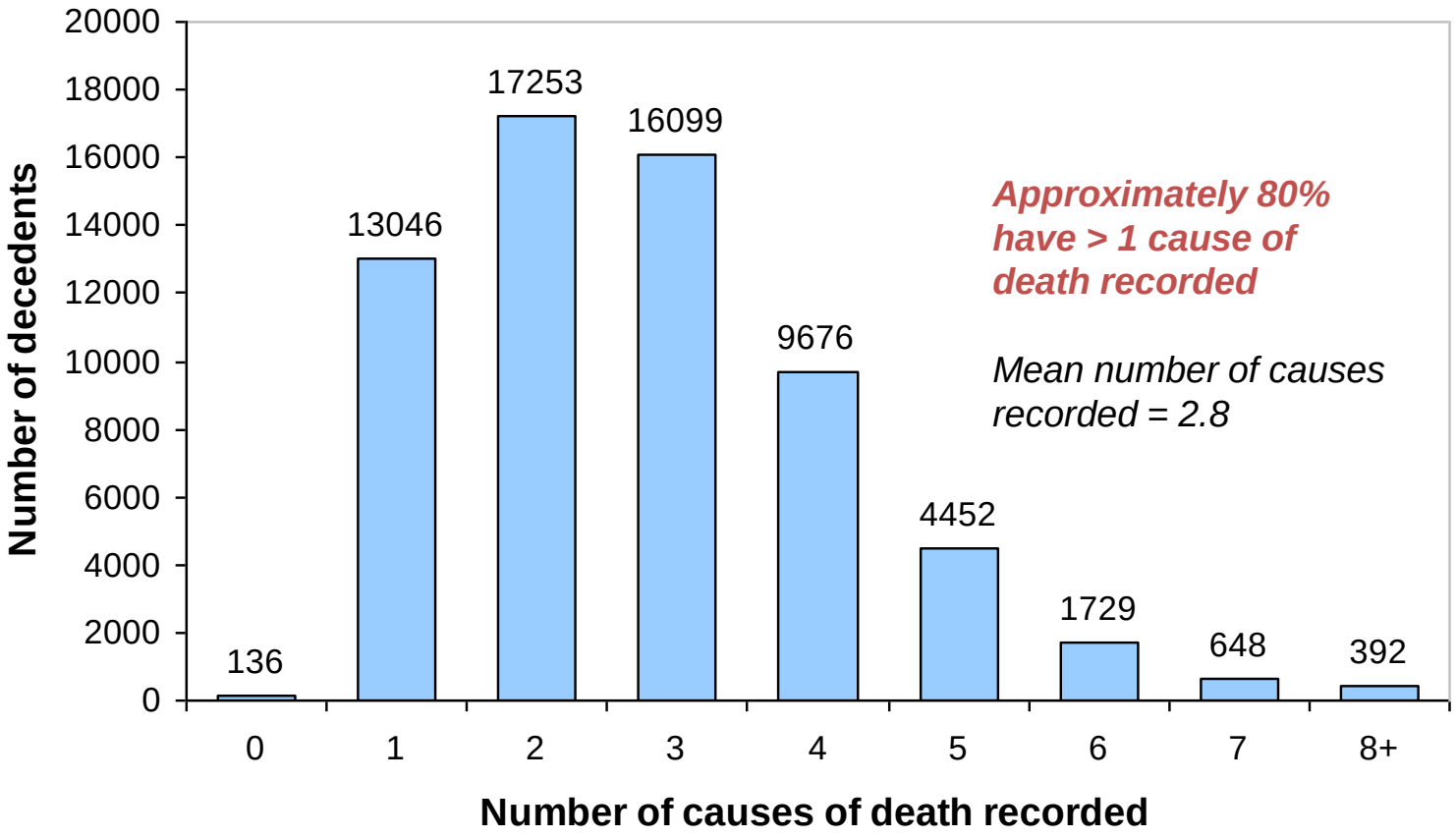
Early identification of life threatening disease for registry enrollment and earlier discussion of goals of care, care plan and coordination



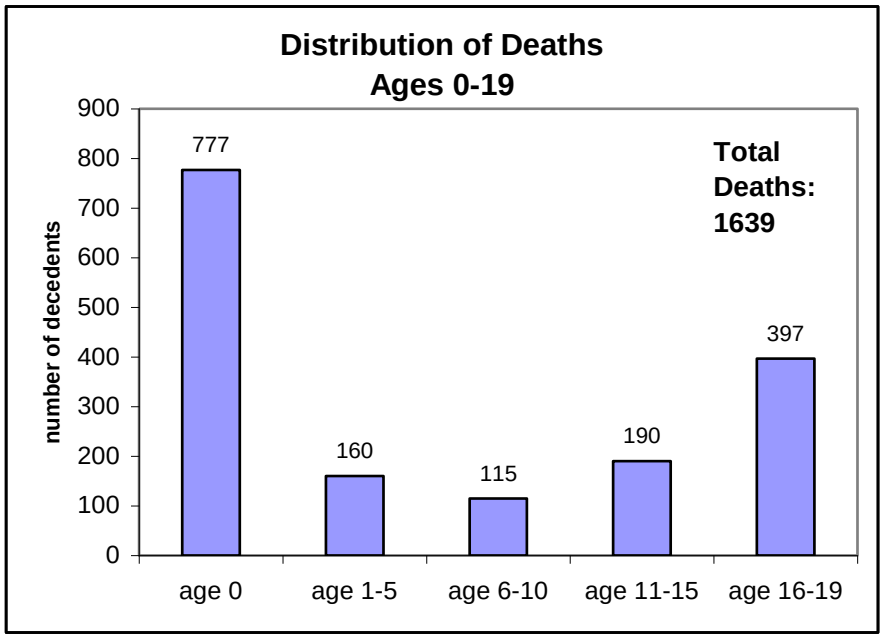
Average number of causes of death, per decedent by age, Nova Scotia, 1998-2005

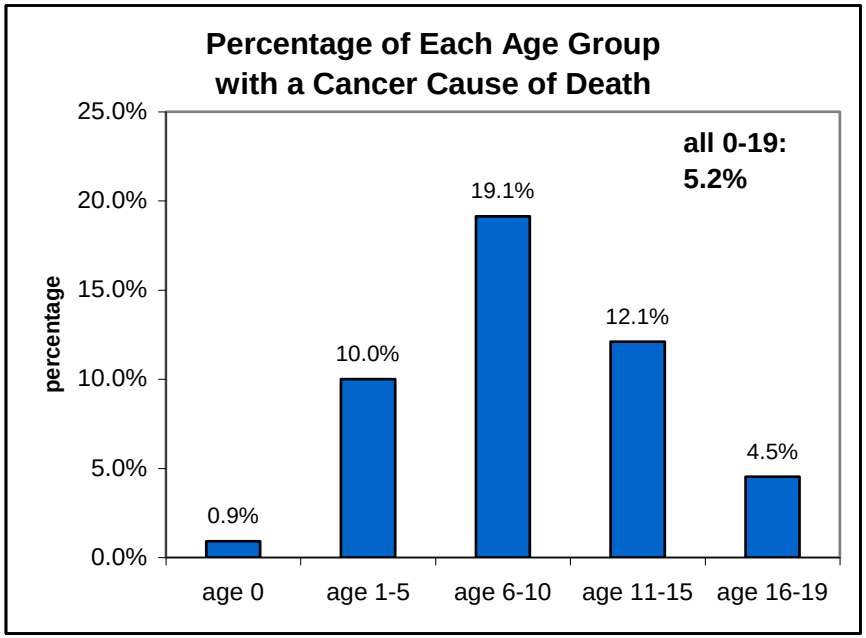


Distribution of number of causes of death, Nova Scotia, 1998-2005



Children and youth who died in Nova Scotia, 1995-2009



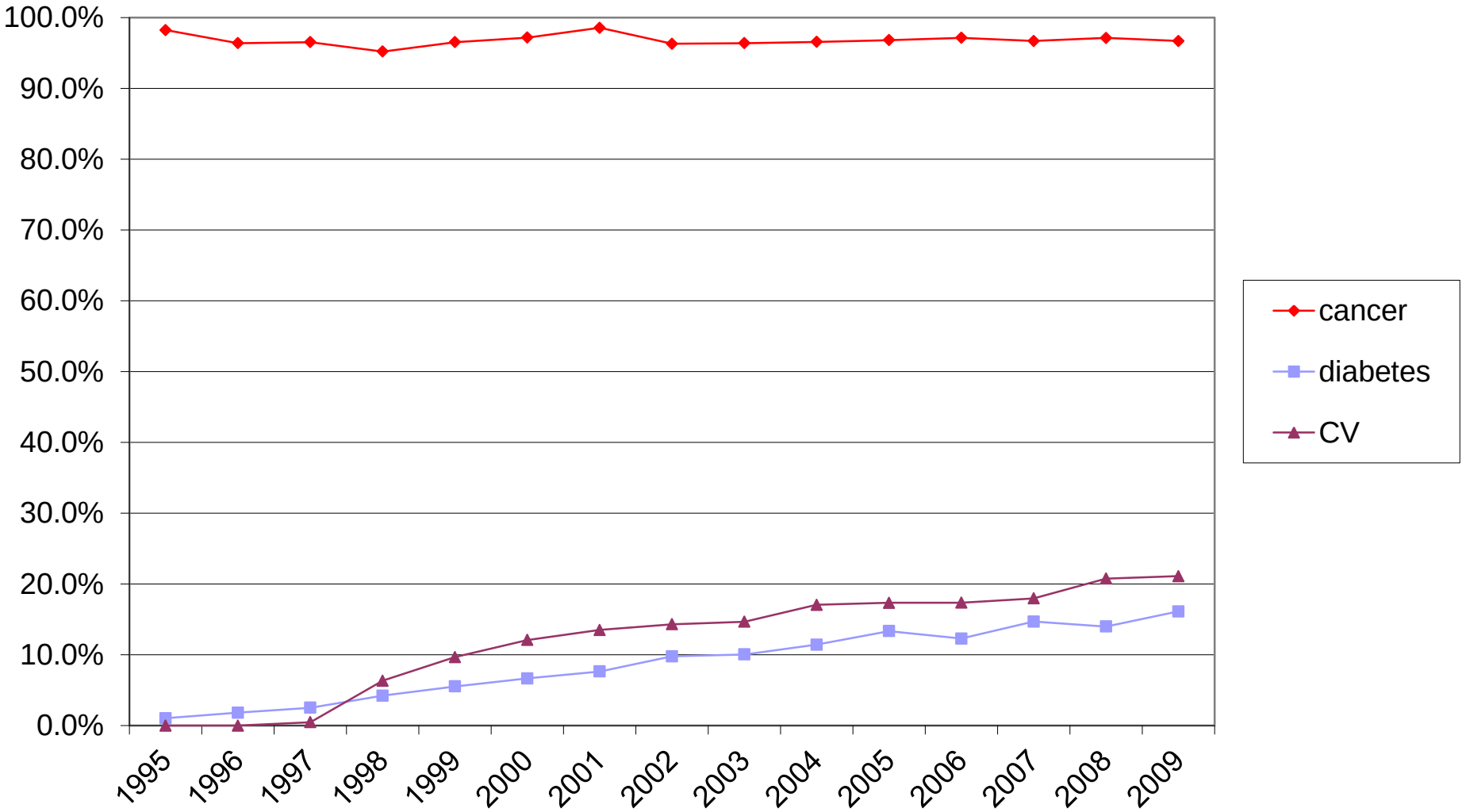


Nova Scotia Hospice Palliative Care Association meeting, Halifax, May 10-12, 2012 **Dr Alix Carter and Rebecca Earle** *"Breaking Down Silos: Building Better Advance Directives"*

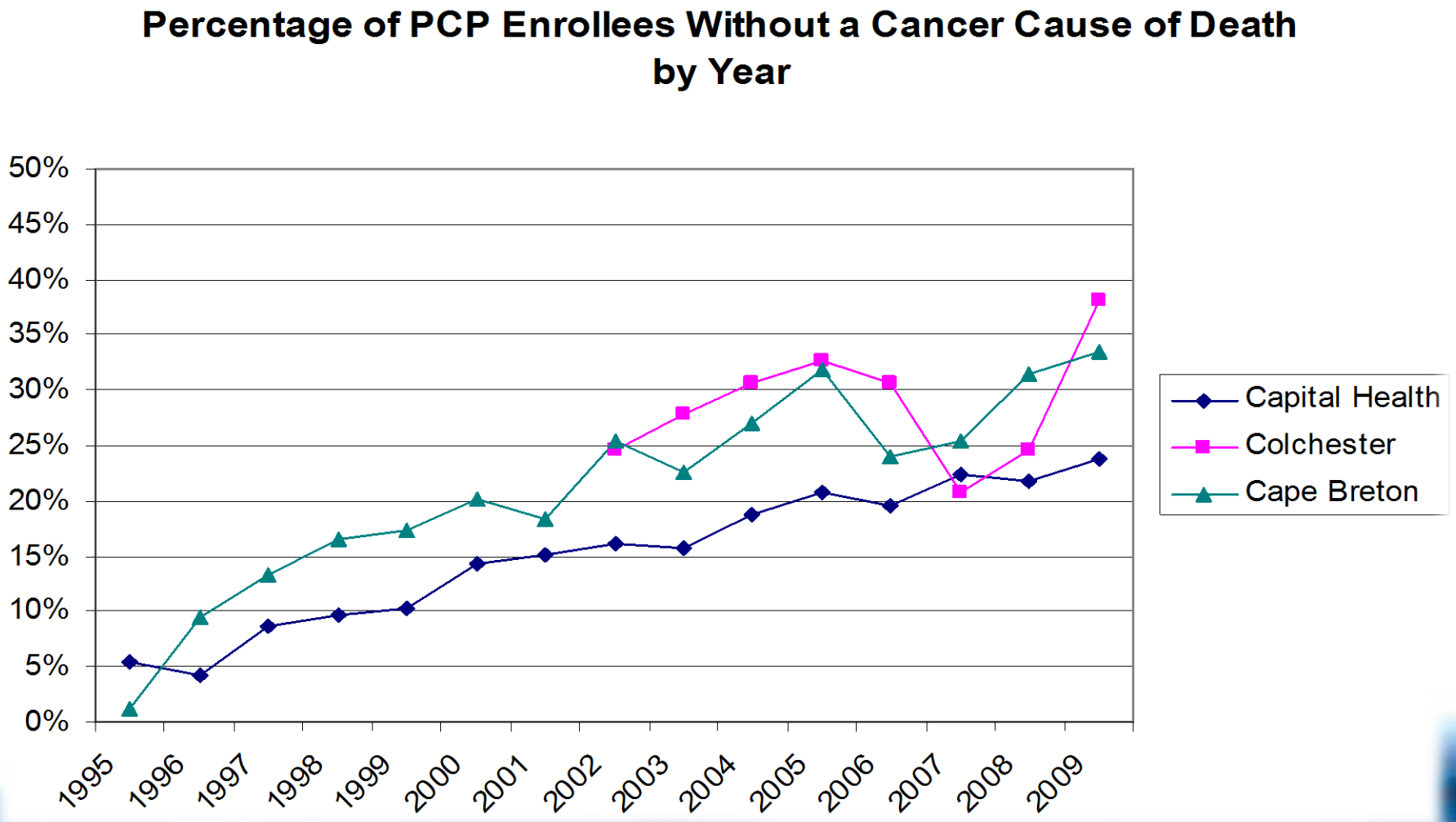
Non-cancer causes of death for Cancer decedents, Nova Scotia, 1998-2005

Selected non-cancer causes of death	Percentage of persons dying of cancer who have this additional disease as a cause of their death
Cardiovascular including CHF and IHD	11.6%
COPD	7.9%
Diabetes	6.0%
Renal	4.6%
Dementia	3.4%

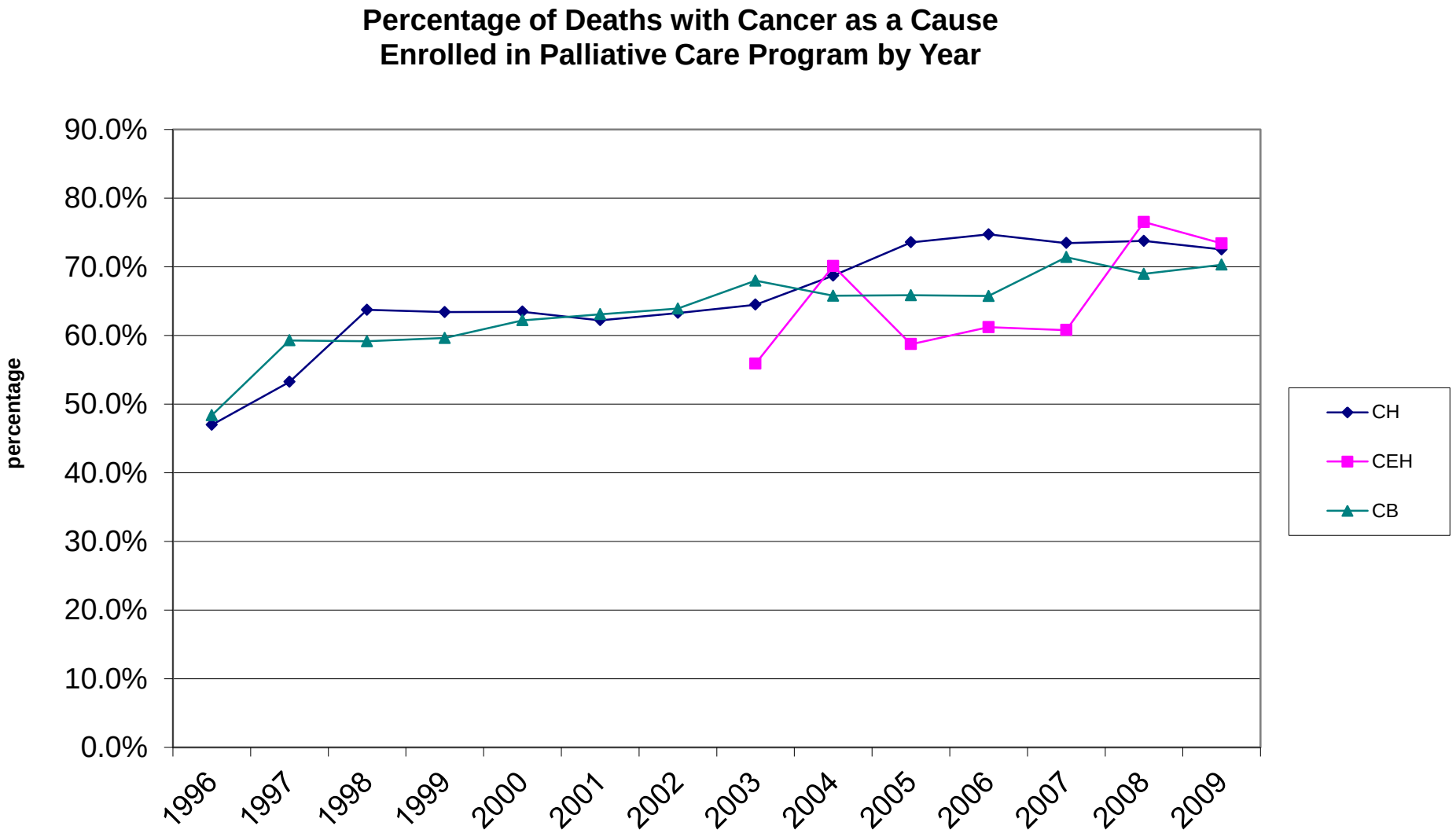
Percentage of Nova Scotia Cancer decedents in provincial chronic disease registries



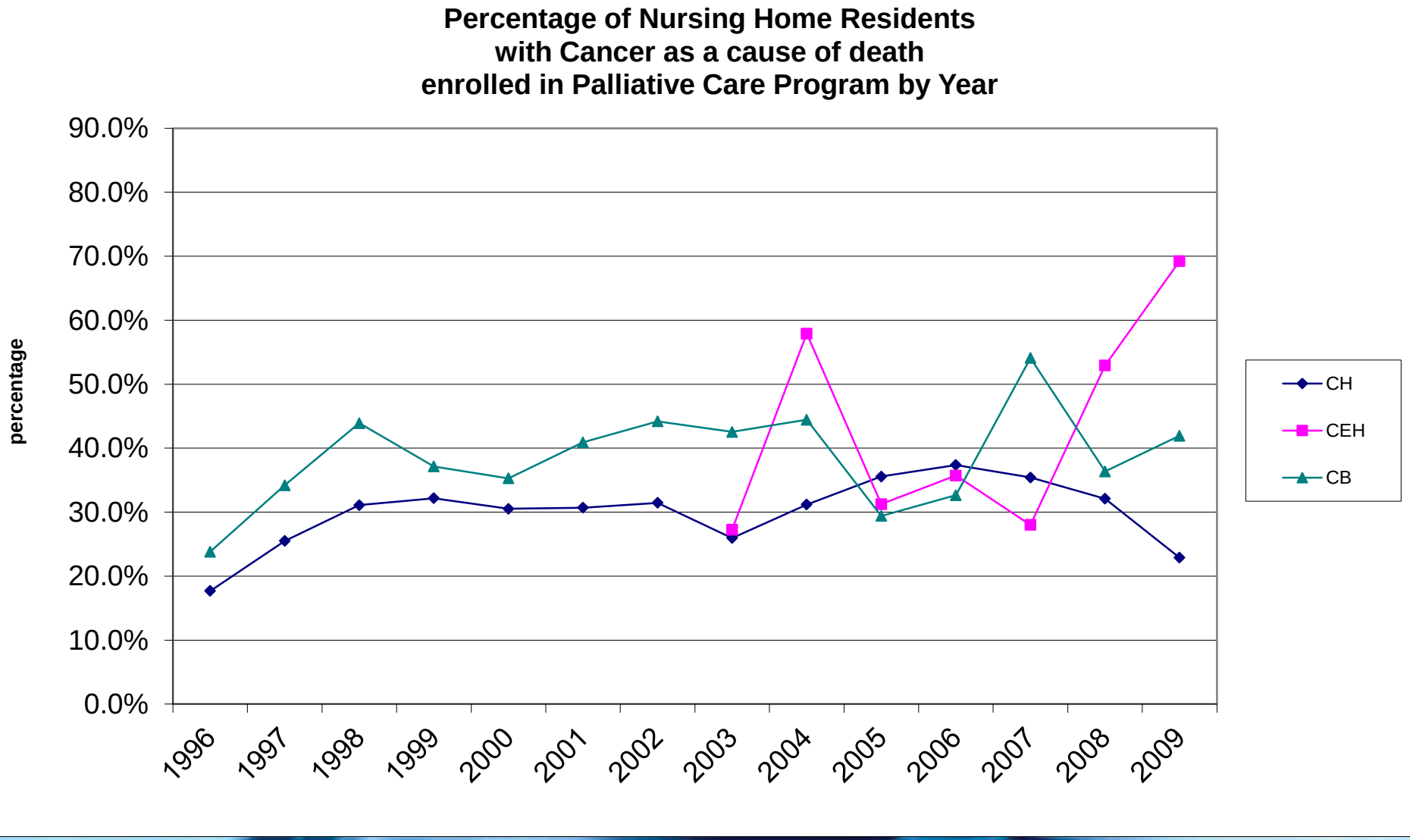
Palliative Care is seeing an increase in number of persons who do not have cancer



Percentage of Cancer decedents seen by Palliative Care Program in Nova Scotia



Nursing Home residents dying of cancer seen by a Palliative Care Program



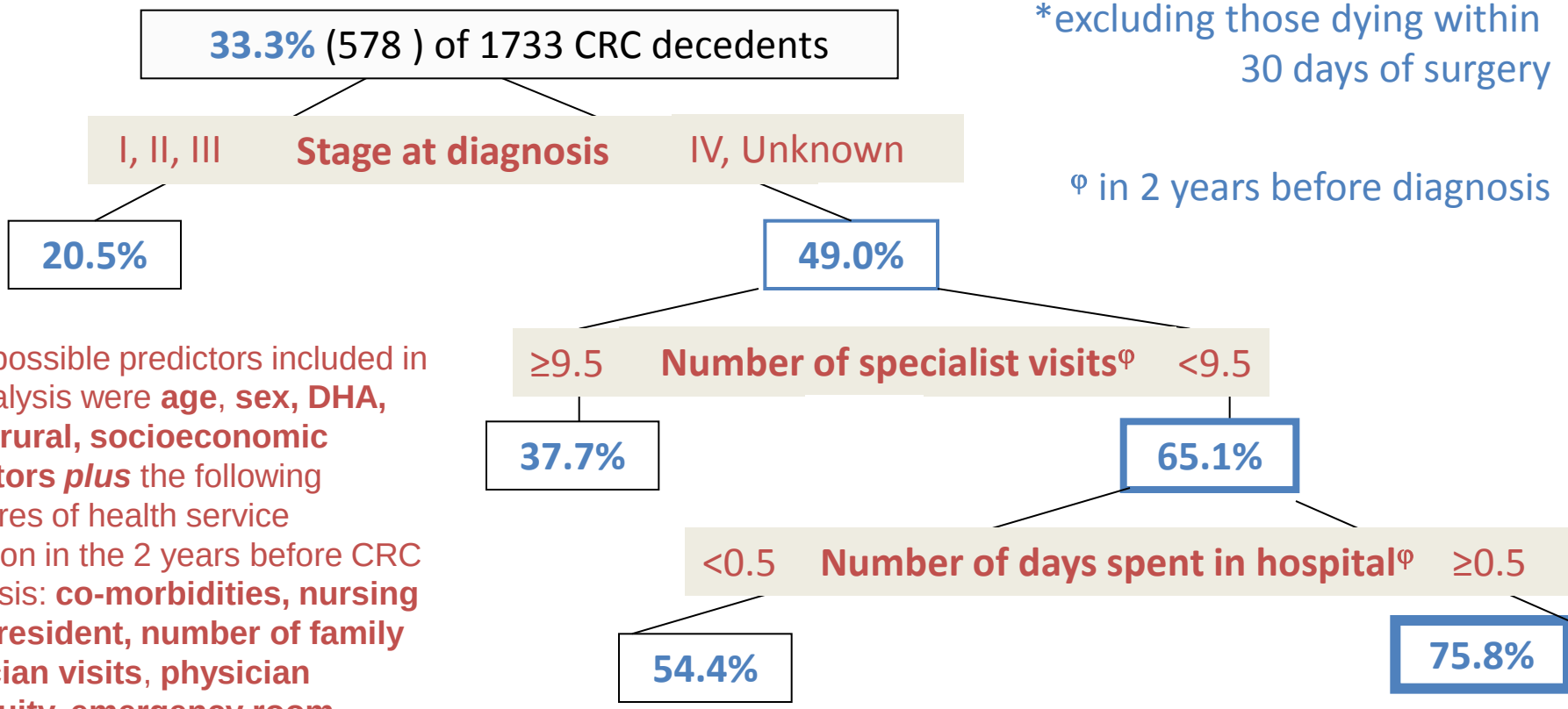
Time from Palliative Care enrollment to death for Cancer decedents, NS, 1996-2009

Enrollment days before death	Palliative Care Program		
	Capital Health	Colchester East Hants	Cape Breton
≤7 days	13.2%	15.0%	20.4%
≤14 days	21.7%	23.3%	28.8%

Percentage who died within 6 months of cancer diagnosis among adults diagnosed with colorectal cancer (CRC) from 2001-2005 who died* between 2001 and March 2008

*excluding those dying within 30 days of surgery

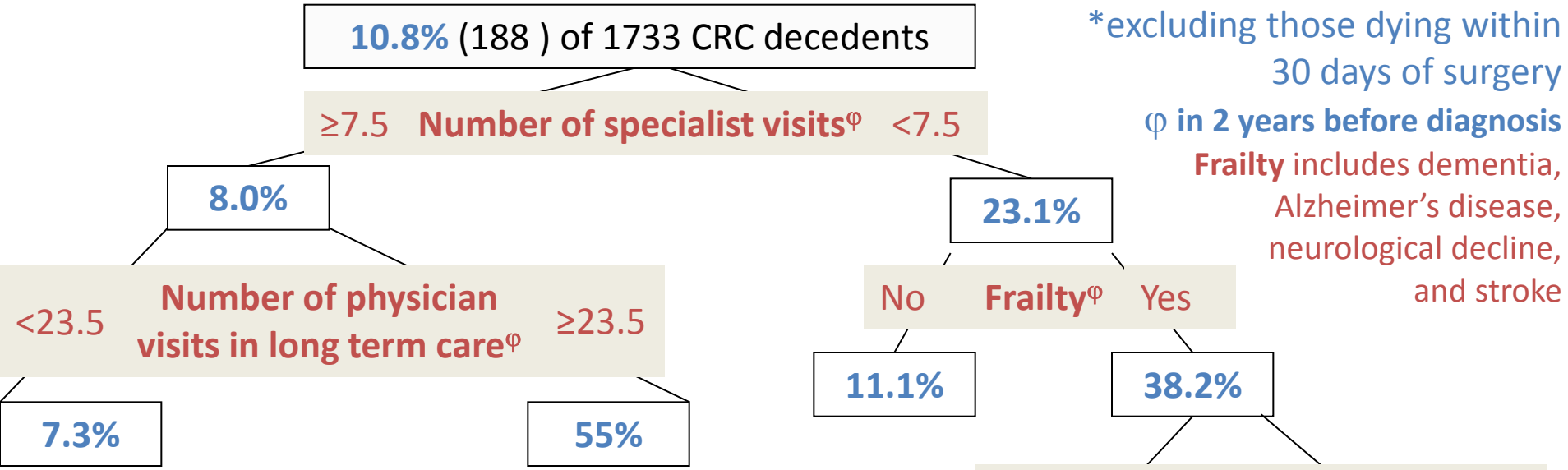
φ in 2 years before diagnosis



Other possible predictors included in the analysis were **age**, **sex, DHA, urban/rural, socioeconomic indicators *plus*** the following measures of health service utilization in the 2 years before CRC diagnosis: **co-morbidities, nursing home resident, number of family physician visits**, **physician continuity, emergency room visits, number of hospital admissions**

Among those diagnosed with stage IV or unknown stage CRC with <9.5 specialist visits and ≥0.5 day in hospital in 2 years before CRC diagnosis, 75.8% died within 6 months of diagnosis

Percentage who died within 4 weeks of cancer diagnosis among adults diagnosed with colorectal cancer (CRC) from 2001-2005 who died* between 2001 and March 2008



*excluding those dying within 30 days of surgery

φ **in 2 years before diagnosis**

Frailty includes dementia, Alzheimer's disease, neurological decline, and stroke

Among those who had ≥7.5 specialist visits and ≥23.5 physician visits in a long term care facility in 2 years prior to diagnosis, 55% died within 4 weeks of CRC diagnosis

Among those who had <7.5 specialist visits, were frail, and <3.5 family physician visits in 2 years prior to diagnosis, 61.4% died within 4 weeks of CRC diagnosis

ABC-SC

Advanced Breast Cancer - Supportive Care

NELS Network for End of Life Studies
ICE Interdisciplinary Capacity Enhancement

Principal Applicants:

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Robin Urquhart, PhD Candidate

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Collaborator:

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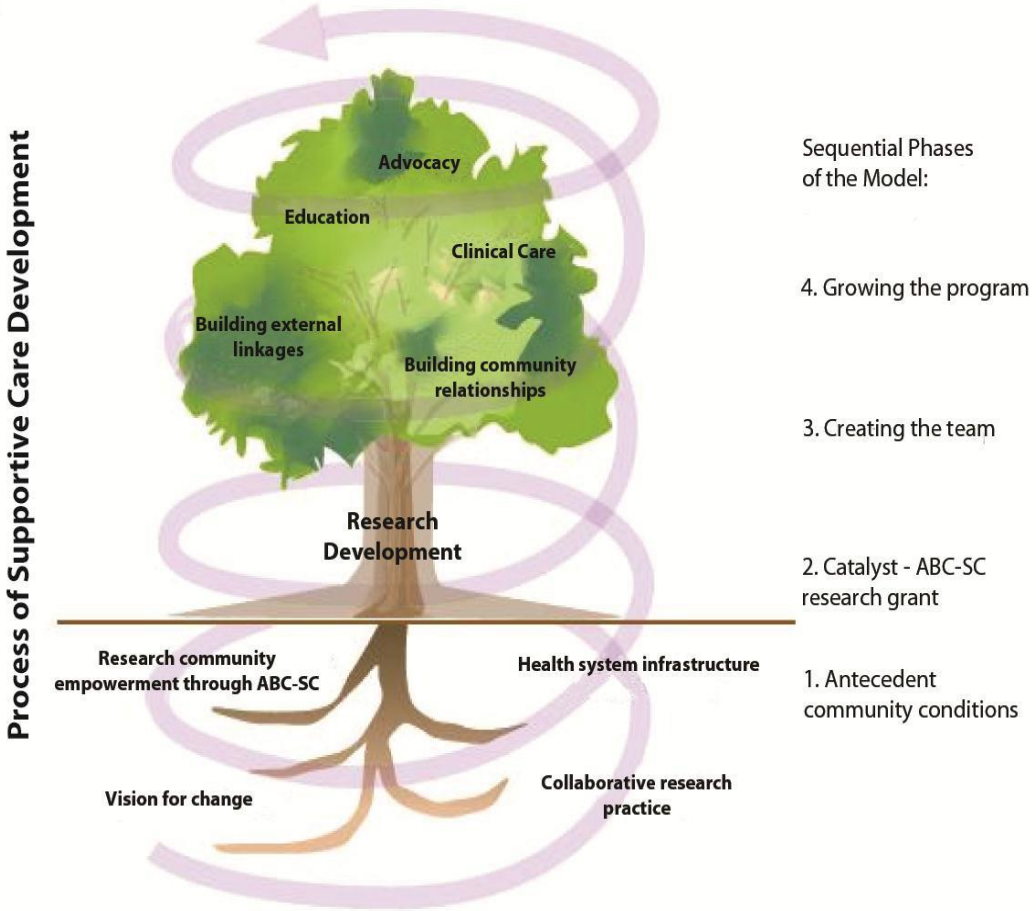
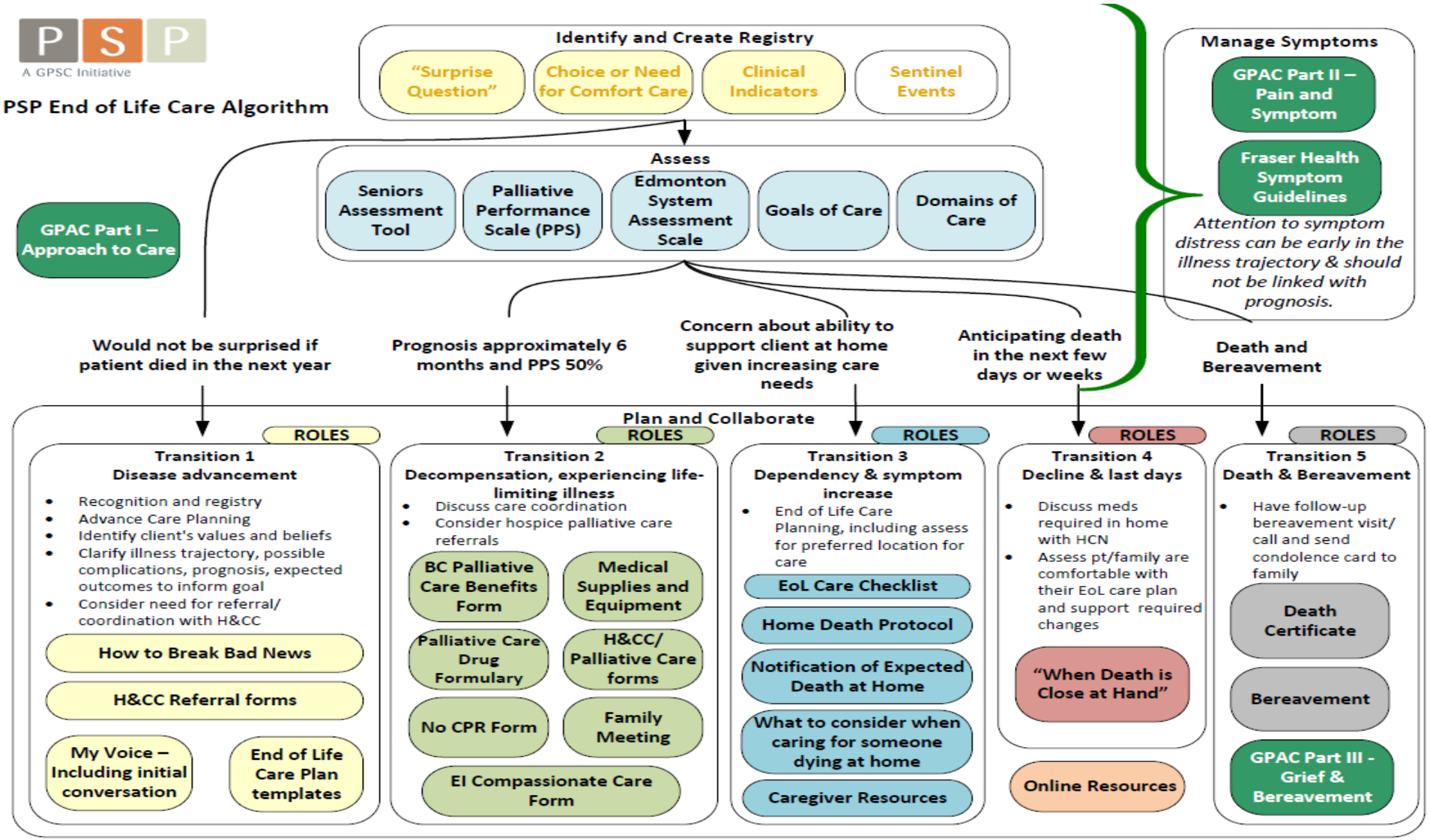


Palliative Support Program (PSP) for British Columbia



Purposes of this concurrent session

1. Follow from February 29, 2012 NELS workshop/ report recommendation to explore adapting British Columbia's Palliative Support Program (PSP) for Nova Scotia (NS)

2. Obtain input from cancer network stakeholders on
   i) relevance of adapting BC PSP for Nova Scotia,
   ii) aspects already in place in Nova Scotia,
   iii) aspects of care/measures that are missing,
   iv) barriers to implementation,
   v) supports needed to reduce barriers & ease implementation

Questions? Comments?

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