

a place of mind



Universal Access to Palliative Care; How is BC doing?

Presented by the UBC Division of Palliative Care
and the Hsu-Hsieh Foundation

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THE VANCOUVER SUN

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Objectives:

to answer these questions;

- ▶ What do British Columbians die from?
 - ▶ Where do British Columbians die?
 - ▶ How does 21st Century Palliative Care help people to live (and die) with dignity?
 - ▶ How many British Columbians have access to Palliative Care?
 - ▶ How is BC doing in comparison with other places?
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Life Expectancy in BC

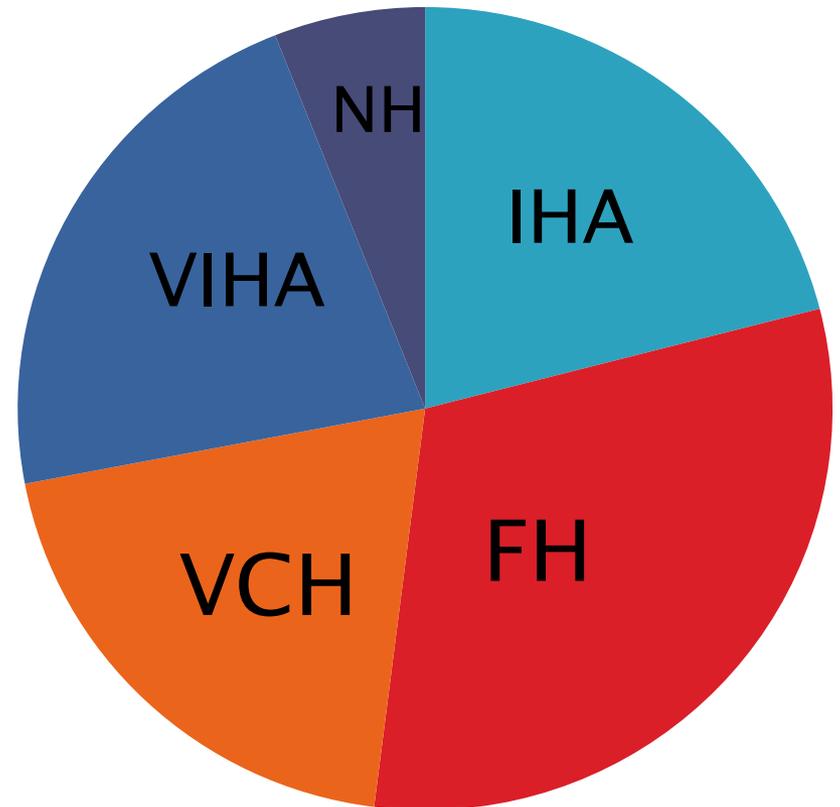
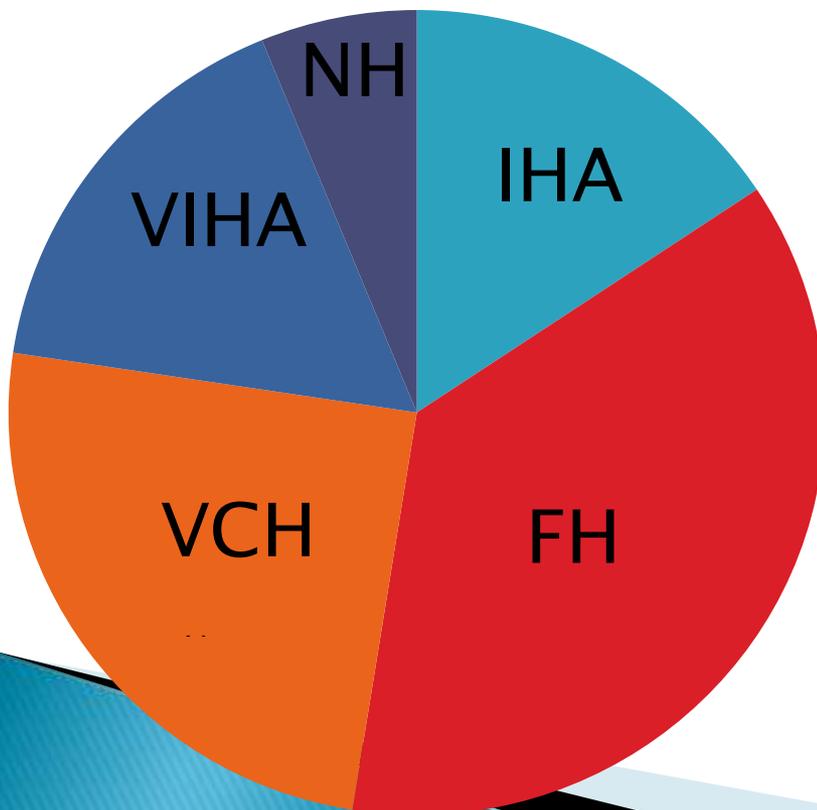
- ▶ British Columbians have the longest life expectancy of all Canadians
[2011 B.C. Vital Statistics Agency]
- ▶ From 2007–2011, life expectancy on the West Coast was 82 years, up from 81.7 for 2006–2010
- ▶ Merle Barwis, the oldest person in Canada died recently at 113 years old, and lived on Vancouver Island



Natural Deaths in BC 2013–14

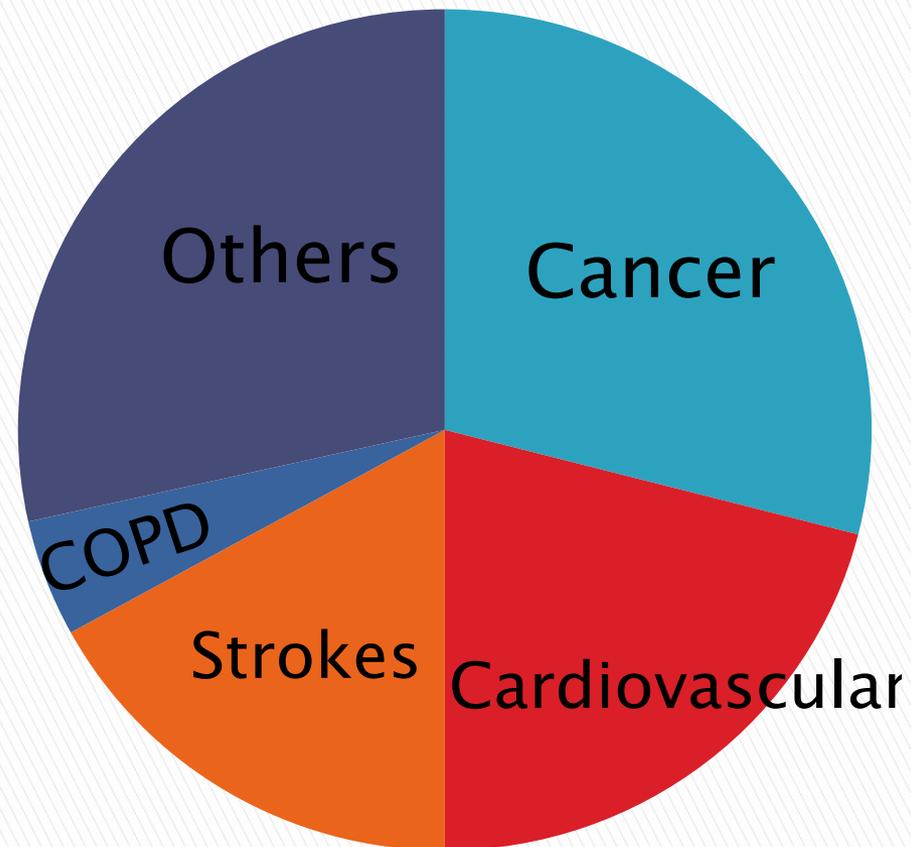
Population: 4,581,978

Deaths: 31,318
(0.68%)



Causes of Death (2010)

- ▶ **Cancer 29%**
[same % for all health regions]
- ▶ **Cardiovascular 21%**
- ▶ **Cerebrovascular 17%**
- ▶ **Chronic lung disease (COPD) 4.5%**
- ▶ Accidents 3.7%
- ▶ Dementia 3.6%
- ▶ Pneumonia/influenza 3.4%
- ▶ Diabetes 3.3%
- ▶ Digestive 2.6%
- ▶ Neurological 2.1%
- ▶ Urological 2.4%
- ▶ Suicide 1.4%



Where do People Die in BC? (2013–14 data)

Cancer patients more likely to die in hospice than non-cancer patients

All Natural Deaths

- ▶ Home 5,062 (16.2%)
- ▶ **Res. Inst. 7,739 (24.7%)**
- ▶ Hospice 4,124 (13.2%)
- ▶ Hospital 13,674 (43.7%)

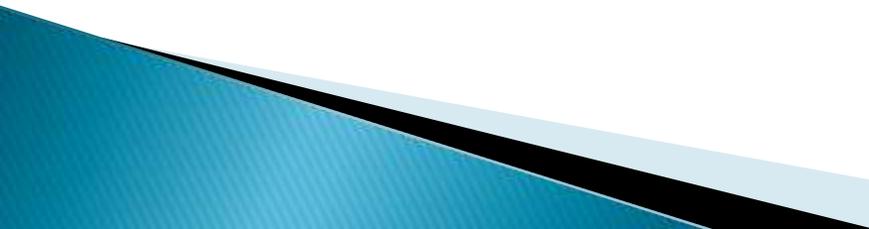
Cancer Deaths

- ▶ Home 1,516 (15.8%)
- ▶ Res.Inst. 905 (9.4%)
- ▶ **Hospice 3,200 (33.4%)**
- ▶ Hospital 3,894 (40.6%)

Only 2 in 5 deaths occur in hospital.
Where you live when sick may be more important.

WHO Definition of Palliative Care

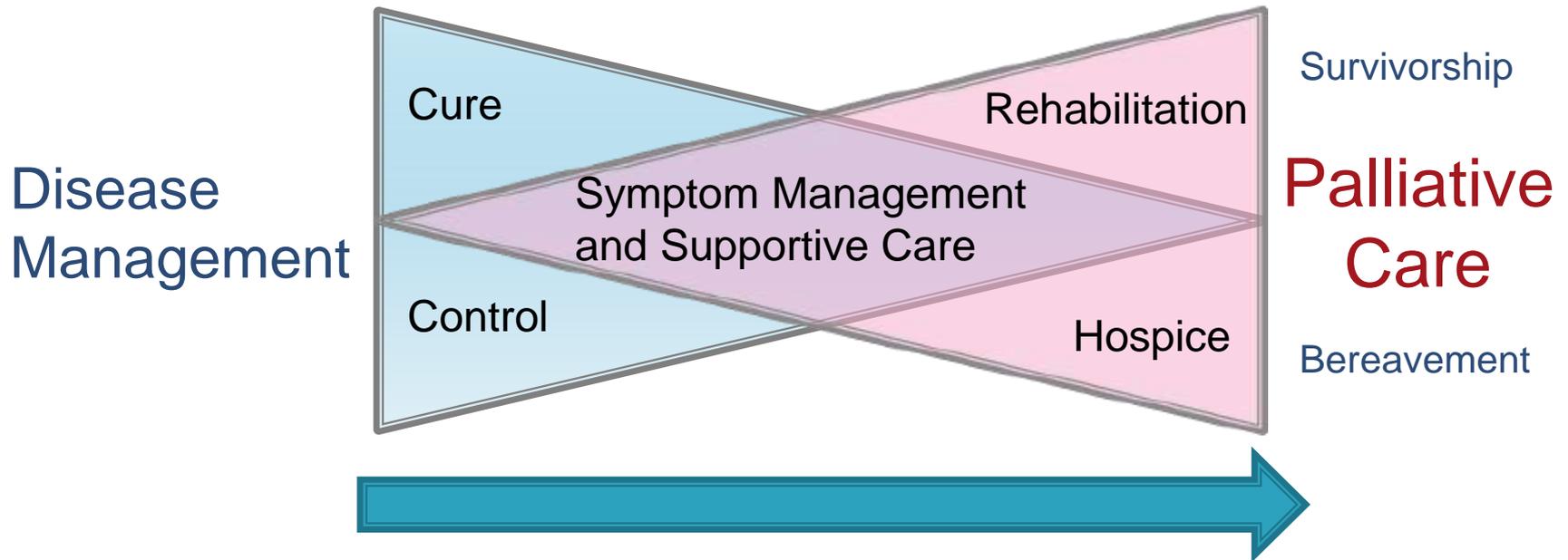
“Palliative care is an *approach* that improves the *quality of life* of *patients and their families* facing the problem associated with *life-threatening* illness, through the *prevention and relief* of suffering by means of *early identification* and impeccable assessment and treatment of pain and other problems, *physical, psychosocial and spiritual.*”



Centre to Advance Palliative Care (USA) Definition

- ▶ Palliative Care is specialized medical care for people with serious illnesses.
- ▶ This type of care is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness –whatever the diagnosis.
- ▶ The goal is to improve quality of life for both the patient and the family.
- ▶ Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors (*including oncologists, family doctors and other specialists*) to provide an extra layer of support.
- ▶ Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.

The Bowtie Model of 21st Century *Palliative Approach to Care*





It's not either-or, rather both....

Not Age-Specific



Or Location-Specific



Integration of Palliative Care with Disease Management

There is now clear evidence that Specialist Palliative Care referral....

- ✓ Improves quality of life of patients
- ✓ Improves quality of life of care-givers
- ✓ Reduces severity of grief
- ✓ Increases the chance of death occurring in the chosen location (home or hospice vs hospital)
and.....

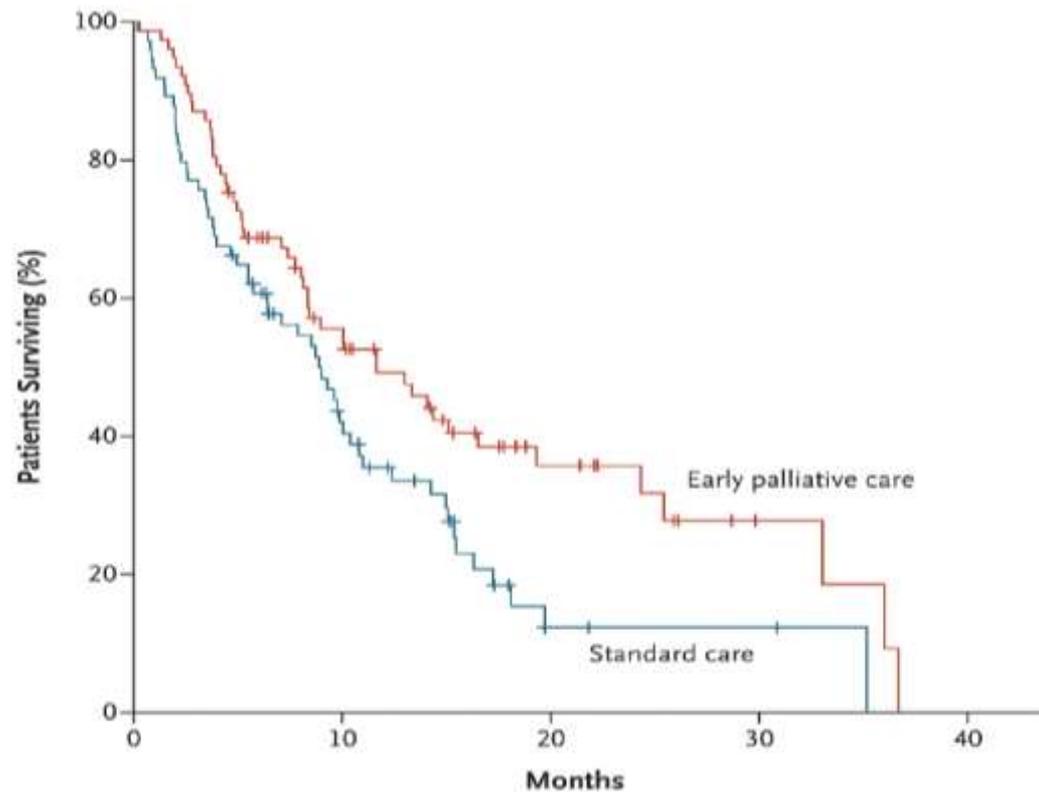
Integration of Palliative Care with Disease Management

- ▶ Reduces risk of having interventions that don't work, e.g.
 - Intensive care admissions where no advance care planning has been done
 - chemotherapy within last days/weeks of life
- ▶ Reduces costs to health care system by reducing
 - Emergency room admissions
 - Hospital stays
 - Doctor visits

Palliative Care May Extend Life

Randomized Controlled Trial of mandatory US Cancer centre PSMPC clinic referral at diagnosis of metastatic lung cancer vs discretionary referral by oncologist

Median Survival
11.6 vs. 8.9 months
 $p < 0.02$



Resources Needed to Deliver Quality Palliative Care

- ✓ An educated workforce, from primary to specialist level, in all health care disciplines
 - ✓ Funding to pay health care workers
 - ✓ Enough beds in hospitals
 - ✓ “Hospice beds”
 - ✓ Support for family caregivers
 - ✓ Drugs and equipment
 - ✓ Patients and families willing to accept help and communicate with their care-providers
- 

Why is Communication Important?

- ▶ A recent study showed that although patients are reporting that they have thought about care options at end of life and only 12% want aggressive life prolonging care, they are not having these conversations with health care professionals
- ▶ Agreement between patients' expressed preferences for End of Life Care and documentation in the medical record was only 30.2%

What Triggers Advance Care Planning?

- ▶ Having been asked about an advance directive by a health care professional increases the chance of actually having one (x10), and **x68 if asked by family and friends**
- ▶ So does having been a care-giver (x 2.5)
- ▶ Chance of having a designated proxy decision-maker increased x1.6 when asked by a HCP and **x1.8 by family and/or friends**

Objectives

- ▶ What do British Columbians die from?
 - ▶ Where do British Columbians die?
 - ▶ How does 21st Century Palliative Care help people to live (and die) with dignity?
 - ▶ Do all British Columbians have access to Palliative Care?
 - ▶ How are we doing in comparison with other places?
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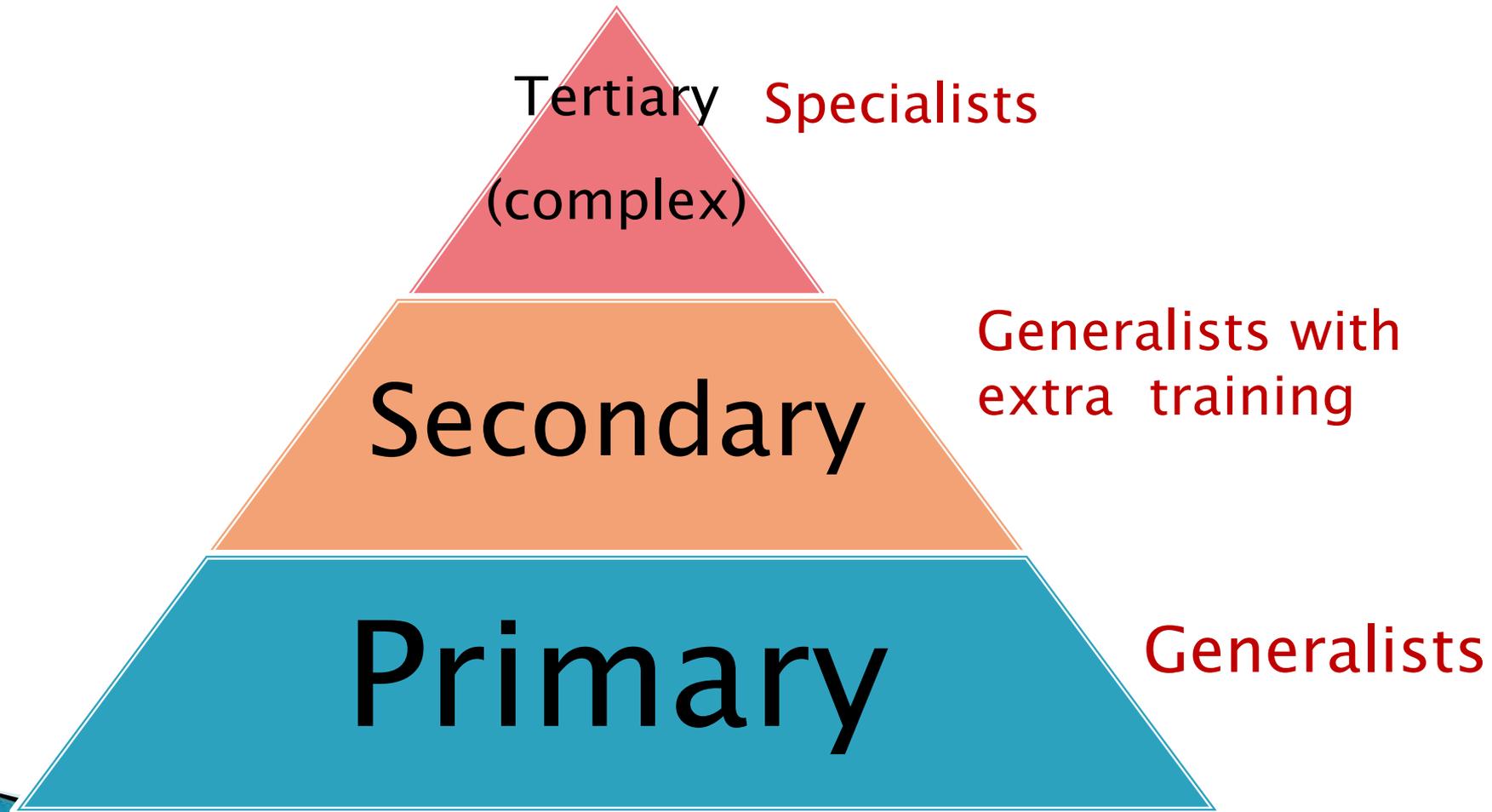
How Do We Know if Someone has Access to Palliative Care?

This is difficult to find out in Canada as we don't have standard ways of measuring it
Access would include:

- ✓ those who received specialist palliative care
- ✓ those who received some “countable” parts of palliative care, like equipment and drugs
 - ❖ But receiving only one part of care does not imply that all components were available or delivered

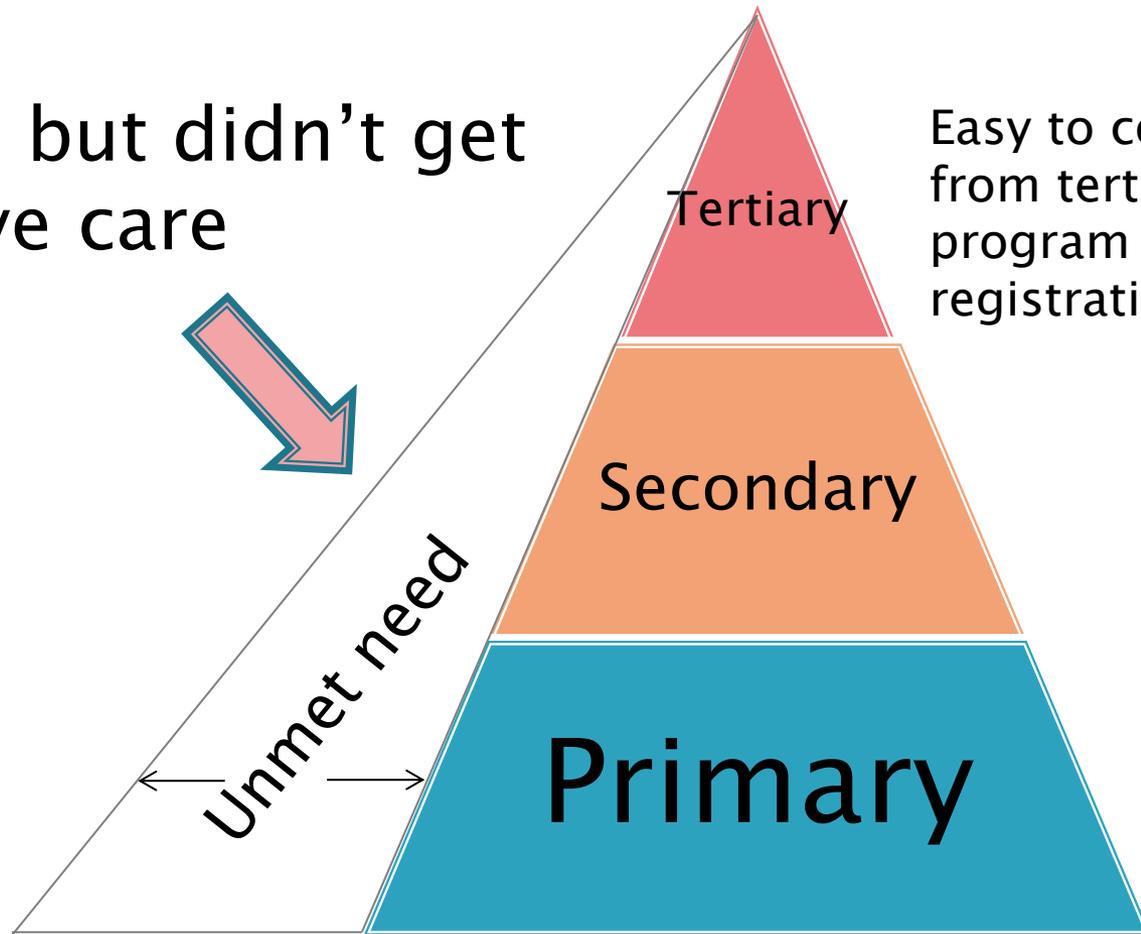
Hmm, this is tricky..... How do places do it?

Palliative Care Needs Model



Countable Groups?

Needed but didn't get palliative care



Easy to count from tertiary program registration

Tertiary

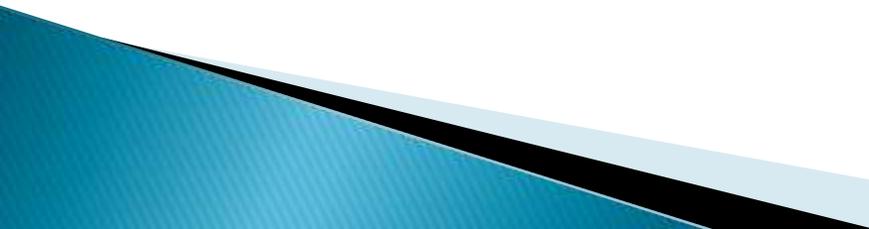
Secondary

Primary

Unmet need

.....People with serious illnesses.....

What Can be Counted?

- ▶ Registrations for Palliative Benefits
 - ▶ Admissions to a palliative care unit or hospice
 - ▶ Registration with palliative home care
 - ▶ Place of death when it includes a bed that is only for palliative care patients
 - ▶ Time from palliative care referral to death
 - ▶ Cancer centre Pain & Symptom Management/Palliative Care team referral
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What Counts?

- ▶ Symptom control?
 - ▶ Quality of life?
 - ▶ Satisfaction with care?
 - ▶ Having an advance directive?
 - ▶ When a patient dies where they said they wanted to die?
 - ▶ What family and friends report about their experience in the months following the death of a loved one?
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What Data Do We Have In BC?

- ▶ Fraser Health has been collecting palliative care program registration data for some years
 - ▶ Attempt to plan services most efficiently
 - ▶ All addresses in health authority covered
 - ▶ Secondary and tertiary services
 - ▶ Does not determine whether the needs were met of all persons who died in Fraser Health
 - ▶ Includes those who received care in hospital, hospice and at home
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Hospice Bed Availability

- ▶ Palliative Care Units are acute hospital beds
- ▶ Hospice beds are non-acute, home-like settings
- ▶ 7.7 hospice beds per 100,000 is standard set by Alberta health Services in 2013
- ▶ In BC we have total 377 hospice and palliative care unit beds, which is 8.22/100,000
- ▶ Hospice/PCU beds not evenly distributed throughout province

Hospices do not have One-Way Doors

- ▶ In 2013–2014, HPC Program Wide, 91.7% of patients (1,211 patients) died while on the palliative program
- ▶ Patients being discharged for other reasons accounted for 8.3%
- ▶ Of these, 32% were discharged to another palliative care program, 27% to home, 8% to acute care, 3% to an inpatient palliative care unit and 17% to residential care.

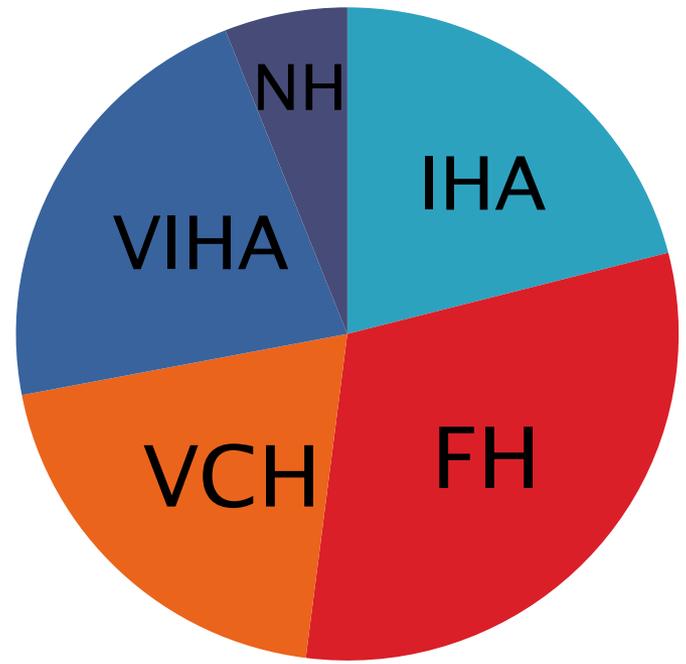
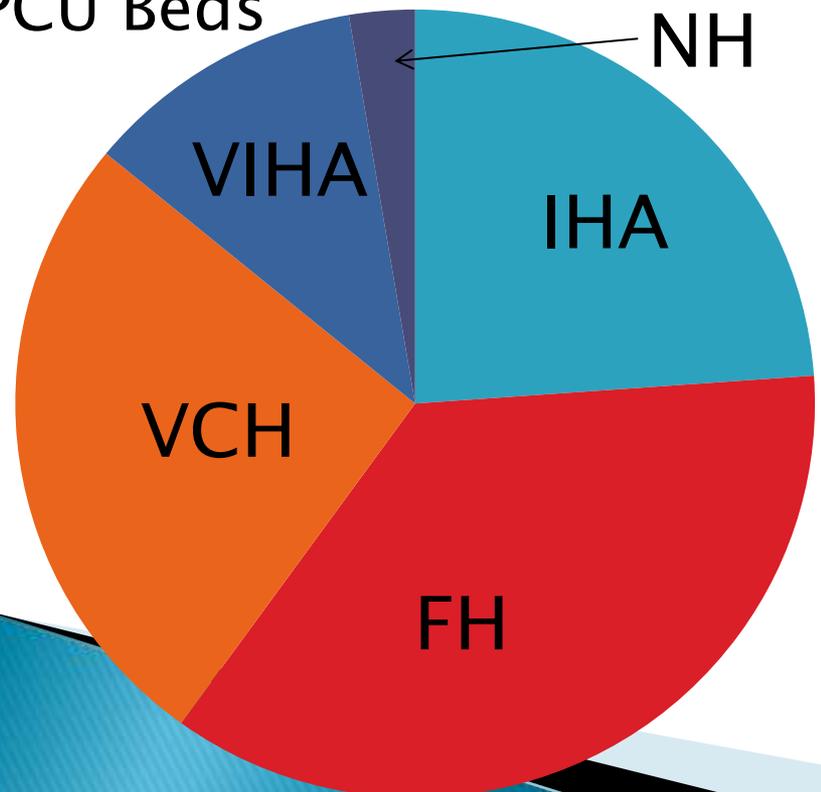
Rate of Hospice Enrollment (FH)

- ▶ 9813 natural deaths, 2154 people died in residential care [residential care in FH generally does not require support from the HPC program]
- ▶ This leaves 7660 who died outside residential care
- ▶ FH HPC program enrolled 4520, i.e. **59% of “eligible” deaths**
- ▶ 70% of new patients referred to the program had a cancer diagnosis (remember cancer only 30% of deaths)
- ▶ This proportion of cancer patients has remained quite consistent over the years and is typical for Canada

Health Authority	Hospice Beds	PCU Beds	Total
FH	96	40	136
VCH	56	42	98
VIHA	28	15	43
IHA	90	0	90
NH	10	0	10

Lower Mainland has disproportionately high proportion of hospice and PCU beds

H/PCU Beds



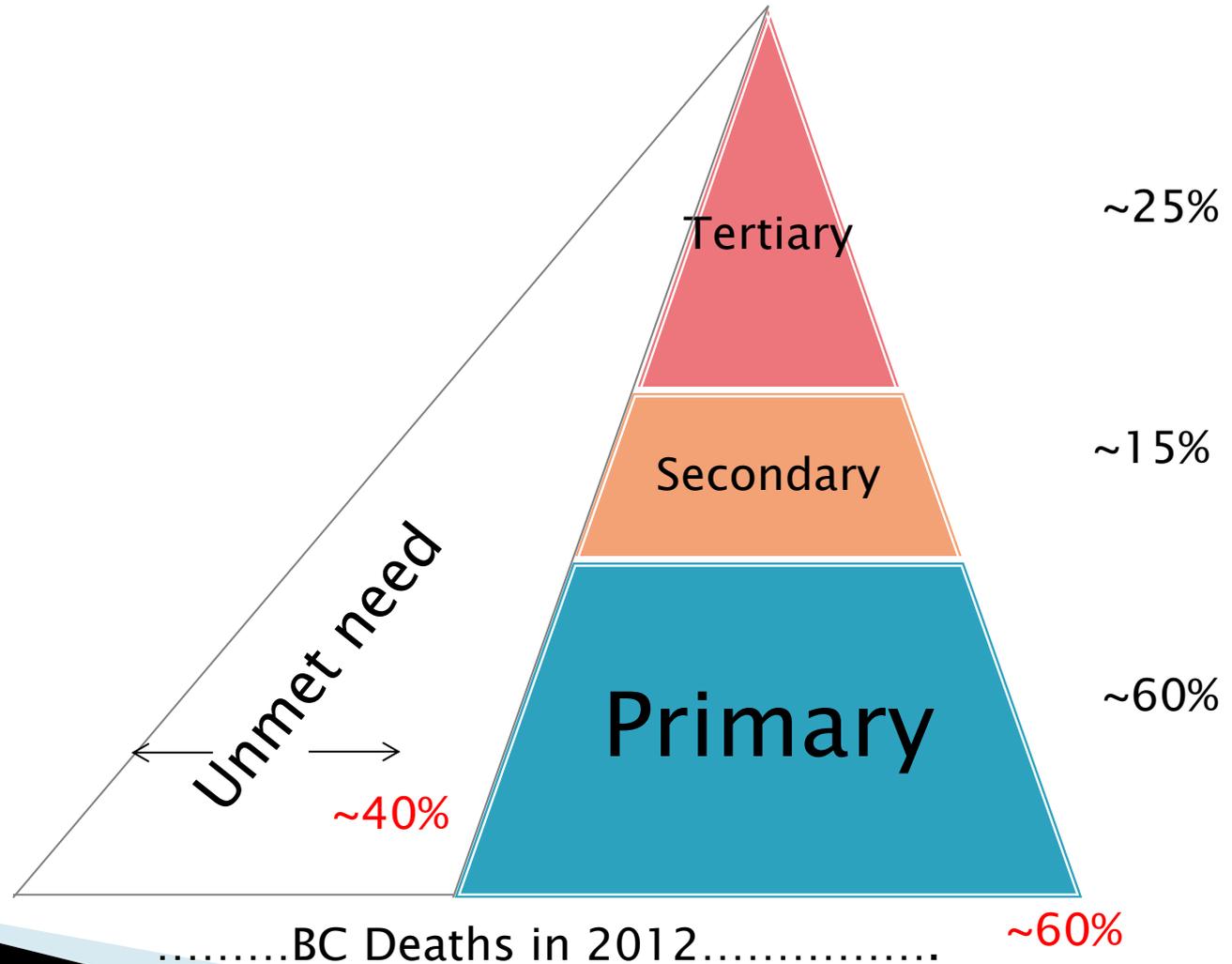
Natural Deaths (31,318)

BC Palliative Populations Exercise –in progress

Goals:

- ▶ Identify adult populations who have palliative care needs
- ▶ Establish characteristics and service use of each group
- ▶ Explore unmet need and differences between urban, rural and remote communities
- ▶ To support subsequent work on
 - determining acceptable service levels for each population
 - develop outcome/performance measures and monitoring mechanisms for palliative care and hospice services

Preliminary Results Similar to FH Data

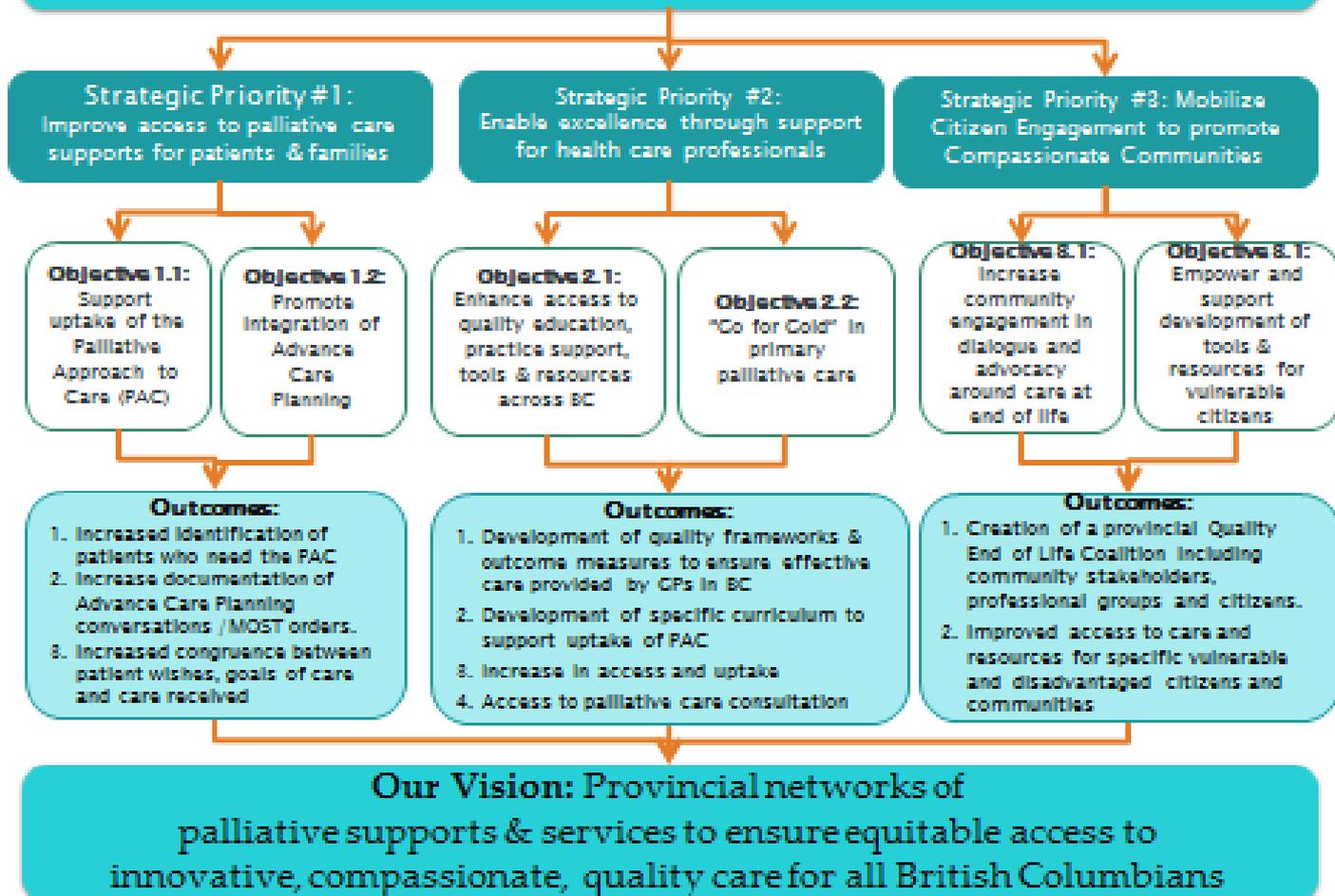


So what are we doing to
improve access to Palliative
Care even further?



BC Centre for Palliative Care

Our Mission: To enable excellence in care for all British Columbians living with & dying from advanced illness



Physician Support

- ▶ 24-hr Provincial Palliative Care Physician Hotline
 - Study of 692 calls (J.Ridley)
 - Large variety of topics addressed, ranging from symptom control to ethical concerns
 - Primary reason was pain management, followed by gastrointestinal symptoms such as nausea, diarrhea, and bowel obstruction
 - Patients with cancer dominated the call volume
- ▶ The majority of calls came from rural areas

MD Education Available

- Undergrad medicine course being renewed
 - Much more formal teaching and more electives
 - Postgraduate palliative care specialist training
 - Clinical rotations and teaching in other specialist training programs
 - Education for doctors in practice
 - Educational events
 - On-on-one consultation support
 - Practice Support Program
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Health Link BC After Hours Patient–Nurse Telephone Support

- ▶ In 2013–2014, 427 calls
 - Fraser Health 60%
 - Island Health (formerly VIHA) 18%
 - Vancouver Coastal Health 11%
 - Interior Health 10%
 - Northern Health 1%
 - Vancouver, Victoria and Kelowna have their own after hours palliative service so do not use the service.
- ▶ For the palliative response nurse–managed calls, 75% of patients remained in their home after the call and 19% were transferred to acute care

What Should Patients and Families Know?

- ▶ The difference between palliative care and hospice
 - ▶ That they have a right to access palliative care
 - Good symptom management
 - Advance care planning
 - Psychosocial support
 - Communication and coordination of care
 - ▶ Your family doctor may not be an expert in palliative care, but can access that expertise from anywhere in BC
- 

Volunteer Involvement

- ▶ Benefits have been shown for volunteers' health and quality of life
- ▶ 2013–2014, Fraser Health HPC Program reported that hospice societies within the health authority had:
 - ✓ 916 volunteers
 - ✓ 65,424 hours
 - ✓ 33.9 Full-Time-Equivalents

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