

CANADIAN PARTNERSHIP AGAINST CANCER / PARTENARIAT CANADIEN CONTRE LE CANCER

# Toward a Population-based Approach in EOL Care Surveillance

CAHSPR Conference  
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Hospice Palliative End-of-life (HPEOL) Network

## Hospice Palliative End-of-life (HPEOL) Care Surveillance Team Network

- Purpose of Project
- HPEOL Network Engagement
- Conceptual Design
- Key Information Products
- Lessons Learned
- Next Steps

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2

## Purpose of Project

### Overall Aim

- Improve quality and use of **existing electronic data** to better understand management of terminally ill cancer patients in final year

### Specific Objectives

- Establish a **methodology/design** for a surveillance system
- Publish a set of **info products** on EOL patient populations
- Improve **quality/use** of existing electronic data sources
- Engage in knowledge translation and capacity building

### Scope

- “EOL care” as last year of life for terminally ill cancer patients, with **non-cancer as comparison**

**Recognized as early design or Proof of Concept only**

## HPEOL Network Engagement - 1

### • Network members

- Types: Partners, collaborators and potential members
- Partners: BC, Alberta, Yukon and Ontario
  - BC: Six Health Authorities, Victoria Hospice, Ministry of Health
  - Alberta: Edmonton palliative care program, *Dept of Health & Wellness*
  - Yukon: Dept of Health and Social Services
  - Ontario: *Ottawa Hospital palliative care program*
- Collaborators: Canadian Institute for Health Information, BC Hospice Palliative Care Association, Health Canada
- Potential members
  - Nova Scotia: Dept of Health, Dalhousie U, Guysborough Antigonish HA
  - New Brunswick: Dept of Health
  - Ontario: *Cancer Care Ontario*

## HPEOL Network Engagement - 2

- **Network organization**
  - Structure: BC Cancer Agency as sponsor, Steering Committee, Project team, partners, collaborators
  - Project Team: researchers, clinicians, analysts (including trainees)
- **Member engagements**
  - Steering Committee: partners and collaborators for oversight
  - Partners: common data definitions, data extraction, report requirements, report reconciliation, potential use
  - Collaborators /others: KT workshops, meetings and Web-survey inputs
  - KT workshops: partners, collaborators and potential members
  - KT assessments: KTE plan and assessment of member perceptions

## Conceptual Design

### **Model Framework**

- Australian palliative approach, population based service planning

### **Palliative Flags**

- 24 flags from location, diagnosis, service, status, intent, prognosis

### **Palliative Cohorts**

- Census, decedent, inception cohorts

### **Service Categories**

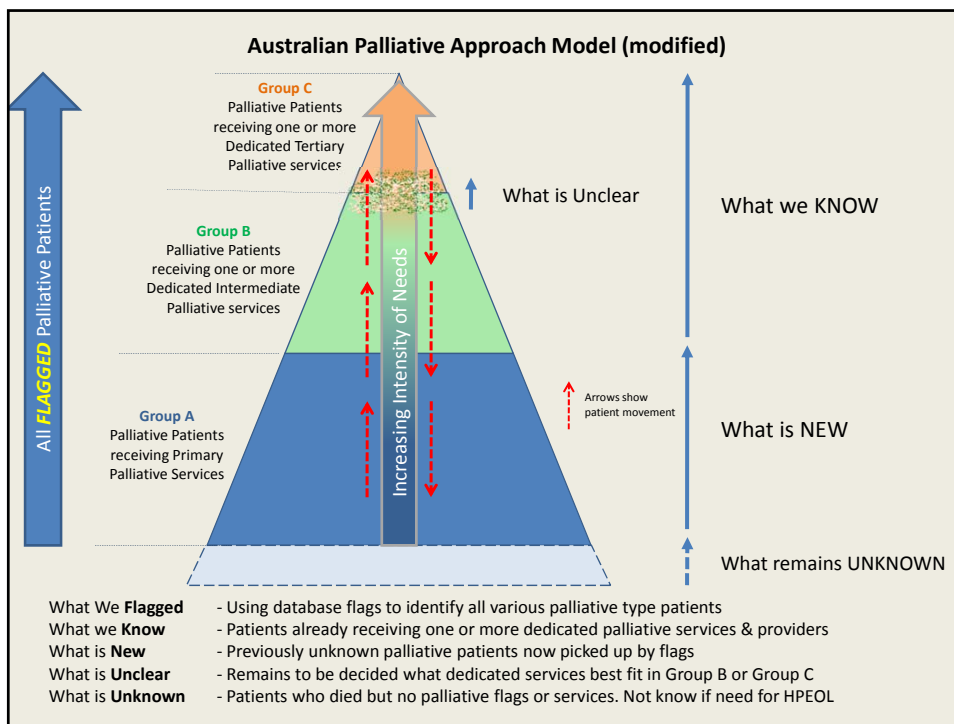
- Dedicated palliative care services, primary palliative care services, general health services

### **Service Costing**

- Per episode, diem, hour, visit (E,P,H,V)

### **Report Types**

- HPC program only, HPC with all services, complete



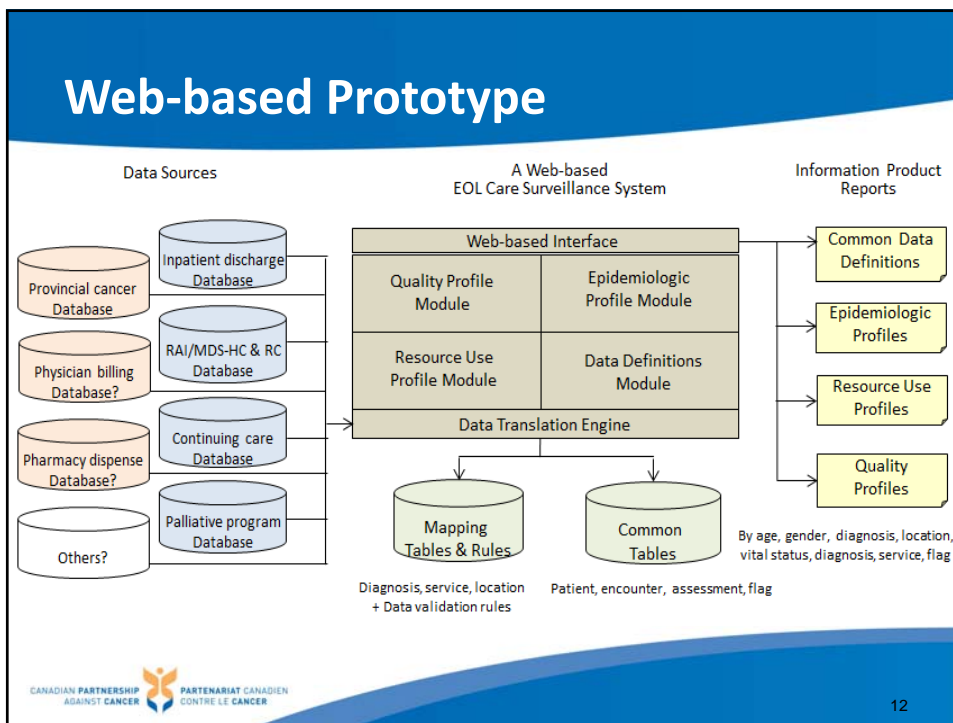
No	Palliative Flags / Population Groups	Group C	Group B	Group A	Group U
1.	Had Care Location of Residential Hospice	✓			
2.	Had Care Location of TPCU	✓			
3.	Had CIHI Client Grouping for EOL Status			✓	
4.	Had Death Location of Residential Hospice	✓			
5.	Had Death Location of TPCU	✓			
6.	Had Dedicated Palliative Care Service		✓		
7.	Had Died with Death Date				
8.	Had Died with No Palliative Flags Present				✓
9.	Had Goals of Care as Palliative in MDS-HC			✓	
10.	Had Hospice Care in MDS-HC			✓	
11.	Had Hospice Care in MDS-RC			✓	
12.	Had ICD Code Z515 for Palliative in DAD			✓	
13.	Had Palliative Benefits Plan Registration			✓	
14.	Had Palliative Cancer Diagnosis			✓	
15.	Had Palliative Chemotherapy			✓	
16.	Had Palliative Home Care			✓	
17.	Had Palliative Long Term Care			✓	
18.	Had Palliative Program Registration But No Palliative Services			✓	
19.	Had Palliative Radiotherapy			✓	
20.	Had Palliative Surgery			✓	
21.	Had Physician Billing Code for Palliative Care Service			✓	
22.	Had Prognosis < 6 Months in MDS-HC			✓	
23.	Had Prognosis < 6 Months in MDS-RC			✓	
24.	Had Service Code 58 for Palliative Care in DAD			✓	

<b>Dedicated Palliative Care Services</b>				
Service Categories / Population Groups	Group C	Group B	Group A	Group U
<b>1.0 Hospital Based Care</b>				
1.1 Tertiary Palliative Care	✓			
1.2 Cancer Centre (palliative chemo/rad/surg treatment)	✓			
<b>2.0 Hospital Based Consult</b>				
2.1 Hospital (Inpatient) Consult	✓	✓		
2.2 Hospital (Outpatient) Consult	✓	✓		
<b>3.0 Hospice Care</b>				
3.1 Residential Hospice Care	✓			
3.2 Day Care	✓			
3.3 Respite Care	✓			
<b>4.0 Community Based Consult</b>				
4.1 Community (In Person) Consult	✓	✓		
4.2 Community (Telephone) Consult	✓	✓		
4.3 Community (Telehealth) Consult	✓	✓		
<b>5.0 Community Special Services (e.g., Palliative Response Team)</b>	✓	✓		
<b>6.0 Palliative Home Care</b>				
<b>7.0 Palliative Drug Benefits (e.g. Plan P)</b>				
<b>Primary Palliative Care Services</b>				
Service Categories / Population Groups	Group C	Group B	Group A	Group U
<b>1.0 Inpatient Care</b>				
1.1 Acute Hospital			✓	
1.2 Cancer Centre (palliative chemo/rad/surg treatment)			✓	
<b>2.0 Physician Services</b>			✓	
<b>3.0 Home Care</b>			✓	
<b>4.0 Residential Care</b>			✓	

<b>General Health Services</b>				
Service Categories / Population Groups	Group C	Group B	Group A	Group U
<b>1.0 Inpatient Care</b>				
1.1 Acute Hospital				✓
1.2 Cancer Hospital (chemo/rad/surg treatment)				✓
1.3 Children's Hospital				✓
1.4 Alternate Level Care				✓
<b>10.0 Laboratory Services</b>				✓
<b>2.0 Outpatient Care</b>				
2.1 Hospital (Ambulatory - Emergency) Care				✓
2.2 Hospital (Ambulatory - Day Surgery) Care				✓
2.3 Hospital (Ambulatory - Clinic) Care				✓
2.4 Cancer Centre Appointment				✓
<b>3.0 Physician Services</b>				
3.1 GP/Family Medicine				✓
3.2 Specialist				✓
<b>4.0 Non-physician Professional Services (e.g., PT, OT, SLP, etc.)</b>				✓
<b>5.0 Home Care</b>				
5.1 Home Nursing Care				✓
5.2 Home Support				✓
5.3 Other Support Services				✓
<b>6.0 Residential Care</b>				
6.1 Nursing Home				✓
6.2 Home Support				✓
6.3 Respite Care				✓
<b>7.0 Community Based Services</b>				✓
<b>8.0 Medications</b>				✓
<b>9.0 Medical Supplies</b>				✓

Palliative Approach Model - Population Groups and Services				
Service Patient Population	Dedicated Palliative Care Service	Primary Palliative Care Service	General Health Service	Type of Care Program and/or Provider
Group C: Palliative patients receiving one or more dedicated tertiary palliative services	TPCU Hospice	Primary Palliative Services?	General Health Services?	Palliative Care Program*
Group B: Palliative patients receiving one or more dedicated intermediate palliative services	Palliative Consults, PRT**	Primary Palliative Services?	General Health Services?	Palliative Care Program*
Group A: Palliative Patients receiving primary palliative services only		Primary Palliative Services	General Health Services?	Primary Care Providers/Specialists
Group U: Unknown Patients? (Decedents Only)			General Health Services	Primary Care Providers/Specialists

\*Refers to designated/formal palliative care programs /services with an annual budget in the organization  
 \*\* Palliative consults include all hospital/community-based consults, PRT= palliative response team



## Key Information Products – *Summary 1*

- **Common data definitions**
  - Common data /codes, data quality checks, validation/mapping methods
  - Australian framework, flags, locations, diagnoses, services, indicators
- **Epidemiologic profiles**
  - Populations, decedents, cancer/non-cancer groups, survival time
  - Age, gender, location, diagnosis, frequency, percent, average
- **Resource Use profiles**
  - Identified palliative populations, decedents, service use/cost
  - Age, gender, location, diagnosis, frequency, percent, average, costing

## Key Information Products – *Summary 2*

- **Quality profiles**
  - Service: % decedents by location, within x days admission, no. of times admitted, LOS by location, decedent LOS by duration, time before/in HPC
  - Clinical % first assessment (eg. ESAS, PPS), symptom prevalence (eg. ESAS)
- **Companion reports, leaflets and topics**
  - BCCA: % population by cancer type, by service (chemo, radiation, surgery), % palliative by cancer type, by service; chemo in last x days
  - Leaflets: Where do people die? Who are palliative patients in my beds? Who do we see and not see?
  - Topics: % decedents by location, within 48hrs admission, by diagnosis
  - Topics: % palliative decedents by location, within 48hrs admission, by dx

## Lessons Learned – *Challenges*

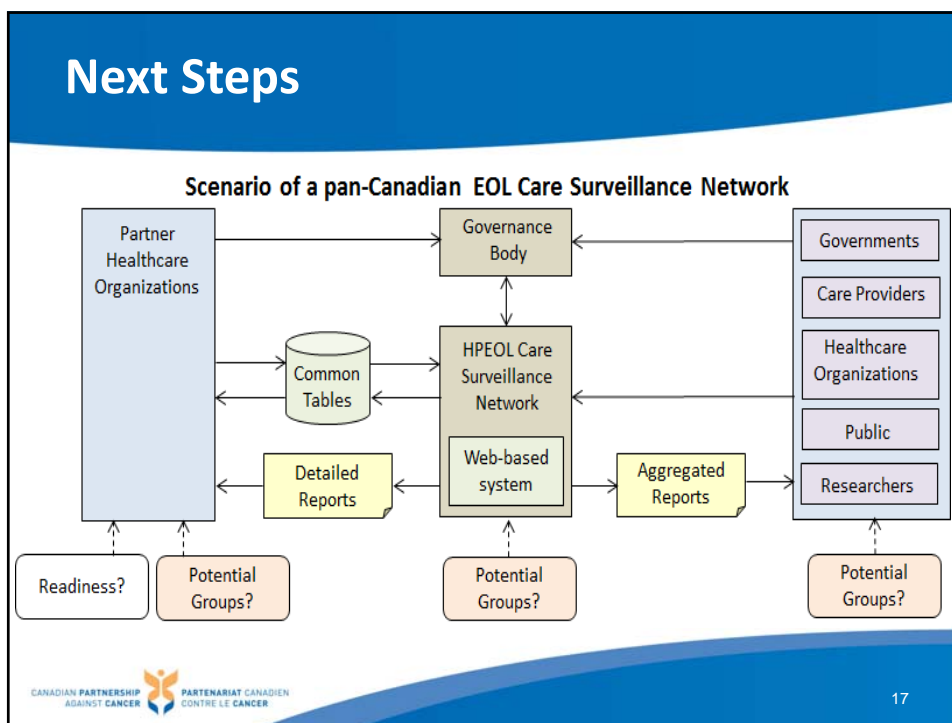
- **Data Sources, Access and Timeline**
  - PIA, ethics, data sharing agreements, service level agreements
  - Admin, HPC program, RAI-HC/RC, cancer registry, limited assessment data
  - Varied in completeness, accuracy and time to extract/validate datasets
- **Reconciliation**
  - Consensus on definitions, common codes and report contents/formats
  - Comparison of outputs with existing HPC statistics if available
- **Report Caveats**
  - Missing vital stats, death locations, diagnosis, provider, HPC registration

## Lessons Learned - *Accomplishments*

- **Innovations**
  - Adapted Australian Model , 24 palliative flags and 3 service categories
  - Successful ‘proof of concept’ but much work lies ahead
- **Comprehensiveness**
  - All existing electronic data sources from partners
  - ~80% deliverables completed, identified issues and lessons
- **New knowledge/insights**
  - Toward consensus on definitions, codes and report contents/formats
  - EOL care profiles for cancer/non-cancer populations in final year
  - Estimates of patients who received dedicated and primary palliative care services, and “unknown” palliative patients (who died)



## Next Steps



## Acknowledgments

- This project has been made possible through a financial contribution from the [Canadian Partnership Against Cancer & Health Canada](#)
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- The views expressed herein do not necessarily represent the views of the Canadian Partnership Against Cancer.