

CANADIAN PARTNERSHIP AGAINST CANCER / PARTENARIAT CANADIEN CONTRE LE CANCER

Toward a Population-based Approach in EOL Care Surveillance

CAHSPR Conference
May 30, 2012

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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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

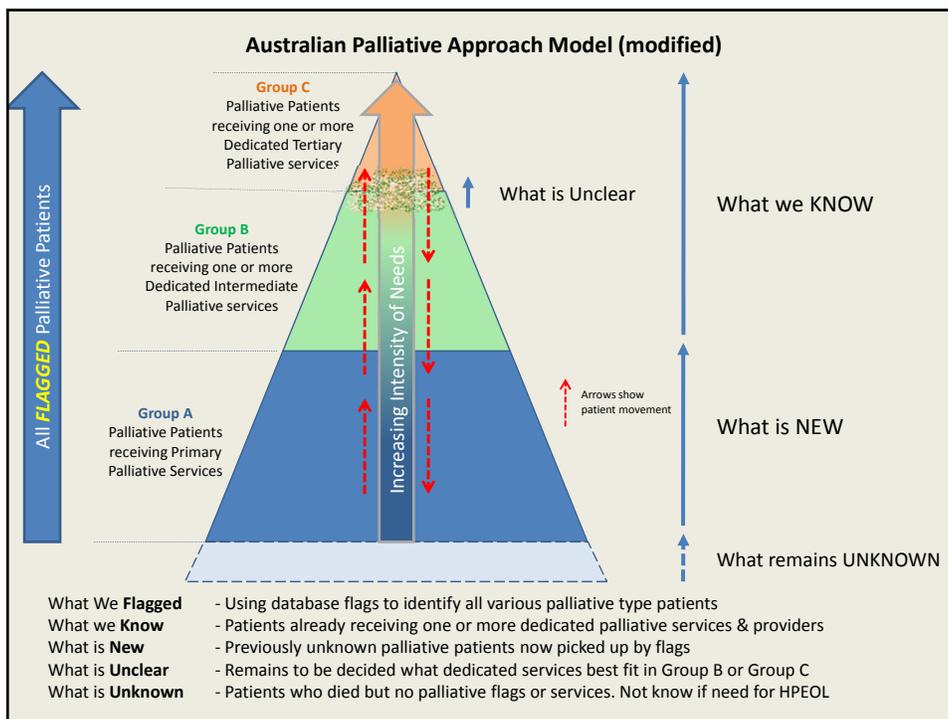
- Dedicated palliative care services, primary palliative care services, general health services

Service Costing

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

Report Types

- HPC program only, HPC with all services, complete



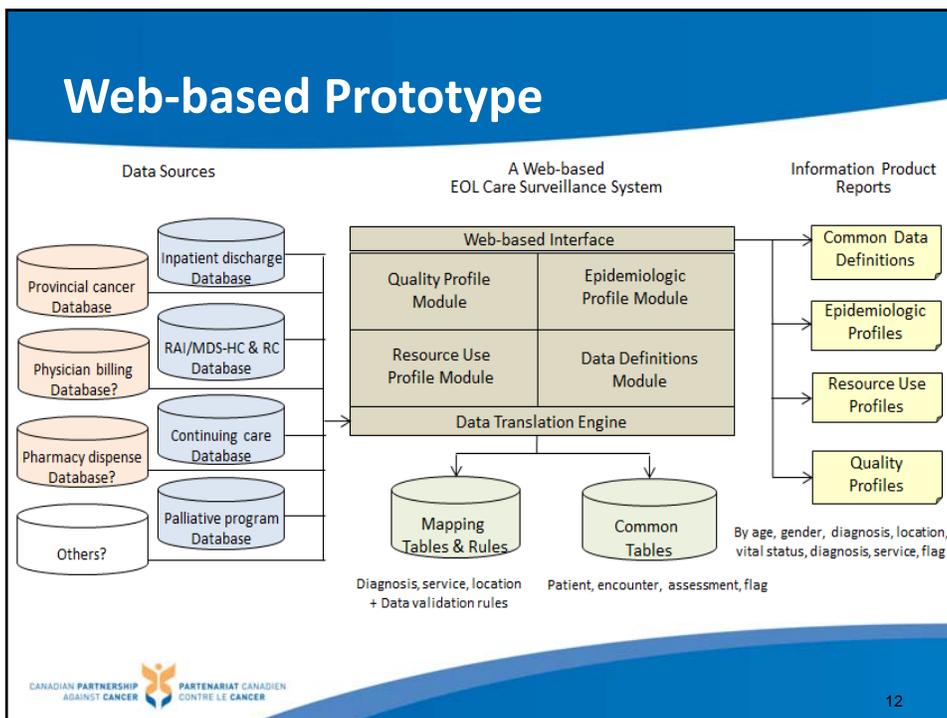
| No | Palliative Flags / Population Groups | Group C | Group B | Group A | Group U |
|-----|--|---------|---------|---------|---------|
| 1. | Had Care Location of Residential Hospice | ✓ | | | |
| 2. | Had Care Location of TPCU | ✓ | | | |
| 3. | Had CIHI Client Grouping for EOL Status | | | ✓ | |
| 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 | | | ✓ | |

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

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

| 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

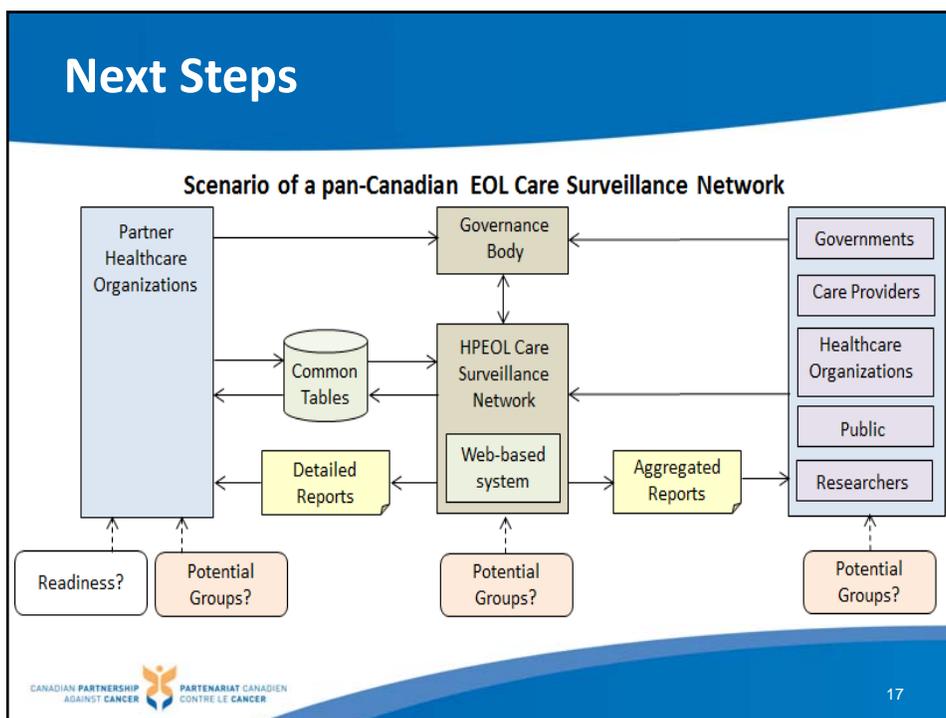
Lessons Learned – *Challenges*

- **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

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- The views expressed herein do not necessarily represent the views of the Canadian Partnership Against Cancer.