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
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

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**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
What We Flagged - Using database flags to identify all various palliative type patients
What we Know - Patients already receiving one or more dedicated palliative services & providers
What is New - Previously unknown palliative patients now picked up by flags
What is Unclear - Remains to be decided what dedicated services best fit in Group B or Group C
What is Unknown - Patients who died but no palliative flags or services. Not know if need for HPEOL
### Dedicated Palliative Care Services

<table>
<thead>
<tr>
<th>Service Categories / Population Groups</th>
<th>Group C</th>
<th>Group B</th>
<th>Group A</th>
<th>Group U</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.0 Hospital based Care</td>
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<td>1.1 Tertiary Palliative Care</td>
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<tr>
<td>1.2 Cancer Centre (palliative chem/rad/surg treatment)</td>
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<tr>
<td>2.0 Hospital Based Consult</td>
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<tr>
<td>2.1 Hospital (Inpatient) Consult</td>
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<td>2.2 Hospital (Outpatient) Consult</td>
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<td>3.0 Hospice Care</td>
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<tr>
<td>3.1 Residential Hospice Care</td>
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<td>3.2 Day Care</td>
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<tr>
<td>3.3 Respite Care</td>
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<td>4.0 Community Based Consult</td>
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<td>4.1 Community (In Person) Consult</td>
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<td>4.2 Community (Telephone) Consult</td>
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<td>5.0 Community Special Services (e.g., Palliative Response Teams)</td>
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<tr>
<td>6.0 Palliative Home Care</td>
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<td>7.0 Palliative Drug Benefits (e.g., Pain P)</td>
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### Primary Palliative Care Services

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<tr>
<th>Service Categories / Population Groups</th>
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<tbody>
<tr>
<td>1.0 Inpatient Care</td>
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<tr>
<td>1.1 Acute Hospital</td>
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<td>1.2 Cancer Centre (palliative chem/rad/surg treatment)</td>
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<td>2.0 Physician Services</td>
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<tr>
<td>3.0 Home Care</td>
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<td>4.0 Residential Care</td>
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### General Health Services

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<tr>
<th>Service Categories / Population Groups</th>
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<td>1.0 Inpatient Care</td>
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<tr>
<td>1.1 Acute Hospital</td>
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<tr>
<td>1.2 Cancer Hospital (chemo/rad/surg treatment)</td>
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<td>1.3 Children’s Hospital</td>
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<td>1.4 Alternate Level Care</td>
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<td>10.0 Laboratory Services</td>
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<tr>
<td>2.0 Outpatient Care</td>
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<tr>
<td>2.1 Hospital (Ambulatory - Emergency) Care</td>
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<tr>
<td>2.2 Hospital (Ambulatory - Day Surgery) Care</td>
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<td>2.3 Hospital (Ambulatory - Clinic) Care</td>
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<td>2.4 Cancer Centre Appointment</td>
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<td>5.0 Physician Services</td>
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<td>5.1 GP/Family Medicine</td>
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<td>4.0 Non-Physician Professional Services (e.g., PT, OT, SEP, etc.)</td>
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<tr>
<td>5.0 Home Care</td>
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<td>5.1 Home Nursing Care</td>
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<td>5.2 Home Support</td>
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<td>5.3 Other Support Services</td>
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<td>6.1 Nursing Home</td>
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<td>7.0 Community Based Services</td>
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<td>8.0 Medications</td>
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<td>9.0 Medical Supplies</td>
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</tbody>
</table>
**Palliative Approach Model - Population Groups and Services**

<table>
<thead>
<tr>
<th>Service Patient Population</th>
<th>Dedicated Palliative Care Service</th>
<th>Primary Palliative Care Service</th>
<th>General Health Service</th>
<th>Type of Care Program and/or Provider</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Group C:</strong> Palliative patients receiving one or more dedicated tertiary palliative services</td>
<td>TPCU Hospice</td>
<td>Primary Palliative Services?</td>
<td>General Health Services?</td>
<td>Palliative Care Program*</td>
</tr>
<tr>
<td><strong>Group B:</strong> Palliative patients receiving one or more dedicated intermediate palliative services</td>
<td>Palliative Consults, PRT**</td>
<td>Primary Palliative Services?</td>
<td>General Health Services?</td>
<td>Palliative Care Program*</td>
</tr>
<tr>
<td><strong>Group A:</strong> Palliative Patients receiving primary palliative services only</td>
<td>Primary Palliative Services</td>
<td>General Health Services?</td>
<td></td>
<td>Primary Care Providers/Specialists</td>
</tr>
<tr>
<td><strong>Group U:</strong> Unknown Patients? (Decedents Only)</td>
<td></td>
<td>General Health Services</td>
<td></td>
<td>Primary Care Providers/Specialists</td>
</tr>
</tbody>
</table>

*Refers to designated/formal palliative care programs /services with an annual budget in the organization

** Web-based Prototype **

- Data Sources
  - Inpatient discharge Database
  - Provincial cancer Database
  - Physician billing Database
  - RAI/MDS-HC & RC Database
  - Pharmacy dispense Database
  - Continuing care Database
  - Palliative program Database
  - Others

- Web-based Interface
  - Quality Profile Module
  - Epidemiologic Profile Module
  - Resource Use Profile Module
  - Data Definitions Module

- Mapping Tables & Rules
- Common Tables

- Information Product Reports
  - Common Data Definitions
  - Epidemiologic Profiles
  - Resource Use Profiles
  - Quality Profiles

- By age, gender, diagnosis, location, vital status, diagnosis, service, flag

- Diagnosis, service, location + Data validation rules
- Patient, encounter, assessment, flag
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

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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

Scenario of a pan-Canadian EOL Care Surveillance Network

Acknowledgments

- This project has been made possible through a financial contribution from the Canadian Partnership Against Cancer & Health Canada

- The original EOL care surveillance information product designs were based on outputs from earlier CIHR funded grants
  - CIHR New Emerging Team Grants in Palliative EOL Care
  - CIHR Partnership in Health System Improvement

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