Chronic Disease and Palliative Care Program Data Linkage and Analysis Project: 
*The 3x3 Network for End of Life Study (NELS)*

**Diabetes**

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April 30, 2012
Purpose of Meeting

- Present some results from the 3x3 data with a focus on diabetes
- Help the NELS team develop a clearer picture of the diabetes registry data
  - Mandate
  - History of registry
  - Specifics on how a registration occurs across province
  - Why some with diabetes may not be in registry
  - Quality indicators used by registry?
  - What would you like to see from the 3x3 data?
  - Learn about the complementary work by registry
Introduction

• The 3x3 NELS study utilizes linked administrative data to study End of Life (EOL) issues

• NS Vital Statistics death certificate data was linked to registry data from 3 provincial disease programs:
  • Cancer
  • Diabetes
  • Cardiovascular

• Data from 3 palliative programs were also linked:
  • Capital Health
  • Colchester East Hants
  • Cape Breton
End of Life Research

• Much of the EOL/palliative care research has focused on cancer
• Other diseases have a terminal phase
• Co-morbidities play a large role
  • e.g. Diabetes risk factor for heart disease
• Administrative data can be a valuable tool
  • Ethical and other sensitivities surrounding EOL data collection
  • Helps provide a more complete picture of health conditions near the EOL
Data

• All deaths in Nova Scotia 1995-2009
  • 121,458
• Linked to other data using probabilistic linkage
• For registry data, identifying information stripped before health service information attached and transferred to NELS ICE analysts
Diabetes Registry data for NELS 3x3

- 10,740 observations linked to VS
  - 8.8% of all deaths were in diabetes registry

- Diabetes Registry Variables:
  - Diabetes type
  - Date of first diagnosis
  - Date of referral
  - Date of first and last visit
  - Treatment type
  - Co-morbidities
Causes of Death

• All causes of death from death certificate utilized

• Can be up to 13 causes of death listed

• Disease types were identified through ICD coding used on the death certificate
Age and Sex Distribution
All Deaths and Individuals with in the Diabetes Registry

Sex Distribution

<table>
<thead>
<tr>
<th></th>
<th>Females</th>
<th>Males</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage</td>
<td>49.5%</td>
<td>50.5%</td>
</tr>
<tr>
<td>Sex</td>
<td>49.3%</td>
<td>50.7%</td>
</tr>
<tr>
<td>Total</td>
<td>56.4%</td>
<td></td>
</tr>
</tbody>
</table>

Age Distribution

- Means:
  - All: 74.5
  - In registry: 73.7
  - Diabetes cause: 76.2
## Diabetes Cause of Death from Vital Statistics and Diabetes Registry

<table>
<thead>
<tr>
<th>Patient Found</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Both</td>
<td>4,435</td>
<td>23.49%</td>
</tr>
<tr>
<td>Registry only</td>
<td>6,035</td>
<td>31.96%</td>
</tr>
<tr>
<td>Vitals only</td>
<td>8,413</td>
<td>44.55%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>18,883</strong></td>
<td><strong>100.0%</strong></td>
</tr>
</tbody>
</table>
Diabetes Cause of Death and Registry Enrollment by Year
Those with a Diabetes Cause of Death Not in Registry

<table>
<thead>
<tr>
<th>Year of Death</th>
<th>1995</th>
<th>1997</th>
<th>1999</th>
<th>2001</th>
<th>2003</th>
<th>2005</th>
<th>2007</th>
<th>2009</th>
<th>1995-2009</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>98.0%</td>
<td>92.4%</td>
<td>91.7%</td>
<td>84.5%</td>
<td>78.2%</td>
<td>77.2%</td>
<td>72.5%</td>
<td>65.6%</td>
<td>65.5%</td>
</tr>
</tbody>
</table>

Year of death
Number of Death Causes

Number of Causes

mean
all: 2.85
registry: 3.31
cause: 4.18

0.0% 5.0% 10.0% 15.0% 20.0% 25.0% 30.0% 35.0% 40.0%
1 2 3 4 5+
all deaths
in registry
diabetes cause

mean
all: 2.85
registry: 3.31
cause: 4.18

all deaths
in registry
diabetes cause
## Cause of Death Frequencies

<table>
<thead>
<tr>
<th>Disease</th>
<th>All Deaths</th>
<th>In Registry</th>
<th>With Diabetes Cause</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>32.2%</td>
<td>33.1%</td>
<td>18.3%</td>
</tr>
<tr>
<td>Cardiovascular Disease</td>
<td>31.6%</td>
<td>41.4%</td>
<td>54.2%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>10.6%</td>
<td>42.4%</td>
<td>100.0%</td>
</tr>
<tr>
<td>Pneumonia</td>
<td>11.7%</td>
<td>9.4%</td>
<td>10.1%</td>
</tr>
<tr>
<td>COPD</td>
<td>11.5%</td>
<td>11.7%</td>
<td>12.5%</td>
</tr>
<tr>
<td>Dementia/Alzheimer’s</td>
<td>10.2%</td>
<td>7.2%</td>
<td>9.8%</td>
</tr>
<tr>
<td>Renal</td>
<td>8.8%</td>
<td>15.2%</td>
<td>18.4%</td>
</tr>
<tr>
<td>observations</td>
<td>121,458</td>
<td>10,470</td>
<td>12,848</td>
</tr>
</tbody>
</table>

* Categories are not mutually exclusive.
## Percent in Other Disease Registries

<table>
<thead>
<tr>
<th>Denominator</th>
<th>In Cardiovascular Registry (%)</th>
<th>In Cancer Registry (%)</th>
<th>In Cancer Registry (%)</th>
<th>Observations</th>
</tr>
</thead>
<tbody>
<tr>
<td>In diabetes Registry</td>
<td>41.6%</td>
<td>46.6%</td>
<td>46.6%</td>
<td>10,470</td>
</tr>
<tr>
<td>With Diabetes Cause</td>
<td>34.5%</td>
<td>31.9%</td>
<td>31.9%</td>
<td>12,848</td>
</tr>
<tr>
<td>Either</td>
<td>35.7%</td>
<td>39.1%</td>
<td>39.1%</td>
<td>18,883</td>
</tr>
</tbody>
</table>
Palliative Care Programs

- Have data form 3 District Health Authorities
  - Capital Health (CH) 1995-2009
  - Colchester East Hants (CEH) 2002-2009
  - Cape Breton (CB) 1995-2009
- CH uses ICD-9 coding for
  - Primary diagnosis
  - Co-morbidities
- CEH and CB – free text
  - Primary diagnosis only
# Individuals with Diabetes in PCPs

<table>
<thead>
<tr>
<th></th>
<th>CH (%)</th>
<th>CEH (%)</th>
<th>CB (%)</th>
<th>Any of the 3 (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes Cause</td>
<td>4.9%</td>
<td>8.6%</td>
<td>7.5%</td>
<td>5.9%</td>
</tr>
<tr>
<td>In Diabetes Registry</td>
<td>8.3%</td>
<td>15.3%</td>
<td>11.9%</td>
<td>9.9%</td>
</tr>
<tr>
<td>Diabetes Diagnosis</td>
<td>5.1%</td>
<td>0.13%</td>
<td>0.23%</td>
<td>3.4%</td>
</tr>
<tr>
<td>Any</td>
<td>13.1%</td>
<td>18.3%</td>
<td>15.8%</td>
<td>14.2%</td>
</tr>
<tr>
<td>observations</td>
<td>12,976</td>
<td>1,569</td>
<td>5,631</td>
<td>19,835</td>
</tr>
</tbody>
</table>

For those with a resident postal code in Capital Health, Colchester East Hants or Cape Breton District Health Authority
Individuals with Diabetes in PCPs Over Time

With Any Indication of Diabetes in PCPs

- Capital Health
- Colchester
- Cape Breton
- All 3 PCPs

Data points for each year from 1995 to 2009.

0.0% 5.0% 10.0% 15.0% 20.0% 25.0%

## PCP Enrollment for Individuals in 3 DHAs with Diabetes

<table>
<thead>
<tr>
<th></th>
<th>% in PCP for Those in Registry</th>
<th>% in PCP for Those with Diabetes Cause of Death</th>
<th>% in PCP for Those with Diabetes Cause of Death or Registry Enrollment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Capital Health</td>
<td>31.1%</td>
<td>14.3%</td>
<td>22.6%</td>
</tr>
<tr>
<td>(1996-2009)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Colchester East</td>
<td>36.2%</td>
<td>27.0%</td>
<td>33.9%</td>
</tr>
<tr>
<td>Hants (2003-2009)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cape Breton</td>
<td>32.6%</td>
<td>19.6%</td>
<td>26.2%</td>
</tr>
<tr>
<td>(1996-2009)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Place of Death

- Location of death is an indicator of quality care near the end of life
- Most patients prefer to die at home
- An algorithm developed by CCNS is used to determine place of death
- The variable constructed indicates if the death occurred in the hospital, a nursing home or “other”
Place of Death

Death Location
All Deaths, Registry, with Diabetes Cause

- Hospital: all deaths (60.0%), in registry (70.0%), diabetes cause (80.0%)
- Nursing Home: all deaths (10.0%), in registry (20.0%), diabetes cause (30.0%)
- Others: all deaths (20.0%), in registry (30.0%), diabetes cause (40.0%)
Discussion from diabetes documentation

• To help determine the magnitude of diabetes mellitus and its related complications in Nova Scotia.

• To provide useful information to the diabetes centre (DC) staff, referring physicians, and district/facility administration. Evidence produced should be used to influence program delivery, operations, and diabetes management decisions.

• To allow for limited cross comparisons and an overview of provincial trends and practices in efforts to discover and apply best/better practice approaches.