The Potential of Linked Cancer Registry Data for Cancer Control

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Definition of cancer control

Cancer control aims to prevent cancer, cure cancer, and to increase the survival rates and quality of life for those who develop cancer by converting the cumulative knowledge gained through research, surveillance and outcomes evaluation into strategies and actions… Should be read in the context of the cancer continuum. (Canadian Strategy for Cancer Control)

All actions that reduce the burden of cancer in the community including every aspect of care, from prevention and early diagnosis to curative treatment and palliative care, all underpinned by the best scientific advice available. (National Cancer Control Initiative)
Cancer control spectrum

- prevention
- screening
- early detection
- treatment
- rehabilitation
- palliation
Analytic framework
Canadian Strategy for Cancer Control

Reduce the burden of cancer

promotion/prevention
screening/detection
treatment & care

Implementation (policies & program delivery)
Decision making

Fundamental research
Knowledge synthesis
Intervention Research
Surveillance and monitoring

Foundations / Infrastructure
“The cancer registry is an essential part of any rational programme of cancer control, benefiting both the individual and society in which he lives.” (Muir et al, 1985)

“The most important element within the cancer control surveillance system is the network of cancer registries...” (Greenwald et al, 1986)
Manitoba linkable databases

- Population Registry
- Hospital Discharges
- Physician Claims
- Pharmacy
- Diabetes
- IBD
- Perinatal
- Health Surveys
- Vital Statistics
- Regional Data
- Cancer Registry
- Communicable Diseases
- Provincial Laboratory
- Screening
- OpTx
Prevention / Risk Factors

- abortion & breast cancer
- vasectomy & prostate cancer
- tubal ligation & breast, ovarian, endometrial cancers
- gastric surgery & colorectal cancer
- diabetes & various cancers
- endometriosis & various cancers
- inflammatory bowel disease & various cancers
## Inflammatory bowel disease and cancer

<table>
<thead>
<tr>
<th>Site</th>
<th>IRR</th>
<th>95% C.I.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Small intestine</td>
<td>10.4</td>
<td>3.0 - 36.1</td>
</tr>
<tr>
<td>Colon</td>
<td>2.7</td>
<td>2.0 - 3.6</td>
</tr>
<tr>
<td>Liver, biliary tract</td>
<td>4.4</td>
<td>1.5 - 12.4</td>
</tr>
<tr>
<td>All cancers</td>
<td>1.2</td>
<td>1.1 - 1.3</td>
</tr>
</tbody>
</table>
**Screening**

- characteristics of breast cancer patients by modes of mammography service delivery
- validity of mammograms of women on HRT
- modeling the impact of breast screening on mortality
- pap smears and cervical cancer among Aboriginals
- validity of self-reported mammograms
- validity of self-reported HRT use
**HRT use and mammogram validity**

<table>
<thead>
<tr>
<th>HRT Use</th>
<th>% False +ve</th>
<th>% False -ve</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current</td>
<td>8.2</td>
<td>27.2</td>
</tr>
<tr>
<td>Previous</td>
<td>6.3</td>
<td>20.7</td>
</tr>
<tr>
<td>Never</td>
<td>6.9</td>
<td>14.2</td>
</tr>
</tbody>
</table>
Treatment / Outcomes

- breast
- rectal
- lung
## Services for Stage IIIb/IV NSCLC patients since last chemotherapy

<table>
<thead>
<tr>
<th>Service</th>
<th>Number</th>
<th>per person</th>
<th>per 100 PWs</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Databases</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical claims</td>
<td>4353</td>
<td>29.8</td>
<td>112.3</td>
</tr>
<tr>
<td>Hospitalizations</td>
<td>271</td>
<td>1.9</td>
<td>7.0</td>
</tr>
<tr>
<td>Prescriptions</td>
<td>3050</td>
<td>20.9</td>
<td>78.7</td>
</tr>
<tr>
<td><strong>Charts</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tests</td>
<td>729</td>
<td>5.0</td>
<td>18.8</td>
</tr>
<tr>
<td>Drugs</td>
<td>259</td>
<td>1.8</td>
<td>6.7</td>
</tr>
<tr>
<td>Procedures</td>
<td>144</td>
<td>1.0</td>
<td>3.7</td>
</tr>
<tr>
<td>Physician visits</td>
<td>135</td>
<td>0.9</td>
<td>3.5</td>
</tr>
<tr>
<td>Other</td>
<td>213</td>
<td>1.5</td>
<td>5.5</td>
</tr>
</tbody>
</table>
## Treatment costs for NSCLC patients since last chemotherapy

<table>
<thead>
<tr>
<th>Service</th>
<th>Total ($)</th>
<th>Avg ($)</th>
<th>per PM ($)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Radiotherapy</td>
<td>43,231</td>
<td>296</td>
<td>48</td>
<td>2.7</td>
</tr>
<tr>
<td>Physician visits</td>
<td>113,459</td>
<td>777</td>
<td>125</td>
<td>7.2</td>
</tr>
<tr>
<td>Prescriptions</td>
<td>147,925</td>
<td>1,013</td>
<td>164</td>
<td>9.4</td>
</tr>
<tr>
<td>Hospitalizations</td>
<td>1,272,904</td>
<td>8,719</td>
<td>1,408</td>
<td>80.7</td>
</tr>
<tr>
<td><strong>Total (CAD)</strong></td>
<td>1,577,520</td>
<td>10,805</td>
<td>1,745</td>
<td>100.0</td>
</tr>
<tr>
<td><strong>Total (USD)</strong></td>
<td>1,151,590</td>
<td>7,888</td>
<td>1,274</td>
<td></td>
</tr>
</tbody>
</table>
Medline search

(cancer OR neoplasms)
AND
("record linkage" OR "data linkage")
Cancer control and record linkage papers

![Bar chart showing the number of papers by year.]

- <1978
- 1978-82
- 1983-87
- 1988-92
- 1992-97
- 1998-02

Number of papers by year:

- <1978: 0
- 1978-82: 50
- 1983-87: 100
- 1988-92: 150
- 1992-97: 200
- 1998-02: 250

Year
Conclusions

• The value of cancer registries for cancer control can be greatly enhanced through record linkage.

• Given the potential of linked databases for cancer control, their use should be encouraged and supported.