A Formula for Registry Survival: 
\[ \sum \text{Research} + \text{the Registry} \]

Withstanding Bugs, Bears and Bioterrorists

Donna Turner, PhD
Epidemiologist and CIHR Sr. Research Fellow
Epidemiology & Cancer Registry
CancerCare Manitoba
Einstein discovers that time is actually money.
Outline

• Cancer Registries and Cancer Control: A Reminder!

• The Case of Cancer Control Research in Manitoba
  - An Introduction to the Environment
  - Data (and Human) Resources
  - Research Initiatives
  - Benefits to the Registry
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What is cancer control?

• Cancer control encompasses all actions taken to reduce the frequency and impact of cancer.
  – prevention
  – earlier diagnosis where this may lead to a better outcome
  – treatment
  – rehabilitation
  – palliative care

(Armstrong, 1992)
Analytic Framework for Cancer Control*

Reduce the burden of cancer

- promotion/prevention
- screening/detection
- treatment & care

Implementation (policies & program delivery)

Decision making

Knowledge synthesis

Intervention Research

SURVEILLANCE & MONITORING

Fundamental research

Foundations / Infrastructure

The Role of the Registry …?

“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, Demaret and Boyle, 1985]

“The most important element within the cancer control surveillance system is the network of cancer registries…” [Greenwald, Sondik and Young, 1986]
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The Canadian Health Care System

- Comprehensiveness
- Universality
- Accessibility
- Portability
- Public Administration
Canadian Cancer Registries

- 10 provinces, 3 territories: all have CRs
- Legisllated mandate or support for population-wide cancer reporting
- All PTCRs report to the Canadian Cancer Registry
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Epidemiology

Director
Erich Kliewer Ph.D.
Epidemiologist

Epidemiologists
Donna Turner Ph.D.
Alain Demers Ph.D.

Analysts
Andre Wajda M.Sc.
Zoann Nugent Ph.D.
Karen Hildebrand M.Sc.

Information Technologists
Grace Musto B.Sc.
Wendy Fonseca-Holt B.Sc.
Xiaoyun Sun B.Sc.
Lin Xue M.Sc.

Director
Erich Kliewer Ph.D.

Epidemiologist

Administrative Officer
Cheryl Clague

Senior Cancer Registrar
Jo-Anne Walker HRT, CTR

Senior Clerical
Alfreda Cookson

Cancer Registry Manager
Jeri Kostyra CTR

Quality Control Technician
Coreen Hildebrand HRT, CTR

Senior Cancer Registrar
Jo-Anne Walker HRT, CTR

Data Processing Clerk
Jennifer Cadger HRT

Registry Clerk
Sharon Lawrence

Cancer Registrars I
Sheila Fukumura HRT
Gail Noonan HRT
Doug Buffie HRT
Angela Deneka HRT
Shannon Kornelsen HRT
Melanie deBerk HRT

Cancer Registrars II
Grace Pontanares HRT
Terri-Lee Handel HRT

Registry Clerk
Sharon Lawrence

Data Processing Clerk
Jennifer Cadger HRT

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Terri-Lee Handel HRT

Registry Clerk
Sharon Lawrence
The Manitoba Cancer Registry (MCR) ... 

- is a **data system** designed for the collection, management and analysis of data on persons with the diagnosis of a malignant neoplasm (cancer)
- is **legally mandated** (by the Public Health Act) to collect data on all cancer cases in Manitoba
- has cases dating back to the **1930s** but became **population-based** in **1956**
MCR Information Flow

Information Flow

- Provincial Hospital Abstracting System
- Vital Statistics
- Health Records
- Inter-provincial & Territorial Exchange of Information
- Letters and Reports of Malignant Neoplasms
- Annual Statistics
- Education / Research Studies
- Canadian Cancer Registry
- Epidemiology / Biostatistics
- Screening program
- Statistics Canada
- Quality Assurance
- Patient Care
- World Health Organization
- International Agency on Cancer Control
- International Association of Central Cancer Registries
- Health Care Planning & Delivery
- Public Interest
- Canadian Cancer Registry
- Statistics Canada
Confidentiality

• Personal Health Information Act (PHIA)
• Oaths of confidentiality
• Requests for information from health care professionals and researchers must get approval from
  – the Resource Impact Committee (CCMB)
  – the University of Manitoba Biomedical Research Ethics Board (BREB) or Health Research Ethics Board (HREB)
Epidemiology

• Major users of the Manitoba Cancer Registry data
• Staff:
  – Epidemiologists
  – Programmer-Analysts
  – Outcomes Analysts
Linked Data Resource for Population-Based Research

- Population Registry
- Hospital Discharges
- Physician Claims
- Pharmacy
- Diabetes
- Communicable Diseases
- IBD
- Provincial Laboratory
- Perinatal
- Screening
- Health Surveys
- Vital Statistics
- Regional Data
- OpTx
Outline

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Analytic Framework for Cancer Control*

<table>
<thead>
<tr>
<th>Cancer Site</th>
<th>Surveillance</th>
<th>Fundamental (Includes Prevention)</th>
<th>Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>All Cancer Sites</td>
<td>♦ Annual reports on cancer incidence, prevalence mortality statistics</td>
<td>♦ Examine relationship between risk factors and cancer (e.g. medical procedures, lifestyle, genetics)</td>
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<td>♦ Cancer incidence and prevalence projections for the next 10 years</td>
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<td></td>
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Cancer - the “usual” surveillance info ...

Cancer Incidence

Rate/100,000

Year

Males - Canada
Females - Canada
Males - MB
Females - MB

Data from Health Canada
Disease Surveillance On-Line
Breast cancer (females, rate per 100,000 women, 1989-99)

- 70.1 - 90.51
- 90.52 - 99.71
- 99.72 - 101.11
- 101.12 - 103.72
- 103.73 - 105.64
Improving Relative Survival of Breast Cancer Cases in Manitoba 1960-1999

Data from the Manitoba Cancer Registry
Cancer in Manitoba: Prevalence Projections

(Kliewer et al, 1999)
# Cancer Control Research

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<td></td>
</tr>
<tr>
<td>Cancer Site</td>
<td>Fundamental (Identifying Risk Factors)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------</td>
<td>----------------------------------------------------------------------------------------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Cancer in Women</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Various</td>
<td>• Risk of cancer among women with endometriosis</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Breast       | • Risk of breast cancer after abortion  
• Risk of breast cancer after tubal ligation                      |
| Cervix       | • Risk of cervical cancer after tubal ligation                                                                   |
| Ovary        | • Risk of ovarian cancer after tubal ligation                                                                    |
| Endometrial  | • Risk of endometrial cancer after tubal ligation                                                                   |
| **Cancer in Men** |                                                                                                               |
| Prostate     | • Risk of prostate cancer after vasectomy                                                                         |
| **Cancer in Men and Women** |                                                                                                               |
| Colorectal   | • Risk of colon cancer after peptic ulcer surgery                                                                   |
| Various      | • Risk of cancer among people with inflammatory bowel disease (IBD, see example)  
• Risk of cancer among diabetics  
• Risk of second primary cancers                                       |
Inflammatory Bowel Disease and Cancer

Illustration: Diagram showing the relationship between the incidence rate of cancer in Manitobans with IBD and Manitobans without IBD.

- **5,529 Manitobans with IBD**
- **5,529 Manitobans without IBD**
- **Manitoba Cancer Registry**

**IRR = Incidence Rate Ratio**

\[
\text{IRR} = \frac{\text{Cancer Incidence Rate in Manitobans with IBD}}{\text{Cancer Incidence Rate in Manitobans without IBD}}
\]

5,529 Manitobans without IBD
### Results: IBD 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>

# Cancer Control Research

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<td>Cancer Site</td>
<td>Intervention</td>
<td>Treatment and Outcomes</td>
<td></td>
</tr>
<tr>
<td>-----------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td><strong>Cancer in Women</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>• In conjunction with the Manitoba Breast Screening Program, assess the impact of the program on breast cancer mortality</td>
<td>• Manitoba Breast Cancer Outcomes Initiative: examine treatment and outcomes (see example)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Investigate the effect of hormone replacement therapy on the capacity to detect breast cancer of mammograms</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cervix</td>
<td>• In conjunction with the Manitoba Cervical Screening program, assess the impact of the program on Pap smear use and cervical cancer mortality</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Cancer in Men</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prostate</td>
<td>• Examine use of PSA tests in the population</td>
<td>• Manitoba Prostate Cancer Outcomes Initiative: examine treatment and outcomes</td>
<td></td>
</tr>
<tr>
<td><strong>Cancer in Men and Women</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Colorectal</td>
<td>• Investigate public acceptance of fecal occult blood testing for colorectal cancer screening</td>
<td>• Manitoba Rectal Cancer Overview: examine treatment patterns and outcomes</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Examine colorectal screening practices (ad hoc and/or within a program, if one is introduced) and effects</td>
<td>• Manitoba Rectal Cancer Outcomes Initiative: Local Recurrence</td>
<td></td>
</tr>
<tr>
<td>Lung</td>
<td></td>
<td>• Manitoba Lung Cancer Treatment and Outcomes Study: examine treatment and outcomes in advanced stage</td>
<td></td>
</tr>
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Manitoba Breast Cancer Outcomes Initiative

- What treatment do Manitoba women with breast cancer receive?
  - In particular, how do the rates of breast surgery compare with official guidelines and other Canadian benchmarks?

- What is the expected survival for Manitoba women with breast cancer?
  - How does it compare to international standards?
Manitoba Breast Cancer Outcomes Initiative

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Clinical Practice Guidelines for the Care and Treatment of Breast Cancer

For patients with stage I or II breast cancer, BCS followed by radiotherapy is generally recommended. In the absence of special reasons for selecting mastectomy, the choice between BCS and mastectomy can be made according to the patient’s circumstances and personal preferences.

CMAJ 1998
## Results: Breast Conserving Surgery

<table>
<thead>
<tr>
<th>Study</th>
<th>Location</th>
<th>Treatment Years</th>
<th>Number Studied</th>
<th>Study Patients</th>
<th>Study BCS</th>
<th>Manitoba BCS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Iscoe CMAJ 1994</td>
<td>Ontario</td>
<td>1989-1991</td>
<td>12,815</td>
<td>Stage I-IV Unilateral surgery</td>
<td>52%</td>
<td>46.1%</td>
</tr>
<tr>
<td>Paszat Int J Radiat Oncol Biol Phys 2000</td>
<td>Ontario</td>
<td>1990-1991</td>
<td>11,016</td>
<td>Stage I-IV</td>
<td>45.7%</td>
<td>43.5%</td>
</tr>
<tr>
<td>Goel CMAJ 1997</td>
<td>Ontario</td>
<td>1991</td>
<td>938</td>
<td>Path node-negative Mult minor exclusions.</td>
<td>67.6%</td>
<td>41.8%</td>
</tr>
<tr>
<td></td>
<td>BC</td>
<td></td>
<td>942</td>
<td></td>
<td>43.8%</td>
<td></td>
</tr>
<tr>
<td>Hebert-Croteau CMAJ 1999</td>
<td>Quebec</td>
<td>1988-1994</td>
<td>1,259</td>
<td>Node Neg Stage I &amp; II</td>
<td>82.5%</td>
<td>?</td>
</tr>
<tr>
<td>Guadagnoli et al J Clin Oncol 1998</td>
<td>Minnesota Mass.</td>
<td>1993-1995</td>
<td>1,514 1,061</td>
<td>Stage I &amp; II</td>
<td>64% 38%</td>
<td>41.2%</td>
</tr>
</tbody>
</table>
Reasons for AND:
• Prognosis
• Regional control
• Treatment decisions
• Improved survival?

Disadvantages:
• Chronic pain
• Swelling of arm
Axillary surgery, whether a full or limited procedure, should not be performed in women with DCIS.
<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total women</strong></td>
<td>3,956</td>
<td></td>
</tr>
<tr>
<td><strong>Total AND</strong></td>
<td>2,906</td>
<td>73.5</td>
</tr>
<tr>
<td><strong>T-class</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tis</td>
<td>99</td>
<td>23.5</td>
</tr>
<tr>
<td>T1</td>
<td>1,620</td>
<td>81.9</td>
</tr>
<tr>
<td>T2</td>
<td>873</td>
<td>88.5</td>
</tr>
<tr>
<td>T3</td>
<td>94</td>
<td>90.4</td>
</tr>
<tr>
<td>T4</td>
<td>75</td>
<td>59.1</td>
</tr>
<tr>
<td>Tx</td>
<td>145</td>
<td>42.5</td>
</tr>
<tr>
<td><strong>Nodal status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Negative</td>
<td>1,893</td>
<td>97.4</td>
</tr>
<tr>
<td>Positive</td>
<td>992</td>
<td>98.3</td>
</tr>
<tr>
<td>Unknown</td>
<td>21</td>
<td>2.1</td>
</tr>
<tr>
<td><strong>Summary stage</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage 0</td>
<td>96</td>
<td>23.3</td>
</tr>
<tr>
<td>Stage I</td>
<td>1,195</td>
<td>99.4</td>
</tr>
<tr>
<td>Stage II</td>
<td>1,210</td>
<td>99.2</td>
</tr>
<tr>
<td>Stage III</td>
<td>151</td>
<td>87.3</td>
</tr>
<tr>
<td>Stage IV</td>
<td>53</td>
<td>38.7</td>
</tr>
<tr>
<td>Unknown</td>
<td>201</td>
<td>24.8</td>
</tr>
<tr>
<td># Nodes examined</td>
<td>DCIS Nodes</td>
<td></td>
</tr>
<tr>
<td>------------------</td>
<td>------------</td>
<td></td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>10 or more</td>
<td>30</td>
<td>31.3</td>
</tr>
<tr>
<td>6-9 nodes</td>
<td>42</td>
<td>43.7</td>
</tr>
<tr>
<td>&lt;6 nodes</td>
<td>16</td>
<td>16.7</td>
</tr>
<tr>
<td>Missing</td>
<td>8</td>
<td>8.3</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>96</td>
<td>100.0</td>
</tr>
</tbody>
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Manitoba Breast Cancer Outcomes Initiative

• What treatment do Manitoba women with breast cancer receive?
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Results: Breast Cancer Survival by Stage
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Benefits to the Registry

1 Transforming data into information

– The two functions (Epi-Registry) are essential for providing meaningful cancer control info
– Raise the profile of the Registry through the use of the data
– Skilled analysts available for (timely) Registry data support who understand the Registry
– Smooth flow of data to analysts (and back) when Registry and research unit are together
Benefits to the Registry

2 Record linkage capabilities

– An enhanced Registry environment
– More data, better coverage of spectrum of cancer control
– “Registry may not be all things to all people but linkage helps us to achieve our goal.”
Benefits to the Registry

3 Data quality

- Improvements in data quality (things discovered during analysis)
- Research funds may be requested to enhance Registry data elements
- Linkage to other datasets: chance to review Registry content
Benefits to the Registry

• *In short* …
  – More “power” in the data
  – More stability of support for the Registry
  – More opportunities!
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www.cancercare.mb.ca:

Epidemiology and Cancer Registry – Reports

donna.turner@cancercare.mb.ca