The Development of an E-Cancer Registry

Princess Margaret Hospital

University Health Network

Darlene Dale
Head, PMH Cancer Registry

“Right off the Bat-Electronic Reporting”

NAACCR June 2005
Outline

• Overview of Princess Margaret Hospital Toronto, Canada
• Case Ascertainment Processes
• Enterprise Data Warehouse integration into the Cancer Registry
• Data Uses
Princess Margaret Hospital

- Princess Margaret Hospital opened in 1958 in Toronto, Canada
  - Hospital Cancer Registry has data back to the beginning
- Comprehensive Cancer Centre Treatment Facility which is part of the *University Health Network* along with 2 Acute Care Facilities
- Over 10,000 new cases per year are seen at PMH
Historical Case Finding Methods

  - Charts were pulled for abstracting
  - Manual process was used to identify second primaries
- 1998-2002 - Demographics from scheduling lists downloaded into Cancer Registry software
  - List of all appointments not just new patients, including non-neoplasics
  - Monthly lists were reviewed to determine cases to process
Since July 2002, physicians required to classify and stage all new patients to PMH

Cases for Physicians to stage automatically downloaded from scheduling system, prepared 2 days in advance

- New Patients

Must be completed within 3 months of the first appointment

- Use on-line staging application developed at PMH with built in UICC staging guidelines
- Audit process in place to ensure completeness
Darlene Dale is logged in since: June 03, 2005 at 02:02PM

Edit Patient Information

Patient's Name: Flinstone, Fred
Birth Date: Jun 3 / 2005
Gender: F
Medical Record Number: 78
Source: Administrator
Record Creation Date: 06/03/05

Cases: IIIB-Malignant-June 03, 2005
Appt Date: Jun 3 / 2005
Disease is: Malignant
Reason for referral: New Diagnosis of Primary
Site Group: Thorax
Malignant Disease: Lung non-small-cell

TNM Help
Clinical T: T3
Clinical N: N0
Clinical M: M0
Post Neo-Adjuvant
Pathological T: T3
Pathological N: N1
Pathological M: M0

Stage Help
OVERALL Clinical Stage: IIIB
OVERALL Pathological Stage: IIIA

Responsible Oncologist: Dr. Cancer Registrar

Record History | Delete Case... | Delete Patient... | No Show | Cancel | Save | Signoff...
Staging Completeness By Department
2003 and 2004

Radiation Oncology
Surgical Oncology
Medical Oncology & Blood Disorders

95% Complete

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E-Cancer Registry
Enterprise Data Warehouse (EDW)

- EDW integrates information from various transactional systems within the UHN in order to provide a single environment that facilitates analysis for both the corporate and research communities.
- *Not just oncology cases, institution wide*
- Currently houses data from over 14 transactional systems including:
  - cancer staging, patient demographics, visits, pharmacy, radiation therapy, surgery
Data Sources in EDW Integrated into the Cancer Registry

- Cancer Staging
- Patient Scheduling
- Clinical Desktop-Electronic Chart
- Radiation Therapy
- Pharmacy
  - Chemotherapy
  - Hormones
- Future
  - Surgery
  - Chemotherapy & Hormones from order/administer system
  - Synoptic Pathology
  - Radiology

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## Data Elements Transferred from EDW to Cancer Registry Software

<table>
<thead>
<tr>
<th>Data Elements</th>
<th>Total Number</th>
<th>Available in Data Warehouse</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract</td>
<td>10</td>
<td>8</td>
</tr>
<tr>
<td>Patient ID</td>
<td>19</td>
<td>11</td>
</tr>
<tr>
<td>Tumour/Extent of Disease</td>
<td>27</td>
<td>12</td>
</tr>
<tr>
<td>Treatment-Surgery</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Treatment-Radiation</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>Treatment-Chemotherapy</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td>Hormone</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Biological</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>Admission/Follow-Up</td>
<td>12</td>
<td>7</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td><strong>97</strong></td>
<td><strong>48 (49.5%)</strong></td>
</tr>
</tbody>
</table>
### Patient Information (at time of diagnosis)

<table>
<thead>
<tr>
<th>Title [Mr., Mrs., Dr.]</th>
<th>Mr.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surname</td>
<td>FLINSTONE</td>
</tr>
<tr>
<td>Given Name</td>
<td>Fred</td>
</tr>
<tr>
<td>Middle Name</td>
<td></td>
</tr>
<tr>
<td>Alias Surname</td>
<td></td>
</tr>
<tr>
<td>Alias - Given Name</td>
<td></td>
</tr>
<tr>
<td>Maiden Name</td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td>Male</td>
</tr>
<tr>
<td>Date of Birth</td>
<td>1999-99-99</td>
</tr>
<tr>
<td>Diagnosis Date</td>
<td>999</td>
</tr>
<tr>
<td>Age at Diagnosis</td>
<td>999 (999 means 'unknown')</td>
</tr>
</tbody>
</table>

### Patient Address at time of diagnosis:

- Address: Street/No: 1155 FIRST STREET
- Cty: NEW TOWN
- County:     
- State/Province: ON Ontario
- ZIP/Postal Code: M1M4M3

### Patient Current Address:

- Address: Street/No: 1155 FIRST STREET
- Cty: NEW TOWN
- County:     
- State/Province: ON Ontario
- ZIP/Postal Code: M1M4M3

- Chart/MRN: 007
- Old T Number:     
- Health Insurance Number: 1111111111
Gaps in Current Case Finding

- Missing some in-patients as they are admitted immediately, not scheduled 2 days in advance:
  - Manually entered
  - As of May 2005, electronically captured
- Missing some palliative radiation, not scheduled 2 days in advance:
  - Manually added once a month
- Missing some surgical cases, booked through surgical booking
  - Manually entered
  - As of June 2005, electronically captured
**Advantages of E-Registry**

- The demographics are downloaded. These are tedious to enter: name, full address, date of birth.
- First contact date gives a hint as to where to start in reviewing the electronic chart which is UHN wide, not oncology specific.
- Can specify what types of cases to download:
  - Malignant, in-situ, benign, non-neoplastic.
- Physician selects generic primary site:
  - Can pull out certain cases if required.

*Staff cannot think of any disadvantages*

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Data Use
PMH Breast Patients by TNM Status

Months After Diagnosis

Overall Survival

TNM=1
TNM=2
TNM=3
TNM=4

Months After Diagnosis
PMH Prostate Patients by TNM Status

Overall Survival

Months After Diagnosis

TNM=1
TNM=2
TNM=3
TNM=4
Data Requests-2004

Total Number of Data Access Requests
80 Requests

- Request for Cancer Registry/Databases
  - 70 Requests
    - Administrative Requests
      - 29 Cases
    - Research Requests
      - 41 Cases

- Requests for Other Data Sources
  - 10 Requests
    - Administrative Requests
      - 2 Cases
    - Research Requests
      - 8 Cases
CRDAC Data Access Requests as of June 2, 2005

- Total Number of Data Access Requests: 71 Requests
  - Request for Cancer Registry/Databases: 42 Requests (59.0%)
    - Administrative Requests: 15 Cases (35.7%)
    - Research Requests: 27 Cases (64.3%)
  - Requests for Other Data Sources: 29 Requests (42.0%)
    - Administrative Requests: 1 Case (1.4%)
    - Research Requests: 28 Cases (40.6%)

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Conclusions

• The Physician-on-line Cancer Staging application drives the registry’s case finding process

• The development of the E-Registry tool and incorporation into the EDW has enabled data to be rapidly accessed, which greatly facilitates analysis for both administrative and research purposes.