The Death Clearance Process: What Do We Gain From Our Efforts?

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Objectives

• Demonstrate the variability of resolution from follow back to hospitals versus physicians.
• Illustrate how much additional information is typically obtained from those followbacks (FBs) which are potential multiple primaries.
• Emphasize some of the key issues that the New York State Cancer Registry (NYSCR) continues to encounter during the followback process.
Background

• NYSCR does not have access to hard copy death certificates or SuperMICAR files
• Rely on Vital Records mortality files
  – Link to multiple cause of death files
  – Include out-of-state deaths
• Also link DCOs to hospital discharge data
  – Additional followback to hospitals where patient was seen prior to death
Linkage

• After the Registry database is linked with the electronic mortality file, an automatic tumor linkage program is run.

• Certain combinations of codes are assumed to represent a single primary. Examples:
  – DC code of liver. Facility reported colon.
  – DC code of bone. Facility reported prostate.

• All remaining patient matches are visually reviewed to determine if additional tumors should be matched based on documented text.
Reconciliation Process

• Followbacks are automatically tracked for resolution in an application monitored by field staff.
• Followbacks that are submitted are linked by facility/MD number, patient’s name, DOB and SSN.
• Information regarding non-reportable or previously-reported cases provided by reporting facilities/MDs is updated in the tracking system by field staff.
2009 Death Clearance

- 3,458 cases did not match
  - 2,740 non-patient matches
  - 718 non-tumor matches
- Some cases were sent to multiple sources for resolution
- 4,298 followback requests were sent
  - 2,159 were sent to hospitals
  - 2,124 were sent to physicians
- 289 out-of-state deaths were not sent for followback
  - Automatically counted as DCOs
Hospital Followbacks

- Hospitals are very responsive
- Lists sent electronically in two rounds approximately two months apart:
  - 1\textsuperscript{st} list contains non-patient matches
  - 2\textsuperscript{nd} list contains additional non-patient matches, but mostly potential non-tumor matches
- One case might be sent for reconciliation to multiple facilities
2009 Hospital Followback Results

• 2,159 cases were sent for reconciliation
  – 1,307 (60.5%) followback cases submitted
  – 302 (14.0%) did not have a reportable cancer
  – 278 (12.9%) confirmed not to have an additional primary
  – 185 (8.6%) were not treated for that cancer at facility
  – 50 (2.3%) patients were unknown to facility or charts were missing
  – 37 (1.7%) cases with no response (mostly VAs)

• 98.3% hospital response rate
• 87.4% were eliminated as DCOs
# Hospital Followback Results

## Percent Unknown/Non-Specific

<table>
<thead>
<tr>
<th>Variable</th>
<th>Patient Non-Match</th>
<th>Tumor Non-Match</th>
</tr>
</thead>
<tbody>
<tr>
<td>DX Conf=9</td>
<td>16</td>
<td>18</td>
</tr>
<tr>
<td>DX Conf=7,8</td>
<td>35</td>
<td>21</td>
</tr>
<tr>
<td>Hist=8000, 8010</td>
<td>44</td>
<td>45</td>
</tr>
<tr>
<td>Dx Month &amp; Day=99</td>
<td>29</td>
<td>29</td>
</tr>
<tr>
<td>SS2000=9</td>
<td>42</td>
<td>46</td>
</tr>
</tbody>
</table>
Physician Followbacks

- Cases are securely mailed
- Response forms are included
- Encourage physicians to obtain Health Commerce System accounts (for electronic reporting)
- Poor response from physicians
- Very labor intensive/not cost effective
2009 Physician Followback Results

- 2,124 cases were sent for reconciliation
  - 324 (15.3%) followback cases submitted
  - 30 (1.4%) patients did not have reportable cancer
  - 253 (11.9%) patients were not treated by MD or MD did not have information about the cancer
  - 38 (1.8%) cases were confirmed to have been previously reported by a hospital
  - 1,479 (69.6%) cases remain outstanding

- 28.6% physician response rate

- 18.5% were eliminated as DCOs (some were duplicates of resolved hospital cases)
## Physician Followback Cases Percent Unknown/Missing

<table>
<thead>
<tr>
<th>Variable</th>
<th>% Unk</th>
<th>Variable</th>
<th>% Unk</th>
</tr>
</thead>
<tbody>
<tr>
<td>Address - City</td>
<td>18</td>
<td>Path TNM</td>
<td>92</td>
</tr>
<tr>
<td>Address - State</td>
<td>7</td>
<td>Clin TNM</td>
<td>85</td>
</tr>
<tr>
<td>Date Dx - Month</td>
<td>21</td>
<td>Summary Rx Status</td>
<td>27</td>
</tr>
<tr>
<td>Primary Site</td>
<td>10</td>
<td>Reg LN surgery</td>
<td>78</td>
</tr>
<tr>
<td>Histology</td>
<td>64</td>
<td>Surgery date</td>
<td>94</td>
</tr>
<tr>
<td>Grade</td>
<td>86</td>
<td>Radiation Type</td>
<td>85</td>
</tr>
<tr>
<td>Confirmation</td>
<td>29</td>
<td>Primary Payer</td>
<td>98</td>
</tr>
</tbody>
</table>
## Cost of Physician DCO Mailing

<table>
<thead>
<tr>
<th>Cost Category</th>
<th>Cost/Letter</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mailing Supplies</td>
<td>$0.55</td>
</tr>
<tr>
<td>Postage</td>
<td>$1.50</td>
</tr>
<tr>
<td>Labor</td>
<td>$3.46</td>
</tr>
<tr>
<td><strong>Total per Letter</strong></td>
<td><strong>$5.51</strong></td>
</tr>
</tbody>
</table>

Total Cost for all MD DCO Mailings: **$11,703.24**
Overall Results (de-duplicated cases)

- 3,458 non-matches
  - 2.90% DCO rate prior to followback
- 1,414 tumors added to database
- 573 potential DCOs eliminated via followback
- 214 eliminated for other reasons (e.g., lab followback)
- 968 DCOs (incl. the 289 out-of-state deaths)
  - 0.81% DCO rate after followback
Potential DCOs Eliminated

- N = 573
- 284 cases were determined to be not reportable (e.g., hematopoietic cases diagnosed prior to 2001, no mention of cancer in the record, SCC/BCC of skin)
- 243 cases confirmed not to have an additional primary
- 46 cases already on database but not linked correctly
Reconciliation of Potential Multiple Primaries

- 690 cases where tumor information was “different enough” such that followback was performed
  - 264 submitted as new primaries
  - 243 cases confirmed not to have an additional primary
  - 183 cases no information/not reconciled (mostly MD cases)
    - Not counted as DCOs
Potential Multiple Primaries

- Therefore, 52% of the potential multiple primaries that were reconciled (264/507) resulted in an additional tumor.

However:
- 41% were submitted with a diagnostic confirmation of 7-9 (radiography, clinical, or unknown).
- 46% were submitted with a histology code reflective of cancer, NOS or carcinoma, NOS.
- 25% were submitted with non-specific diagnosis dates.
Top Five Sites Reconciled As “Missed” Multiple Primaries

1. Lung
2. Bone Marrow (approx 1/3 myelomas)
3. Pancreas
4. Prostate
5. Colon
Cases Confirmed Not to Have An Additional Primary

- Verification that site on death certificate was mets or extension from primary (ex. prostate with extension to bladder)
- No mention of multiple primary in medical record
- DC reflects a non-malignant condition and was miscoded
## Examples of Miscoded Death Certificates

<table>
<thead>
<tr>
<th>Coded</th>
<th>Actual</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>bladder</td>
<td>gallbladder</td>
<td>multiple</td>
</tr>
<tr>
<td>pancreas</td>
<td>ductal carcinoma of breast</td>
<td>multiple</td>
</tr>
<tr>
<td>multiple myeloma</td>
<td>malignant melanoma</td>
<td>multiple &amp; vice versa</td>
</tr>
<tr>
<td>pharynx</td>
<td>thyroid</td>
<td>various head &amp; neck issues</td>
</tr>
<tr>
<td>adrenal gland</td>
<td>olfactory neuroblastoma</td>
<td></td>
</tr>
</tbody>
</table>
Summary

• Following back potential multiple primaries results in finding missed cases (50% yielded an additional tumor)
• Question reliability of information on certain multiple primaries
• Subsequent hematopoietic primaries appeared to have more complete information
Summary

• Physician followback is costly and very labor intensive
• Results in minimal followbacks
• Many followbacks contain poor quality data
• NYSCR is temporarily discontinuing following back to physicians
• Will reassess in future
Summary

• NYSCR has developed procedures to automate DCO tumor linkage process and tracking of follow-back reports
• Death clearance continues to be a time consuming process
• Estimate 700-750 staff hours annually
• Feedback from other registries is important to inform the NAACCR Death Clearance Process
Thank You!

Questions?