Finding “Zombies” in Your Registry Database by Confirming Source Record Vital Status

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Why is Vital Status Data Important?

- Cancer control planning
- Patient follow-back
- Survival analysis
- Outcomes of cancer care
- Some research studies need to be conducted on patients known to be alive
Ways to Determine Vital Status

- **State mortality database (SMD)**
  - For deaths of your state’s residents

- **Social Security Death Index (SSDI)**
  - For your cancer cases moved to another state
  - No COD
  - Only for SSA beneficiaries

- **National Death Index (NDI)**
  - For your cancer cases moved to another state
Not all Deaths Discoverable

- People who died out-of-country
- Deaths never reported to the state (no death certif)
- Death information reported late after NDI closes its current death year
Cases Reported as Deceased

- Death information in patient’s medical record
  - Copy of death certificate
  - Note from primary physician
- Follow-up with primary physician
- Obituary search
- Hopefully source of death information was recorded in the “Text--Remarks” field!
Cases not linking to SMD, SSDI, NDI

- Reported alive but really deceased, case considered an “Immortal” – forever living in your registry
- Reported deceased but really alive, case considered a “Zombie” – the undead!
Why are Zombies in Your Registry?

- Registrar had good death information from the medical record or from patient follow-back
- OR... it was a typo!
- Look in “Text--Remarks” field for death documentation
- If no documentation, then Zombie candidate
Why Do We Care About Zombies?

- We want accurate vital status information
- They usually don’t show up on a registry’s radar for verification
How Do We Find Zombies?

- Easier to find Zombies than Immortals.
- For Immortals, how can you tell if a living patient is actually supposed to be deceased?
  - High survival for lethal cancers
  - Patients 105+ years old
  - Presentation by Diane Nishri, Cancer Care Ontario
- If you track death linkages, you can flag deceased cases without SMD, SSDI, or NDI linkages
- Can also use “Follow-up Source Central”
Alaska’s Zombie Study

- Alaska Cancer Registry (ACR) has 3 non-NAACCR flag fields for linkages with SMD, SSDI, and NDI
- After annual SMD linkage, ACR identified 85 potential Zombie cases
- 0.2% of total reportable cases
- 44 cases (51.2%) reported by other central cancer registries
  - 37 by OOS registries
  - 7 by Alaska Native Tumor Registry
Knocking Down the Zombies

- After SSDI linkage, 50 case verified as deceased
- After NDI linkage, 15 more cases verified as deceased
- Total of 65 (76.5%) resolved by SSDI & NDI linkage
- 20 cases remained for manual review
Manual Review

- Alaska-specific databases used to verify vital status
  - Alaska Permanent Fund Dividend (PFD) Applicant database
  - State Police (Troopers) database
Manual Review Results

- 14 cases (70% of manual review cases) were true Zombie cases & verified as alive – vital status changed to alive

- Remaining 6 cases verified as deceased
  - 3 died out of country, death info documented in abstract
  - 2 died in-state (no death certificate), death info documented in abstract
  - 1 OOS source record, verified as deceased by that registry
## Study Summary

<table>
<thead>
<tr>
<th>Category</th>
<th># of Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Potential Zombie cases discovered after death clearance</td>
<td>85</td>
</tr>
<tr>
<td>Resolved by SSDI linkage</td>
<td>50</td>
</tr>
<tr>
<td>Further resolved by NDI linkage</td>
<td>15</td>
</tr>
<tr>
<td>Potential Zombie cases remaining</td>
<td>20</td>
</tr>
<tr>
<td>True Zombie cases, confirmed alive, changed vital status</td>
<td>14</td>
</tr>
<tr>
<td>Died out of country</td>
<td>3</td>
</tr>
<tr>
<td>Died in state</td>
<td>2</td>
</tr>
<tr>
<td>OOS source record</td>
<td>1</td>
</tr>
</tbody>
</table>
Implication for Other Registries

- Manual reviewed 20 cases for Alaska, but relatively small annual caseload
- Caseloads of most other states are much larger.
- Potential manual review cases for largest states:
  - 662 for NY
  - 701 for TX
  - 728 for FL
  - 1040 for CA
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