

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

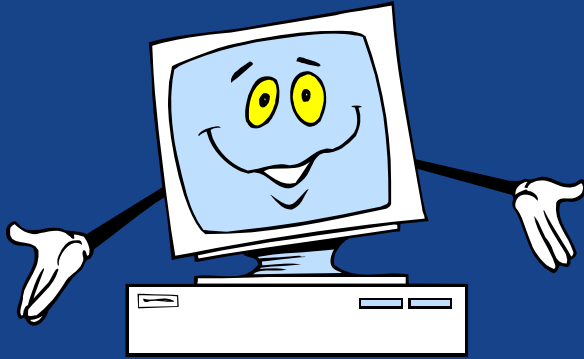
	# of Cases
Potential Zombie cases discovered after death clearance	85
Resolved by SSDI linkage	50
Further resolved by NDI linkage	15
Potential Zombie cases remaining	20
True Zombie cases, confirmed alive, changed vital status	14
Died out of country	3
Died in state	2
OOS source record	1

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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Thanks very much!

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