

Assessment of Duplicate Cancer Cases in Utah and Idaho: Improving Interstate Cancer Surveillance

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Cancer Data Registry of Idaho

NAACCR 2013 CONFERENCE

June 13, 2013

Cancer Data
Registry of Idaho



The Team

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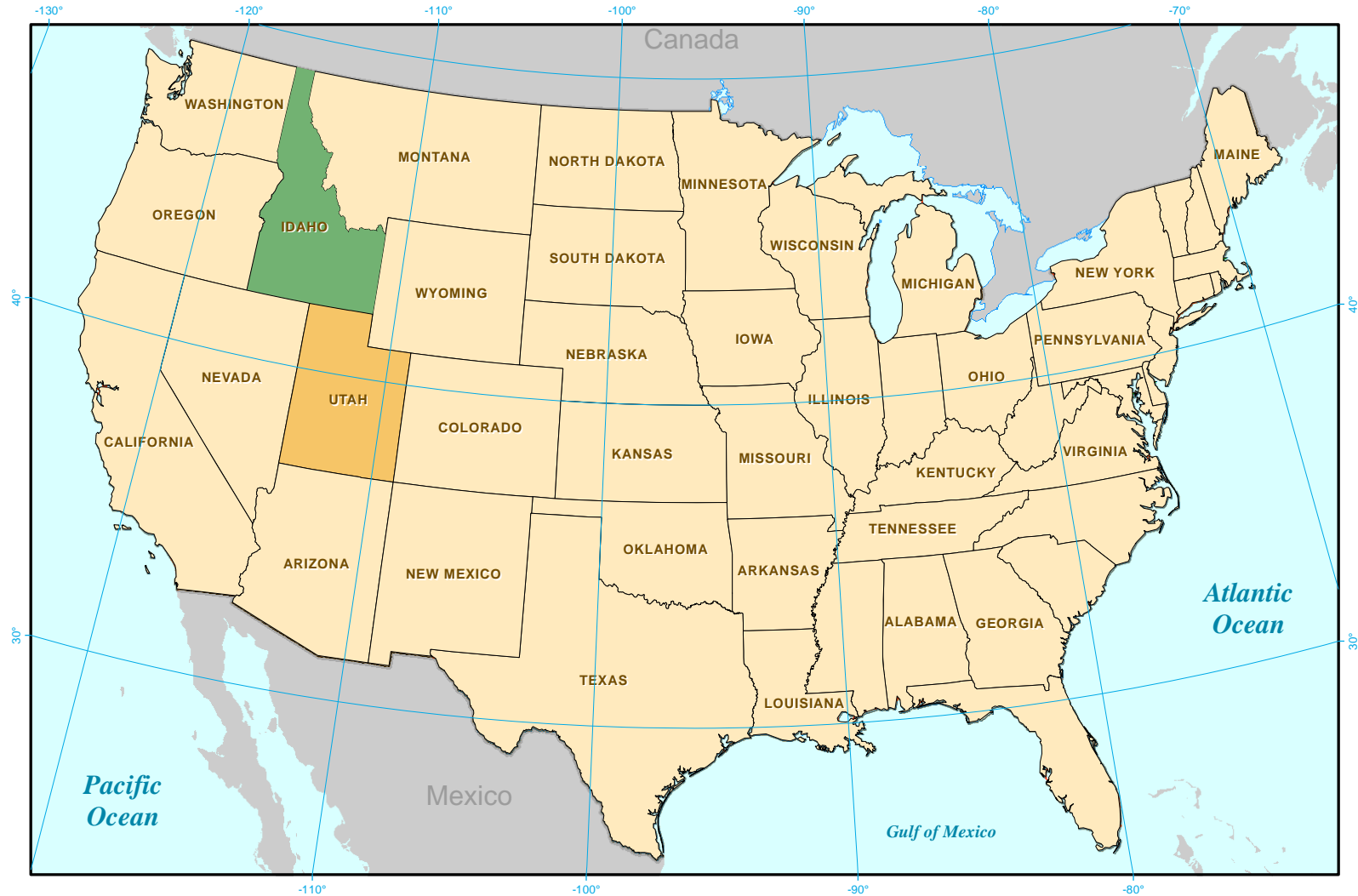
The Project

- Cancer surveillance across the United States (US) occurs within state and territorial administrative boundaries.
- Central registry staff make decisions about residential status and reportability based on information submitted by health care providers and hospital tumor registrars.

The Project

- Because these data are de-identified and pooled for national statistics, it is not possible to consolidate information on the same case from multiple states and address issues related to case duplication.
- Furthermore, it is unknown what impact interstate consolidation and de-duplication might have on measures of the US cancer burden, such as incidence rates, or data quality indicators, such as percent of cases reported solely via death certificates.

The Project

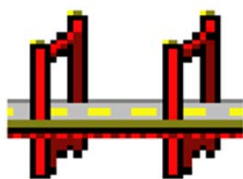


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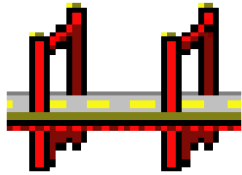
IRB Determinations

- Submitted to both University of Utah and Idaho Division of Public Health Institutional Review Boards.
- Determination by both IRBs was that project did not meet the definitions of Human Subjects Research according to Federal regulations.



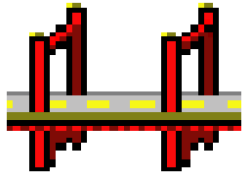
Person Linkage

- Each state created a dataset of 1980-2010 state resident cases.
- From these, each state created a person-specific dataset for the linkage using the most recently reported case for each person.
- Utah: 174,571 people
- Idaho: 136,125 people



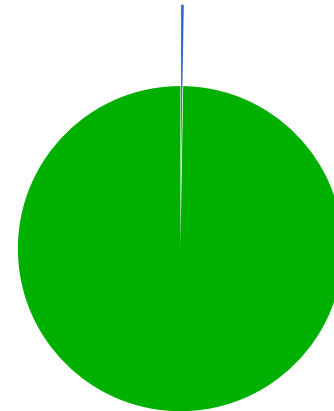
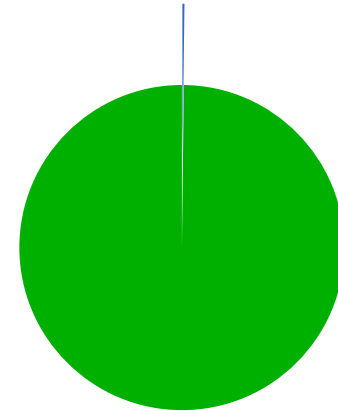
Person Linkage

- **Link Plus Software**
 - (V2 on one machine, V3 on another)
- **Blocking Variables:**
 - Soundex functions of Last Name, First Name, Middle Name; SSN, Birth Date.
- **Matching Variables:**
 - Last Name, First Name, Middle Name, SSN, Birth Date, Sex.
- **Manual Review.....**
 - With High Cutoff Score = 20.0, **N=344 matches**
 - After Manual Review, **N=352 matches**
 - Lowest Score deemed to be a match = 13.9



Person Linkage

- N=352 matches
- Utah:
 $352 / 174,571 = 0.20\%$
- Idaho:
 $352 / 136,125 = 0.26\%$



Case Deduplication

- For the 352 matching people, collect all of the cases from each registry.
 - Multiple records per person – one for each tumor.
- Utah: 381 cases 1980-2010
2 cases earlier than 1980
2 cases later than 2010
- Idaho: 386 cases 1980-2010
- Combined: **771 cases**

Adjudicate Potential Duplicates

- How to decide which state keeps the cases?



Adjudicate Potential Duplicates

1. Using IARC/IACR MP/H Rules (IARCCrgTools).
2. Using alpha version of SAS Program to implement SEER MP/H Rules.
3. CTR staff review case history for each person and use SEER MP/H rules to determine duplicate cases.

Adjudicate Potential Duplicates Using IARC MP/H Rules

- Three runs of IARCcrgTools Multiple Primary Program
 - Idaho cases alone
 - Utah cases alone
 - Combined cases

Adjudicate Potential Duplicates Using IARC MP/H Rules

1995-2010 Case Counts for Linked Persons
Under IARC MPH Rules

Type of Reporting Source	One State Alone		Combined Data		Characteristics of "Double-Counted"	
	Idaho	Utah	Idaho	Utah	Idaho	Utah
Hospital inpatient	156	189	109 70%	157 83%	47 30%	32 17%
Laboratory only	10	24	6 60%	18 75%	4 40%	6 25%
Physician office	31	3	18 58%	1 33%	13 42%	2 67%
Death certificate only	35	5	7 20%	1 20%	28 80%	4 80%
Other	1	0	1 100%	0 -	0 0%	0 -
Total	233	221	141 61%	177 80%	92 39%	44 20%

Note that IARC MPH Rules do not consider in situ cases besides bladder.

Adjudicate Potential Duplicates Using IARC MP/H Rules

1995-2010 Case Counts for Linked Persons
Under IARC MPH Rules

Primary Site (Top 10)	One State Alone					
	Idaho			Utah		
	Beh 0	Beh 2	Beh 3	Beh 0	Beh 2	Beh 3
Prostate	0	0	43	0	0	41
Breast	0	0	31	0	0	26
Lung and Bronchus	0	0	19	0	0	18
Melanomas - Skin	0	0	19	0	0	10
Colon and Rectum	0	0	14	0	0	15
Leukemia	0	0	14	0	0	14
Non-Hodgkin Lymphoma	0	0	10	0	0	14
Brain and Other Nervous System	1	0	9	4	0	6
Urinary Bladder	0	3	6	0	7	6
Pancreas	0	0	8	0	0	7

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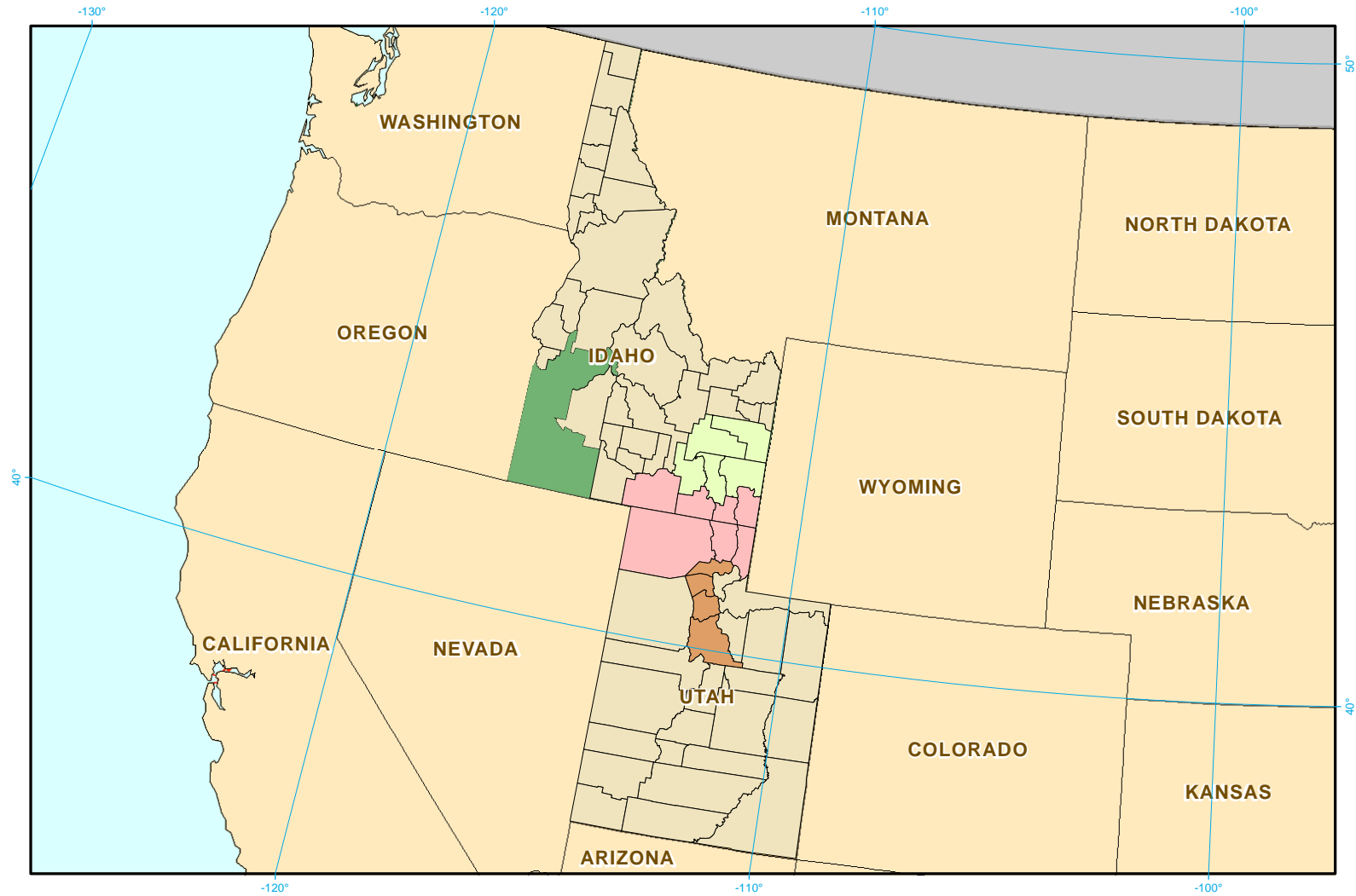
Adjudicate Potential Duplicates Using IARC MP/H Rules

1995-2010 Case Counts for Linked Persons
Under IARC MPH Rules

Primary Site (Top 10)	Characteristics of "Double-Counted"					
	Idaho		Utah			
	Behavior 3		Behavior 2		Behavior 3	
Prostate	22	51%	0		11	27%
Breast	17	55%	0		6	23%
Lung and Bronchus	5	26%	0		4	22%
Melanomas - Skin	7	37%	0		1	10%
Colon and Rectum	4	29%	0		4	27%
Leukemia	6	43%	0		3	21%
Non-Hodgkin Lymphoma	4	40%	0		1	7%
Brain and Other Nervous System	4	44%	0		0	0%
Urinary Bladder	3	50%	2	29%	1	17%
Pancreas	3	38%	0		0	0%

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Does Geography Matter?



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Adjudicate Potential Duplicates Using IARC MP/H Rules

1995-2010 Case Counts for Linked Persons
Under IARC MPH Rules

Geographic Area	State Alone	"Double-Counted"	
Idaho: Border	35	11	31%
Idaho: Near Border	74	32	43%
Idaho: Boise Metro	54	19	35%
Idaho: Other	70	30	43%
Utah: Border	25	3	12%
Utah: Wasatch Front	142	26	18%
Utah: Other	54	15	28%

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Adjudicate Potential Duplicates Using SEER MP/H Rules (SAS program)

- Actually, 19 SAS programs that create lookup tables, define functions, and run macros to process the cases.
- Thanks!!!
 - Gary Levin, Florida Cancer Data System and Florida Department of Health
 - Genevieve Boucher, Quebec Public Health Information Center
 - Rabia Louchini, Quebec Public Health Institute

Adjudicate Potential Duplicates Using SEER MP/H Rules (SAS program)

1995-2010 Case Counts for Linked Persons
Under SEER MPH Rules

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	Idaho	Utah	Idaho	Utah	Idaho	Utah
Hospital inpatient	166	202	130 78%	181 90%	36 22%	21 10%
Laboratory only	12	28	8 67%	24 86%	4 33%	4 14%
Physician office	36	3	28 78%	1 33%	8 22%	2 67%
Death certificate only	35	5	17 49%	2 40%	18 51%	3 60%
Other	1	0	1 100%	0 -	0 0%	0 -
Total	250	238	184 74%	208 87%	66 26%	30 13%

Adjudicate Potential Duplicates Using SEER MP/H Rules (SAS program)

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Breast	0	3	31	0	5	27
Melanomas - Skin	0	6	21	0	5	12
Lung and Bronchus	0	0	19	0	0	19
Colon and Rectum	0	0	15	0	0	15
Leukemia	0	0	15	0	0	14
Non-Hodgkin Lymphoma	0	0	10	0	0	14
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Melanomas - Skin	0 0%	1 5%	0 0	0 0%
Lung and Bronchus	0	4 21%	0	5 26%
Colon and Rectum	0	5 33%	0	1 7%
Leukemia	0	4 27%	0	1 7%
Non-Hodgkin Lymphoma	0	4 40%	0	0 0%
Brain and Other Nervous System	0	4 44%	0	0 0%
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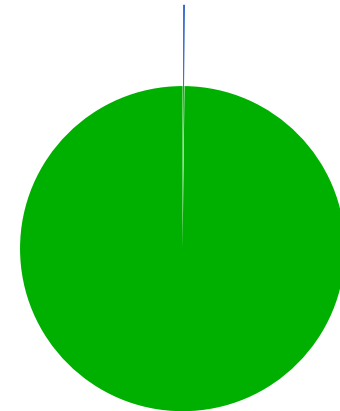
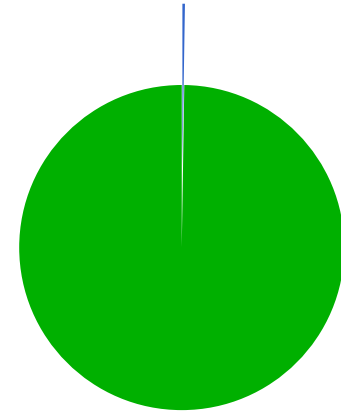
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Geographic Area	State Alone	"Double-Counted"	
Idaho: Border	36	8	22%
Idaho: Near Border	79	28	35%
Idaho: Boise Metro	59	9	15%
Idaho: Other	76	21	28%
Utah: Border	27	1	4%
Utah: Wasatch Front	155	19	12%
Utah: Other	56	10	18%

Duplicate Case Adjudication

- Under SEER Rules:
- Idaho, 1995-2010:
 - $66 / 98,981 = 0.07\%$
 - $250 / 98,981 = 0.25\%$
- Utah:
 - $30 / 128,707 = 0.02\%$
 - $238 / 128,707 = 0.18\%$



Limitations and Caveats

- IARCcrgTools does not consider in situ cases besides bladder.
- In the combined incidence dataset, Utah data had 6 digits for date of diagnosis, so there is some fuzz built in regarding which state, ID or UT, should claim the case.
- The SAS program for implementing SEER MPH rules *REQUIRES* full dates of diagnosis, so these were imputed with day=15 or mmdd=0701. This caused some discrepancies in comparison to the IARC rules, so I hand-edited 15 cases to make them consistent.

The Project

- To our knowledge, this is the first attempt to assess cancer case duplication across state boundaries.

What is left to do?

- One state's DCO is the other state's lost to follow-up
- Accuracy of primary site for DCO cases is not great (often, a metastatic site is listed in place of the primary site).
- Some of the remaining DCO cases are likely duplicates, but the site categories don't match.
- This will only be reconciled by CTRs using full text, potentially death certificates, and may require follow-back to hospitals.

Recommendations for NAACCR

- Although not a significant issue for Utah/Idaho, interstate linkages may yield very different results for populations that are more transient or high "commuting" areas such as NY/NJ, NJ/PA, MD/DC etc.
- There may be more bang for the buck in focusing on DCO cases.
 - In Idaho, 18-35 DCOs out of 2,200 for 1995-2010 could "go away" (up to 1.6%).
 - Could have a significant impact in registries with high DCO rates.

