National Center for Health Statistics
Data Linkage

Use of Alternate Information to Improve Linkage with the National Death Index (NDI)

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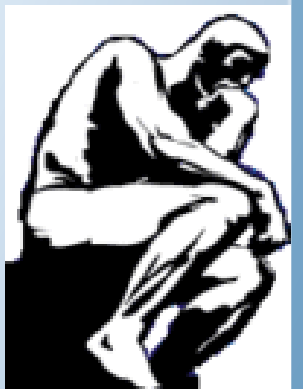
The findings and conclusions in this report are those of the author(s) and do not necessarily represent the official position of the CDC

Why Am I Here?

- Special Projects Branch (SPB) within the National Center for Health Statistics (NCHS - CDC)
  - Regularly conducts data linkages between population-based surveys and the NDI

- From previous experience in a cancer registry, recognize the importance of mortality linkages and feel these methods could potentially benefit registries

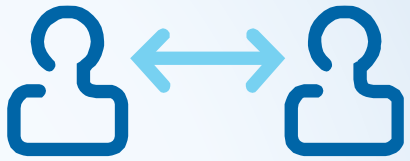


Reasons for Mismatches in Data Linkage

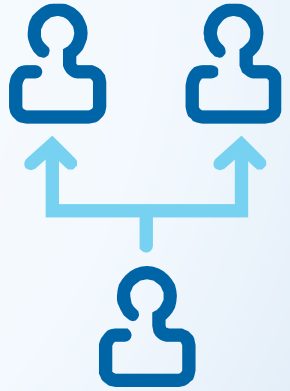
- Data entry errors
- Misreporting
- Variations between reporting sources
  - For example, a nickname versus proper name

Quick Background on Data Linkage

- Deterministic
  - Exact match on linkage variables
    - Frank ≠ Francis
    - 123456789 ≠ 213456789



- Probabilistic
  - Accounts for imperfect data
  - Probability of a match
    - Frank ≈ Francis
    - 123456789 ≈ 213456789



Novel (To Me) SPB Linkage Method

- To increase the likelihood of correctly linking records (and reduce false negatives), SPB creates additional records with alternate information available
- The file of survey participants used to link with administrative data (e.g. NDI) contains multiple records per person with every combination of available information
- Intuitively makes sense but has not been evaluated

Case Study: National Health Interview Survey Linkage with the NDI

- National Death Index (NDI)
  - A national file of identifying death record information (beginning with 1979 deaths)
    - File with records through December 31, 2011
  - Every few years we link survey participants to NDI to identify participant deaths
- NHIS (1986-2009)
  - In-person household survey
  - Conducted continuously by the CDC's NCHS since 1957
  - Extensive data collection
  - Large sample sizes
    - ~35,000 households per year

NDI Matching Fields

- Social Security Number (last 4 digits beginning in 2007)
- First name
- Middle initial
- Last name
- Date of birth (Month, Day, Year)
- Sex
- Father’s surname (for women when available)
- State of birth
- Race
- State of residence
- Marital Status

Alternate Information Includes

- SSNs
  - From other sources or linkages
- Dates of birth
  - From other sources or linkages
- Names
  - From other sources or linkages
  - Name look-up tables
  - Algorithms

Alternate Name Possibilities

- Substitute any alternate names available from other sources
- Substitute nickname with proper name (and *vice versa*)
- Multi-part first name (e.g. Billy Joe)
- Multi-part last name (e.g. Kidd-Gilchrist)
- Switch first name and middle name
- Submit a blank middle name
- Hispanic: Replace last with middle name
- Asian: Switch first and last name

Nickname Lookup Table (Extract)

SEX	NICKNAME	PROPER NAME
M	ABE	ABRAHAM
F	AGGIE	AGNES
M	AL	ALBERT
M	ALEX	ALEXANDER
M	ALF	ALFRED
F	ALLIE	ALBERTA
M	**ANDY**	**ANDREW**

Example: If first name='Andy' then alternate record first name='Andrew'

Alternate Name Records Example

Number	First	Middle	Last
1	David	Américo	Arias Ortiz
2	David	Américo	Ortiz
3	David	Américo	Arias
4	David		Américo
5	Big		Papi

Study Objectives

- Determine the effectiveness of this method
  - **Question 1**: How many links (and %) had an alternate record as the highest scoring record?
  - **Question 2**: Which alternate information was used most often?
  - **Question 3**: How many links were identified with an alternate record that would have been missed otherwise?

Methods

- **Question 1**: How many links (and %) had an alternate record as the highest scoring record?

- **Question 2**: Which alternate information was used most often?

  - File 1
    - Final disposition (vital status) merged with alternate record flags
      - Flags are created for each type of alternate record
        - » Name, SSN, DOB

Methods

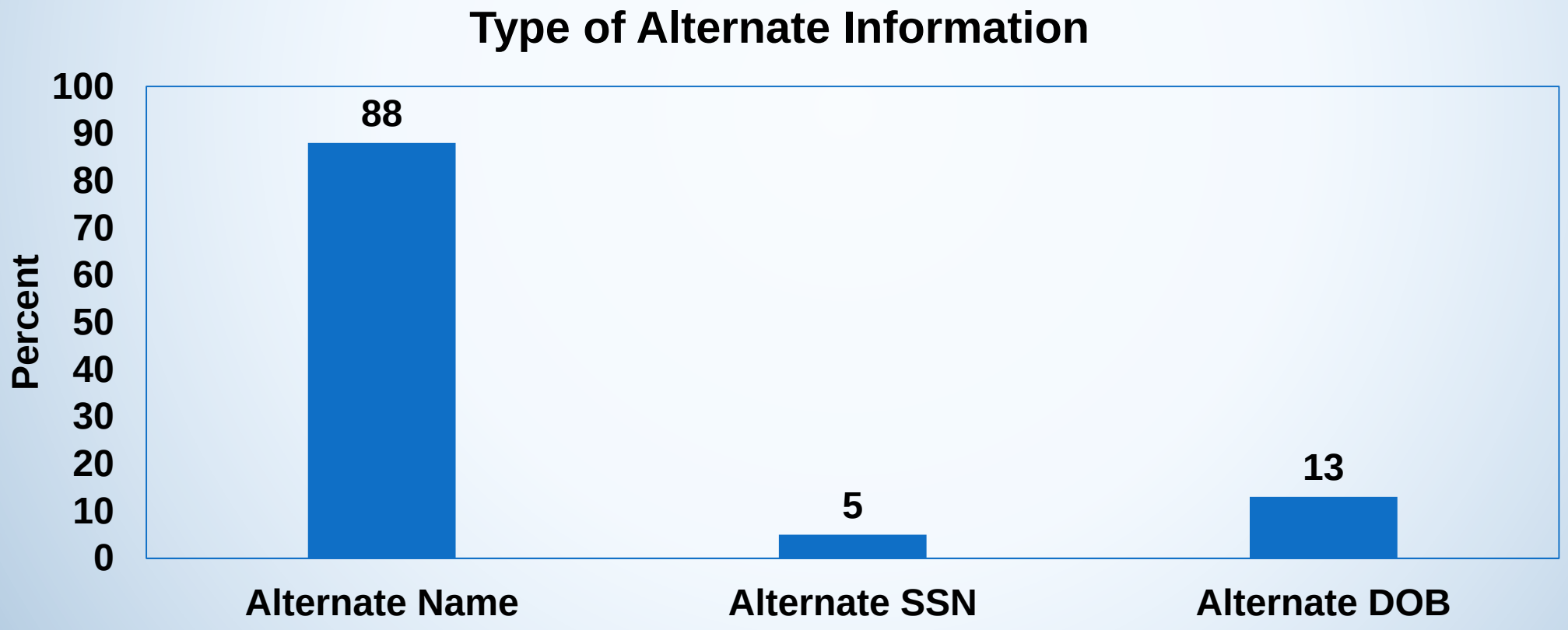
- **Question 3**: How many links were identified with an alternate record that would have been missed otherwise?
  - File 2
    - File with all alternate records and all possible matches with the NDI
      - Select the highest scoring original record and highest scoring alternate record
        - » Based on score cutoffs used to determine links, compare number considered linked for original and alternate records

Study Population

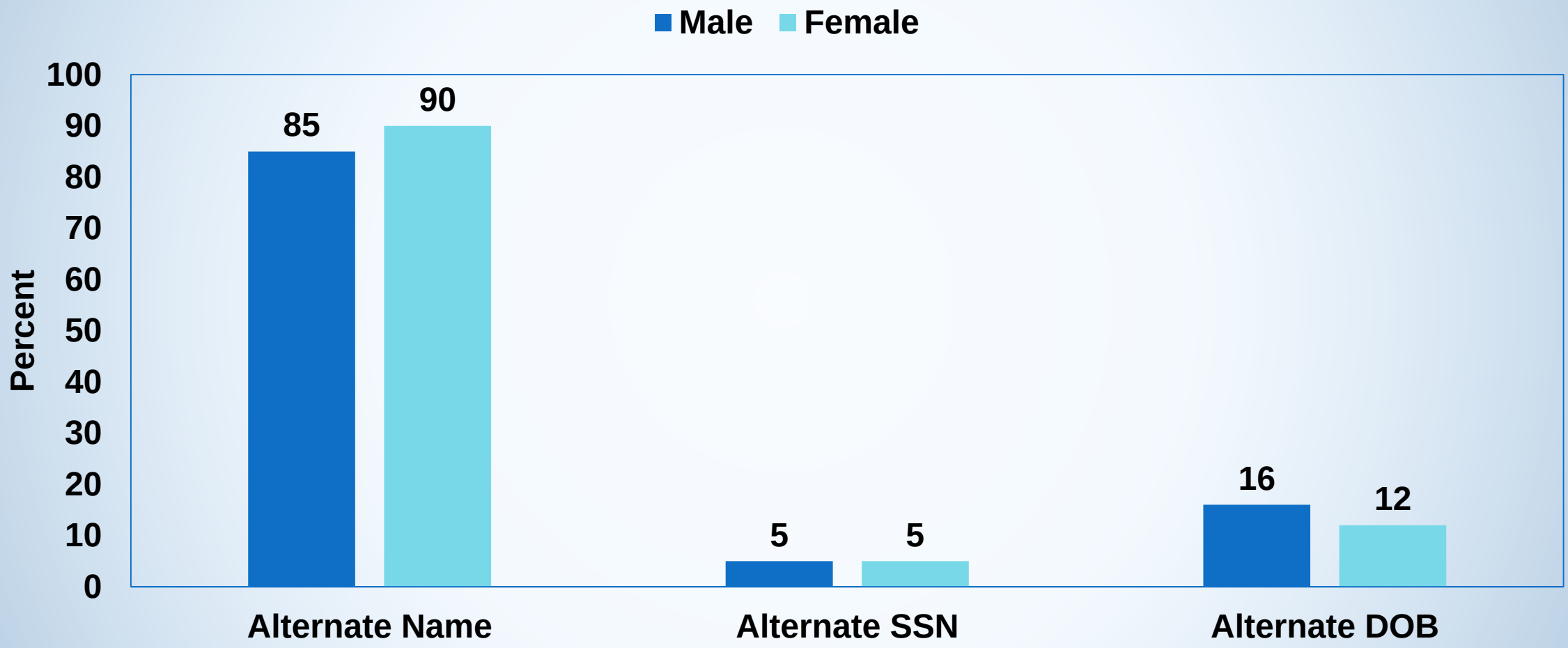
- There were 2,235,985 participants included in this analysis
  - 275,729 (12%) were considered linked to an NDI record
    - Ranges from 23% in 1986 NHIS to 2% in 2009 NHIS

Results – Questions 1 and 2

- Of those considered linked
  - Approximately 23% included some alternate information (i.e. highest scoring record)



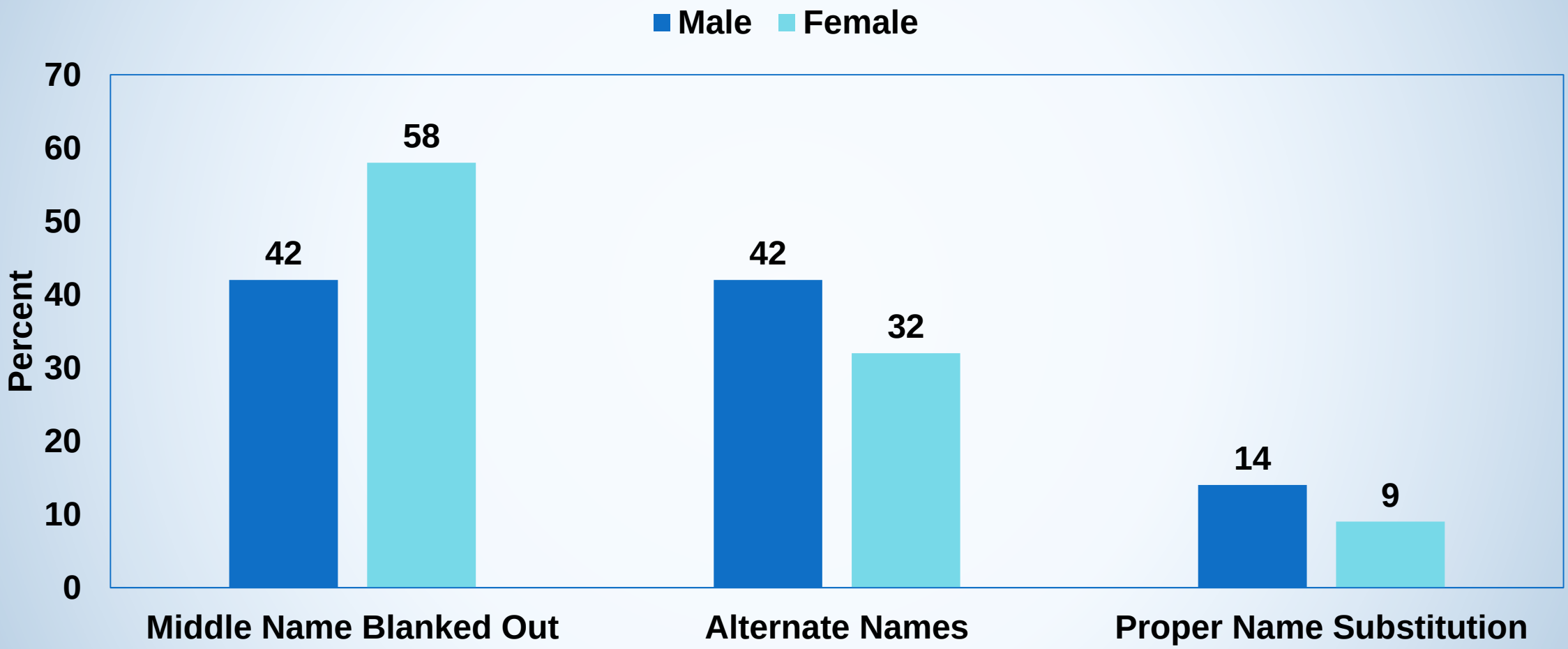
Type of Alternate Information by Sex



Frequency of Alternate Name Records Used

Type of Alternate Name Record	N	Percent
Blank Out Middle Name	28,990	52%
Alternate Name (First, Middle, or Last) from Another Source	19,981	36%
Proper Name to Replace Nickname	6,757	12%
Multi-Part First Name	746	1%
Switch First and Middle Name	477	0.9%
Multi-Part Last Name	300	0.5%
Asian: Switch First and Last Name	115	0.2%
Nickname to Replace First Name	102	0.2%
Hispanic: Switch Middle and Last Name	92	0.2%

Type of Alternate Name Information by Sex



Results – Question3

- How many links were identified with an alternate record that would have been missed otherwise?
  - There were close to 5,000 links that were found with an alternate record that would have been missed with only the original record
    - Translates to ~2% of links

Summary

- Almost one quarter of the highest scoring links used some type of alternate information
- While the percentage of additional links was small (~2%), the method added a meaningful number of links
- For alternate name records, blanking out middle name, replacing nicknames and using names from other sources (if available) were most effective

Limitations

- Used a study population with a relatively high number of participants without SSN
- Were not able to isolate use of ethnic specific name substitution
- There is some potential to create false positive links
  - But with appropriate score cut-offs risk appears small
  - We were not able to fully evaluate this yet

Conclusions

- Use of alternate records was successful at finding links that would have been missed
- May be beneficial for cancer registries to use alternate names (or replace nicknames), SSNs and/or dates of birth for multiple submissions in linkages
- Registries may want to experiment linking with and without middle name/initial

Thanks!

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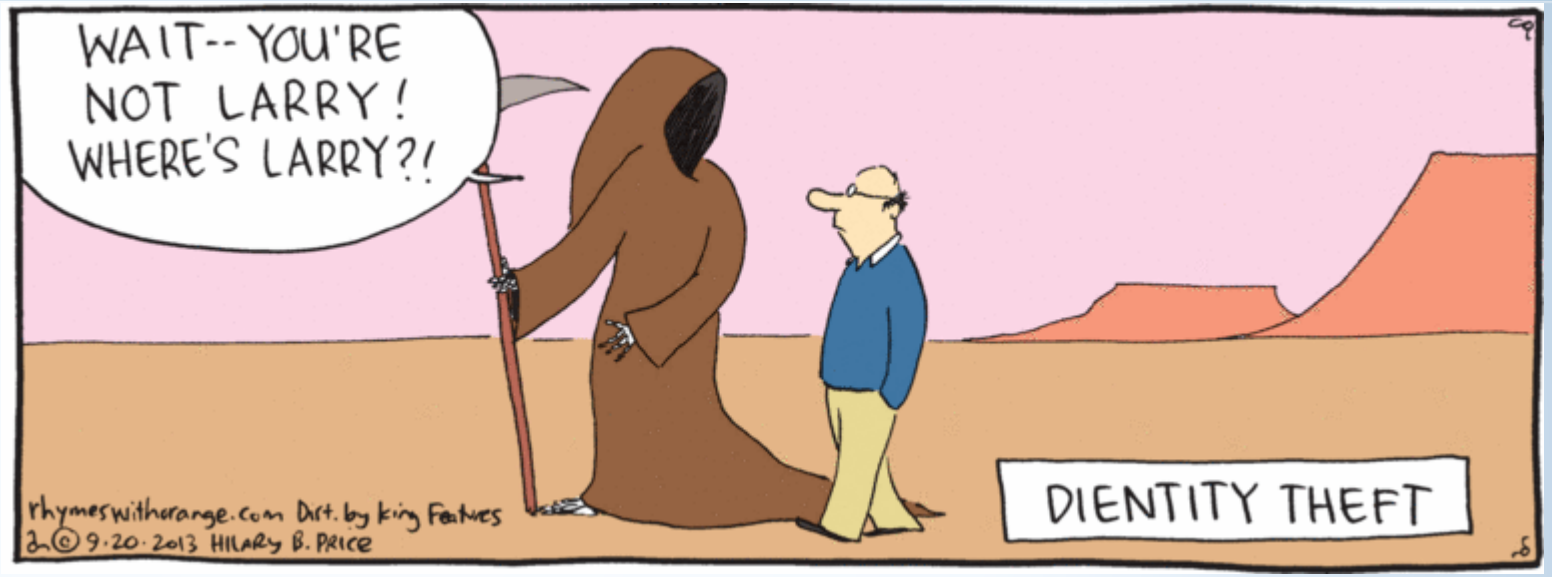

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