



National Center for Health Statistics

Data Linkage

Analytic Challenges with National Data Linked to State-Level Data

The National Health Interview Survey – Florida Cancer Data System Linkage

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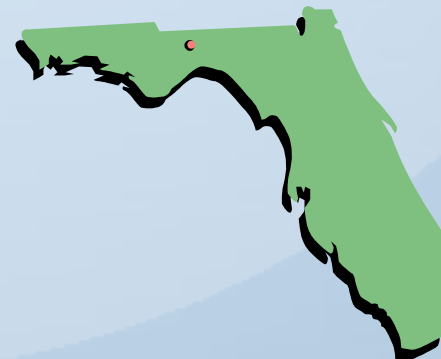
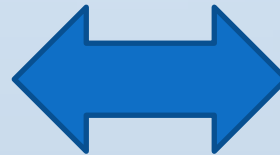
National Center for Health Statistics (NCHS)



National Center for Health Statistics
Office of Analysis and Epidemiology

Pilot Project

- Linkage of the Florida Cancer Data System (FCDS) Data to National Health Interview Survey (NHIS)
- Objectives
 - Feasibility
 - Value / Utility



Data Linkage

**National Health Interview
Survey (1986 – 2009) +
Dummy Records**

~2 Million Records

**Florida Cancer Data System
(1981 – 2010)**

~2.5 Million Records

**8,217 linked
survey participants**

How Does This Apply to Other Linkages?

- Some of the issues we have encountered with this linkage could be relevant for other National/State linkages
- For example
 - State-level analysis of national survey data (*e.g.* NHIS) linked to Medicaid or Supplemental Nutrition Assistance Program (SNAP)

Description of the Data

- Cancer Registries
 - Collect, manage, and analyze data about cancer cases and cancer deaths
 - Are essential for monitoring progress in cancer prevention and control

U.S. Cancer Death Rate Continues to Fall

REPORTER'S FILE

The Rising Incidence of Thyroid Cancer

NATIONAL
The Check-Up: Lung Cancer Rates Declining

Today's health headlines

Data Collected by Cancer Registries

- Cancer-related
 - Incident cancers
 - Type, extent (*i.e.* stage) and location of tumor
 - Date of diagnosis
 - Type of initial treatment
- Demographics
- Vital status

Description of the Data



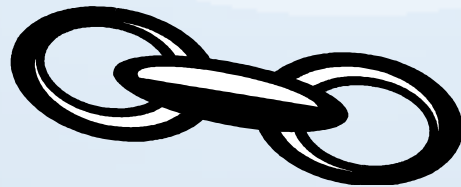
- NHIS
 - In-person household survey
 - Conducted continuously by the CDC's NCHS since 1957
 - Large sample sizes
 - ~35,000 households in the U.S. per year
 - Complex sampling with some populations oversampled

Data Collected by NHIS

- Risk factors (*e.g.* smoking, alcohol use, obesity)
- Health conditions, diseases, and disabilities
- Cancer screening history (selected years)
- Occupation/Industry
- Socioeconomic information (*e.g.* income, education, health insurance/access to care)

Data Linkage

- Linking the information from these two sources could potentially provide a valuable resource for cancer research



- Linkage adds:
 - Longitudinal component to survey
 - Quality of life/health after diagnosis
 - Risk factor, SES, screening history, access to care, and comorbidity information to registry data

Also Adds Complexity

- NHIS is a nationally representative sample of the civilian, non-institutionalized (CNI) population of the United States
 - i.e. not just Florida
- FCDS is intended to capture (almost) all cancers diagnosed among Florida residents

Examples of Challenges

- Creation of survey weights
- Survey participant mobility

Challenge #1 – Survey Weights

- NHIS weights were available to represent the US CNI population
- Weights needed to be created to represent the Florida population
 - NCHS (Dean Judson) created weights to be representative of the Florida CNI population for each year of the survey

Creation of Florida Weights

- Used NHIS sample weights
 - Limited to Florida survey participants
 - Adjusted for linkage ineligibility using PROC WTADJUST in SUDAAN
 - Based on race, sex and age
 - Linkage ineligibility
 - Did not refuse
 - Did not provide sufficient personally identifiable information

Creation of Florida Weights

- Post-stratified to the Florida CNI population
 - Method 1: Using Florida CNI estimates directly from NHIS
 - Method 2: Using estimates of the CNI population based on average CNI percent of total Florida population
- Methods highly correlated ($r=0.99$) and had little effect on estimates

Comparison

Percent of survey participants with a cancer record in the FCDS who ever smoked by race/ethnicity, and post-stratification method

| | Post-stratification Method 1 | Post-stratification Method 2 |
|--------------------|---|---|
| | Ever Smoked % (SE) | Ever Smoked % (SE) |
| Hispanic | 48.2 (3.52) | 48.0 (3.44) |
| White Non-Hispanic | 63.9 (1.63) | 64.1 (1.52) |
| Black Non-Hispanic | 45.7 (3.33) | 46.2 (3.23) |

Consequence of Current Weighting Strategy

- Participants are weighted to the CNI Florida population in the year of their survey
- This means if you were interviewed in Minnesota but diagnosed with cancer in Florida, you get a weight of 0
 - Data for these respondents are not included in the analysis
 - Not a trivial number

Challenge #2 - Movers

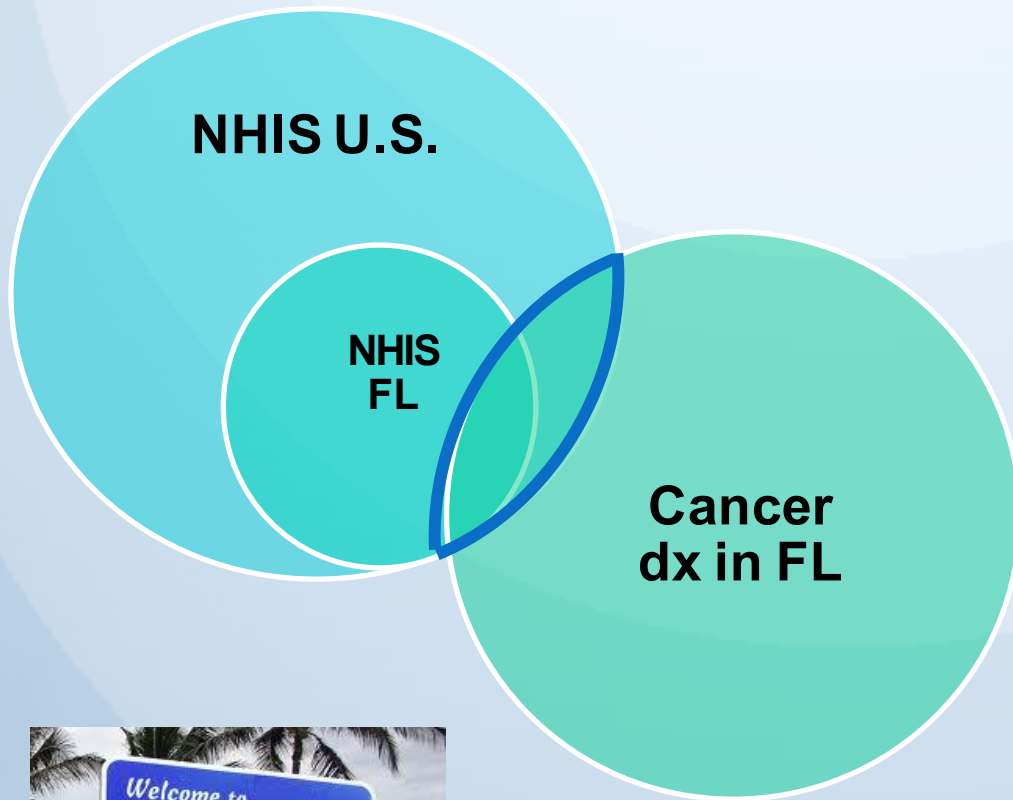
- People moved to Florida after the survey
 - Some were diagnosed with cancer
 - In the FCDS
 - Some were not



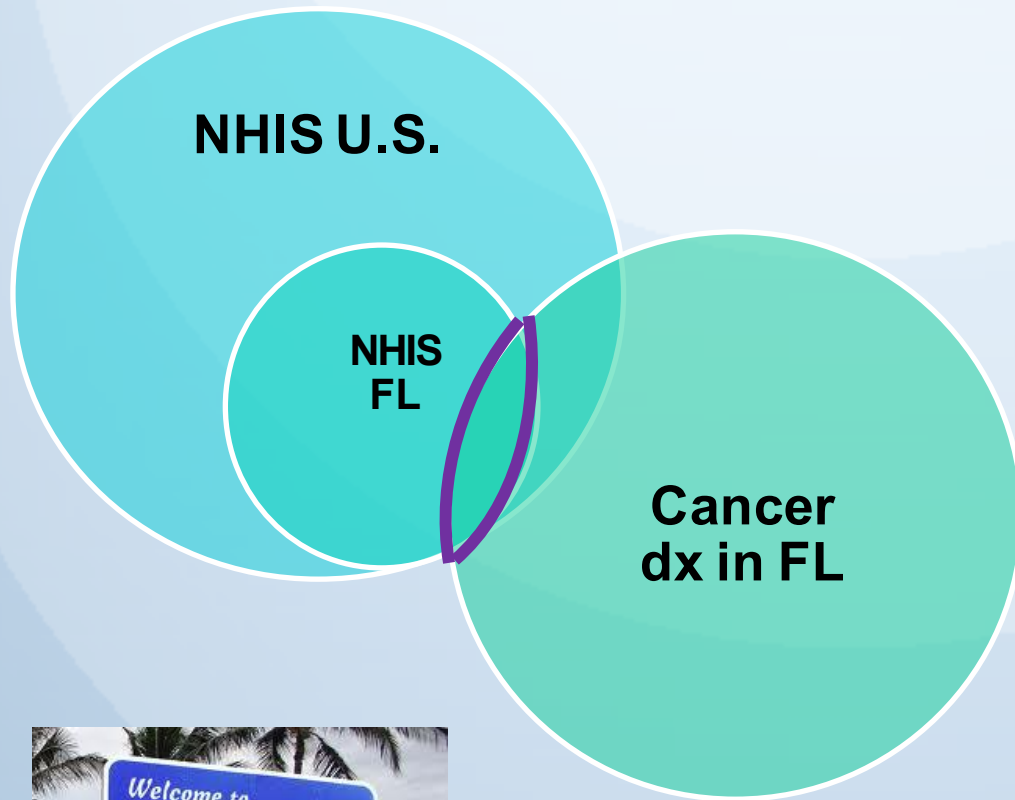
- Analytic implications
 - With current weighting strategy loss of sample size limits the ability to look at individual cancer types or at demographic differences

Movers to Florida

- Number of Survey Participants Linked to FCDS=8,217



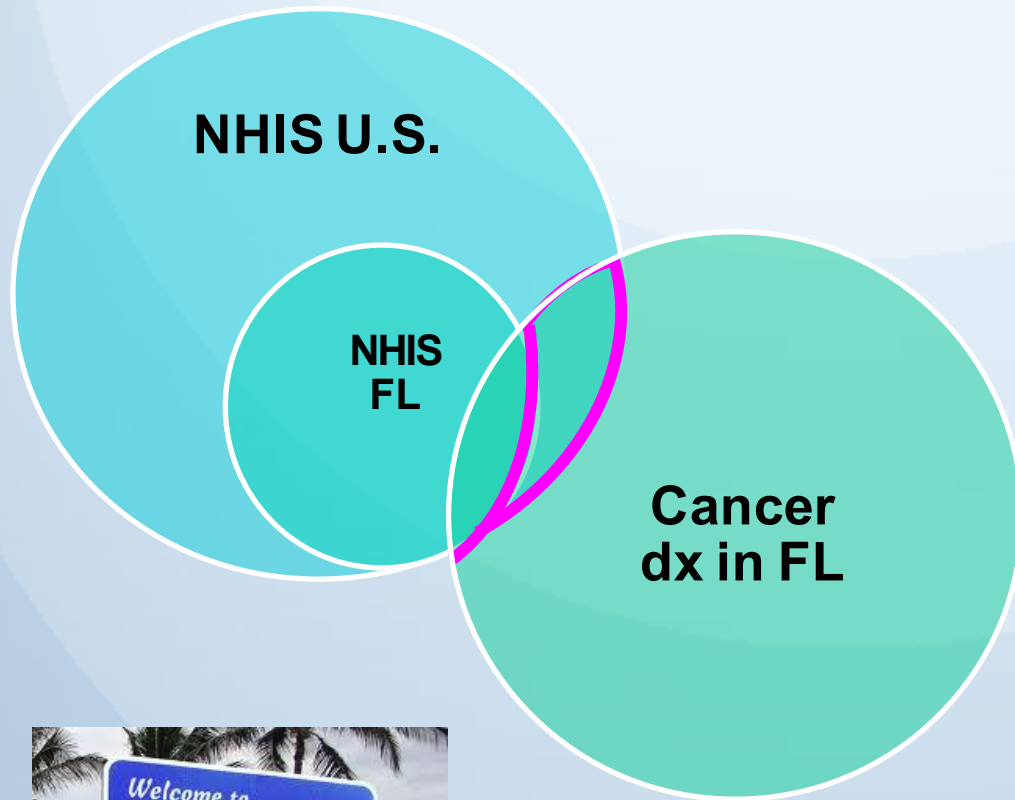
Movers to Florida



- Number of Survey Participants Linked to FCDS=8,217
- Number of FL survey participants linked to FCDS=6,366



Movers to Florida



- Number of Survey Participants Linked to FCDS=8,217
- Number of FL survey participants linked to FCDS=6,366
- Number who moved to FL after survey and were dx'd with cancer=1,851 (23%)



Reason for Current Strategy

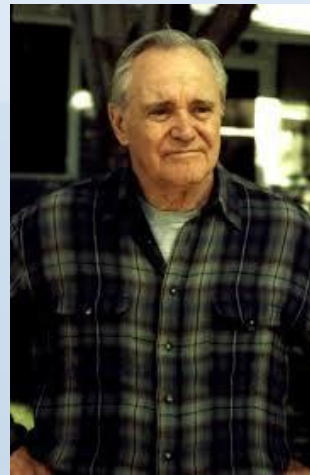
Walter from MN



Don - Florida Native



Jack - MN Transplant



If Walter moves to Florida and is dx'd with cancer, he is more comparable to Jack who moved to Florida and did not get cancer.

Reason for Current Strategy

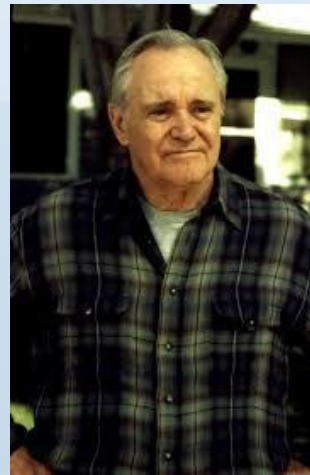
Walter from MN



Don - Florida Native



Jack - MN Transplant



But we do not have a way to know about Jack in the data.

Comparison of Demographic Characteristics Among Participants Linked with FCDS by Residency at Survey

| | Florida Residents % | Movers % |
|-------------------------------|------------------------|-------------|
| Male* | 49.6 | 52.7 |
| Race/Ethnicity* | | |
| White | 83.6 | 91.8 |
| Black | 14.3 | 5.8 |
| Hispanic | 21.0 | 5.5 |
| Mean Age (as of 2009)* | 61.3 | 56.7 |
| Education Level* | | |
| < High School (HS) | 7.0 | 14.0 |
| HS Graduate | 45.3 | 46.3 |
| > HS | 47.7 | 39.7 |

*P<0.05 for difference between groups

Comparison of Health Characteristics Among Participants Linked with FCDS by Residency at Survey

| | Florida Residents % | Movers % |
|------------------------------|------------------------|-------------|
| Smoking Status* | | |
| Never | 40.0 | 33.0 |
| Current | 23.5 | 27.7 |
| Former | 36.3 | 39.3 |
| Self-rated Health* | | |
| Excellent / Very Good / Good | 76.3 | 85.0 |
| Fair / Poor | 23.7 | 15.0 |

*P<0.05 for difference between groups

Comparison of Cancer Types Among Participants Linked with FCDS by Residency at Survey

| Cancer | Florida Residents %** | Movers %** |
|------------------|--------------------------|---------------|
| Bladder | 6.2 | 6.2 |
| Breast (Female)* | 19.0 | 15.4 |
| Colorectal | 12.8 | 12.4 |
| Lung | 13.8 | 13.4 |
| Prostate | 18.6 | 20.0 |
| Thyroid | 1.5 | 1.2 |
| Uterus | 3.6 | 2.7 |

*P<0.05 for difference between groups

**Percent of all cancer diagnoses. Cancer types are not mutually exclusive and table does not include all categories. Not intended to add up to 100%.

Alternate Weighting Strategy

- Statistical matching
 - For movers (in-migration) find a similar survey participant from Florida and split weight between Florida and non-Florida resident
 - Could limit to those diagnosed with cancer within a certain number of years (e.g. with 5 years of survey)
 - Could base magnitude of split on number of years between survey and diagnosis in Florida
 - e.g. 5 years: 90% FL /10% not FL, 1 year: 50%/50%

Challenge #2B: Movers Out of Florida

- People moved out of Florida after the survey
 - Some were diagnosed with cancer
 - Some were not



Movers Out of Florida

- Change of address data are available to see who moved from Florida
 - But we do not have a way to identify survey participants who were diagnosed with cancer in another state
 - This would require linkages with cancer registries nationally



Movers Out of Florida

- Analytic implications
 - Can affect the representativeness of the estimates if a sizeable number of participants moved out of state
 - Currently do not have a way to address movers out of state



Conclusions

- Linking national survey data to state-level data produces additional analytic considerations
 - And opportunities for further research
- When linking national and state-level data, it is important to consider the potential impact of “movers”

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www.cdc.gov/nchs/data_access/data_linkage_activities.htm

Thanks!