NAACCR 2013 Conference
THINKING BIG: The Future of Cancer Surveillance

Austin, Texas
June 8 – 14, 2013

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The Institute of Medicine and the National Cancer Institute have encouraged researchers to utilize health data set linkages to broaden research perspectives that might inform efforts to improve the quality of cancer care and reduce disparities.

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Linkages of Central Cancer Registry Data and Health-Related Data Sets Enhance Study of Breast Cancer Disparities

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The University of Illinois at Chicago
National Cancer Institute P50 CA106740

Focus: Breast Cancer Disparities

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Principal Investigator

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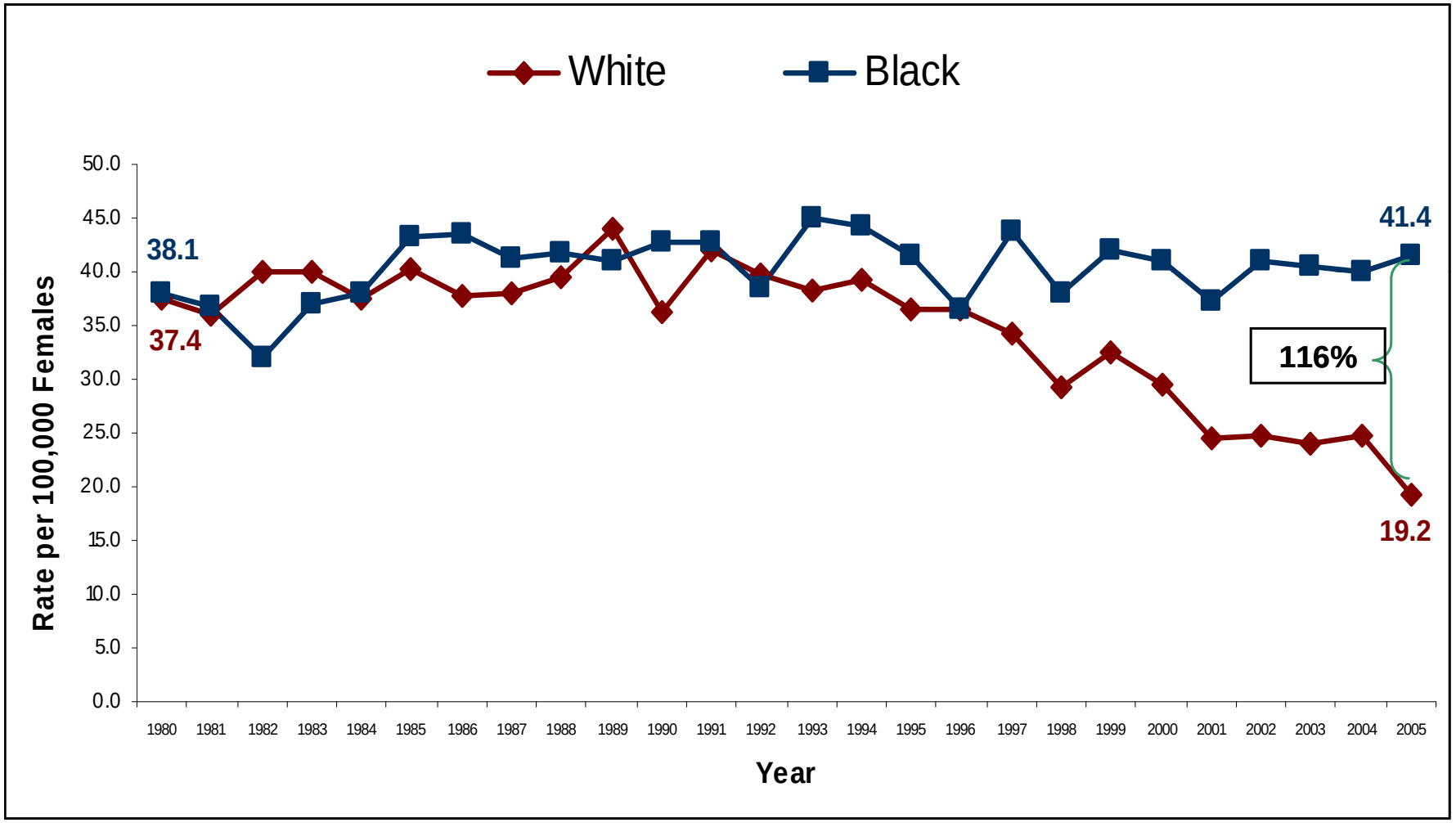
Breast Cancer Mortality Rates Chicago (1980-2005)



Hirschman et al.(2007) Cancer Causes and Control

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Overview

4 Examples of Linkage Research

Linking Central Cancer Registry Data to:

1. 1990 and 2000 Census Data
2. Illinois Hospital Discharge Data
3. Greater Circle Distance Measures
4. Radiology Data

CPHHD Project: Neighborhood and Individual Effects on Stage at Diagnosis

CPHHD Investigators:

Richard T. Campbell, Ph.D.

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Linkage to 1990 and 2000 Census Data

CPHHD Project: Neighborhood and Individual Effects on Stage at Diagnosis

1994-2000 Female Breast Cancer Incidence Data in Cook County, Illinois

Supplement Study: 1998-2002

Boston, Chicago (updated), Detroit,

Los Angeles, Philadelphia, Washington DC

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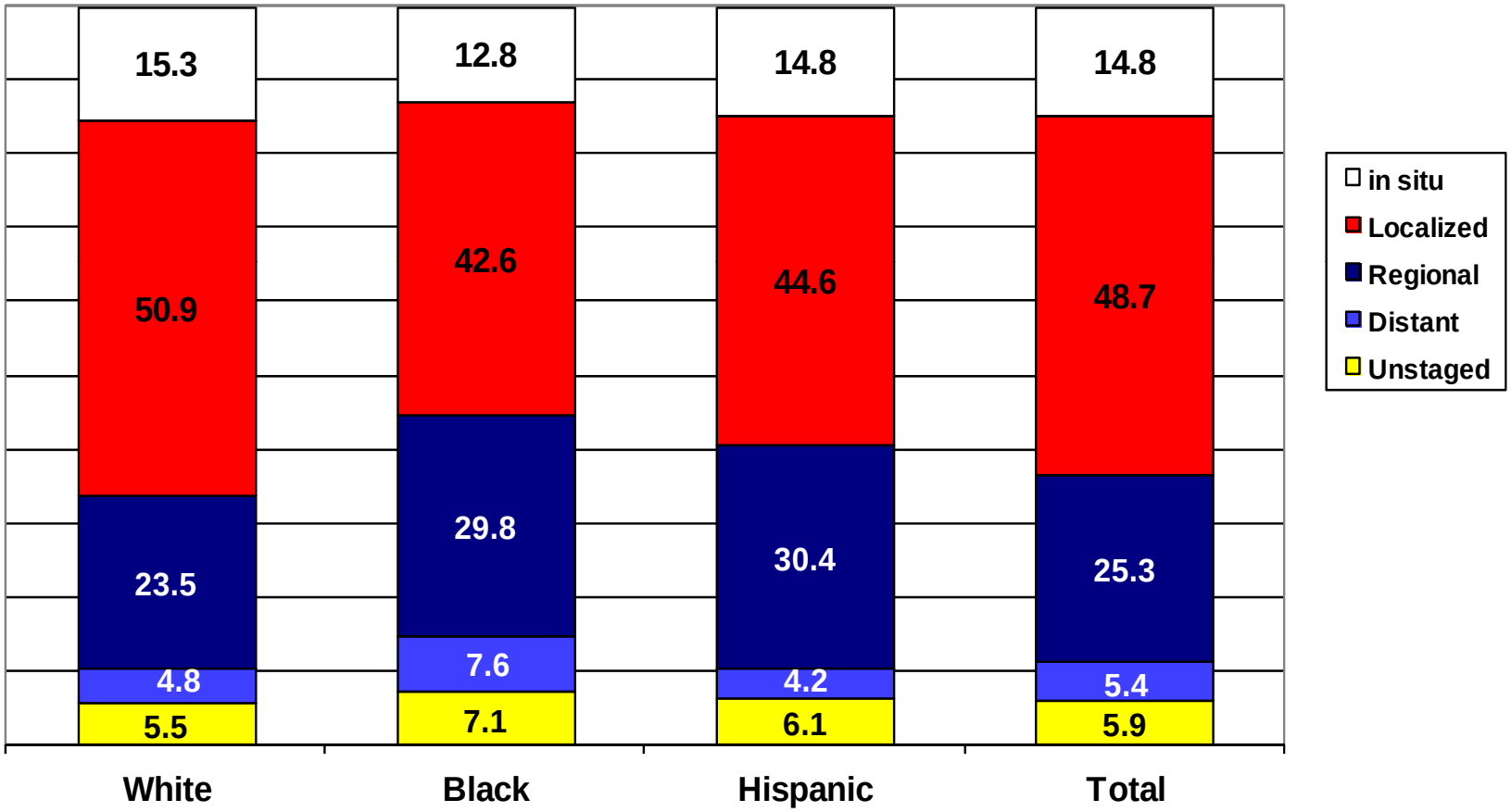
Percent Stage at Diagnosis of Breast Cancer by Race/Ethnicity, Cook County, Illinois, 1994-2000



Source: Illinois Department of Public Health, Illinois State Cancer Registry, November 2004.

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Research Aims

- Examine effects of race, ethnicity, SES and age on stage at diagnosis
- Focus on disparities both in terms of race/ethnicity and SES
- Explore race-SES interactions
- Communicate results to the policy community and the community at large.

ISCR Data, 1994-2000
Cook County, Illinois

- Female breast cancer cases
- Ages (30-89 years)
- Race/ethnicity (white non-Hispanic, black non-Hispanic, Hispanic
- Geocoded residential address

  (census tract, block group, block)
- SEER general summary stage

  in situ, localized, regional, distant, unstaged

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Area-Based Socioeconomic Measure

- Poverty estimates (i. e. the proportion of persons below the poverty line) for residential census tract.
- Census estimates were interpolated to the mid point of the observation interval (1997) based on the 1990 and 2000 Census.
- The census tract specific female poverty rate for the age and race/ethnic group of the breast cancer case under study.

Final Analytic Data

- Census tract data (*N* = 1,137 tracts) from Cook County, IL, in both 1990 and 2000
- Cancer registry breast cancer data for 21,516 female breast cancer cases residing in these census tracts from 1994-2000

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Dependent variable and Covariates

Dependent variable

Ordinal outcome-

Stage at diagnosis

- 1: in situ
- 2: localized
- 3: regional
- 4: distant

Covariates

- Age in years (quadratic and cubic effect) age: 30-89
- Poverty (quadratic effect)

  poverty: 0-85
- Race (white nh, black nh and Hispanic. Coded with two dummy variables.)
- Race/ethnicity by age (age quadratic) interaction
- Race/ethnicity by poverty (poverty quadratic) interaction

Age Effects

R.T. Campbell et al. / Health & Place 15 (2009) 870–879

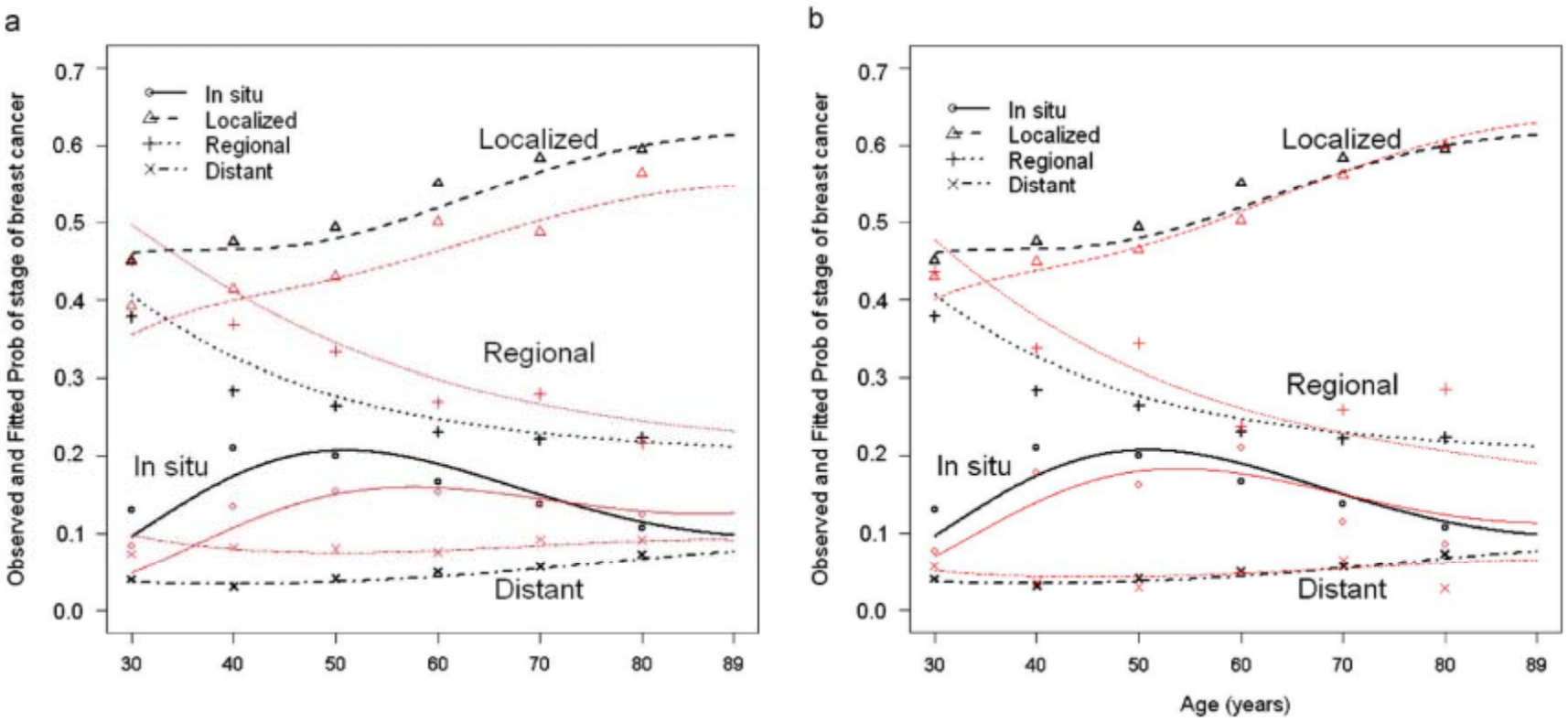

Fig. 2. (a) Fitted and observed stage at breast cancer diagnosis by age for women aged 30–89*. *Non-Hispanic black (red lines) and non-Hispanic white (black lines), poverty held at median for each group. (b) Fitted and observed stage at breast cancer diagnosis by age for women aged 30–89*. *Hispanic (red lines) and non-Hispanic whites (black lines), poverty held at median for each group.

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Poverty Effects

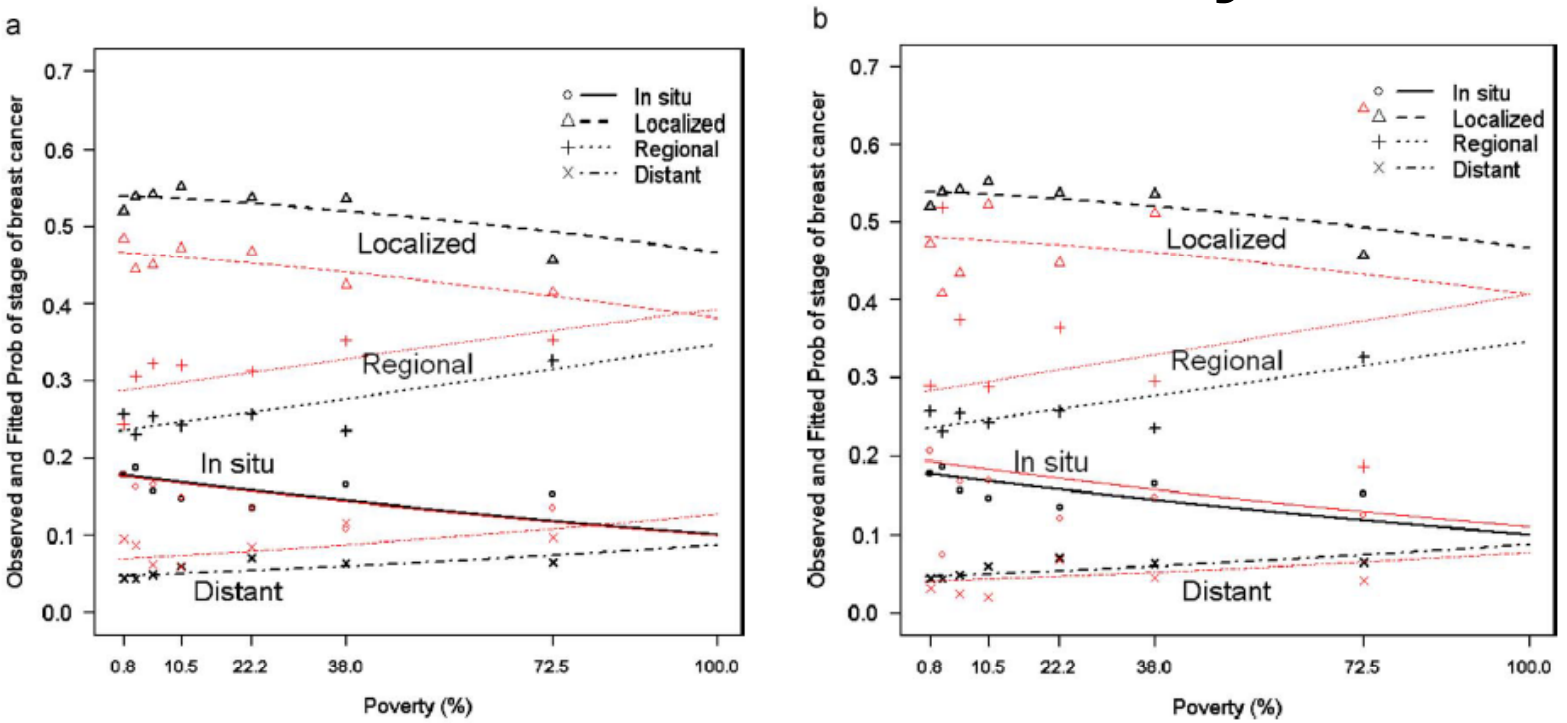

Fig. 3. (a) Fitted and observed stage at breast cancer diagnosis by poverty level for women aged 30–89[a]. [a]Non-Hispanic black (red lines) and non-Hispanic white (black lines), poverty held at median for each group. (b) Fitted and observed stage at breast cancer diagnosis by poverty level for women aged 30–89[a]. [a]Hispanic (red lines) and non-Hispanic whites (black lines), poverty held at median for each group.

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Summary for Six Geographic Areas

- Blacks at greater risk of late stage diagnosis.
- Late stage diagnosis experienced by black women is conditional on age, with the disparity being greatest at younger ages.
- In areas with sufficiently large Hispanic populations, findings similar to blacks though less extreme result for Hispanic women.
- Poverty was found to have a strong effect on the probability of being diagnosed at a later stage, regardless of race/ethnicity.
- So, equal access to early detection and treatment should produce equal outcomes in stage at diagnosis and mortality

Pilot Study Evaluation of Breast Cancer Disparities Using Large Data Set Linkage

Investigators:
Therese A. Dolecek, Ph.D.
Richard T. Campbell, Ph.D.
Garth H. Rauscher, Ph.D.

Ticket for the Cure

Funding from Lottery Ticket Sales in Illinois

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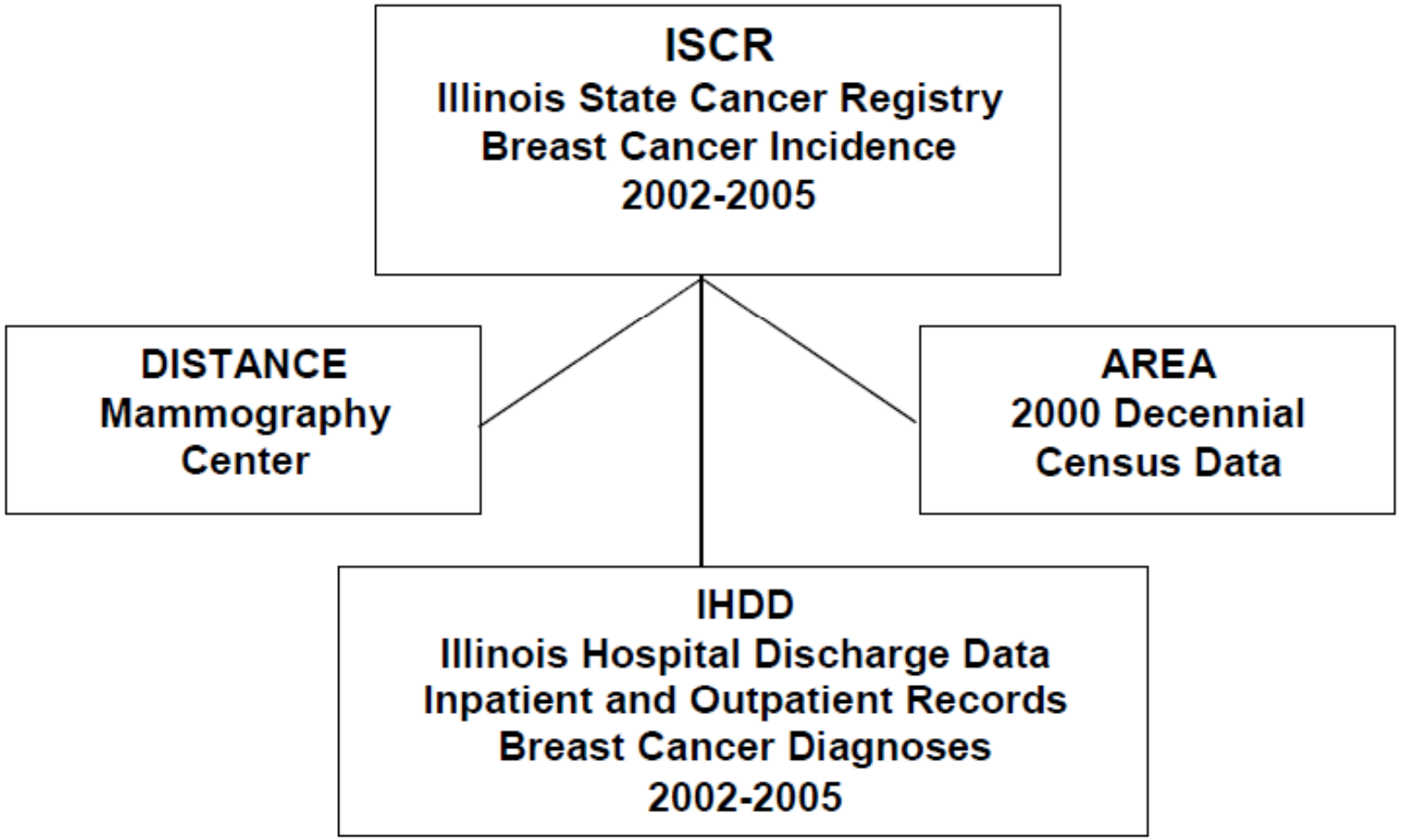
ISCR
Illinois State Cancer Registry
Breast Cancer Incidence
2002-2005
DISTANCE
Mammography
Center
AREA
2000 Decennial
Census Data
IHDD
Illinois Hospital Discharge Data
Inpatient and Outpatient Records
Breast Cancer Diagnoses
2002-2005

Ticket for the Cure Study:
Pilot Study Evaluation of Breast Cancer Disparities Using Large Data Set Linkage

Linkage Variables	
Illinois State Cancer Registry	**Illinois Hospital Discharge Data**
Primary Site	***Diagnosis/Related Procedures***
Sex: Females only	***Patient Sex***
Reporting Facility Name/Number	***Reporting Facility Name/Number***
Diagnosis Date: Month/Day/Year	***Date of Admission***
	Date of Discharge
Date of Birth: Month/Day/Year	***Date of Birth: Month/Day/Year***
Case Residential Zipcode	***Patient Residential Zipcode***
Case Residential County	***Patient Origin: County code***

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Ticket for the Cure Study:
Pilot Study Evaluation of Breast Cancer Disparities Using Large Data Set Linkage

Additional Variables	
Illinois State Cancer Registry	**Illinois Hospital Discharge Data**
Race (Detailed)	***Secondary Diagnosis Codes (7)***
Computed Hispanic Ethnicity	***Principal Procedure Code***
Computed Age at Diagnosis	***Secondary Procedure Codes (5)***
Birthplace	***Charges (10 categories)***
Case Residence Geocodes	***Payer ID/Type Code (3 Possible)***
Latitude/Longitude Coordinates	***In Patient Length of Stay (Days)***
Census Tract, Block Group	
SEER General Summary Stage	
Morphology	

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Linkage

- 38,247 ISCR records - primary breast cancer site
- 161,74 IHDD breast cancer diagnosis

  (subset of 2,961,063 inpatient & 2,961,685 outpatient surgery discharge records for females 1/1/2002 – 12/31/2005)

  Probabilistic Linkage performed Using Automatch software, Matchware Technologies, Inc.
- 29,381 ISCR records linked to a one-to-many match with 44,696 IHDD records

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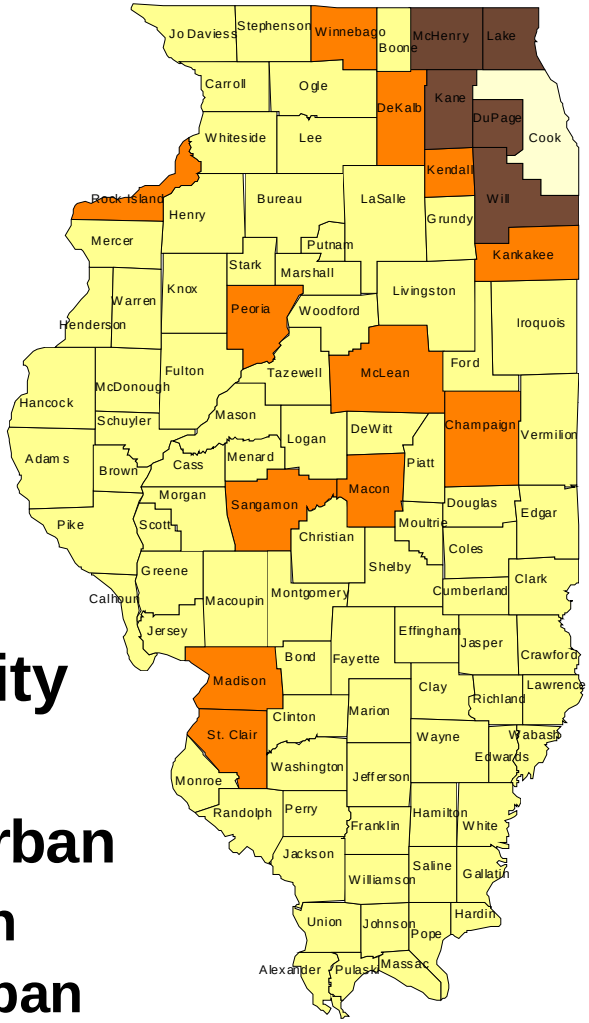
Match Rates for IHDD Records				
Procedures	History Only	Primary Dx	Secondary Dx	Primary or Secondary Dx
None	0.9%	31.5%	7.9%	17.0%
Biopsy only	7.8%	84.2%	61.2%	82.4%
Biopsy + Lumpectomy	4.5%	83.1%	57.7%	82.7%
Biopsy + Mastectomy	0 of 3 records	78.9%	35.9%	76.4%
Biopsy + Lumpectomy + Mastectomy	0 of 1 record	81.6%	0 of 0 records	81.6%
Lumpectomy only	5.3%	78.1%	49.4%	77.3%
Lumpectomy + Mastectomy	0 of 6 records	74.3%	64.0%	73.5%
Mastectomy only	4.0%	65.0%	58.8%	64.9%
Any Above Procedure	5.6%	76.4%	55.5%	**75.7%**

Illinois Counties by Population Density Strata



Population Density

- Rural
- Small Urban
- Suburban
- Large Urban

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Multiple logistic regression analysis of risk factors and late stage diagnosis of female breast cancer cases (N=5,486) in rural counties of Illinois, 2002-2005

Factor	Odds ratio (95% CI)	P	Factor	Odds ratio (95% CI)	P
Age (yrs)		<0.001	Insurance		<0.001
50-64	Referent		Insured	Referent	
< 40	2.14 (1.59-2.87)		Medicare	1.04 (0.80-1.36)	
40-49	1.09 (0.91-1.31)		Medicaid	1.972 (1.48-2.62)	
65-74	0.78 (0.59-1.04)		Uninsured	1.24 (0.73-2.08)	
75+	0.98 (0.0.74-1.30)				
Race			Distance ‡		
White	Referent	<0.01	< 5 miles	Referent	<0.05
Black	1.92 (1.28-2.89)		5-9 miles	1.15 (092-1.43)	
Other	0.87 (0.362-2.09)		10-14 miles	1.32 (1.07-1.63)	
			15+ miles	1.32 (1.07-1.64)	

‡ distance from case residence to nearest mammography centers

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1 R01 HS018366-01A1
Comparative effectiveness of breast imaging modalities: a natural experiment

Garth H. Rauscher, Ph.D., Principal Investigator
Therese A. Dolecek, Ph.D., Co-Investigator

Purpose is to examine the comparative effectiveness of screening and diagnostic imaging and biopsy procedures.

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Specific Aims Overview

- Examine the comparative effectiveness

- Screening with digital mammography vs. film screen mammography, overall and within clinically relevant subgroups
- Diagnostic imaging (digital mammography, film screen mammography, breast ultrasound and breast MRI)
- Diagnostic breast biopsy procedures (stereotactic, ultrasound and MRI-guided needle biopsies; stereotactic vacuum-assisted biopsy and surgical biopsy)

- Describe learning curves associated with the introduction of computer-aided diagnosis and digital mammography

Sources and Methods

- Advocate Health Care
  - PendRad radiology database
    - 355,000 patients
      (~65,000 AA, 23,000 Hispanic)
- Illinois State cancer Registry (ISCR)
  - Incident cancer cases
- Probabilistic linkage (Automatch) on names, DOB, SSN, and weaker identifiers
- Minimize sharing of identifiers

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Process for data linkage and creation of analysis datasets

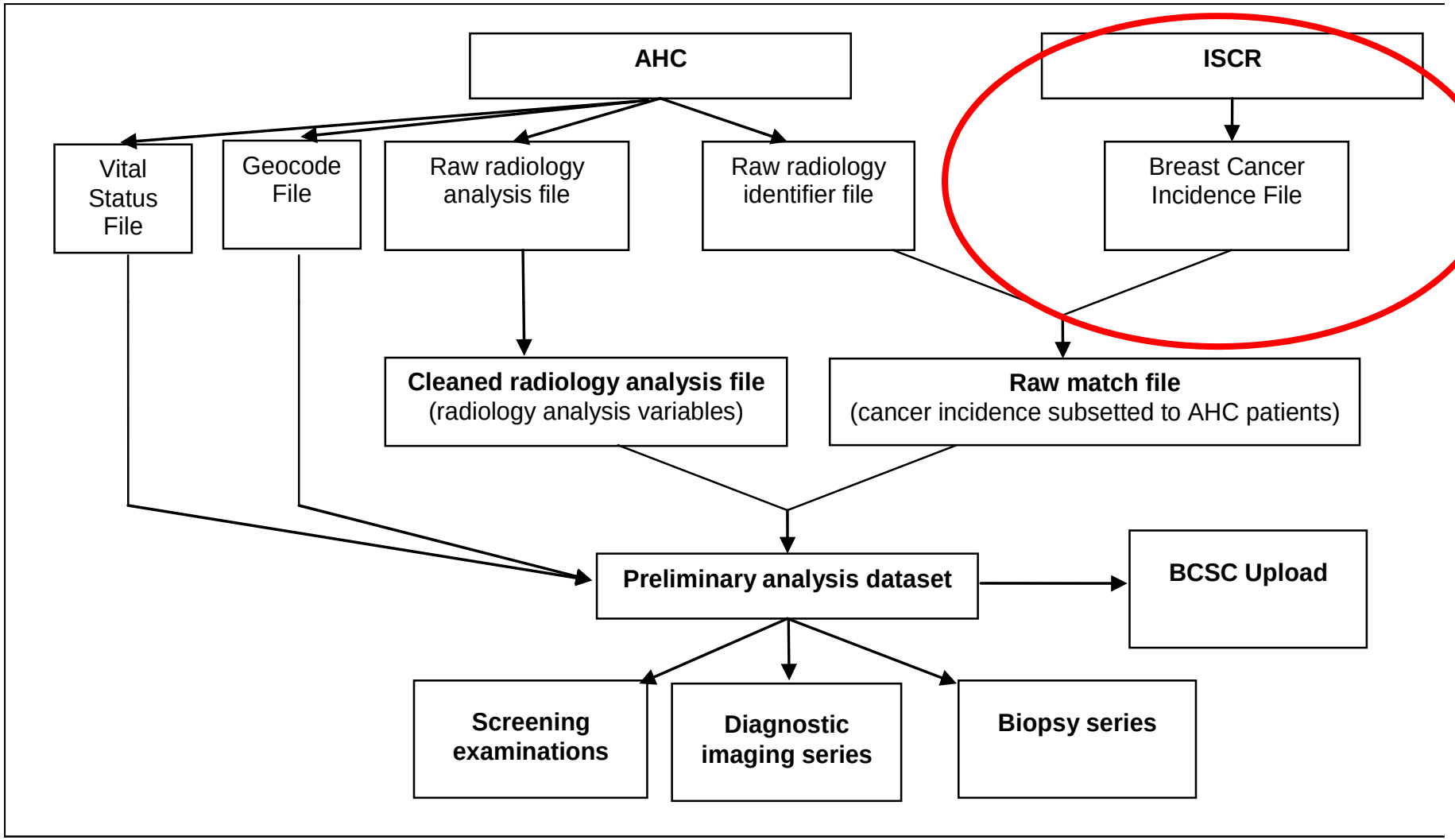

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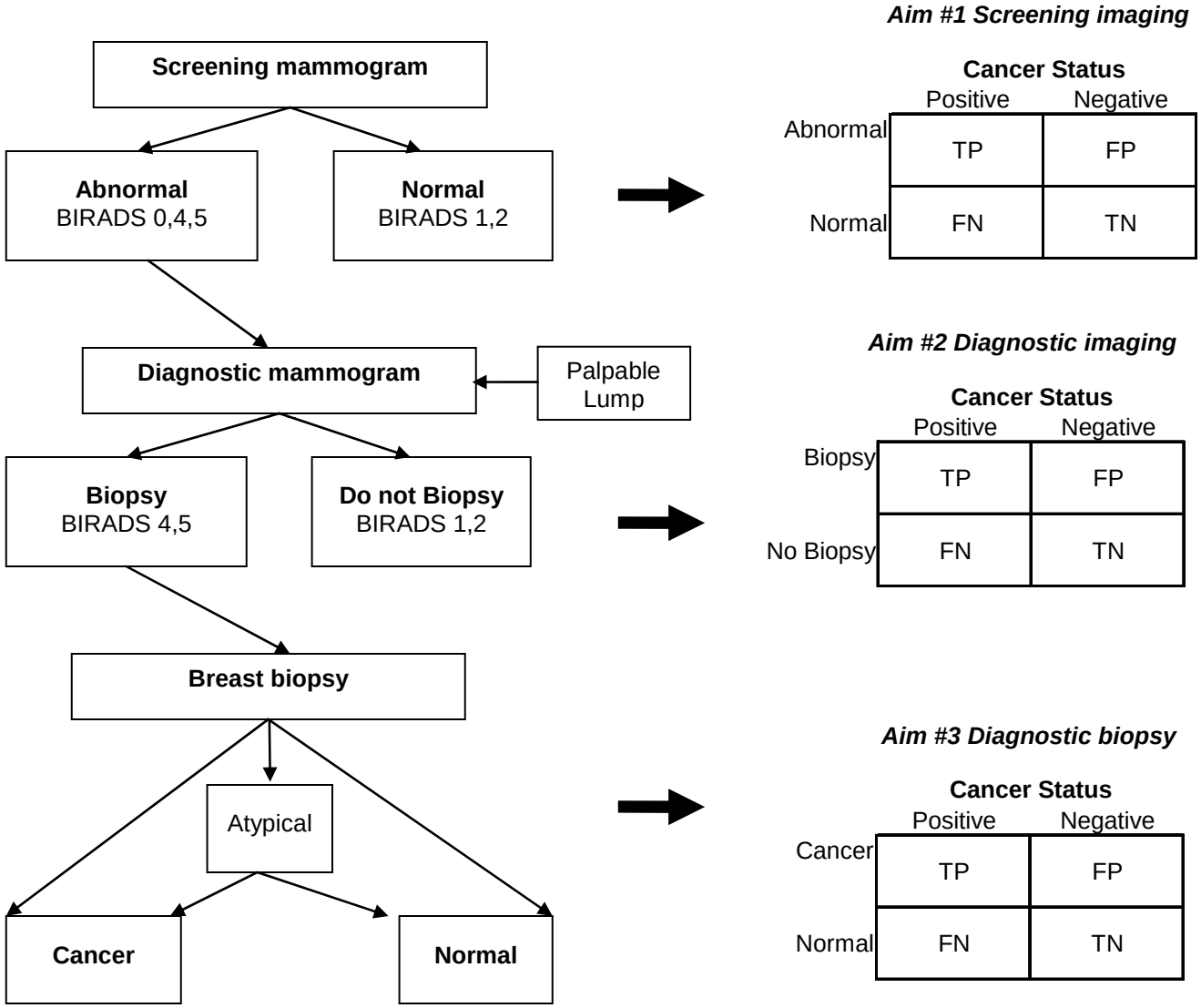
Figure 3. Relationship between data and study aims



Note: BIRADS 3 imaging results will be analyzed separately.

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Results of Linkage, April 2013

- 254,155 ISCR records – female primary breast cancer site diagnosed 1/1/1986 – 12/31/2010
- 413,086 AHC radiology records for screening and dx breast imaging exams for females 1/1/2001 – 12/31/2011)

  Probabilistic Linkage performed Using Automatch software, Matchware Technologies, Inc.
- 22,741 ISCR records matched in a one-to-many relationship to 20,945 unique AHC records

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Coding from the Linkage Algorithm

```
PROGRAM GEOMATCH
DICTA iscr
DICTB adv
;
BLOCK1 CHAR L_sdx L_SDX
BLOCK1 CHAR F_sdx F_SDX
;
MATCH1 UNCERT LName LAST NAME  0.9 0.01 700
MATCH1 UNCERT FName FIRST_NAME 0.9 0.01 700
MATCH1 CHAR MidInit MIDDLE_INIT 0.9 0.01
MATCH1 CNT DIFF SSN1 SSN1 0.9 0.01 2
MATCH1 CNT_DIFF DOB2 DOB 0.9 0.01 1
MATCH1 CNT_DIFF ZIP5 ZIP5 0.9 0.01 1
;
CUTOFF1 35 28 35
;
;
BLOCK2 NUMERIC DOB2 DOB
;
  ...
```

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Match Rate

The match rate for the 2001-2009 AHC exams was estimated at 98%. Matches for 2010 AHC exam records were also found, but at a much lower match rate, so these data should be used cautiously.

Summary

Population-based central cancer registries play an important role in the study of health disparities and linkages to other health datasets expand the utility of this valuable resource in cancer control and population science.

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Acknowledgement
Central Cancer Registries

Major Source:

Illinois State Cancer Registry

Supplement Study Data:

California Cancer Registry

District of Columbia Cancer Registry

Massachusetts Cancer Registry

Metropolitan Detroit Cancer Surveillance System

Pennsylvania Cancer Registry

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Citation

Campbell RT, Li X, Dolecek TA, Barrett RE, Weaver KE, Warnecke RB. Economic, racial and ethnic disparities in breast cancer in the US: towards a more comprehensive model. Health Place. 2009 Sep;15(3):870-879. Epub 2009 Feb 26. PubMed PMID: 19307146; PubMed Central PMCID: PMC2754280.

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