

Data Issues in Studying Small Populations

Challenges, Opportunities, and a Case Study

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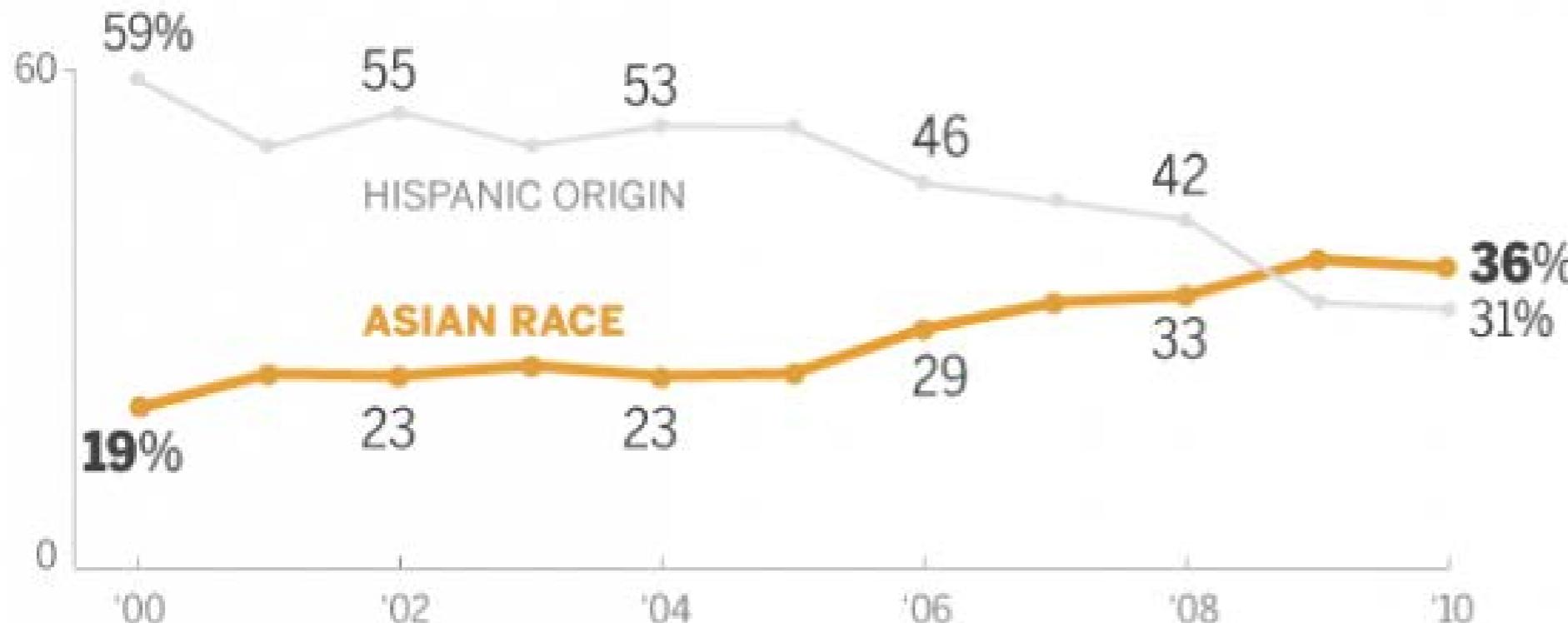
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Meet the New Immigrants: Asians Overtake Hispanics

Percent of immigrants, by year of arrival, 2000-2010



A rapidly growing population

U.S. Asian-American Population, 2011

18,205,898

TOTAL U.S. ASIAN AMERICANS

THEY MAKE UP 5.8% OF THE
TOTAL U.S. POPULATION.

SIX GROUPS MAKE UP AT LEAST 83%
OF THE TOTAL ASIAN-AMERICAN POPULATION

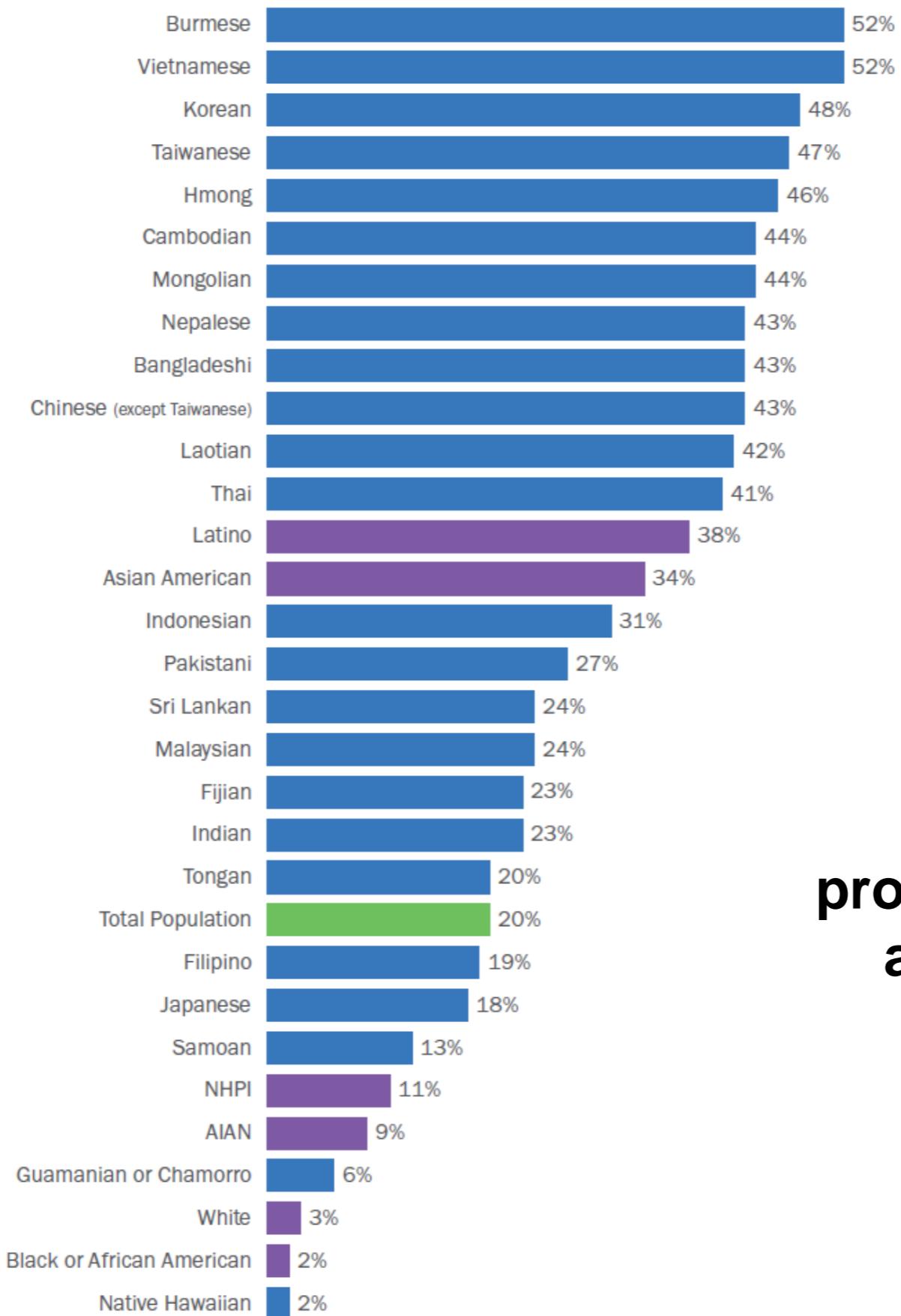
Chinese	4,010,114
Filipino	3,416,840
Indian	3,183,063
Vietnamese	1,737,433
Korean	1,706,822
Japanese	1,304,286

From "The Rise of Asian Americans." Pew Report. 2012

Population Who Is Limited English Proficient for

Those 5 Years of Age & Older

by Race, Hispanic Origin, and Ethnic Group, California 2006–2010



**Tremendous
heterogeneity &
hidden
socioeconomic
disparities**

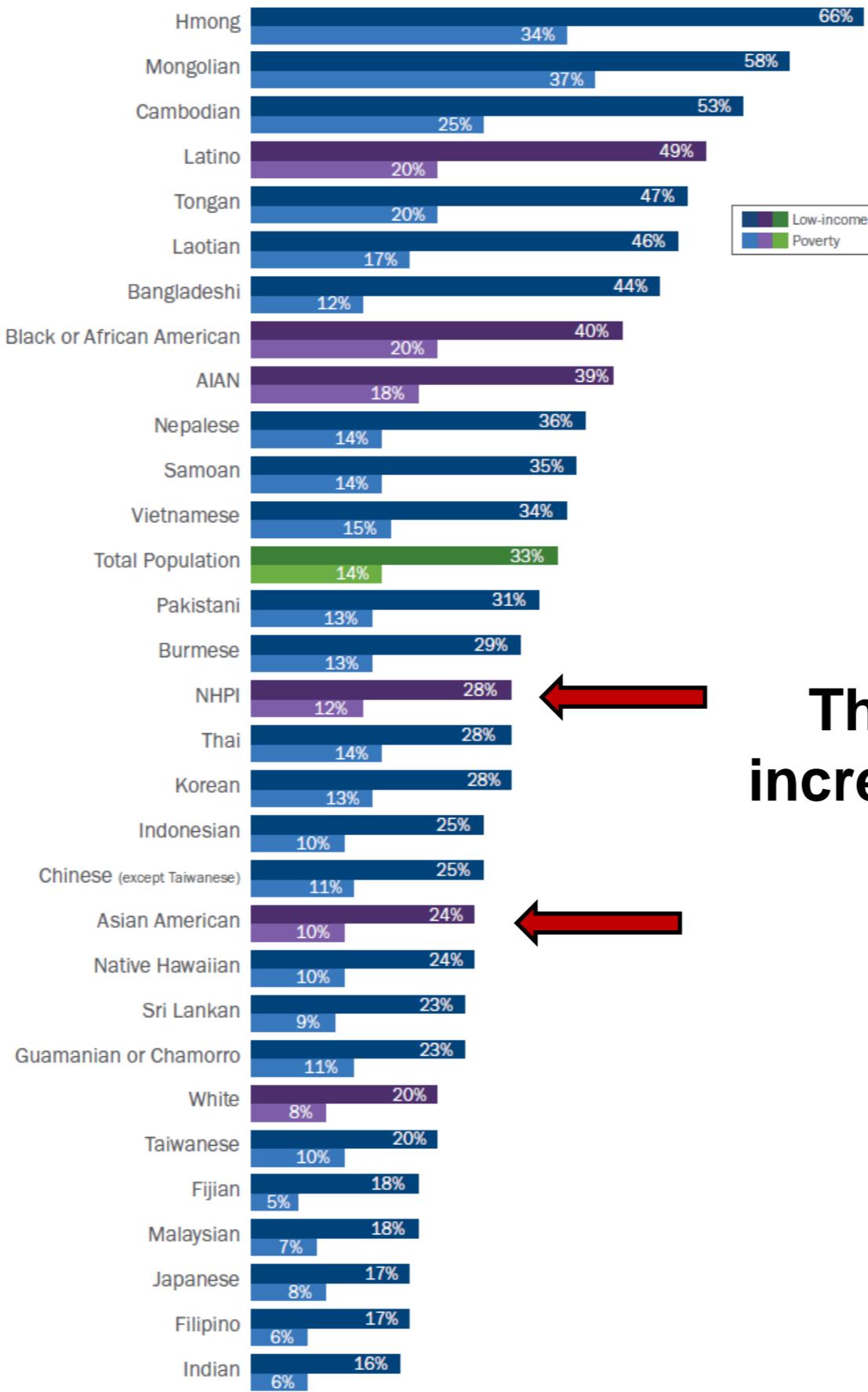
**% limited English
proficient range from 52%
among Burmese and
Vietnamese to 18%
among Japanese.**

From “A Community of Contrasts. Asian Americans, Native Hawaiians and Pacific Islanders in California.”

Asian American Center for Advancing Justice. 2013.

Poverty & Low-income

by Race, Hispanic Origin, and Ethnic Group, California 2006–2010,
Ranked by Percent Low-income



The number of poor AAs increased 50% between 2007 and 2011.

Case Study:

Breast cancer in Asian American women



Breast cancer incidence rates*, California, 1988-2004

Race/Ethnicity	Rate (95% CI)
N-H White	146.1 (145.5-146.7)
Asian **	82.7 (81.6-83.8)

* Rates, per 100,000, adjusted to the US 2000 standard

** Asian = Chinese + Japanese + Filipina + Korean + Vietnamese + South Asian



Breast cancer incidence rates*, California, 1988-2004

Race/Ethnicity	Rate (95% CI)
N-H White	146.1 (145.5-146.7)
Asian **	82.7 (81.6-83.8)
Chinese	73.5 (71.6-75.4)
Japanese	102.5 (99.3-105.9)
Filipina	100.4 (98.1-102.8)
Korean	46.3 (43.8-49.0)
South Asian	77.0 (72.1-82.1)
Vietnamese	59.9 (56.7-63.1)

* Rates, per 100,000, adjusted to the US 2000 standard

** Asian = Chinese + Japanese + Filipina + Korean + Vietnamese + South Asian

From: Gomez et al. Am J Public Health 2010



Breast cancer incidence rates*, California, 1988-2004

Race/ ethnicity	Combined (US+foreign born)	US-born	Foreign- born	Rate ratio (95% CI) (US/foreign)
N-H White	146.1	-	-	-
Asian**	82.7	120.6	76.3	1.6 (1.5-1.6)
Chinese	73.5	122.1	66.3	1.8 (1.7-2.0)
Japanese	102.5	106.1	103.1	1.0 (1.0-1.1)
Filipina	100.4	129.5	98.2	1.3 (1.2-1.4)

* Rates, per 100,000, adjusted to the US 2000 standard

** Asian = Chinese + Japanese + Filipina + Korean + Vietnamese + South Asian

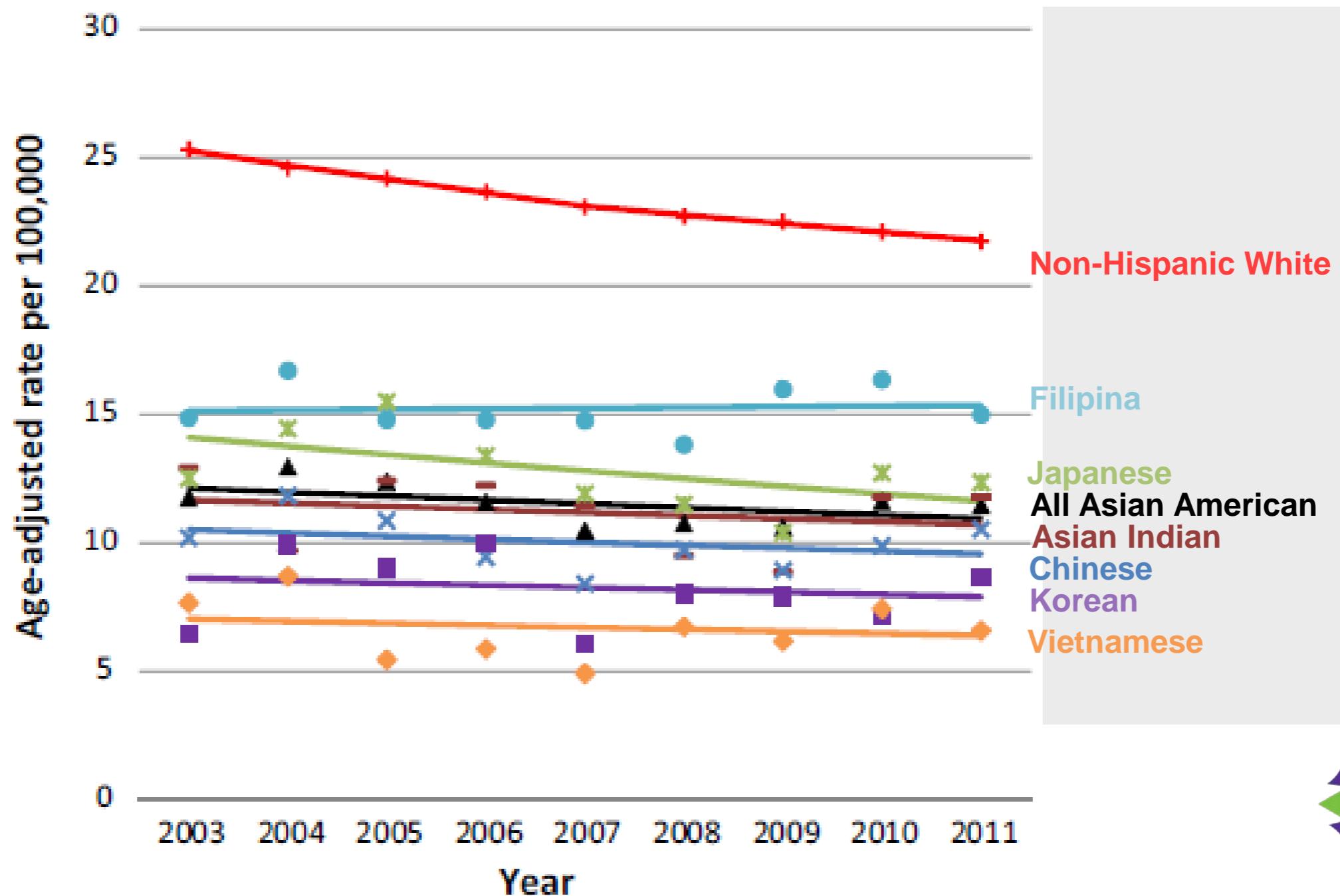
From: Gomez et al. Am J Public Health 2010



The Burden of Cancer in Asian Americans: A Report of National Mortality Trends by Asian Ethnicity

Caroline A. Thompson^{1,2}, Scarlett Lin Gomez^{3,4,5}, Katherine G. Hastings⁶,
Kristopher Kapphahn⁷, Peter Yu⁸, Salma Shariff-Marco^{3,4,5}, Ami S. Bhatt^{9,10},
Heather A. Wakelee^{5,11}, Manali I. Patel^{11,12}, Mark R. Cullen^{6,13}, and Latha P. Palaniappan⁶

Breast cancer
mortality, U.S.,
2003-2011



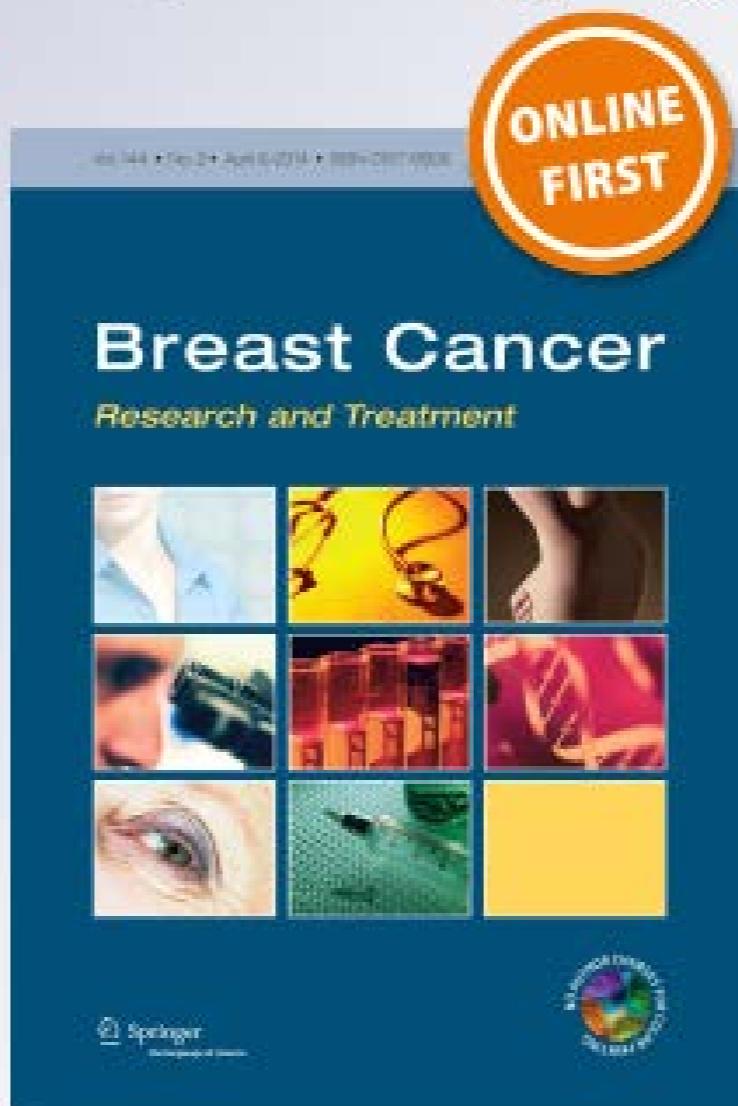
Breast cancer in Asian Americans in California, 1988–2013: increasing incidence trends and recent data on breast cancer subtypes

**Scarlett Lin Gomez, Julie Von Behren,
Meg McKinley, Christina A. Clarke,
Salma Shariff-Marco, Iona Cheng, Peggy
Reynolds, et al.**

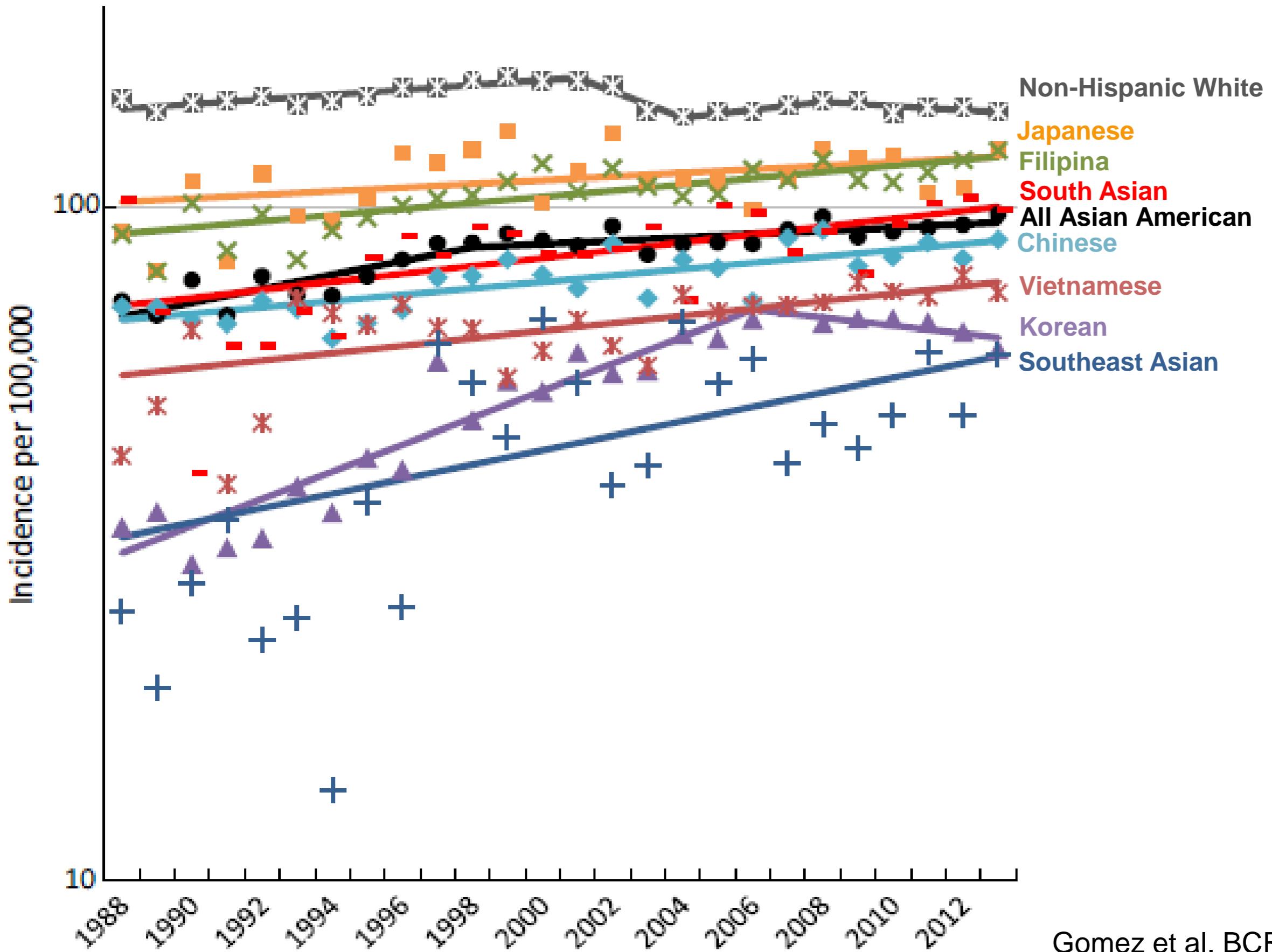
Breast Cancer Research and
Treatment

ISSN 0167-6806

Breast Cancer Res Treat
DOI 10.1007/s10549-017-4229-1



Incidence rates over time of invasive breast cancer among Asian American ethnic groups and non-Hispanic Whites, California, 1988-2013



Higher incidence of breast cancer in young Asian American women?

- 3 studies showed higher incidence rates in young Asian American women (~age <50) relative to non-Hispanic White women*
 - More pronounced in US-born Asian American women (Gomez et al. AJPH 2010)
- Recent international analysis shows trend may be due to cohort (Sung et al. JNCI 2015) or period (Wang et al. Int J Env Res Pub Health 2015) effects of increasing breast cancer rates among Asian populations worldwide, not age-specific effect
 - due to changing risk factors



Breast cancer incidence rates* by age, California, 1988-2004

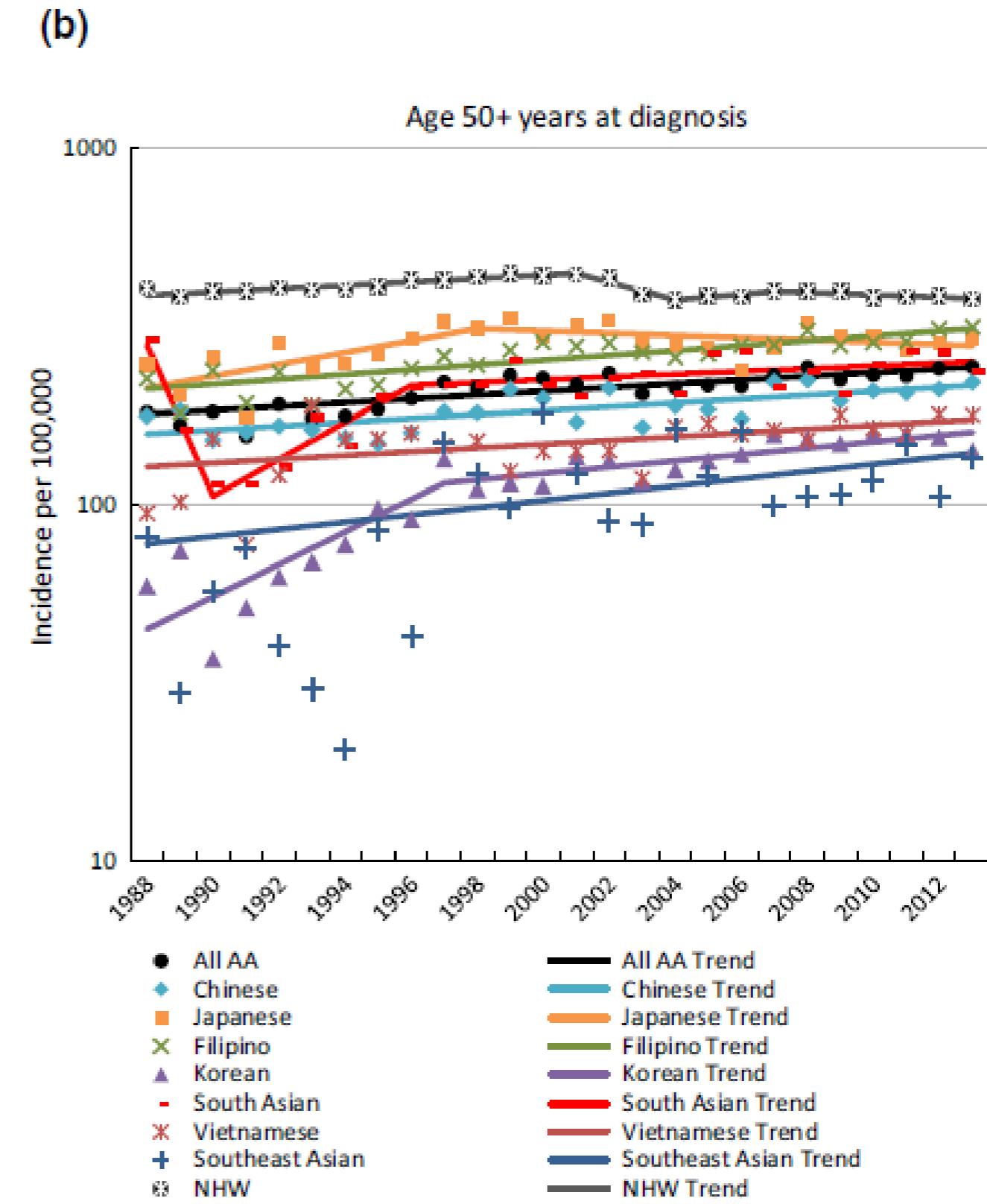
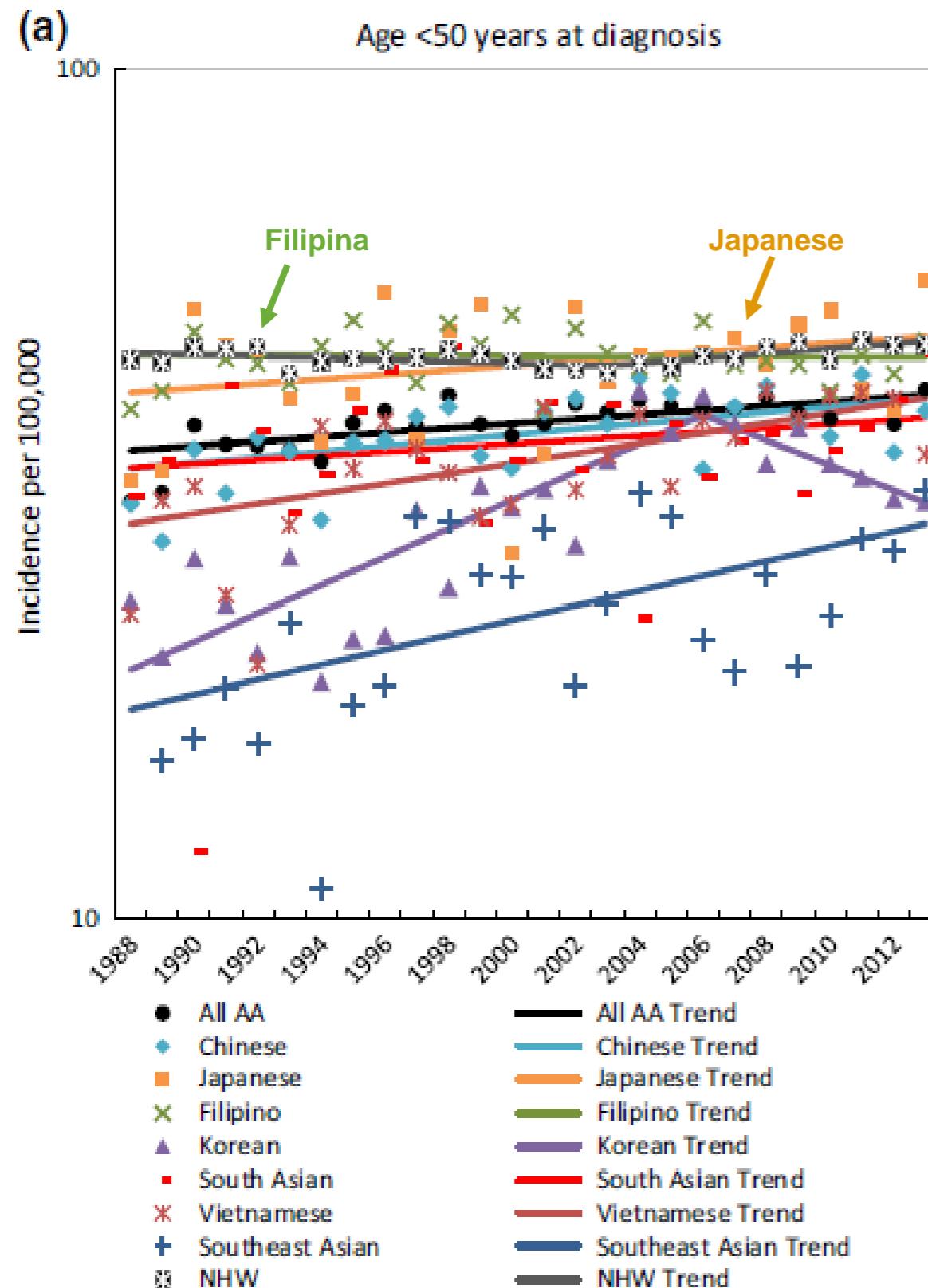
Race/ethnicity	\leq 44 yrs	45-54 yrs	\geq 55 yrs
N-H White	27.1	240.7	449.2
US-born			
Chinese	39.8	276.9	275.6
Japanese	23.9	205.8	294.2
Filipina	43.1	334.3	263.8
Foreign-born			
Chinese	18.9	161.2	167.9
Japanese	24.8	196.0	283.6
Filipina	25.9	215.1	245.0

Rates, per 100,000, adjusted to the US 2000 standard

From: Gomez et al. Am J Public Health 2010



Higher incidence of breast cancer in young Asian American women (cont)?



Disparities within ethnic groups

- More HER2Neu+ tumors?
 - Higher proportional prevalence of HER2Neu+ tumors (Telli et al. BCRT 2010)
 - Compared to non-Hispanic white women, Filipinas and older Vietnamese women had higher incidence rates of some HER2+ subtypes (Gomez et al., BCRT 2017)
- Increasing rates of distant stage disease among Filipinas (2.1% per year) (Gomez et al., BCRT 2017)



Conclusions

Disaggregated data by ethnicity, nativity, and age shows that:

- Vastly differing patterns in incidence, mortality, and incidence and mortality trends across sub-populations.
- Burden of breast cancer is not low among Asians!



“I was diagnosed with breast cancer 5 years ago. When the doctor told me that I had breast cancer I was in shock because I thought this is a white women/old people disease. Later, I was even more surprised to find out that many of the Asian women I knew had breast cancer, but nobody talked about it.”

(personal communication from a breast cancer survivor in NYC, 2010)



Breast Cancer Rates Rise Among Asian-American Women as Others Stay Stable

by Grace Hwang Lynch / Apr. 21. 2017 / PM ET



Why are breast cancer rates rising among Asian-Americans in California?

Tracy Seipel

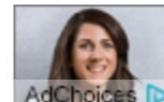
PUBLISHED: April 17, 2017 at 10:17 am | UPDATED:
California News, Environment & Science, Health, La



“When Margaret Abe-Koga was diagnosed with breast cancer in 2015, she was as surprised as anyone. After all, no one ever had breast cancer in her Japanese-American family, she doesn’t have the genetic marker, and she’d been led to believe that Asian-Americans weren’t – as Abe-Koga put it – “a high-propensity group” for the disease.

[The results from the study] stunned Abe-Koga, 46, ... For generations, she said, Asian-Americans have been under the wrong impression that breast cancer “is not prevalent in our community” so “it’s not something that people think about.” ”

Tracy Seipel (Mercury News), Chicago Tribune, April 27, 2017



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- App Store Review

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HEALTHY LIVING

08/01/2017 03:08 pm ET | Updated Aug 01, 2017

More Asian-Americans Are Facing Breast Cancer And Westernization May Be Why

Women could be suffering the unintended consequences of assimilation.



By Jessica Prois

Chicago Tribune

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Life & Style / Health

Breast cancer on the rise among Asian-Americans



Feliz Ng, 4, kisses her mother, Sherry Cava, at their Daly City home on April 13, 2017. Cava, who immigrated from the

Cancer research in Asian Americans, Native Hawaiians, Pacific Islanders: Challenges & opportunities



Cancer Incidence Trends Among Asian American Populations in the United States, 1990 to 2008

Scarlett Lin Gomez, Anne-Michelle Noone, Daphne Y. Lichtensztajn, Steve Scoppa, James T. Gibson, Lihua Liu, Cyllene Morris, Sandy Kwong, Kari Fish, Lynne R. Wilkens, Marc T. Goodman, Dennis Deapen, Barry A. Miller

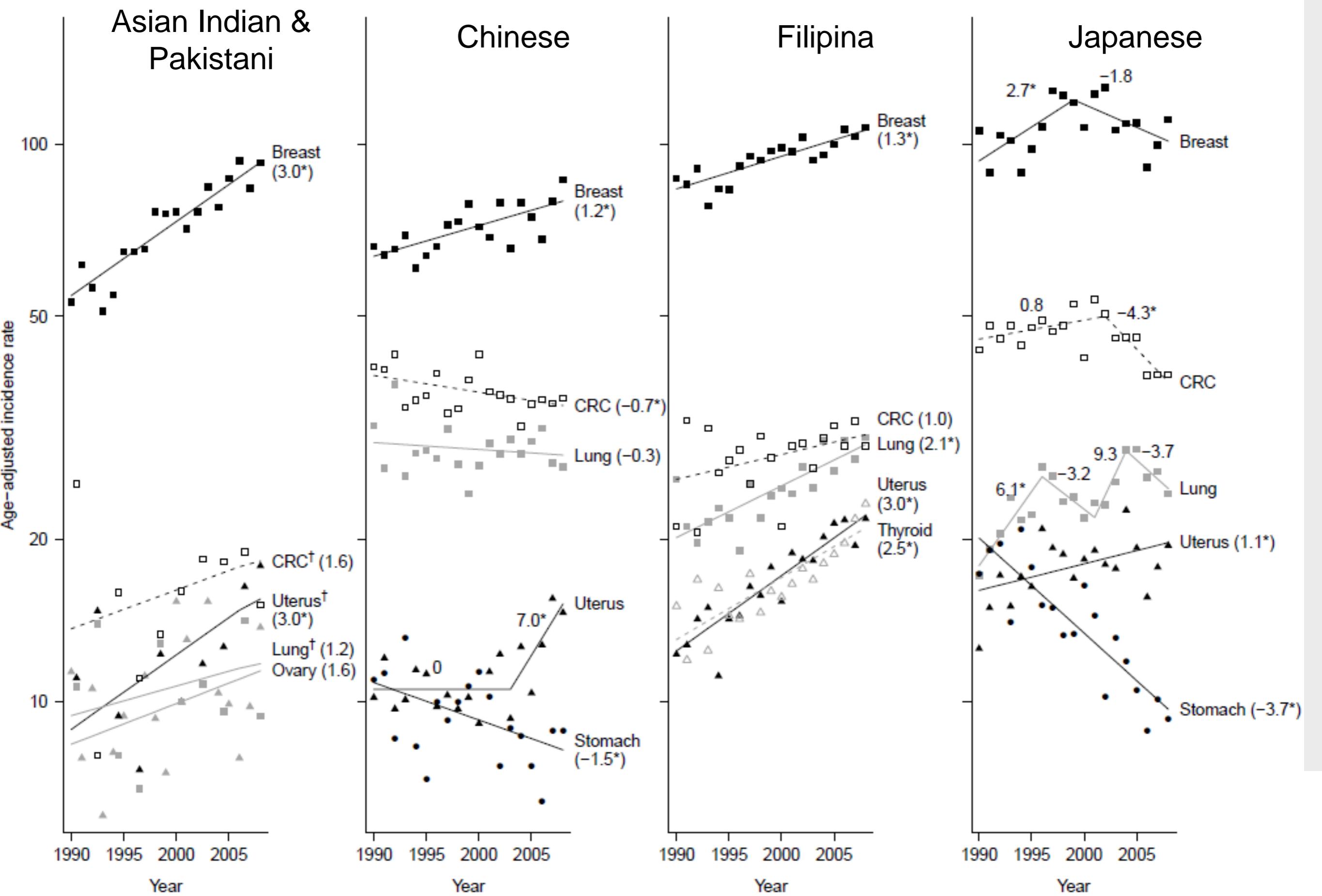
Manuscript received September 19, 2012; revised April 17, 2013; accepted April 18, 2013.

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Journal of the National Cancer Institute 2013

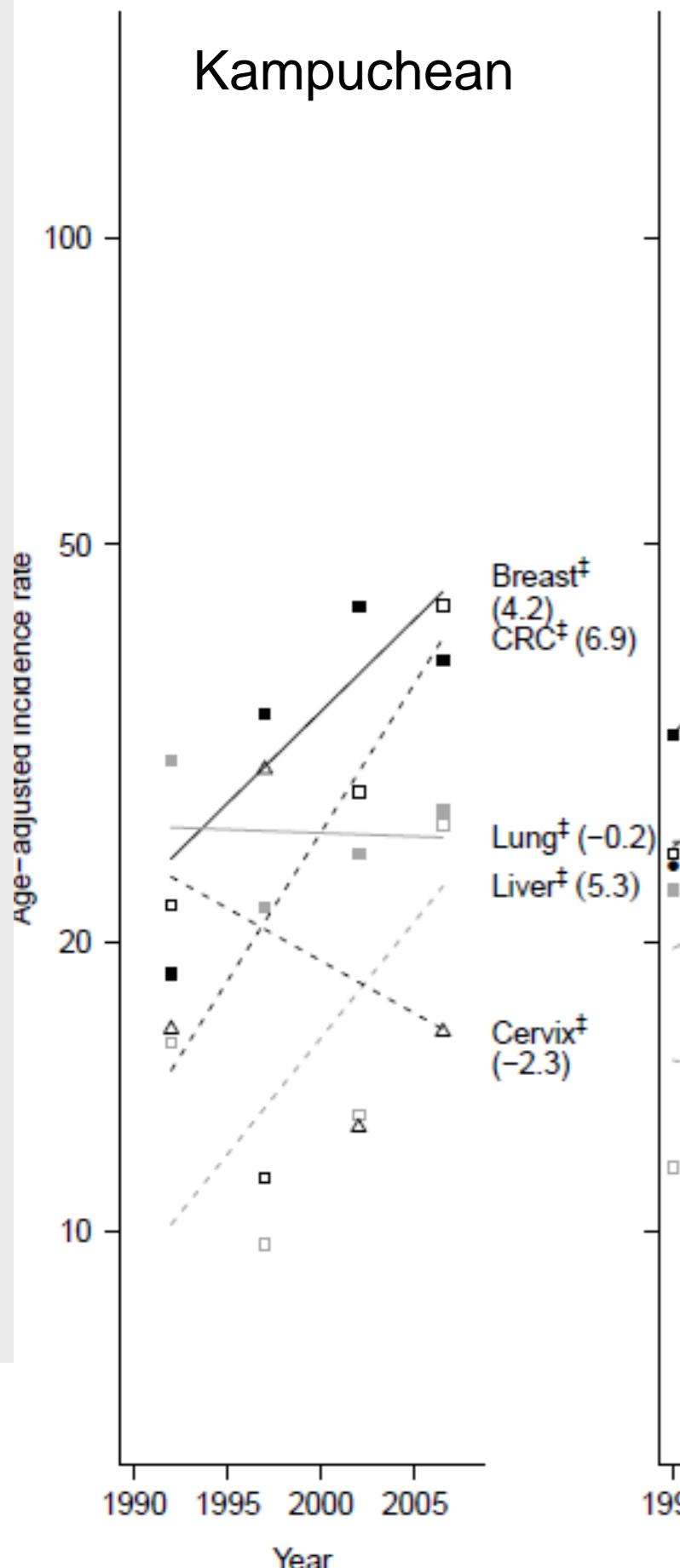


Cancer incidence trends by Asian American group, females, SEER 13, 1990-2008

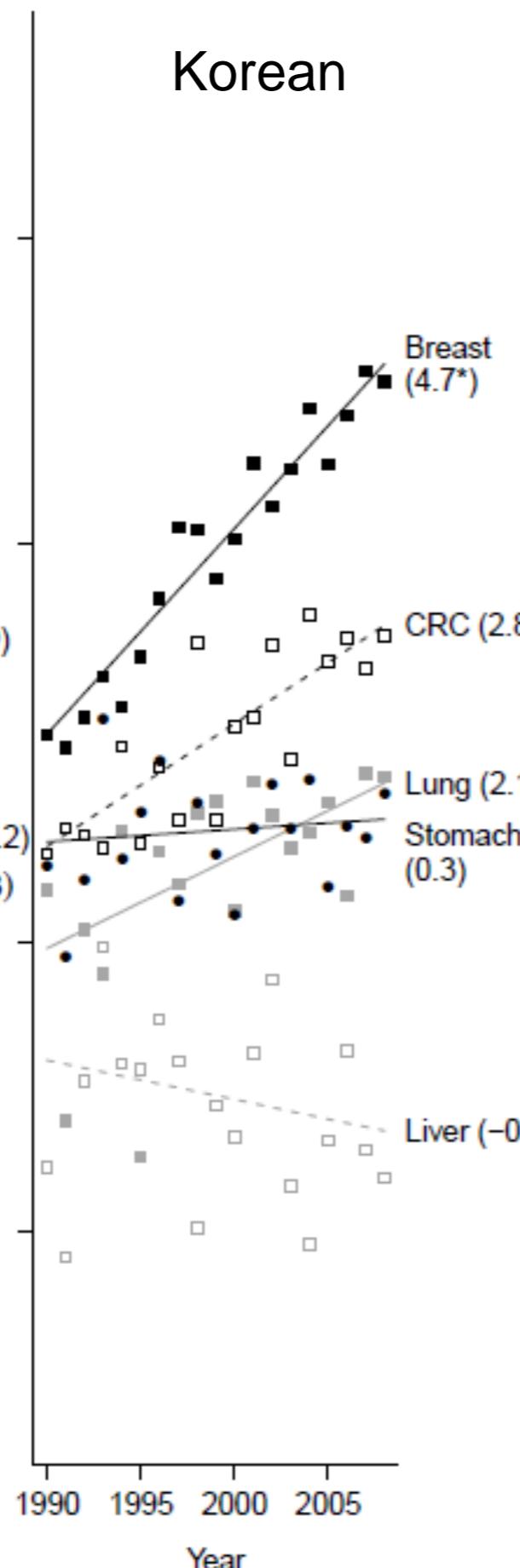


Cancer incidence trends by Asian American group, females, SEER 13, 1990-2008

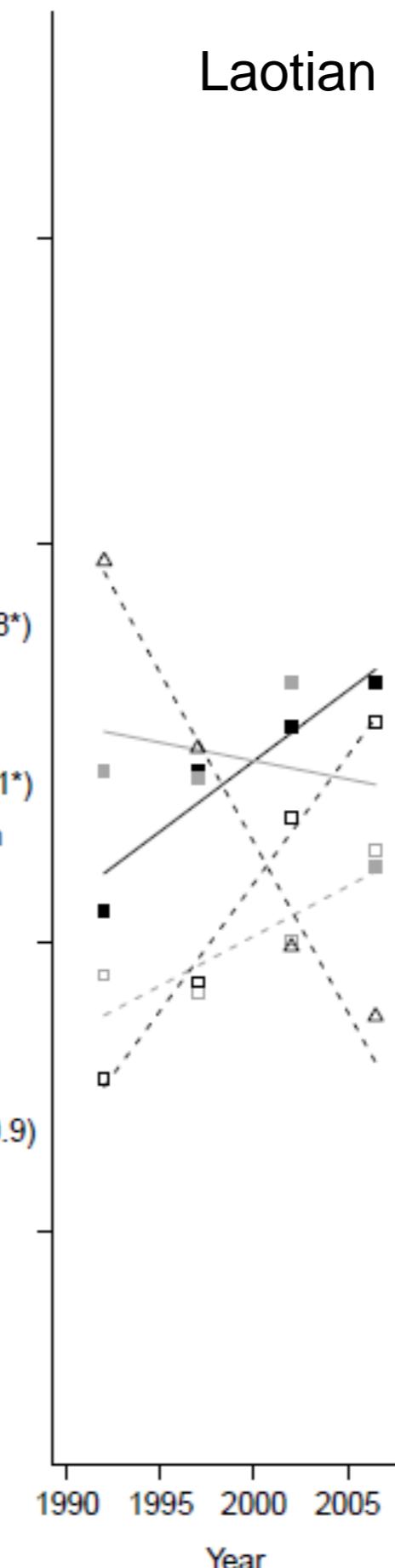
Kampuchean



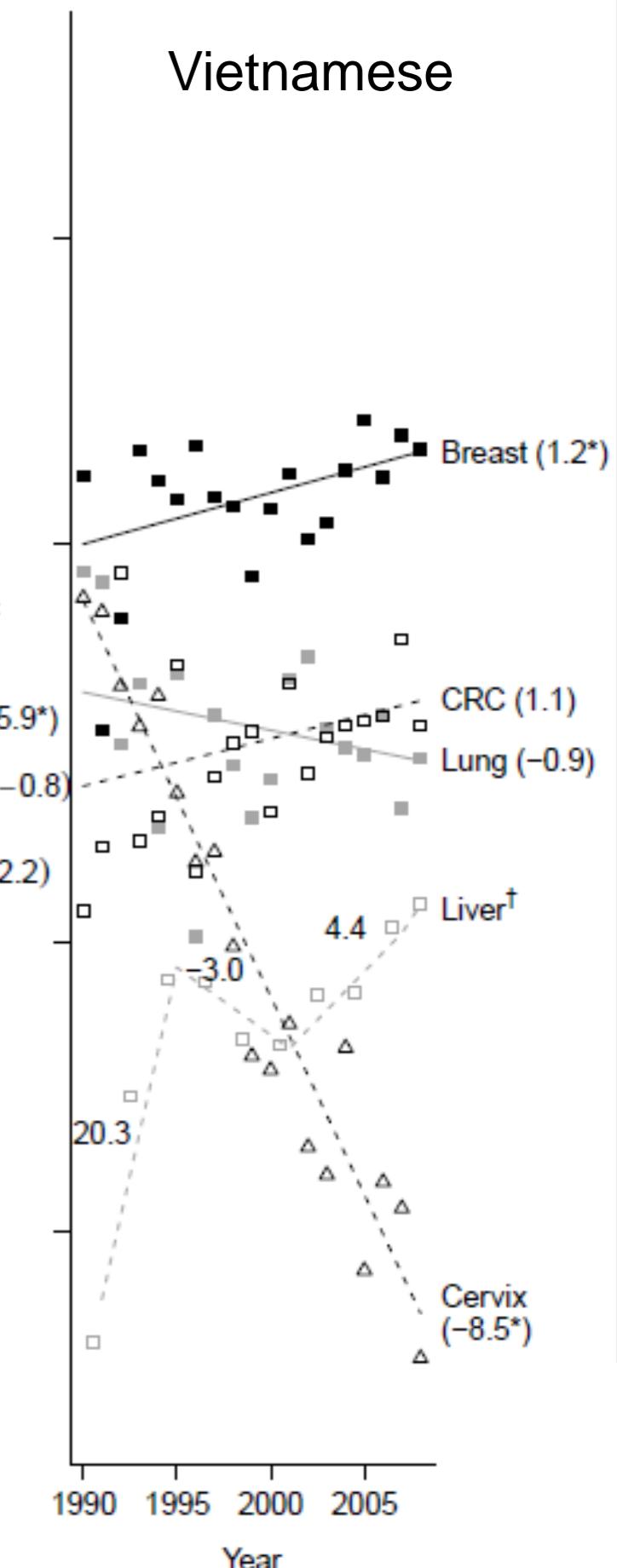
Korean



Laotian



Vietnamese



Gaps in research

- NCI portfolio review showed virtually no studies of cancer etiology focused on this population (Nguyen, Srinivasan, et al., CEBP 2014)
 - Lack of representation in current NCI-funded Cancer Epidemiology Cohorts and other cohorts
 - Multiethnic Cohort (MEC) includes only Japanese Americans and Native Hawaiians (with sufficient numbers for ethnic-specific analyses)
 - Many cohorts in Asia, but none in the U.S.



Challenges

- Small numbers in many ethnic groups
 - How granular can we go?
- Ethnicity information (often) not captured in health surveys, registries, hospital data
- Lack of standardization in data collection
- Other relevant data not captured, e.g., nativity, immigration factors, language, SES



Size + heterogeneity = Opportunities for accelerating cancer discoveries

- Heterogeneity (risk factors, disease risk) within population provides potential opportunities for identifying novel risk factors
- Research into what determines favorable prognosis despite poor prognosis tumor biology
- Potential of migrant studies, longitudinal studies, intergenerational studies

CEBP FOCUS

Cancer Research in Asian American, Native Hawaiian, and Pacific Islander Populations: Accelerating Cancer Knowledge by Acknowledging and Leveraging Heterogeneity

Scarlett Lin Gomez^{1,2}, Sally L. Glaser^{1,2}, Pamela L. Horn-Ross^{1,2}, Iona Cheng^{1,2}, Thu Quach^{1,2}, Christina A. Clarke^{1,2}, Peggy Reynolds^{1,2}, Salma Shariff-Marco^{1,2}, Juan Yang¹, Marion M. Lee³, William A. Satariano⁴, and Ann W. Hsing^{1,2}



"My 1991 diagnosis was only obtained after I sought a second opinion, following a surgical oncologist's "refusal" to biopsy a very prominent and palpable breast lump. The reasons he refused to perform the biopsy was because I was "*too young to have breast cancer*", had "*no family history of cancer*", and "***besides, Asian women don't get breast cancer***". I believe the latter statement was made because of his familiarity with NCI SEER race/ethnic cancer data for "API" populations, which -- as you are well aware -- were then and continue to be reported in the aggregate. I have that surgeon to thank for turning me into a fierce cancer advocate" (*personal communication from Susan Shinagawa, cancer survivor*)



Thank you!

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