



University of California
San Francisco



Challenges & Opportunities: a SEER Registry Perspective

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Director, Greater Bay Area Cancer Registry

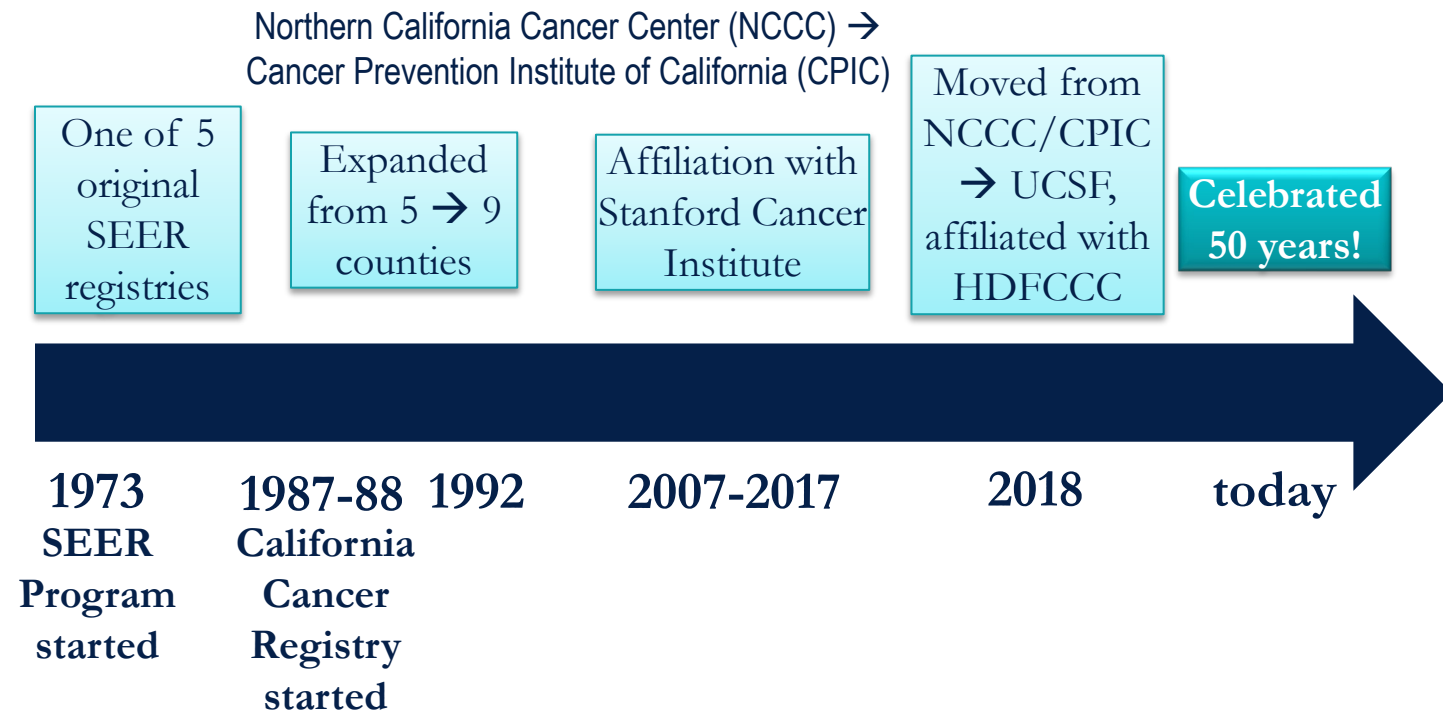
Department of Epidemiology & Biostatistics
Helen Diller Family Comprehensive Cancer Center



History of the Greater Bay Area Cancer Registry

A part of the California Cancer Registry

- 3 regional registries in California

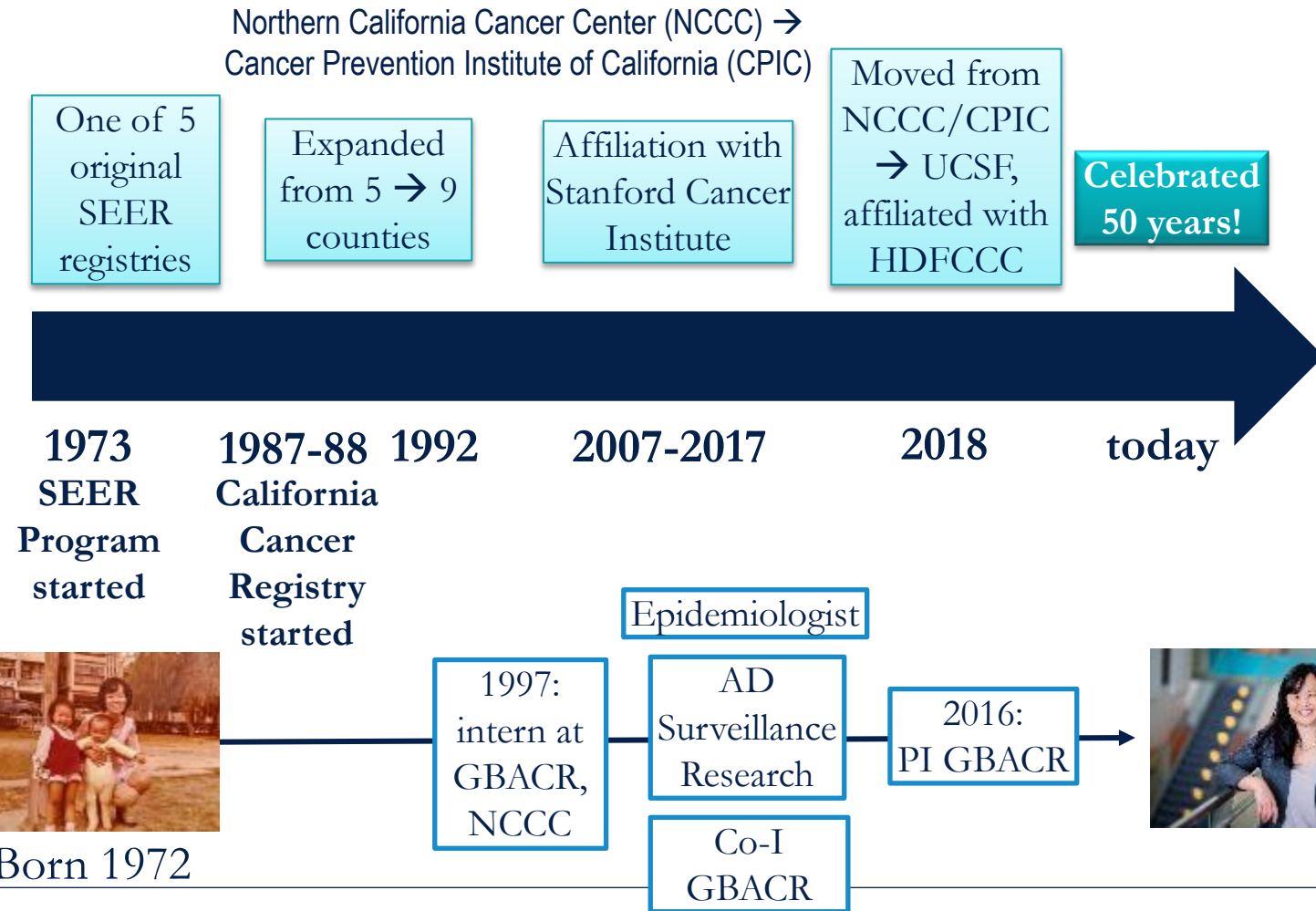


CancerRegistry.ucsf.edu

History of the Greater Bay Area Cancer Registry

A part of the California Cancer Registry

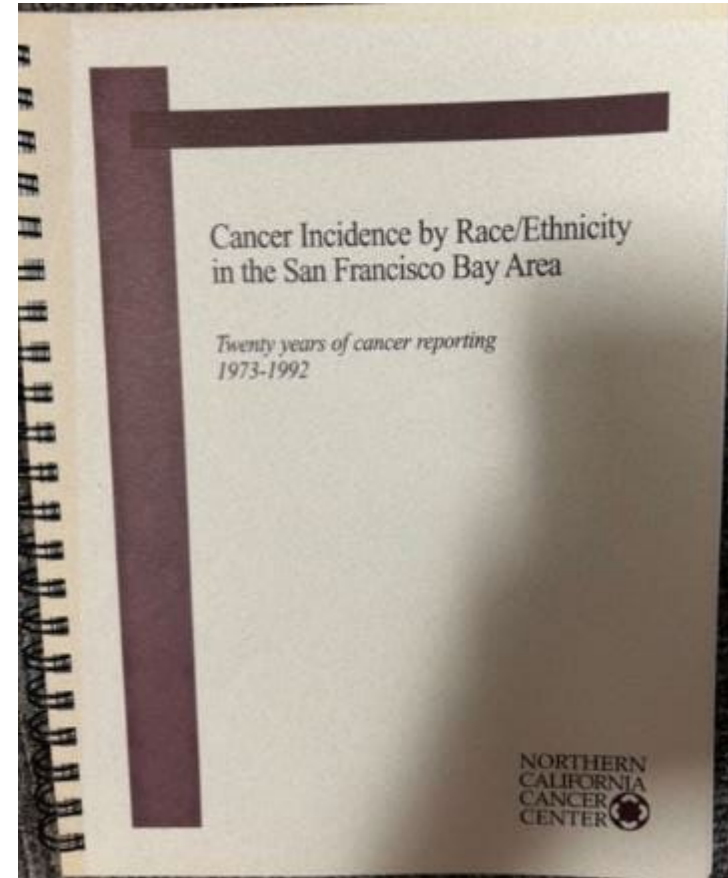
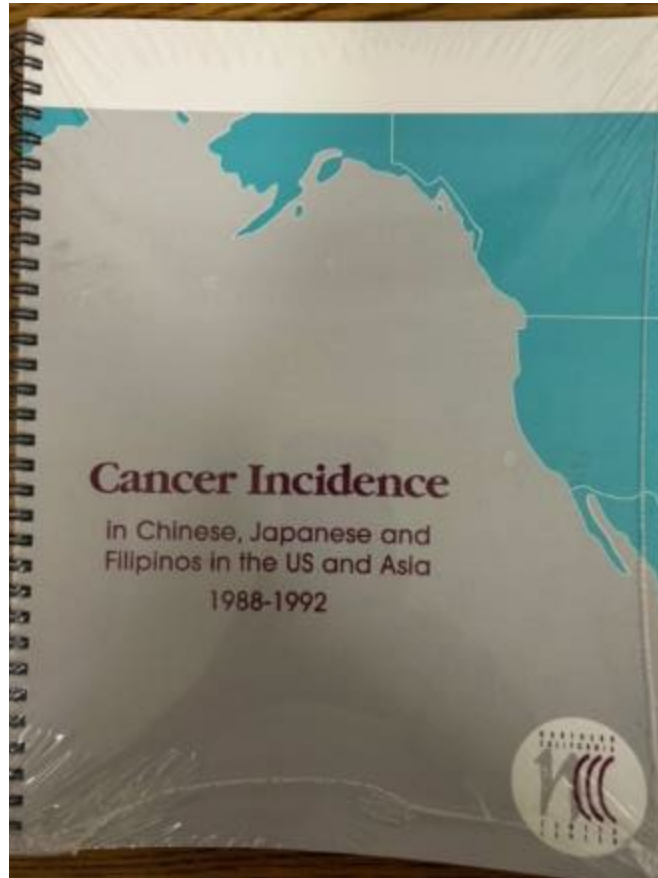
- 3 regional registries in California



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Challenges & opportunities in: data dissemination

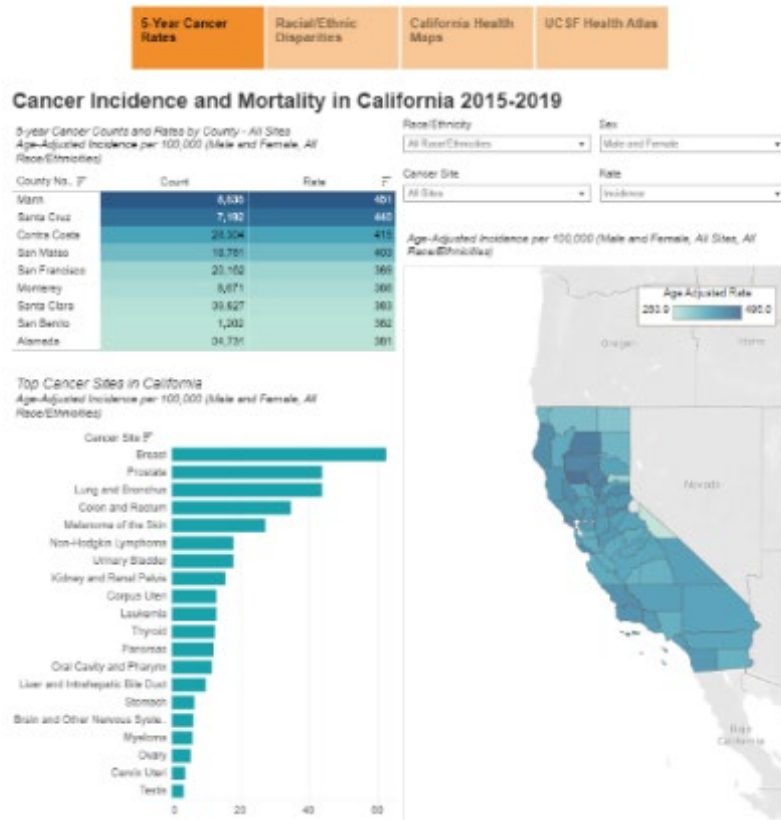
From hard copy reports...



Challenges & opportunities in: data dissemination

...to online dashboards and maps for broader dissemination, to enable access and utilization by more diverse stakeholders

Greater Bay Area Cancer Registry Dashboard



California Health Maps is an interactive mapping tool of health data for geographies beyond the county level in California. You can map cancer incidence for 12 of the most common invasive cancer sites and filter by sex and race/ethnicity. [Visit Learn](#) to review methodology, data sources, and more.

Cancer Incidence

Select Area Type
Zone

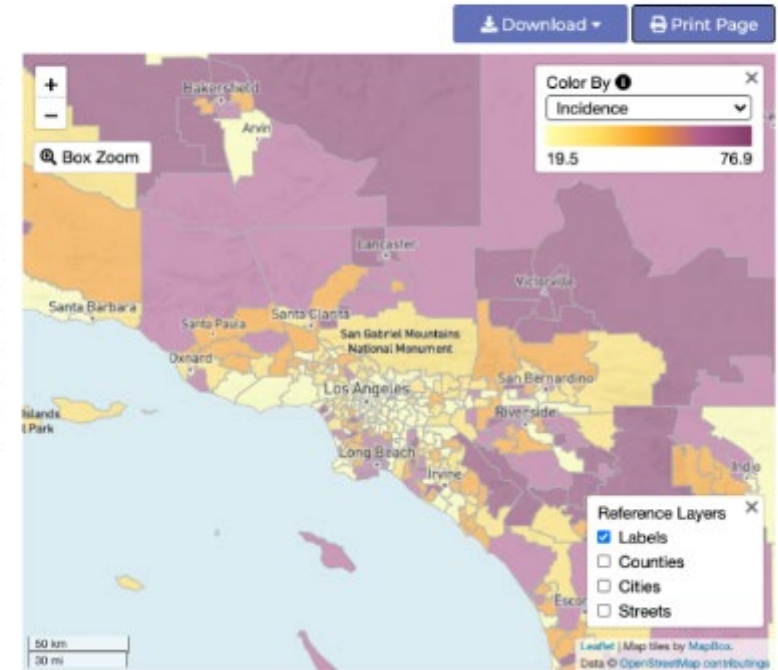
Location Search
Search by address or city

Date Range
5-Year: 2013-2017

Cancer Site/Type
Lung Cancer

Sex
All Sexes

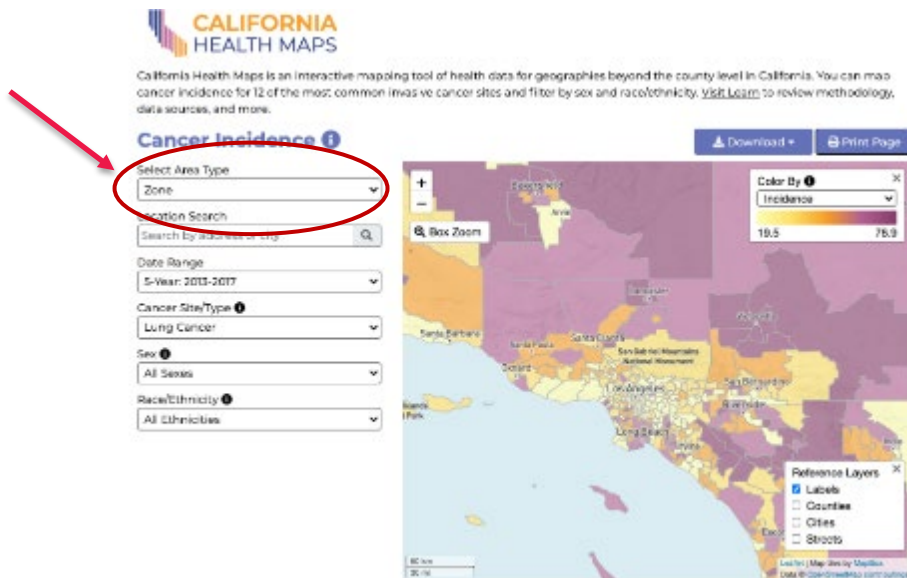
Race/Ethnicity
All Ethnicities



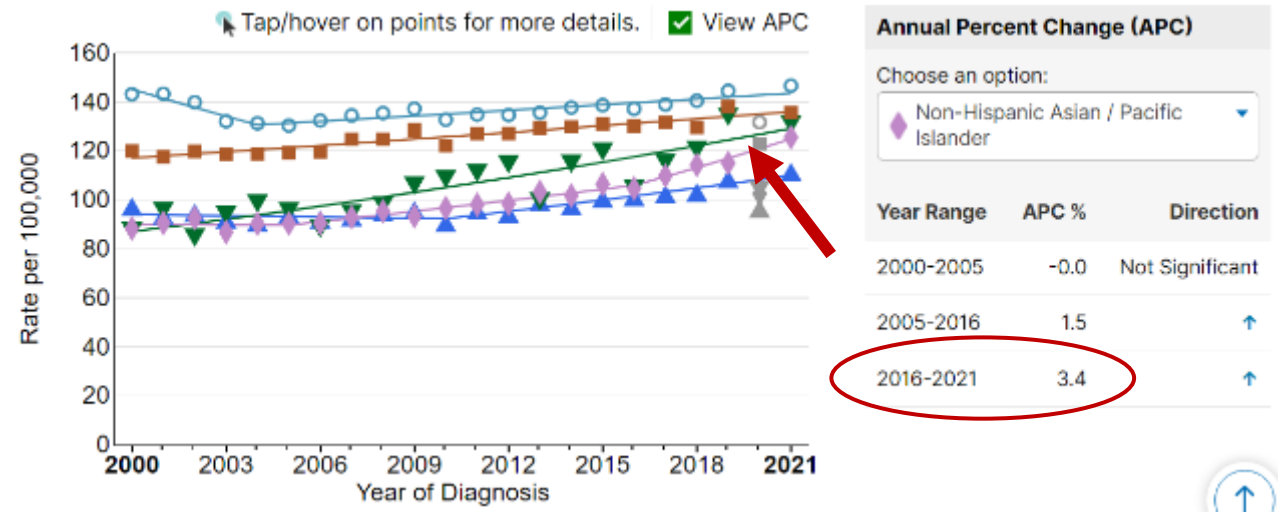
Challenges & opportunities in: data dissemination

Challenges:

- Timely availability of denominator data
 - Small areas (census tracts)
 - Detailed population groups (e.g., Asian American ethnicities)
- Balance between granularity and small numbers (suppression)
- Compatibility with OMB standards (race/ethnicity)



Age-adjusted breast cancer incidence rates by race/ethnicity, SEER, 2000-2021



Challenges & opportunities in: data access

Challenges in data release & data access

- Increasingly difficult
- Varies by state (depending on state policies)
- Limits data use → research discoveries
- Are we better protecting human subjects?

CANCER EPIDEMIOLOGY, BIOMARKERS & PREVENTION | COMMENTARY

Advancing Social and Environmental Research in Cancer Registries Using Geomasking for Address-Level Data

Hari S. Iyer¹, Xun Shi², Jaya M. Satagopan³, Iona Cheng⁴, Charlotte Roscoe^{5,6}, Robert H. McLaughlin⁷, Antoinette M. Stroup^{1,8}, Soko Setoguchi⁹, Elisa V. Bandera¹, Brenda Y. Hernandez¹⁰, Jennifer A. Doherty¹¹, Mei-Chin Hsieh¹², Richard Knowlton¹³, Bo Qin¹, Francine Laden⁶, Timothy R. Rebbeck⁵, and Scarlett L. Gomez⁴



Challenges & opportunities in: data availability & quality

- High % missing, for ex:
 - Birthplace
 - Hispanic origin
- Lack of relevant data
 - Recurrence & disease progression
 - Health behaviors
 - Relevant patient sociodemographic data, e.g., SOGI
- Data quality & completeness can vary across registries

Challenges & opportunities in: linkages

Challenges:

- Linkages help to overcome issues with data gaps
- Administratively difficult given need to share patient identifying information (PII)

Opportunities:

- Leverage privacy protecting record linkage (PPRL) methods
- Institutional privacy offices?
- Patient advocates?

Germline Genetic Testing After Cancer Diagnosis

Allison W. Kurian, MD, MSc; Paul Abrahamse, MA; Allison Furgal, PhD; Kevin C. Ward, PhD; Ann S. Hamilton, PhD; Rachel Hodan, MS; Rachel Tocco, MS; Lihua Liu, PhD; Jonathan S. Berek, MD, MMSc; Lily Hoang, BS; Amal Yussuf, BS; Lisa Susswein, MS, MHA; Edward D. Esplin, MD, PhD; Thomas P. Slavlin, MD; Scarlett L. Gomez, PhD; Timothy P. Hofer, MD; Steven J. Katz, MD, MPH

Ann Surg Oncol
https://doi.org/10.1245/s10434-024-15707-w

Annals of
SURGICAL ONCOLOGY
OFFICIAL JOURNAL OF THE SOCIETY OF SURGICAL ONCOLOGY



ORIGINAL ARTICLE – BREAST ONCOLOGY

Disparities in the Occurrence of Long-Term Effects of Bone Marrow Suppression after Treatment in Adolescent Young Adult Breast Cancer Survivors

A. Bellini, MD^{1,2}, T. H. M. Keegan, PhD^{1,3}, Q. Li, MS³, F. B. Maguire, PhD⁴, V. Lyo, MD^{2,5}, and Candice Sauder, MD^{1,2}

frontiers | Frontiers in Pediatrics

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Long-term trends in cancer incidence and mortality among U.S. children and adolescents: a SEER database analysis from 1975 to 2018

Xiao-Wei Tang^{1,2}, Jiao Jiang^{1,2}, Shu Huang^{1,3}, Xiao-Min Shi^{1,2}, Huan Xu^{1,2}, Jia Xu^{1,2}, Jie-Yu Peng^{1,2}, Wei Zhang^{1,2}, Lei Shi^{1,2}, Xiao-Lin Zhong^{1,2}, Min Kang^{1,2} and Mu-Han Lu^{1,2,4}



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Thrombosis Research

journal homepage: www.elsevier.com/locate/thromres

Full Length Article

Late venous thromboembolism in survivors of adolescent and young adult cancer: A population-based study in California

Renata Abrahão^{a,*}, Ann Brunson^a, Jessica Chubak^b, Karen J. Wernli^{b,c}, Hazel B. Nichols^d, Chun Chao^{c,e}, Kathryn J. Ruddy^f, Erin E. Hahn^{c,e}, Qian Li^a, Marcio H. Malogolowkin^g, Candice A.M. Sauder^{h,i}, Lawrence H. Kushi^j, Ted Wun^a, Theresa H.M. Keegan^a

JAMA Oncology | Original Investigation

Bilateral Mastectomy and Breast Cancer Mortality

Vasily Giannakeas, PhD, MPH; David W. Lim, MDCM, MEd, PhD; Steven A. Narod, MD

JAMA Health Forum



Brief Report

Race and Ethnicity Representation in Phase 2/3 Oncology Clinical Trial Publications: A Systematic Review

Kekoa Tappara, MD, PhD; Ryan Benavente, BS; Jonathan J. Shih, BS; Megan Y. Gimmen, BS; Paul Tominez, BS; Kā'eo Kekumano; Eric Pineda, BS; Gisèle Hakualani; Henrietta Calobau; Ethan B. Ludmir, MD; Curtland Deville Jr, MD; Jeffrey Peppercorn, MD, MPH; Scarlett L. Gomez, PhD, MPH; Linda Bosserman, MD; Fumiko Chino, MD; Manali I. Patel, MD, MPH; Chirag Shah, MD

