

# Institutional Humility & Engaging Diverse Communities in Cancer Research



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1.28.2020

# My background, training and experiences are diverse



**BA '91: Linguistics**  
**MS '93-96: Health Sciences**



**MD '93-98**  
**Resident '98-'05: Surgery**  
**Colorectal Fellowship '07**  
**Health Policy Fellowship '08**



**MPH '06**  
**Minority health disparities**



**Assistant & Associate Professor '08-'16**

**Board of Directors,  
Bay Area Black Women's  
Health Project ('93-'96)**



**Saturday School  
for Community  
Leaders ('95)**



**Community Based  
Participatory  
Research Training  
(12)**



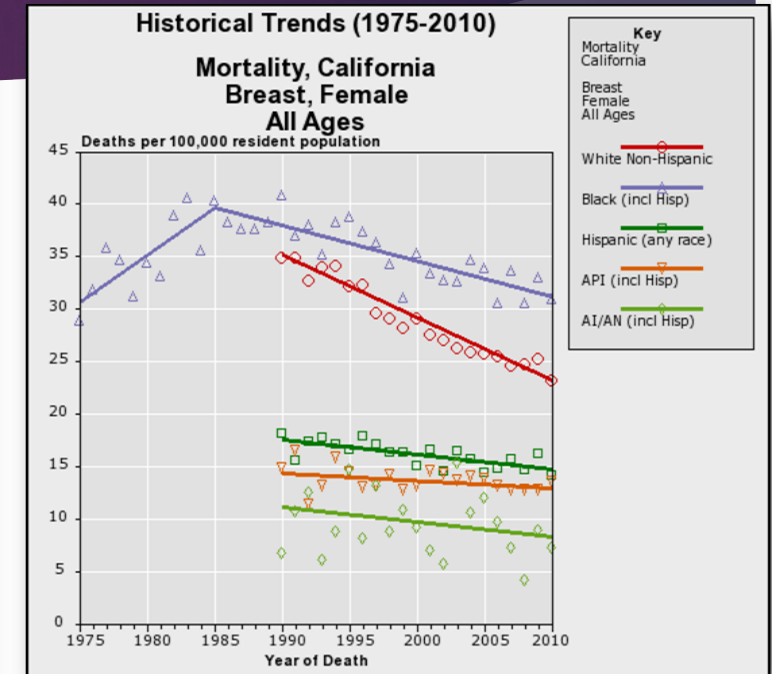
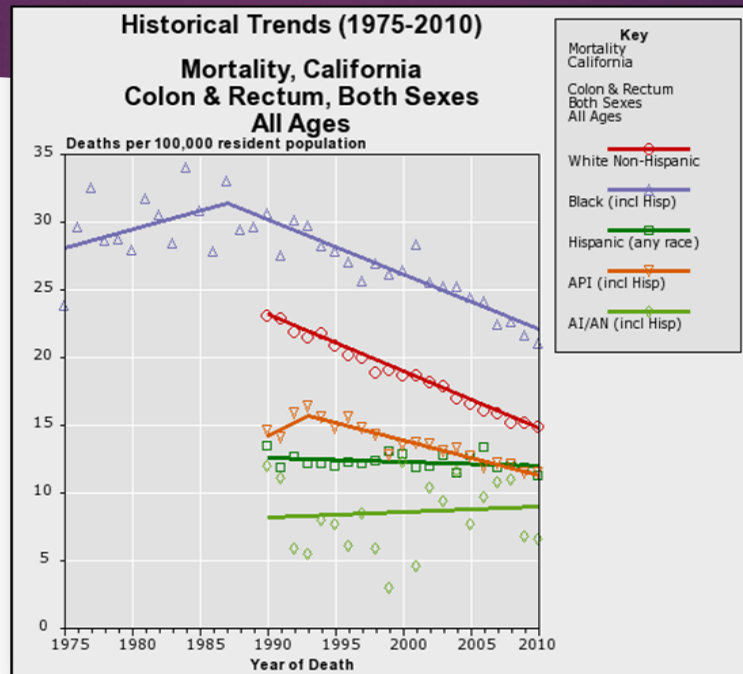
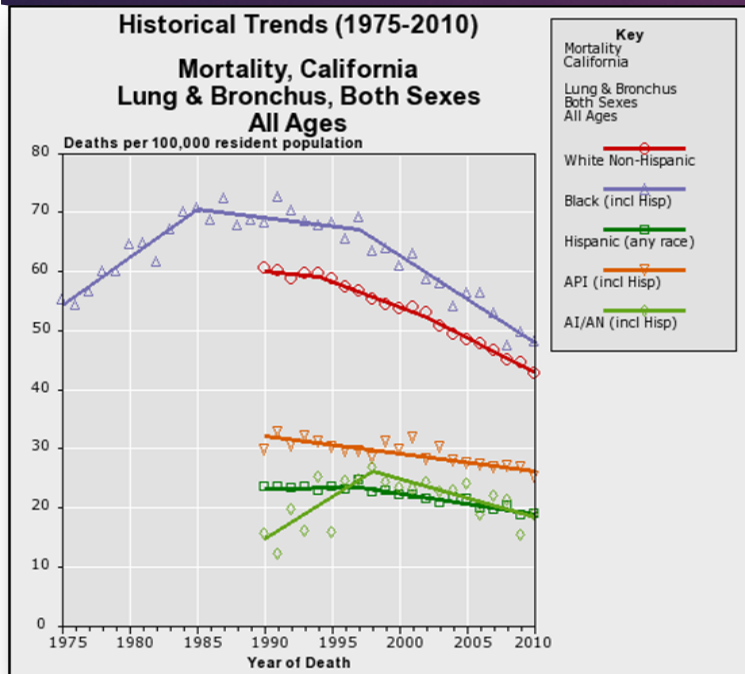
# Jeannette Barnes (1935-1993)

## Motivation for my work in health equity & disparities



- 58 years old
- Presented with a locally advanced breast mass (stage IIIB)
- Admitted for IV antibiotics; chemotherapy
- Died in the hospital  
(never having received palliative radiation therapy)

# Disparities in Cancer are Longstanding



NCI website: <http://statecancerprofiles.cancer.gov> last access 3/1/2015

# Traditional explanations for disparities in cancer survival focus on the individual

## **Patient Characteristics**

- ▶ Chronic disease/comorbid states
- ▶ Late stage at diagnosis

## **Insurance Status**

- ▶ Lack of access to care contributes to poor outcomes

## **Genetic explanations**

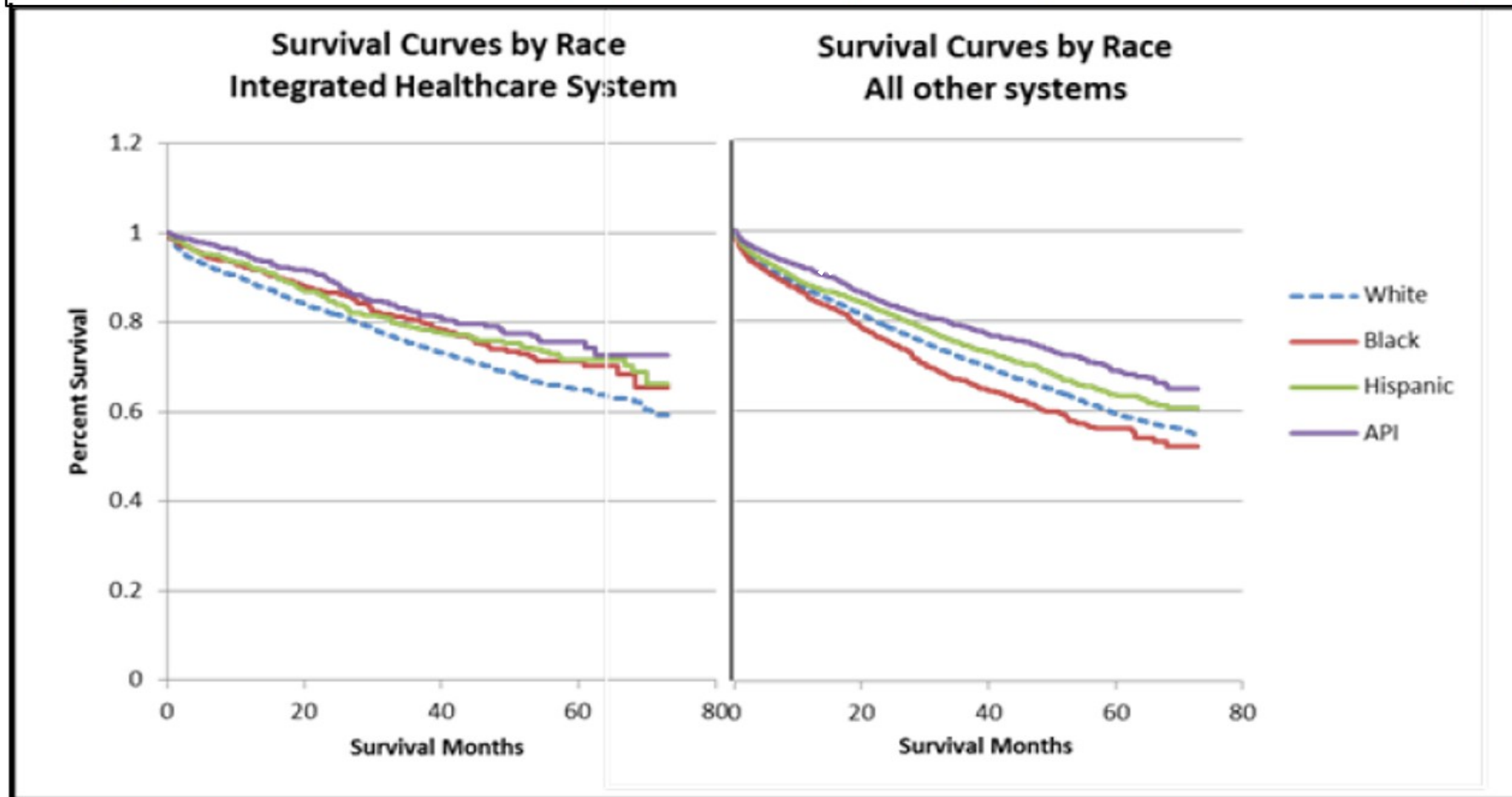
- ▶ Racial/ethnic minorities have more aggressive tumors



Health disparities are a  
population level problem

# No disparities in colon cancer survival within an integrated system

Kaplan-Meier Curves Comparing Survival by race/ethnicity in the integrated setting versus all other settings (Colon Cancer, stage I-III; California 2001-2006)



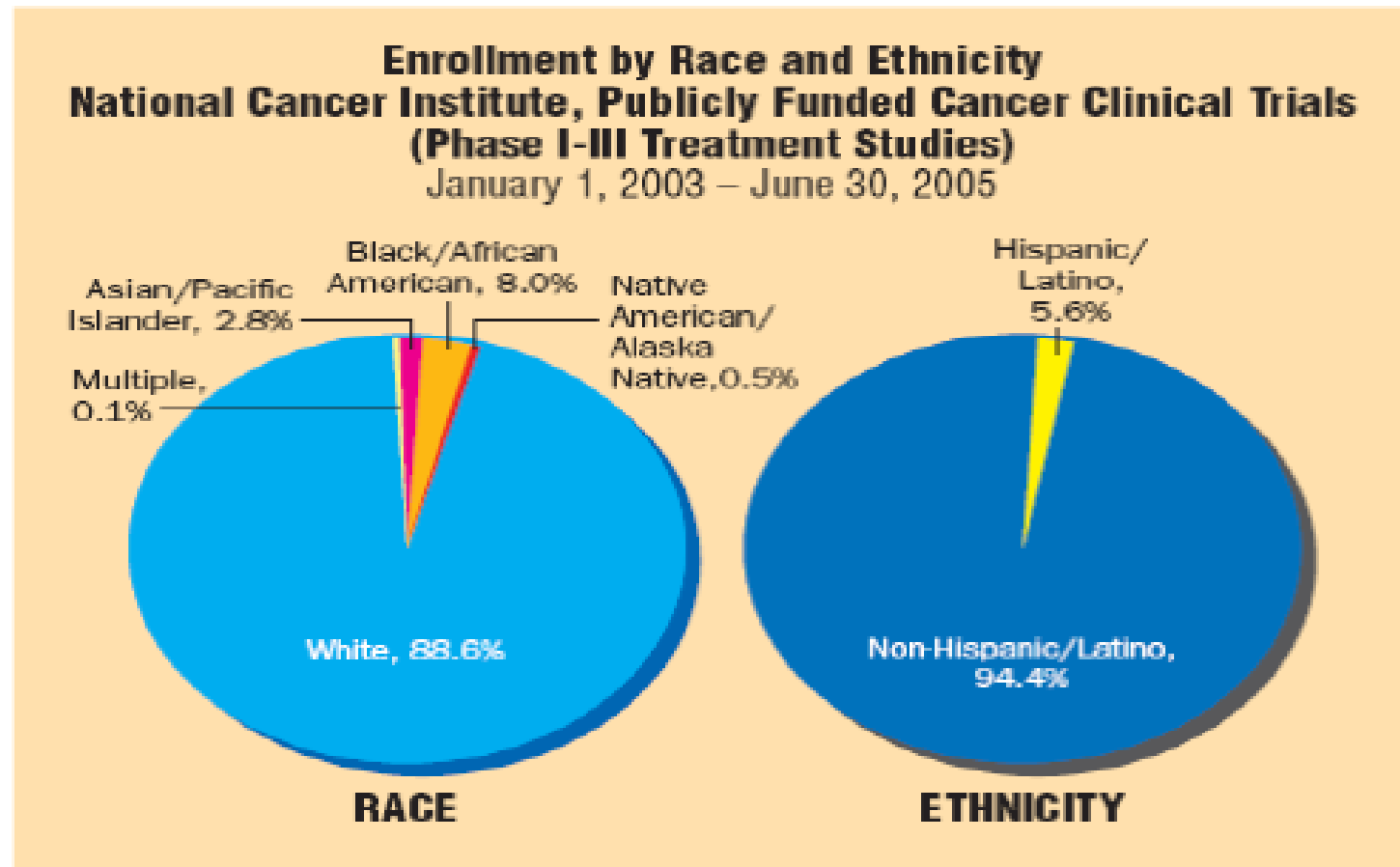
Rhoads KF &  
Patel MI.  
*JCO* 2015

# Place Matters

**WHERE YOU GO  
FOR CARE  
DETERMINES WHAT  
CARE YOU GET**



# Racial/Ethnic Diversity is Low in Cancer Clinical Trials, Nationally



Source: Baseline Study of Patient Accrual Onto Publicly Sponsored Trials, Coalition of Cancer Cooperative Groups for the Global Access Project, National Patient Advocate Foundation, April 2006.

**'Lack of Trust'** is an  
expected response to  
(historically)  
**untrustworthy** behavior

**FOOD FOR  
THOUGHT**

# Magnitude of structural & physician and patient barriers to inclusion

## Methods:

- ▶ N=13 trials
- ▶ N=8800 patients

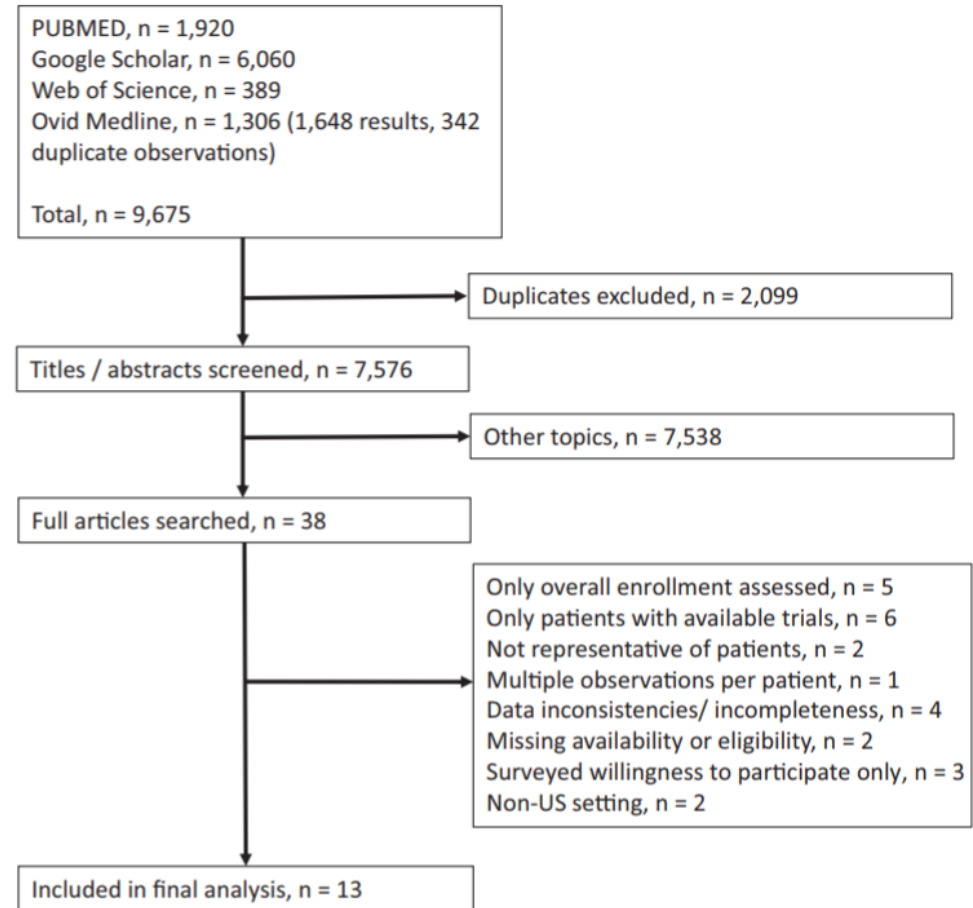
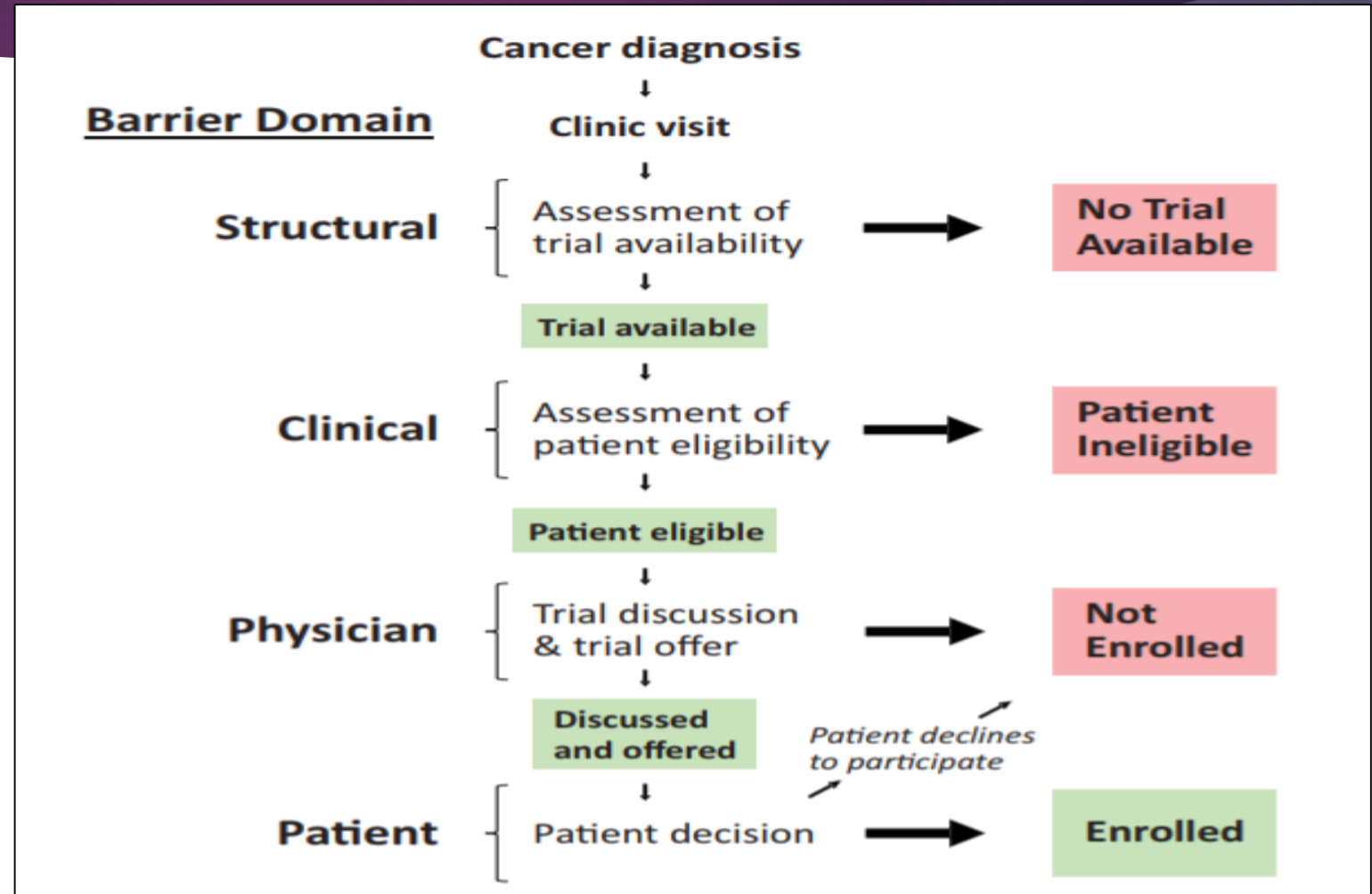


Figure 2. Selection of studies included in the analysis.

# Magnitude of structural & physician and patient barriers to inclusion

Multi-level determinants of clinical trial inclusion

Unger, et al. JNCI 2019



# Magnitude of structural & physician and patient barriers to inclusion

252 | JNCI J Natl Cancer Inst, 2019, Vol. 111, No. 3

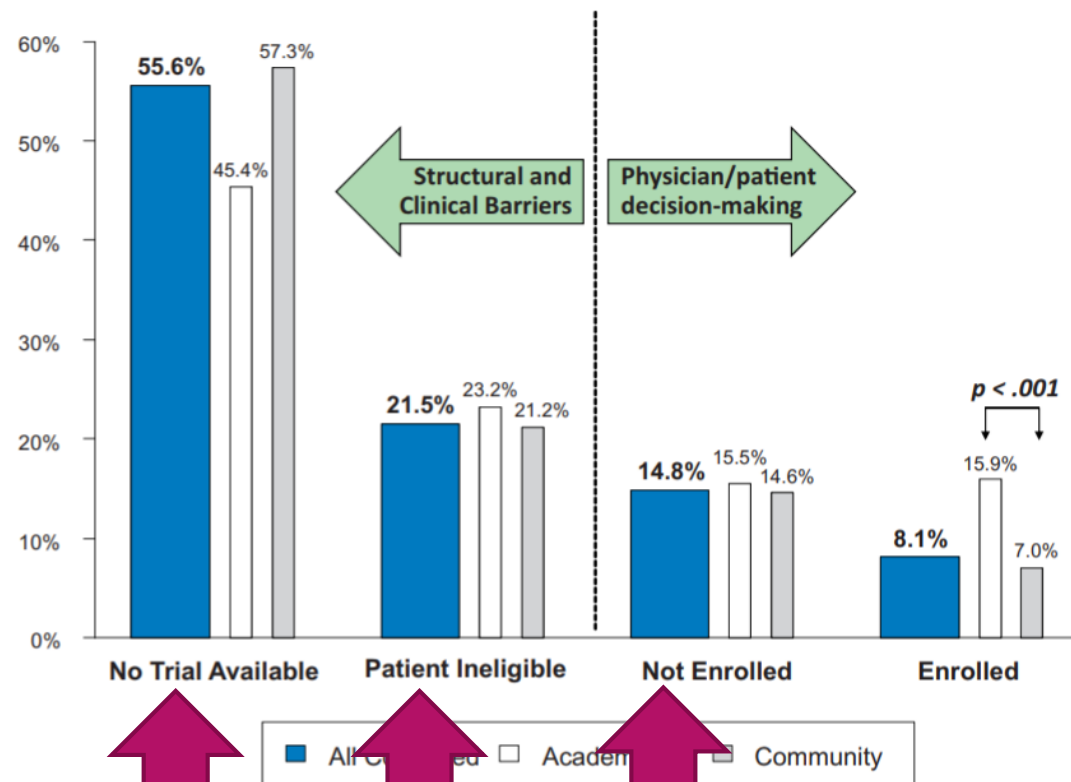
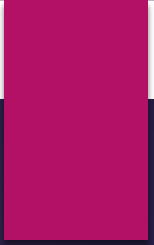


Figure 4. Magnitude of barriers for each domain for academic sites, community sites, and all combined. The P value was derived from a z score in a random effects model. A two-sided test was used.



Population level problems  
require system level  
solutions

# Create Patient centered trial portfolios

- ▶ **Assess the match between available trials & patients**
  - ▶ Be intentional about the development of trial portfolios
  - ▶ Cancer Centers need to increase the efficiency of opening trials
- ▶ **Consider partnerships with community based care settings**
  - ▶ These settings serve a higher proportion of racial/ethnic minorities
  - ▶ But have a higher proportion of mismatch (patients to trials)
- ▶ **Leverage institutional opportunities to make participation appealing & feasible**
  - ▶ Community Advisory Board—consultation on trial design/recruitment approaches; cultural tailoring of materials
  - ▶ Patient Family Advisory Council—improving patient experience; reducing financial barriers, increasing financial transparency

The System Won't Change Unless We  
(Organize &) Demand It!



be the  
change  
you wish  
to see in the  
world...  
-gandhi

UCSF Helen Diller Family  
Comprehensive  
Cancer Center

About

Office of Community Engagement

Office of Community Engagement

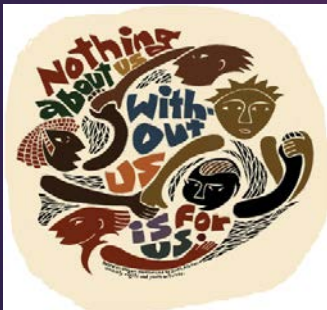
Working collaboratively  
to eliminate the impact of cancer





# Institutional Humility & Engaging Diverse Communities in Cancer Research

THANK  
YOU!



**UCSF** Helen Diller Family  
Comprehensive  
Cancer Center