



Engaging Minority Communities

KATYA CORADO
HEALTH SCIENCES ASSOCIATE PROFESSOR OF MEDICINE AT UCLA
DIVISION OF HIV AT HARBOR-UCLA

Why is participation low?

- ▶ National Institutes of Health Revitalization Act of 1993
 - ▶ Mandates inclusion of women and minorities in human subject research that evaluate safety and efficacy of pharmaceutical and behavioral interventions
 - ▶ Enrolling representative populations is essential to the generalizability of study findings
- ▶ Several factors affect the participation of COC in studies
 - ▶ Logistical
 - ▶ Informational
 - ▶ Sociocultural
 - ▶ Attitudinal
 - ▶ **Mistrust** of academic and research institutions and investigators is the most significant attitudinal barrier to research participation

Farmer et al. Attitudes of African American and low socioeconomic status white women toward medical research. *J Health Care Poor Underserved*. Feb; 2007 18(1):85–99

UyBico et al. Recruiting vulnerable populations into research: a systematic review of recruitment interventions. *J Gen Intern Med*. Jun; 2007 22(6):852–863

Mistrust

- ▶ Long and complicated relationship between communities of color and the medical community
- ▶ Medical community = research community
- ▶ More than Tuskegee

Scharff et al. More than Tuskegee: Understanding Mistrust about Research Participation. *J Health Care Poor Underserved*. 2010;21:879-897

- ▶ US sponsored medical study Guatemala 1946-1948
 - ▶ Nearly 700 men and women, prisoners, soldiers, mental patients
 - ▶ Intentionally infected with syphilis without knowledge and consent
 - ▶ Only came to light in 2010 when historian Susan Reverby uncovered records of this experiment while doing research related to the Tuskegee study

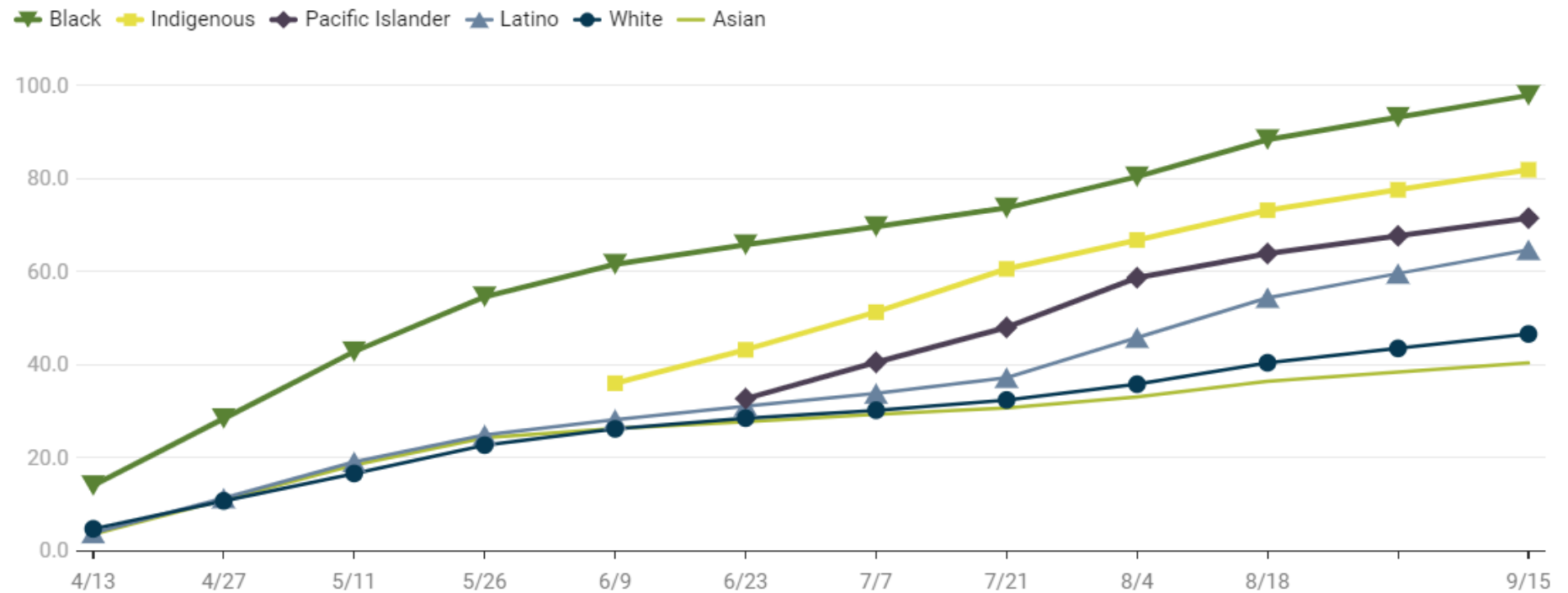
More than Tuskegee

- ▶ “Medical Research” is associated with terms such as experimentation, rats and test tubes
 - ▶ Experimentation is viewed in a negative light, often using the term “guinea pig”
- ▶ No benefit to COC
 - ▶ Perception that relationships with White America have historically been one-sided
 - ▶ Access to study results
 - ▶ Research findings rarely benefit COC
- ▶ Recent examples of racism or discrimination
 - ▶ Negative experiences in health care settings
 - ▶ Treatment of COC in the US

COVID-19

Black & Indigenous Americans experience highest death tolls from COVID-19

Cumulative actual COVID-19 mortality rates per 100,000, by race and ethnicity, April 13-Sept. 15, 2020



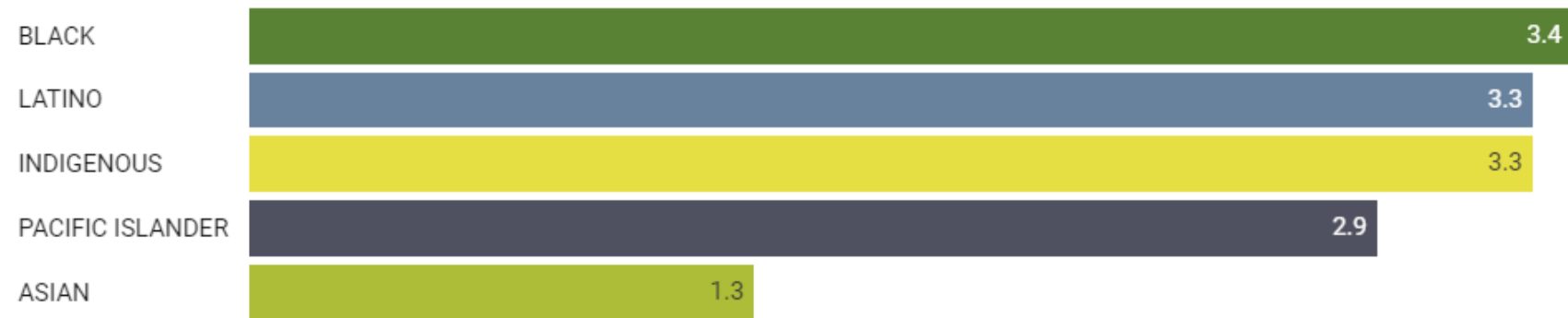
Note: Dates prior to 8/18 are 14 days apart, except for 5/11-5/26, which is a 15-day period. The interval from 8/18 to 9/15 reflects a 4-week period, unlike the 2-week period in most of the series. Midpoint data between 8/18 and 9/15 has been interpolated.

Source: [APM Research Lab](#) • [Get the data](#) • Created with [Datavrapper](#)

COVID-19

Adjusted for age, other racial groups are this many times more likely to have died of COVID-19 than White Americans

Reflects mortality rates calculated through Sept. 15.



Indirect age-adjustment has been used.

Source: [APM Research Lab](#) • [Get the data](#) • Created with [Datawrapper](#)

All Cases and Deaths associated with COVID-19 by Race and Ethnicity

Race/Ethnicity	No. Cases	Percent Cases	No. Deaths	Percent Deaths	Percent CA population
Latino	355,086	61.1	7,778	48.6	38.9
White	100,382	17.3	4,786	29.9	36.6
Asian	32,359	5.6	1,881	11.8	15.4
African American	24,802	4.3	1,217	7.6	6.0
Multi-Race	6,335	1.1	114	0.7	2.2
American Indian or Alaska Native	1,588	0.3	48	0.3	0.5
Native Hawaiian and other Pacific Islander	3,151	0.5	78	0.5	0.3
Other	57,848	9.9	94	0.6	0.0
Total with data	581,551	100.0	15,996	100.0	100.0

Cases: 831,225 total; 249,674 (30%) missing race/ethnicity

Deaths: 16,131 total; 135 (1%) missing race/ethnicity

***884 cases with missing age**

****Census data does not include 'other race' category**

Why is participation of COC critical?

- ▶ Confidence that study results will be generalizable
 - ▶ This cannot occur if there is no representation from diverse groups
- ▶ COC have been disproportionately affected, and it is prudent to study efficacy of vaccines (and other therapies) in communities that most would benefit

How to bridge this gap

- ▶ Years of establishing relationship with the Latinx and Black communities
- ▶ Representation from COC within all levels of study development and implementation
- ▶ Ability to have a representative of the community speak to their own communities in their own language
- ▶ Clear messaging
- ▶ Transparency