CMSS Presents:

Using Clinical Registries to Address Disparities in Covid-19

September 1, 2020 | 2:30 – 4:00 pm ET

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CMSS WEBINAR SERIES

Advancing Clinical Registries to Support Pandemic Treatment and Response

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CMSS WEBINAR SERIES

Advancing Clinical Registries to Support Pandemic Treatment and Response

The series will address key questions related to the rapid development, deployment and implementation of Covid-19 focused clinical registries and clinical repositories by specialty societies and academia.

SUMMER 2020 | FREE TO ATTEND

About the Series:

- Made possible with funding from the Gordon and Betty Moore Foundation

- To foster collaboration between specialty societies and academia, we are grateful to collaborate with the Association of Academic Medical Colleges

Continue the Conversation:

- Use #COVIDRegistries when tweeting about the webinar series

- Follow @CMSSMed and visit CMSS.org for frequent updates

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CMSS WEBINAR SERIES

Advancing Clinical Registries to Support Pandemic Treatment and Response

Today's Webinar:

Using Clinical Registries to Address Disparities in Covid-19

Moderator:

Helen Burstin, MD, MPH, MACP
Chief Executive Officer
Council of Medical Specialty
Societies (CMSS)

Panelists:

Kirsten Bibbins-Domingo, PhD, MD, MAS
Professor and Chair, Department of Epidemiology and Biostatistics; Lee Goldman, MD Endowed Chair in Medicine; Vice Dean of Population Health and Health Equity, School of Medicine UCSF

Eliseo Perez-Stable, MD
Director of the National Institute on Minority Health and Health Disparities (NIMHD), National Institutes of Health (NIH)

Bill Wood, MD, MPH
Chair, Data Hub Oversight Group, ASH Research Collaborative; Associate Professor of Medicine, Division of Hematology, University of North Carolina at Chapel Hill

Clyde Yancy, MD, MSc, MACC, FAHA, MACP, FHFSA
Vice Dean, Diversity & Inclusion, Magerstadt Professor of Medicine, Professor of Medical Social Sciences, Chief, Division of Cardiology Northwestern University, Feinberg School of Medicine

THE COLOR OF CORONAVIRUS:
COVID-19 DEATHS BY RACE AND ETHNICITY IN THE U.S.

- **KEY FINDINGS:**

- **Through August 4, The coronavirus has claimed more than 155,000 American lives through Aug. 18, 2020**

- Overall, American death rates from COVID-19 data (aggregated across all states with available data and the District of Columbia) have reached new highs for all race groups:

- **1 in 1,125 Black Americans has died** (or 88.4 deaths per 100,000)

- **1 in 1,375 Indigenous Americans has died** (or 73.2 deaths per 100,000)

- **1 in 1,575 Pacific Islander Americans has died** (or 63.9 deaths per 100,000)

- **1 in 1,850 Latino Americans has died** (or 54.4 deaths per 100,000)

- **1 in 2,450 White Americans has died** (or 40.4 deaths per 100,000)

- **1 in 2,750 Asian Americans has died** (or 36.4 deaths per 100,000)

Data now reported from 45 states; race/ethnicity data on 93% deaths; most recent update August 4, 2020

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- The latest overall COVID-19 mortality rate for **Black Americans** is about 3.6 times as high as the rate for Whites; for Indigenous people 3.4 times as high; for Latinos, 3.2 times as high, Pacific Islanders, 3.0 times as high and Asians, 1.3 times as high.

- **If they had died of COVID-19 at the same actual rate as White Americans, about 19,500 Black, 8,400 Latino, 600 Indigenous, and 70 Pacific Islander Americans would still be alive.**

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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 Aug. 18.

BLACK	3.6
INDIGENOUS	3.4
LATINO	3.2
PACIFIC ISLANDER	3
ASIAN	1.3
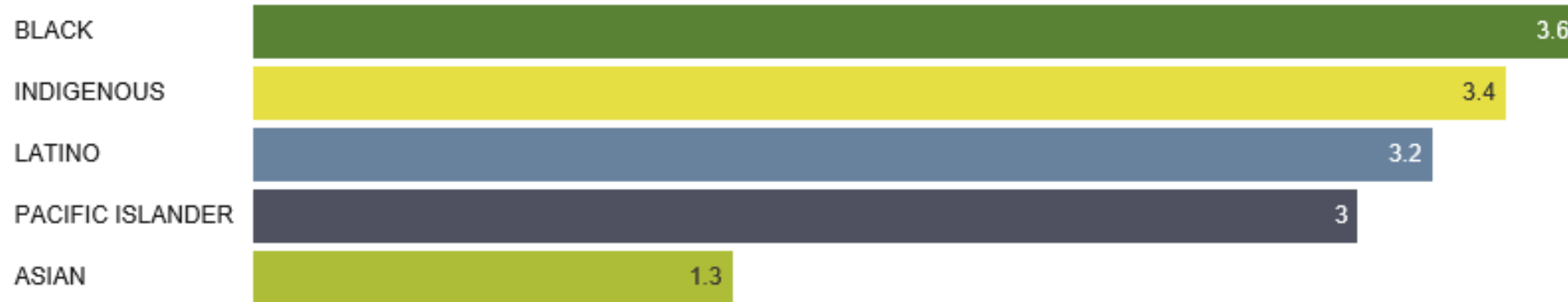
Indirect age-adjustment has been used.

Source: APM Research Lab • Get the data • Created with Datawrapper

The extent of the crisis:

- **Chicago:**
  - **50% of COVID-19 cases & nearly 70% of COVID-19 deaths involve black individuals, although blacks make up only 30% of the population.**
  - **Moreover, these deaths are concentrated mostly in just 5 neighborhoods on the city's South Side.[6]**
- **New York City**
  - **Blacks and Hispanics, have accounted for 28% and 34% of deaths, (population representation: 22% and 29%) respectively.[8]**

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Defining a Crisis Point:

Viewpoint

April 15, 2020

COVID-19 and African Americans

Clyde W. Yancy, MD, MSc[1]

» Author Affiliations | Article Information

The US has needed a trigger to fully address health care disparities; COVID-19 may be that bellwether event.

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A Piece of My Mind   FREE

April 15, 2020

Failing Another National Stress Test on Health Disparities

William F. Owen Jr, MD[1]; Richard Carmona, MD, MPH[2,3]; Claire Pomeroy, MD, MBA[4]

» Author Affiliations | Article Information

We propose that the overarching cause of these tragic statistics is decades of the effects of adverse social determinants of health.

People must make good choices, but they must have good choices to make.

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Editorial

ONLINE FIRST | FREE

May 11, 2020

COVID-19 and Health Equity—A New Kind of "Herd Immunity"

David R. Williams, PhD, MPH[1,2]; Lisa A. Cooper, MD, MPH[3,4]

» Author Affiliations | Article Information

Compared with white individuals,
African American individuals have
higher rates of uninsurance and underinsurance.
 Segregation of health care also contributes to
 racial disparities in health care with access to primary care
 and especially specialty care physicians more limited in communities of color.

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- "These data highlight that social inequities are patterned by place..."
- "The problem of segregation is not residing among persons of the same race, but the clustering of social disadvantage and systematic disinvestment in marginalized communities..."
- "The striking racial/ethnic disparities reported for COVID-19 infection, testing, and disease burden are a clear reminder that failure to protect the most vulnerable members of society not only harms them but also increases the risk of spread of the virus, with devastating health and economic consequences ... "
- "The US must develop a new kind of "herd immunity," whereby resistance to the spread of poor health in the population occurs when a sufficiently high proportion of individuals, across all racial, ethnic, and social class groups, are protected from and thus "immune" to negative social determinants."

- "As the cases of coronavirus disease 2019 (COVID-19) continue to increase

across the world, evidence is continuing to emerge that the pandemic could be

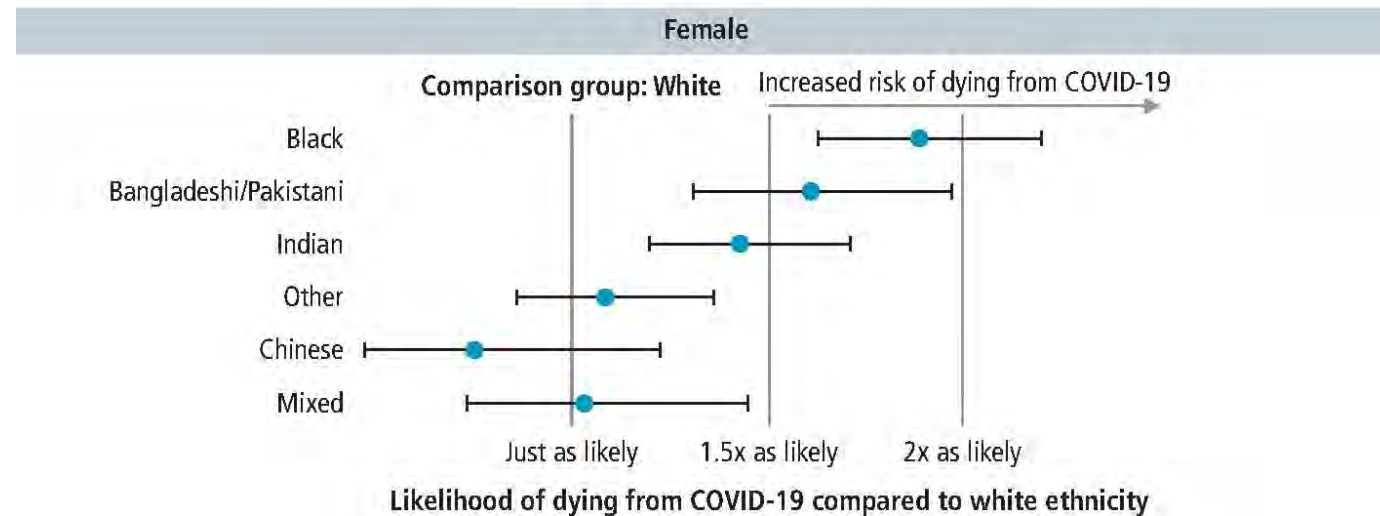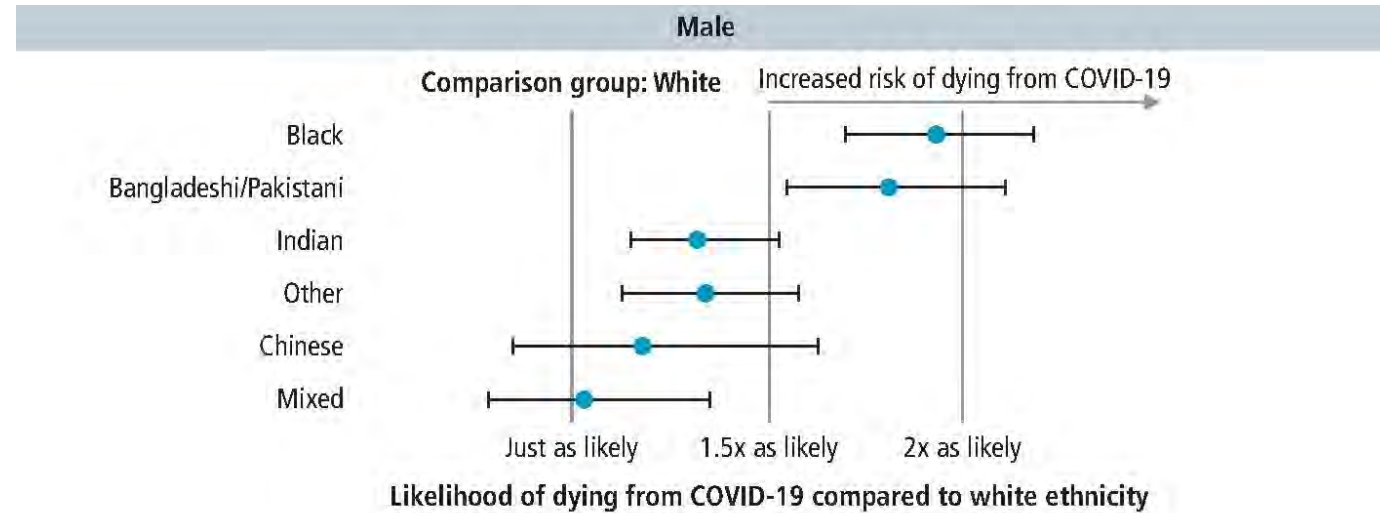disproportionately affecting people from black, Asian, and minority ethnic(BAME) communities...

... In the UK, this trend first came to public attention during media reports

that showed the first 11 doctors who sadly lost their lives to COVID-19,

were all from BAME communities..."

COVID19 deaths in UK healthcare workers

Male

Comparison group: White — Increased risk of dying from COVID-19

- Black
- Bangladeshi/Pakistani
- Indian
- Other
- Chinese
- Mixed

Just as likely — 1.5x as likely — 2x as likely

Likelihood of dying from COVID-19 compared to white ethnicity

Female

Comparison group: White — Increased risk of dying from COVID-19

- Black
- Bangladeshi/Pakistani
- Indian
- Other
- Chinese
- Mixed

Just as likely — 1.5x as likely — 2x as likely

Likelihood of dying from COVID-19 compared to white ethnicity

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Manuelo Andreoni

- **Brazil has had more infections and more deaths than any country but the United States.**

- Latin America became an epicenter of the coronavirus pandemic in May, driven by Brazil's ballooning caseload, even as the number of known infections in Europe fell. Six months after its first known case, Brazil has had over 3.6 million cases — more than all of Europe — and about 115,000 deaths.

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Global cases: 25,533,086; COVID19 dashboard; JHU (09/01/2020)

Definitions

IOM Report: Differences, Disparities, and Discrimination

Disparities-racial or ethnic differences in healthcare that are not due
To access related factors, clinical needs, patient preferences or the
Appropriateness of the intervention.
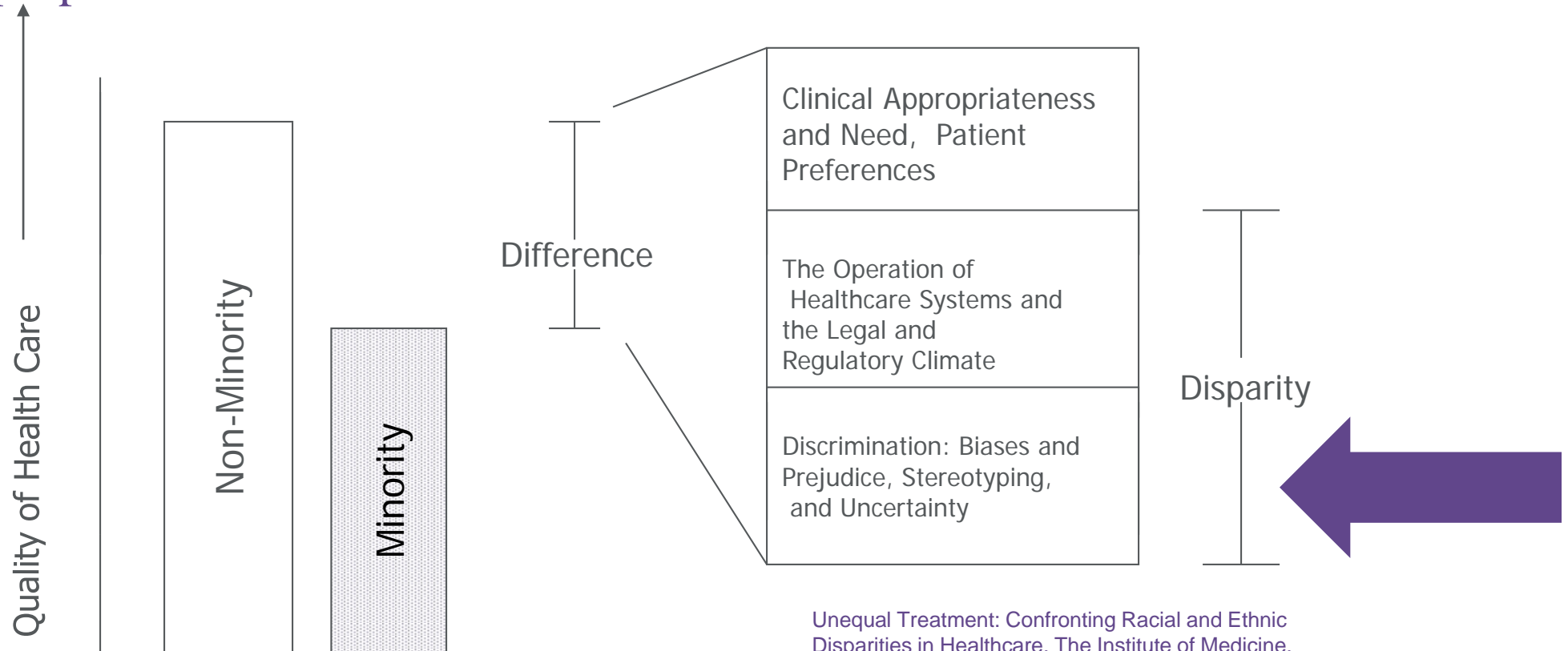
Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare. The Institute of Medicine, National Academies Press, Washington, DC. 2002

Exploring Equal/Equity/Reality
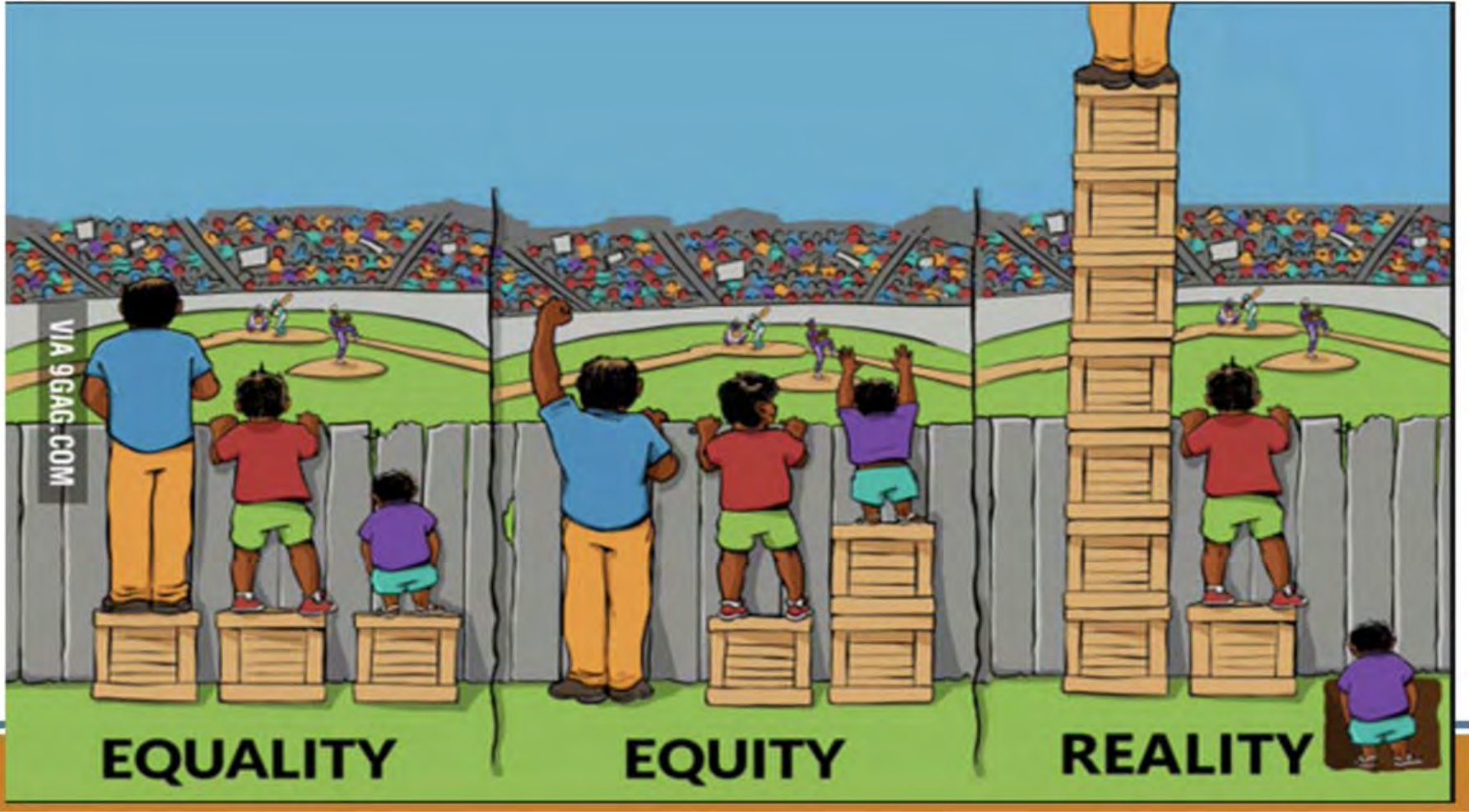
Circulation

Home > Circulation > Vol. 132, No. 9 > Social Determinar

🔓 FULL ACCESS
ARTICLE

📄 **PDF/EPUB**

🔧 Tools   ⇜ Share

Social Determin

A Scientific Stateme

Edward P. Havranek, Mahasi
Cheryl R. Dennison-Himmelfa
and on behalf of the America
Prevention, Council on Cardi

Originally published 3 Aug 2015

Table 1. Social Determinants of Health
SEP
Race, ethnicity
Social support
Culture and language
Access to care
Residential environment
SEP indicates socioeconomic position.

IMPACT OF SOCIAL DETERMINANTS OF HEALTH

Social determinants of health have tremendous affect on an individual's health regardless of age, race, or ethnicity.

Socioeconomic Factors

Education · Job Status · Family/Social Support · Income · Community Safety

40%

Physical Environment

10%

Health Behaviors

Tobacco Use · Diet & Exercise · Alcohol Use · Sexual Activity

30%

20 %

Health Care

Access to Care Quality of Care
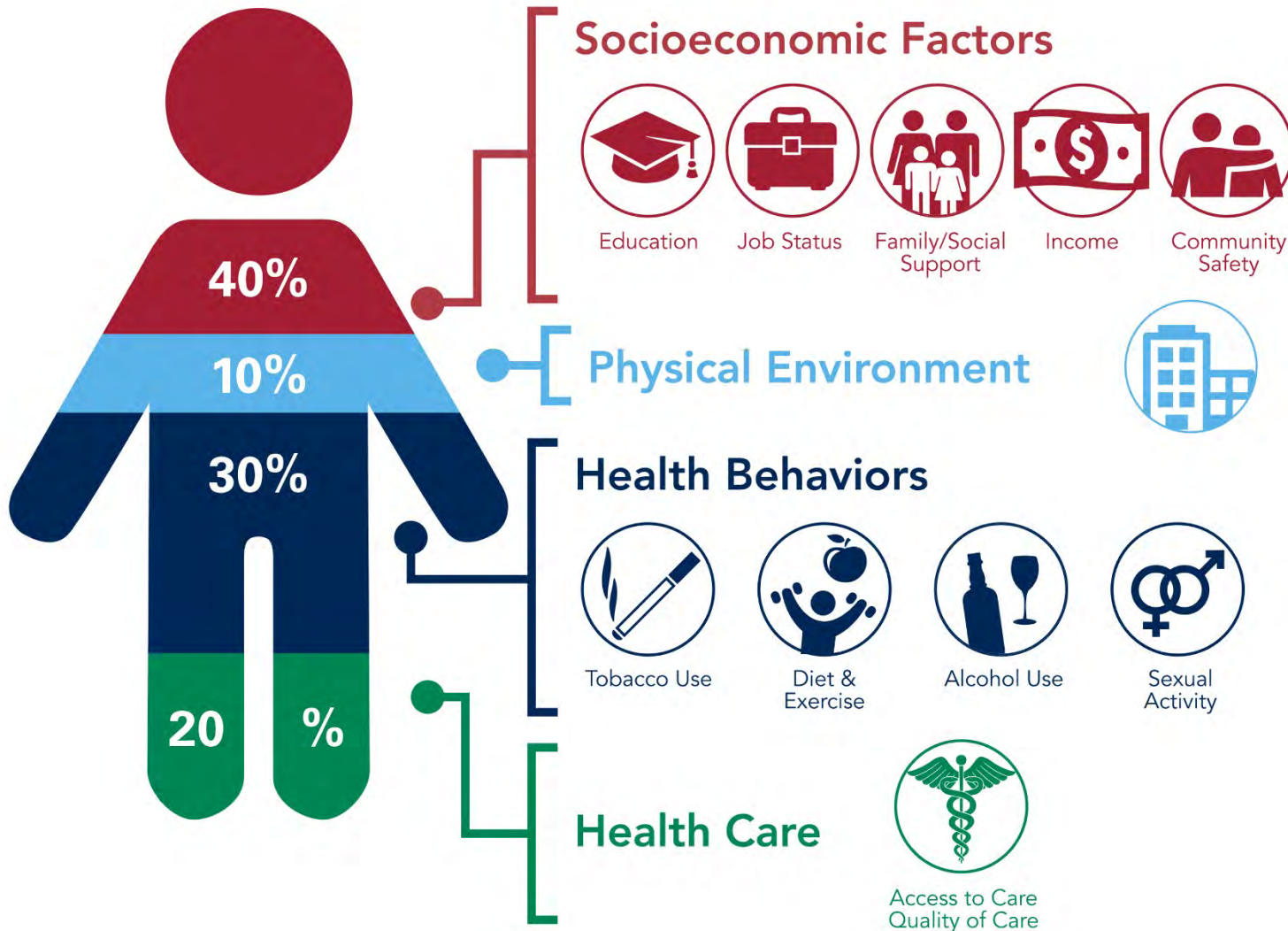
➤ SDOH Impact

20 percent of a person's health and well-being is related to **access to care** and **quality of services**

The **physical environment**, **social determinants** and **behavioral factors** drive **80 percent** of health outcomes

Appropriate Public Health Initiatives; Ubiquitous Testing in High Risk Communities-

- Testing: targeting communities with higher infection rates
- Follow the SVI – Social Vulnerability Index
- https://svi.cdc.gov/
- "...resilience of communities when confronted by external stresses on human health, stresses such as natural or human-caused disasters, or disease outbreaks..."
- uses 15 U.S. census variables at tract level ...
- Possible scores range from 0 (lowest vulnerability) to 1 (highest vulnerability).

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SVI map, Chicago, (2016)

Census Tract 814.03, Cook County, Illinois

2016 Overall SVI Score:

0.0886

Possible scores range from **0** (lowest vulnerability) to **1** (highest vulnerability).

🔍 Zoom to

(1 of 2)

Census Tract 6812, Cook County, Illinois

2016 Overall SVI Score:

0.9371

Possible scores range from **0** (lowest vulnerability) to **1** (highest vulnerability).
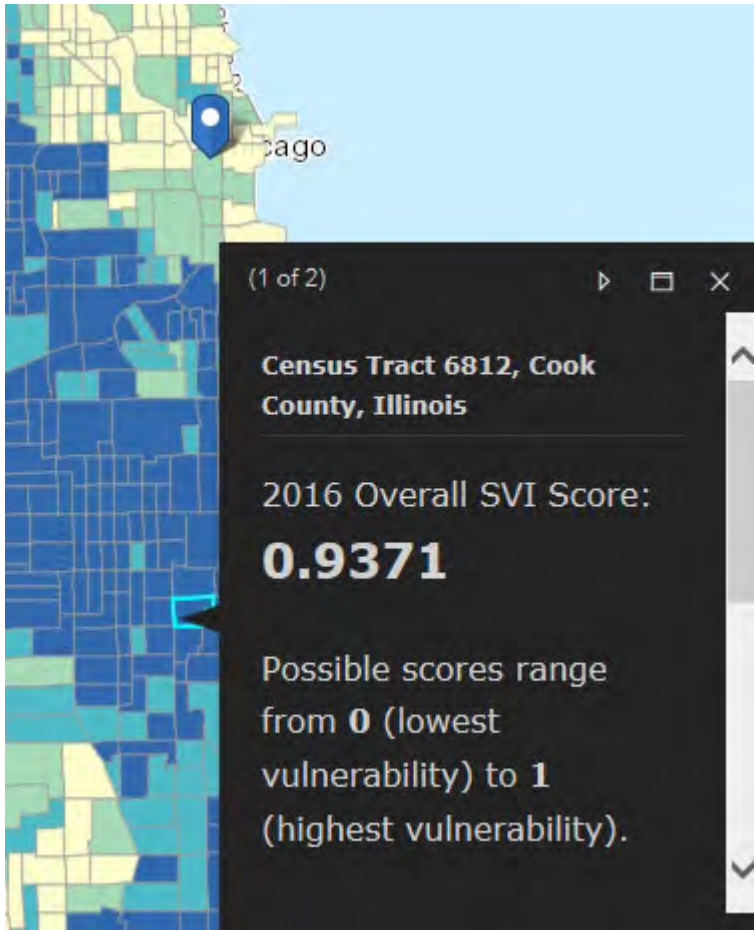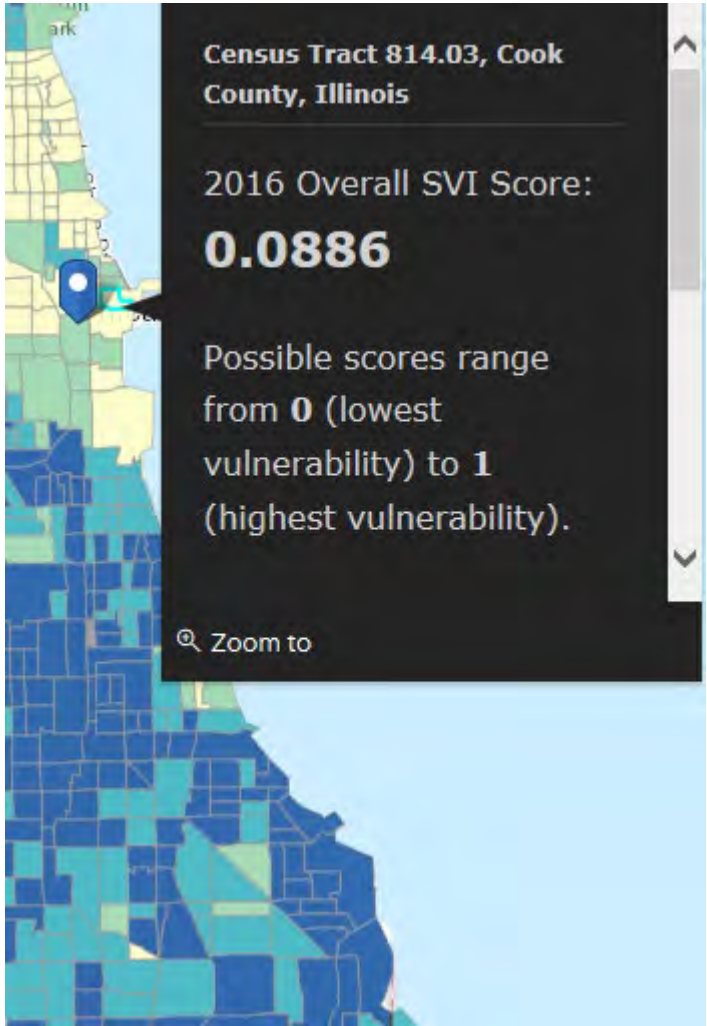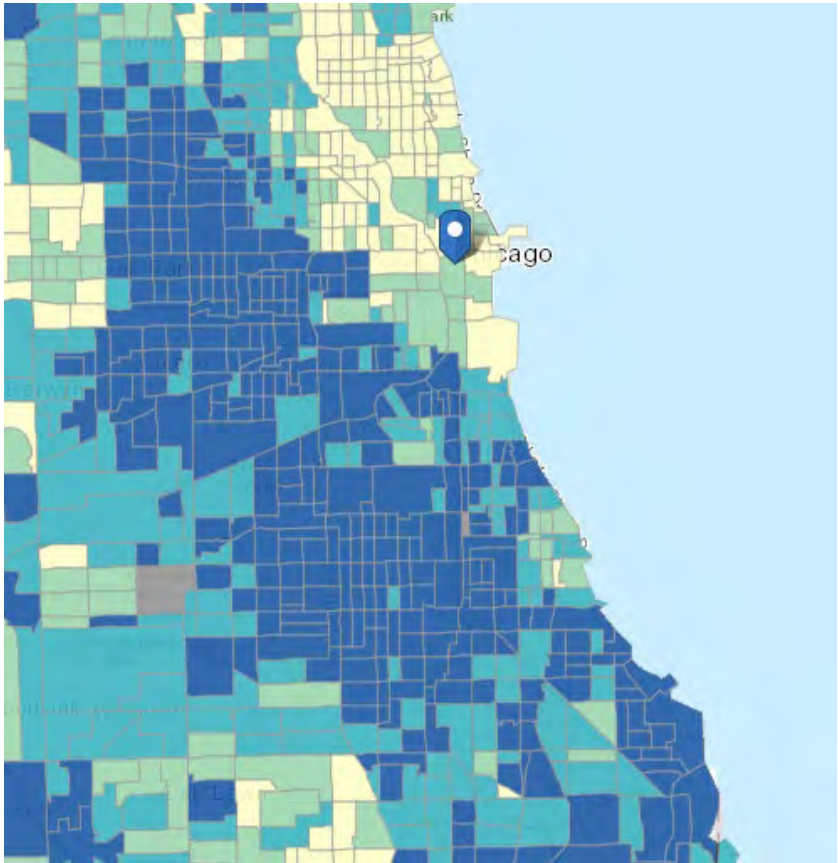
Chicago COVID and the Inequities

Risk scores by zip code
As of April 6, 2020

Locations of COVID-19 fatalities
represented by green dots

-2.126570 - -0.728220
-0.728219 - -0.465970
-0.465969 - 0.385980
0.385981 - 1.015180
1.015181 - 1.871470

Background

Population Health Data Initiative (PHDI):

1. Increase population health data access
   a. Geocoding addresses within electronic health records (EHRs) at UCSF Health, San Francisco Health Network, and other UC medical centers
   b. Linking these data with existing population-level datasets at the neighborhood-level (i.e. US Census and California Health Interview Survey)

2. Partner with healthcare systems and the department of public health to align research, quality improvement, and programming using patient and population-level data
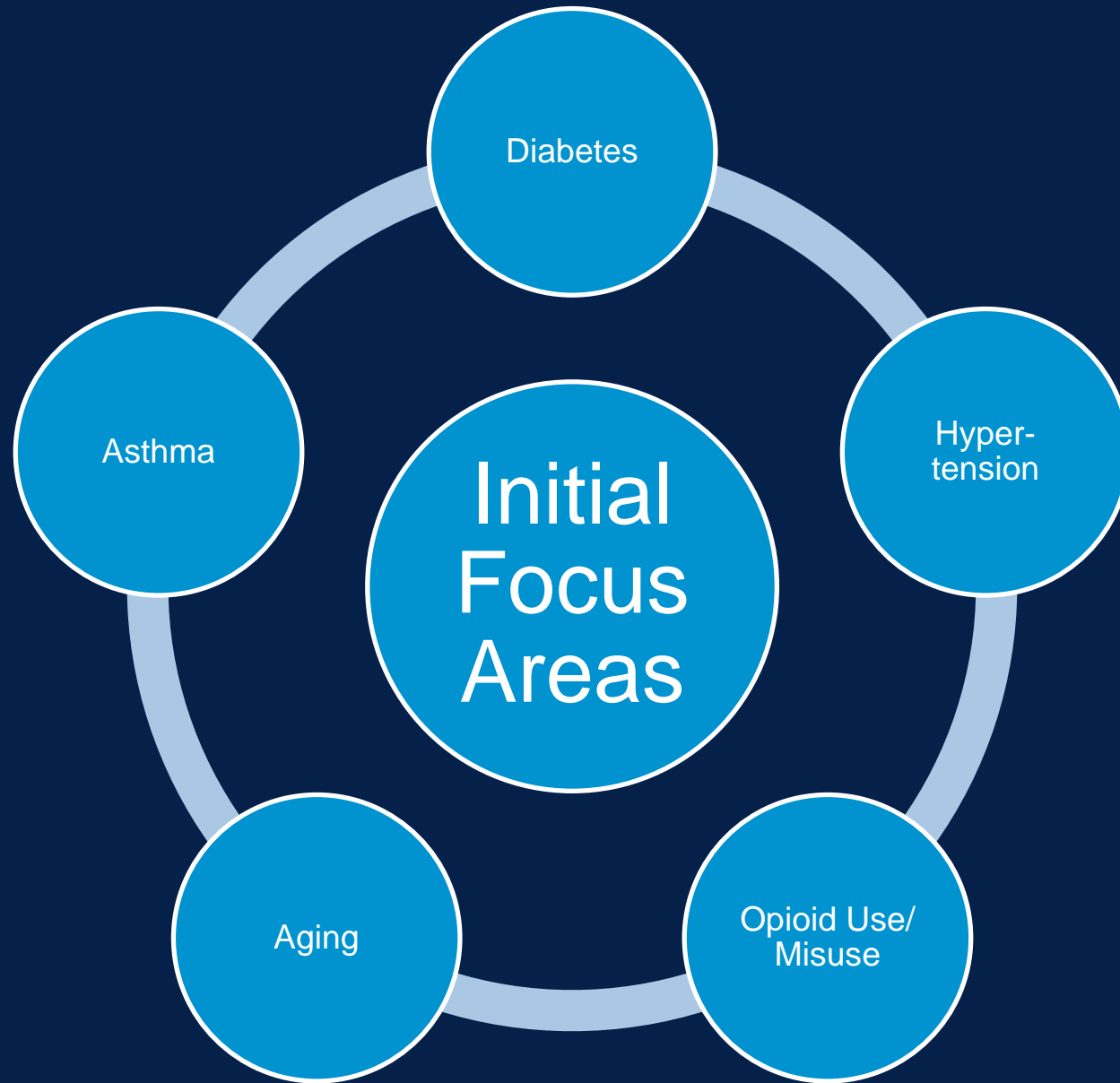
UCSF

Neighborhood Socioeconomic Status (nSES)

UCSF Population Health Data Initiative

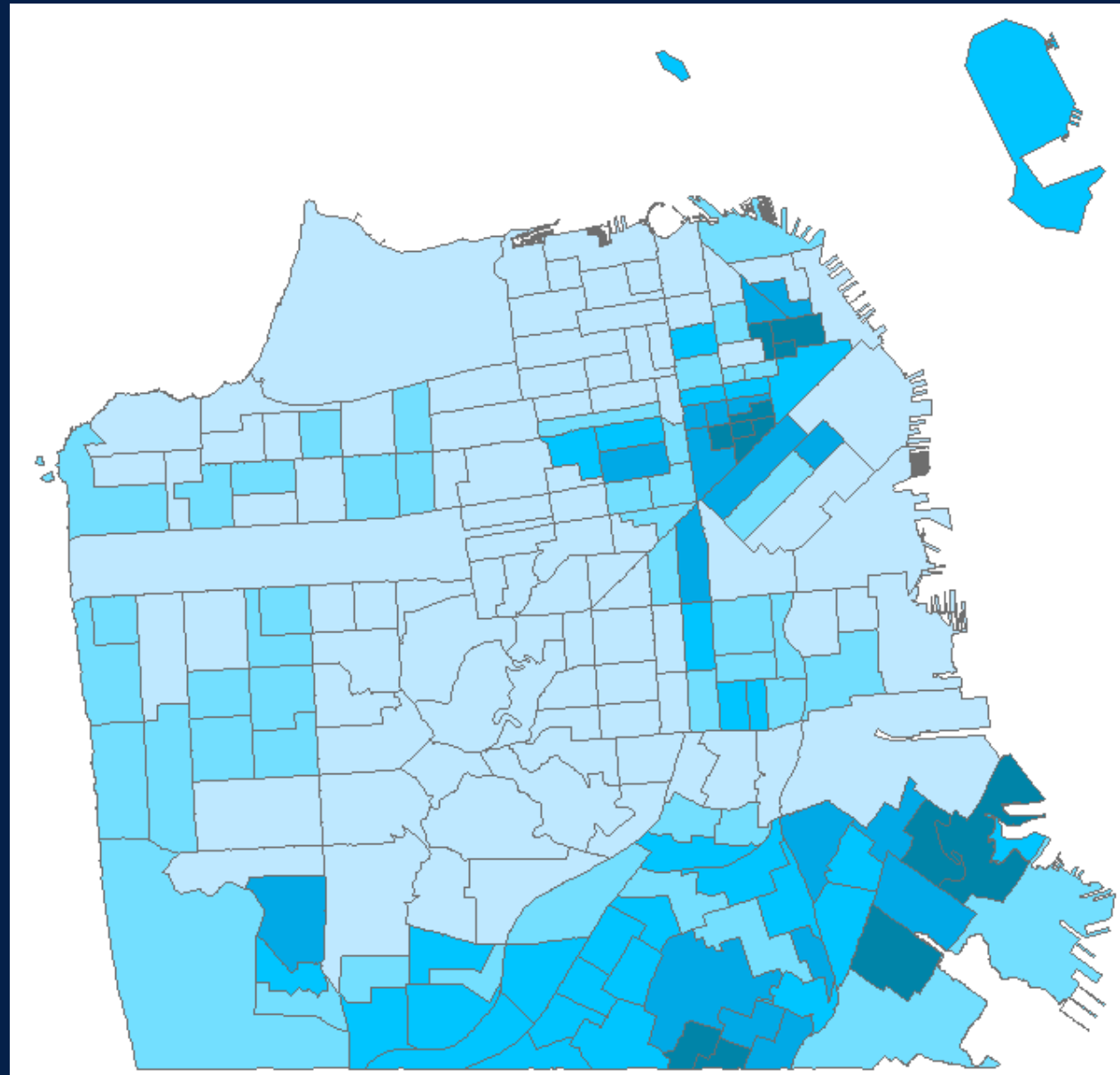Maps created by: UCSF DREAM Lab

Data Sources:

Gomez, SL, et al. *Cancer Causes & Control*. 2011.

Census 2000 Summary File 3 Technical Documentation/prepared by the U.S. Census Bureau, 2002.

American Community Survey. 2011. Available from: http://www.census.gov/programs-surveys/acs/data.html

nSES

Low   High

UCSF

UCSF Health Uncontrolled Diabetes Clusters Overlaying nSES

UCSF Population Health Data Initiative

Maps created by: UCSF DREAM Lab

Data Sources:

Gomez, SL, et al. *Cancer Causes & Control*. 2011.

Census 2000 Summary File 3 Technical Documentation/prepared by the U.S. Census Bureau, 2002.

American Community Survey. 2011. Available from: http://www.census.gov/programs-surveys/acs/data.html

Uncontrolled diabetes clusters

nSES

Low   High
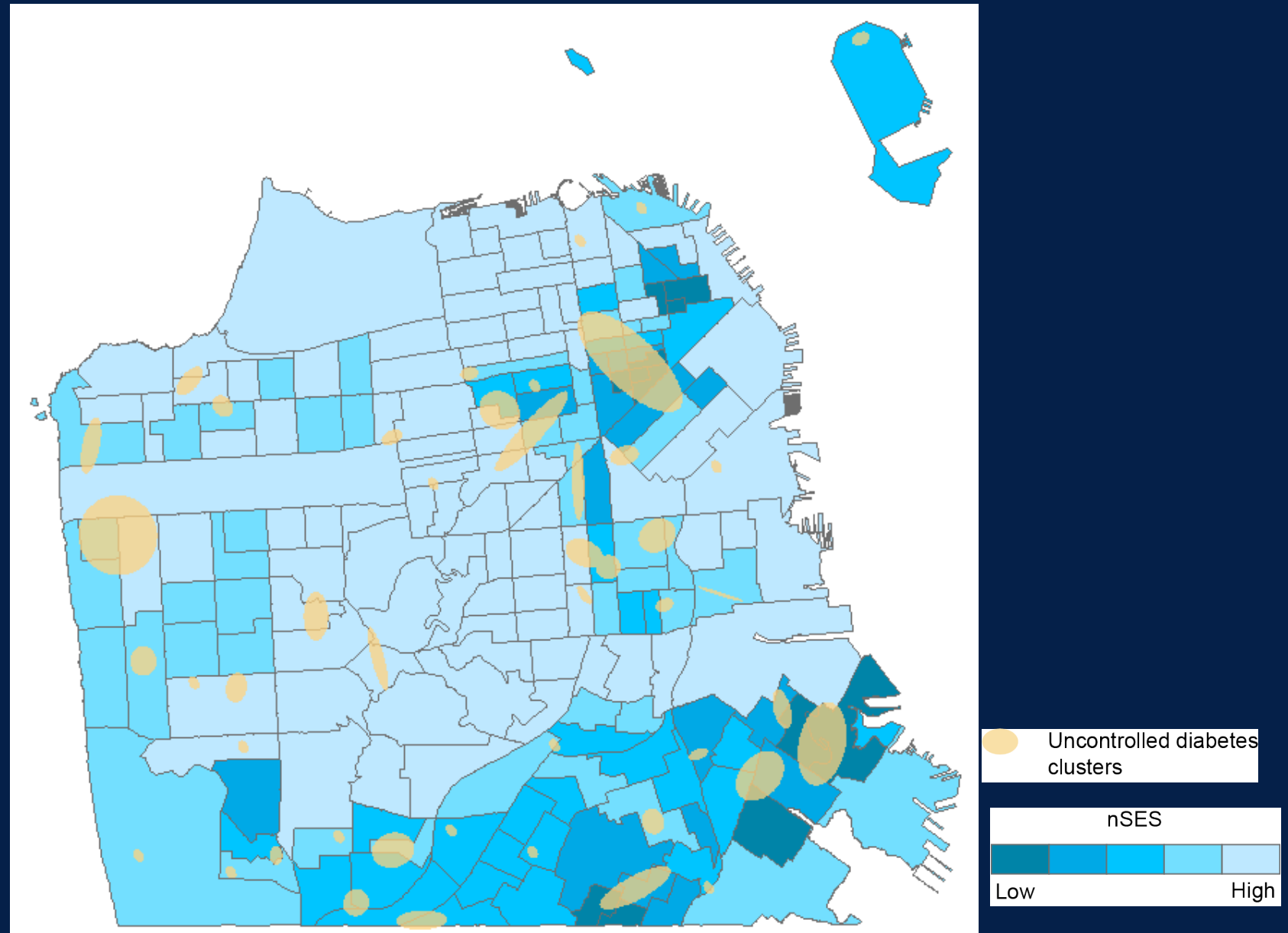
UCSF

- A second clinical site for UCSF is the public delivery system, the San Francisco Health Network
  - Includes Zuckerberg San Francisco General Hospital and community clinics throughout the city and county
  - Creating matched geocoded cohorts of patients with diabetes, hypertension, and opioid use
    - Using same UCSF Health protocol for geocoding second system's EHR data

Percent Controlled Blood Pressure Among Hypertension Patients in Two San Francisco Health Systems Overlaying Census Tracts According to Street Connectivity
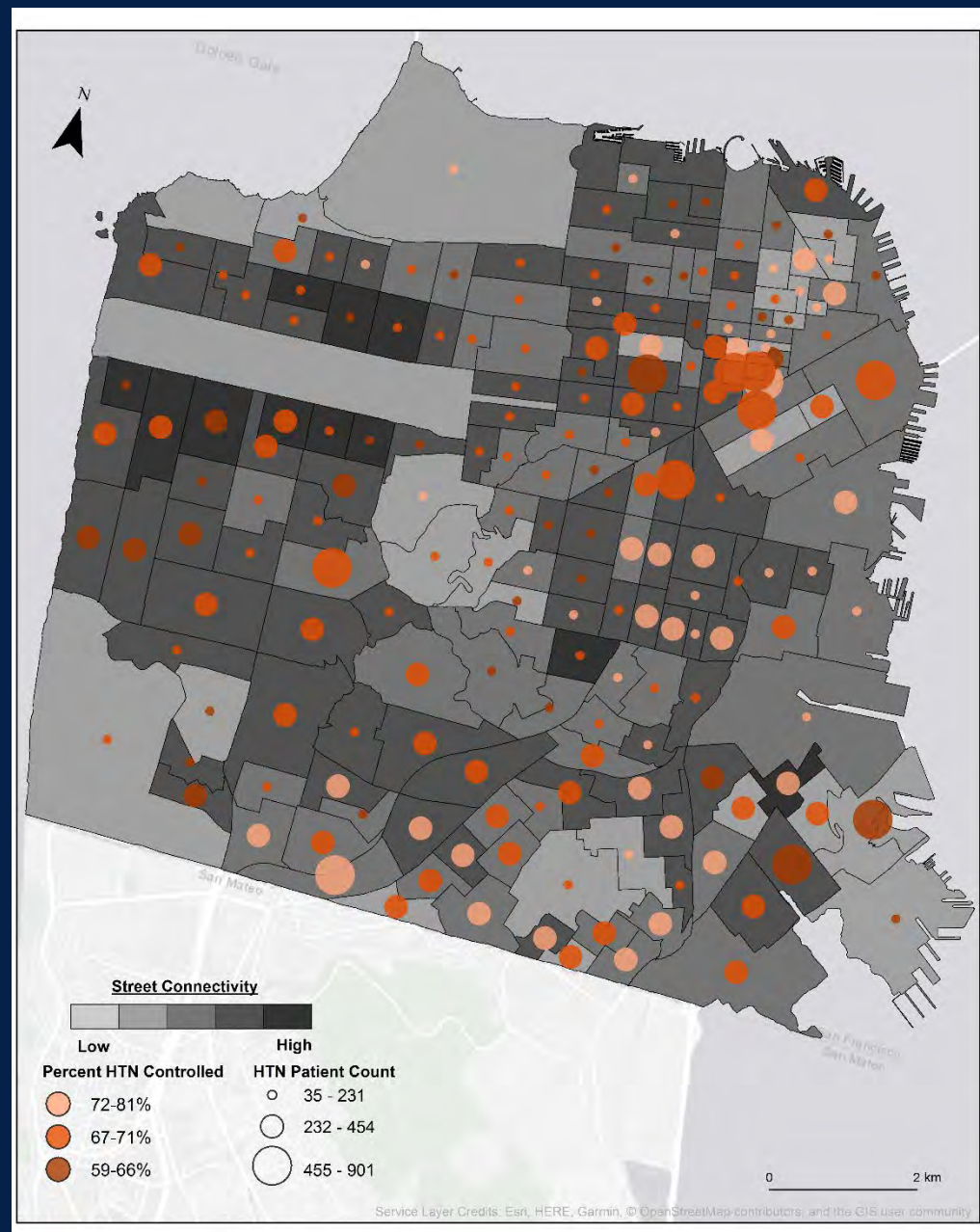
UCSF Population Health Data Initiative

Map created by UCSF DREAM Lab

Data Sources:
California Neighborhoods Data System, Gomez et al. 2011
NavTeq. NAVSTREETS Street Data Reference Manual v3.7.12010.

But we know we're not the entire population!

San Francisco Department of Public Health
Greg Wagner
Acting Director of Health

City and County of San Francisco
London N. Breed
Mayor

As part of the 54-city Partnership for Healthy Cities, San Francisco pursues citywide public health data project to tackle chronic disease

San Francisco is committed to preventing chronic diseases as part of a global network of cities

FOR IMMEDIATE RELEASE

Contact Rachael Kagan 415 554-2507, 415 420-5017cell, rachael.kagan@sfdph.org

San Francisco (October 31, 2018)—On World Cities Day, Mayor London Breed affirmed her commitment to proven public health policies that prevent deaths and injuries as part of the Partnership for Healthy Cities. The San Francisco Department of Public Health is pursuing a city-wide initiative to leverage clinical data from San Francisco's largest health systems to better address an array of chronic diseases that afflict city residents. This would allow for more timely and accurate information about chronic disease in San Francisco, which enables the Department of Public Health to more effectively tackle the greatest burdens of disease in the community.

UCSF
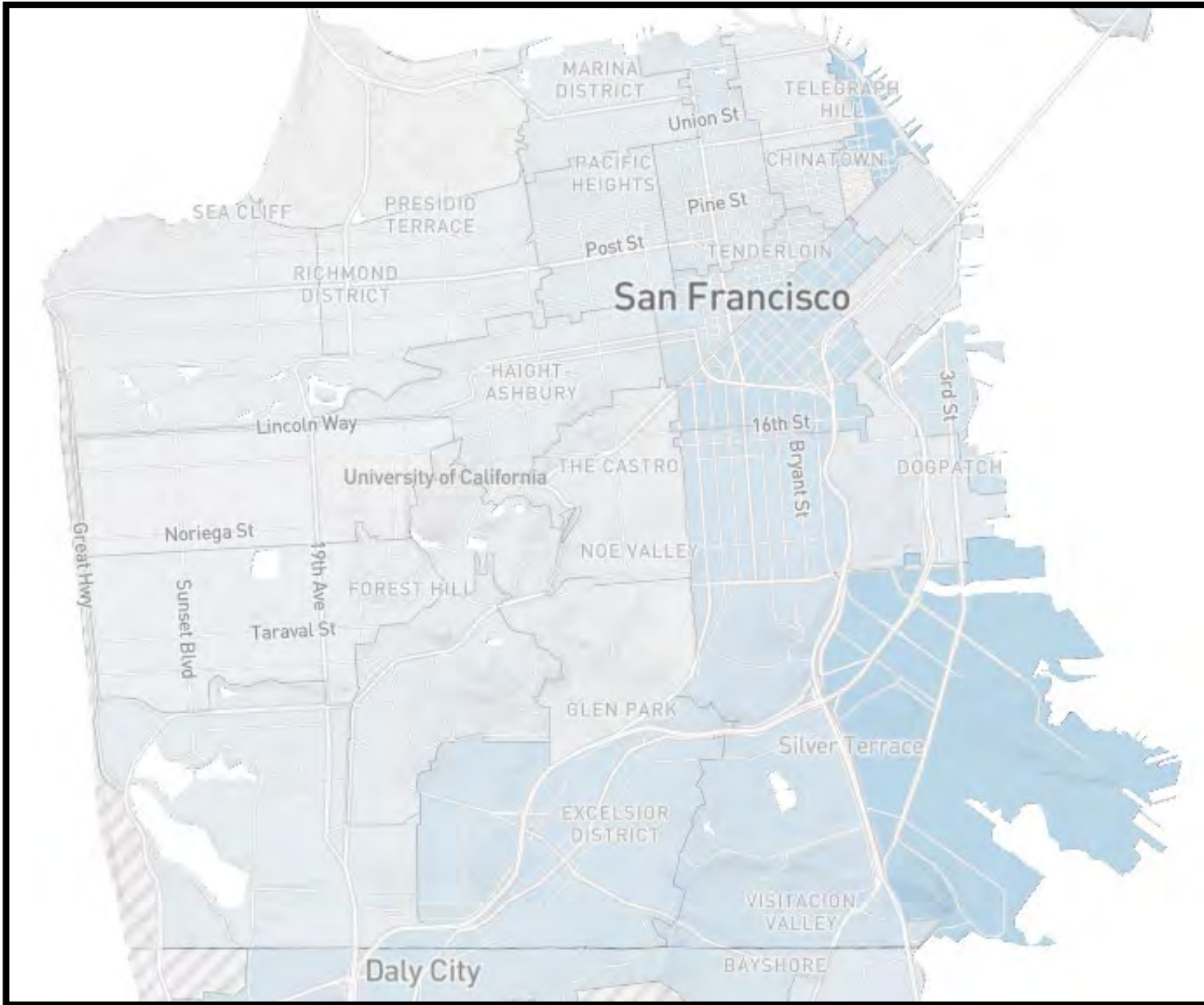
- COVID-19 in San Francisco

- San Francisco 165.3 cases per 100,000, but 10 fold difference in rates across highest and lowest zip codes

Screening in Mission Neighborhood Census Tract
Diane Havlir/Gabe Chamie

APRIL 25-28 | 9AM - 5 PM
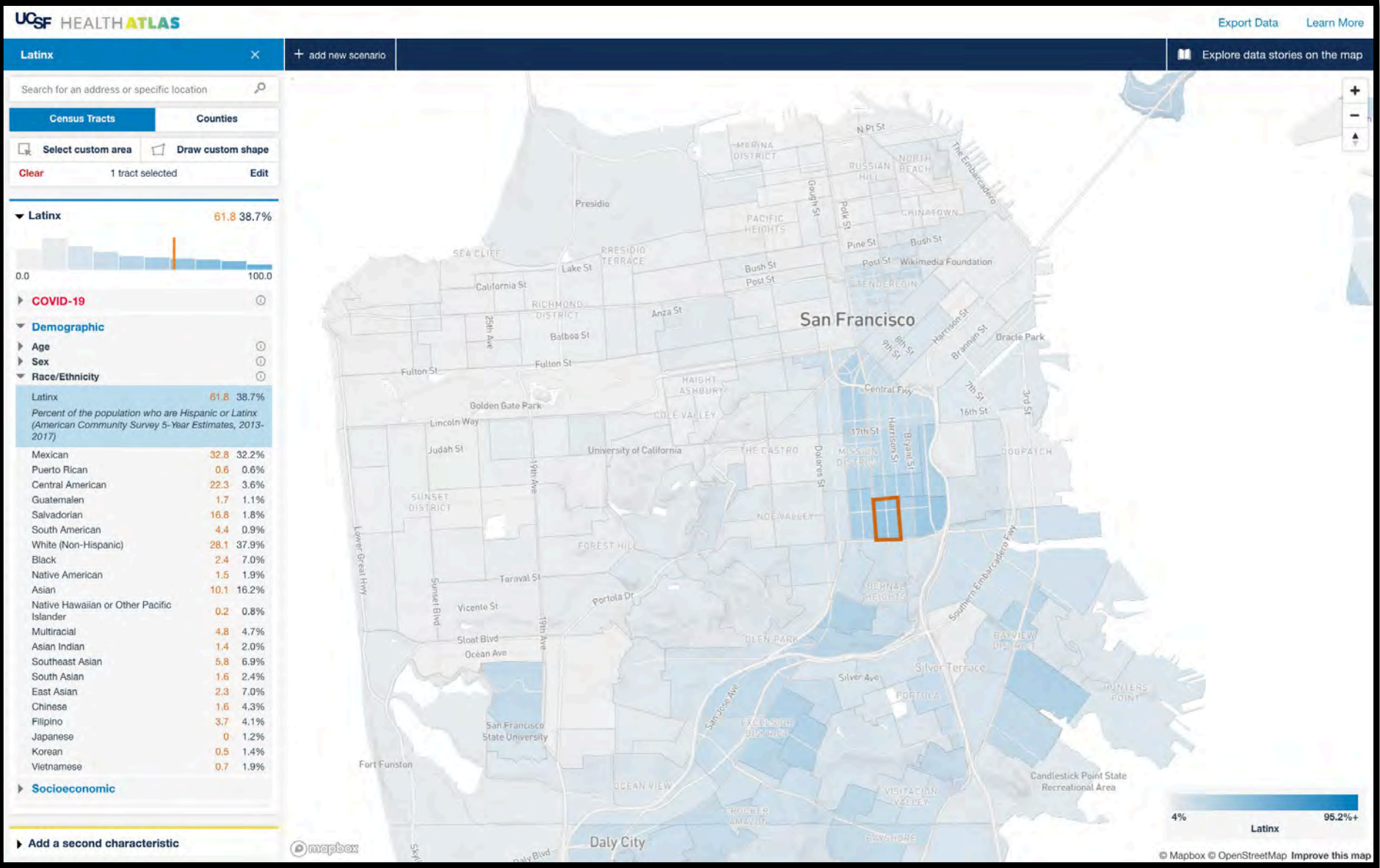FREE COVID-19 TESTING for Mission residents
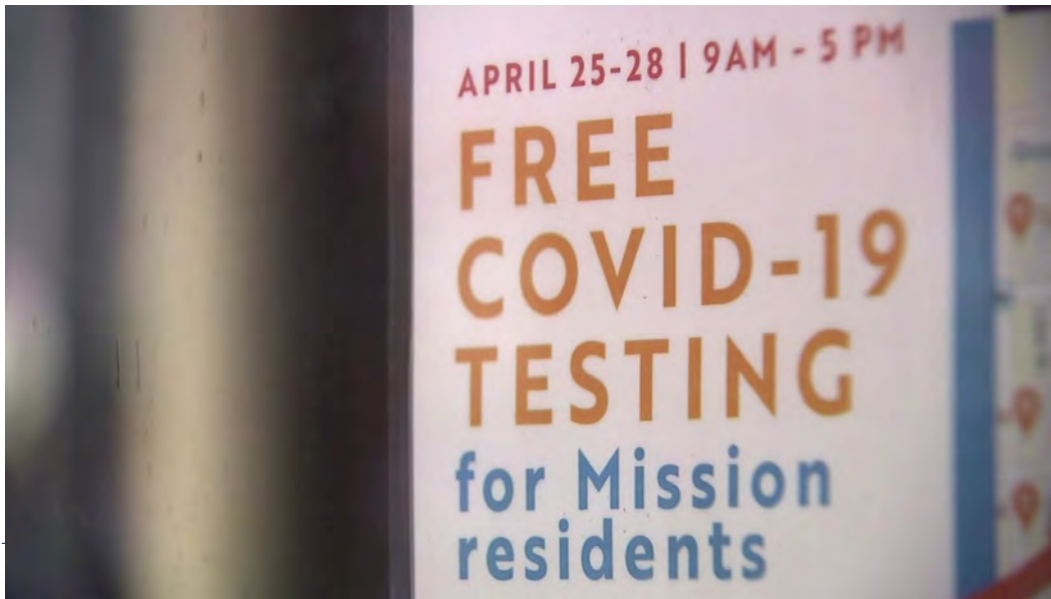
Researchers expand free Mission testing campaign to a larger area (update)

By Lydia Chávez and Julian Mark | Apr 27, 2020 | Featured, Front Page, Mobile, Newsletter, Today's Mission | 11 💬
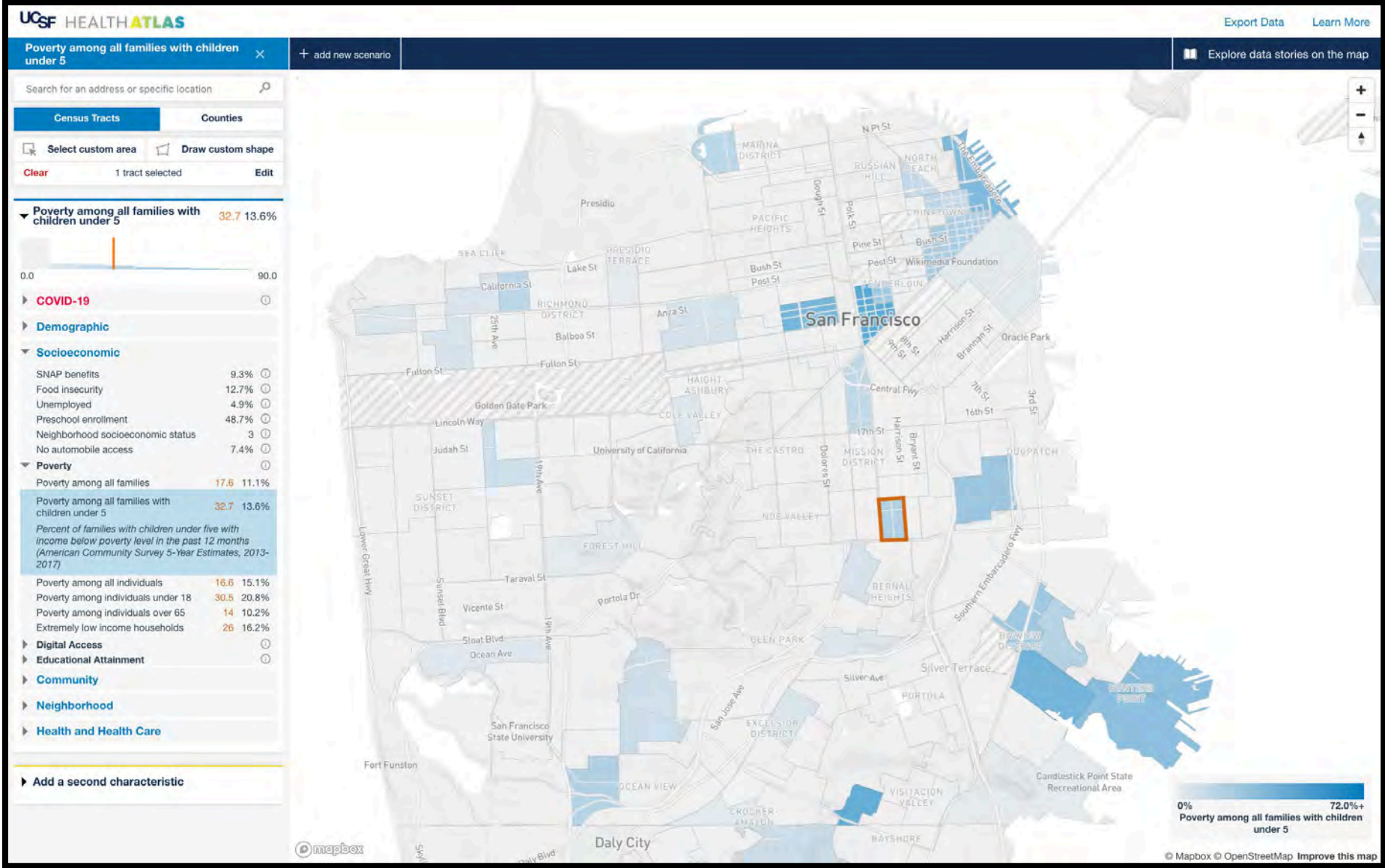
Share this:

Demographics of Mission Census Tract

Poverty in families with children <5 years of age

Overcrowding
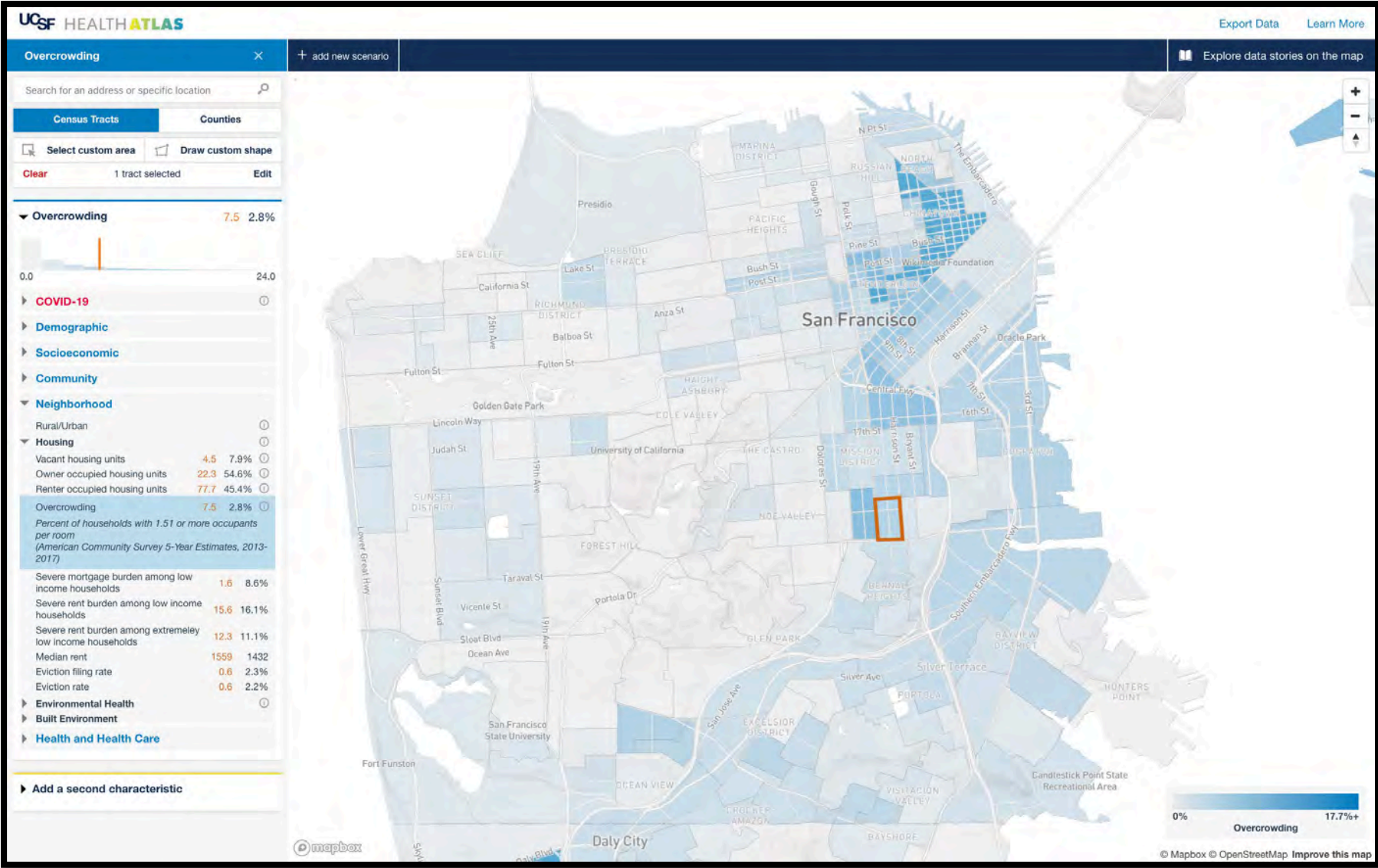
Testing Results: PCR+ for COVID-19

Tract 022901
PCR+ Prevalence
Among tested

6.1%

2.1%

1.4%

62/2,959
Community Total
(residents/workers)

26/426
Tract workers

36/2,533
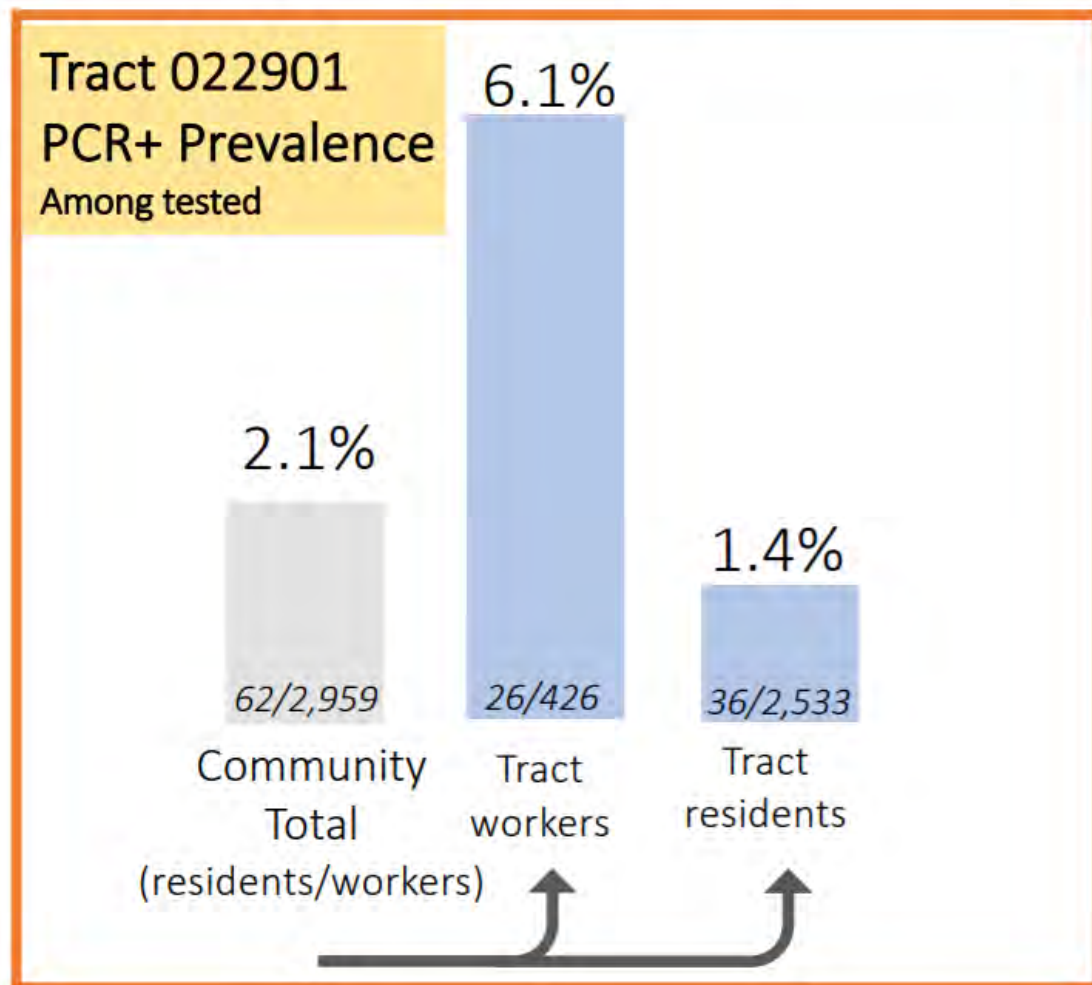Tract residents

>95% positive cases were LatinX (only 44 % of sample)

>90% cannot work from home

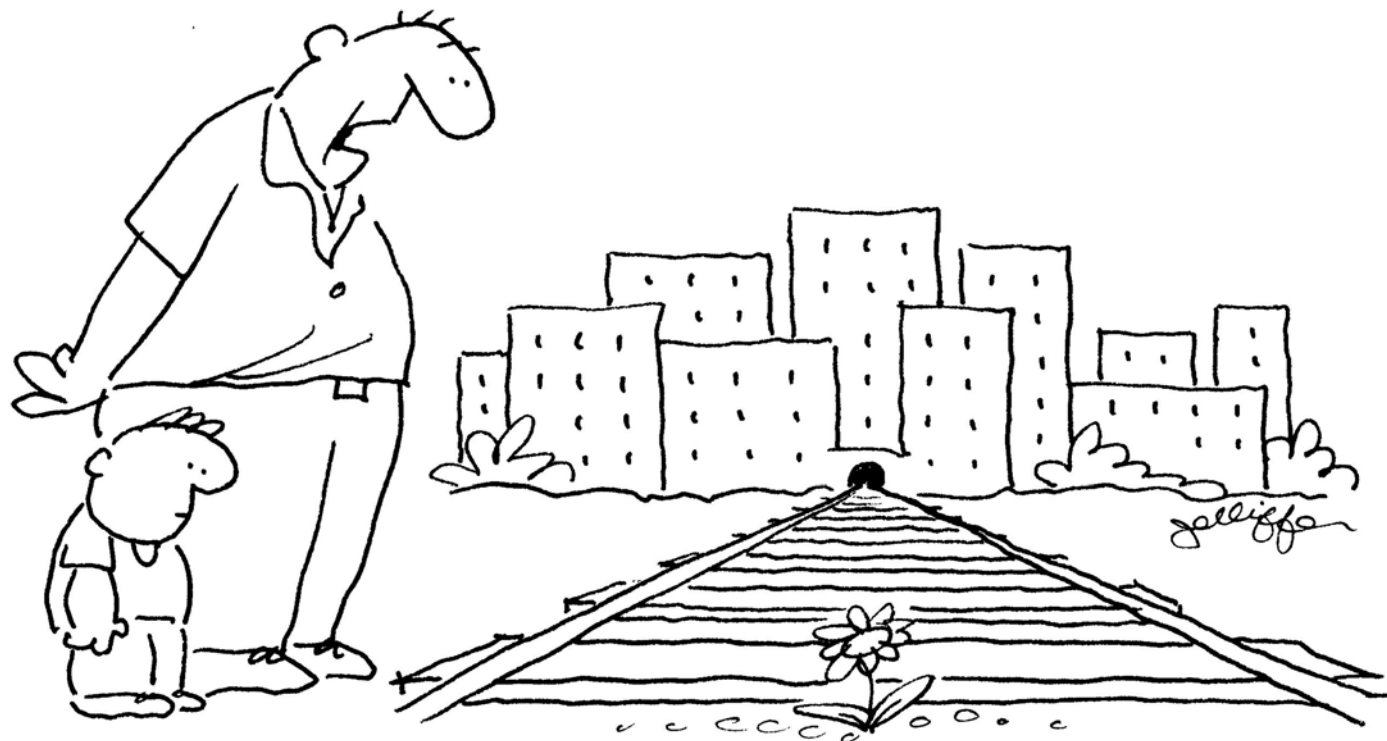>50% asymptomatic

Low-Barrier "test to care" approach

- Partnership: Unidos en Salud (UCSF and Latino Task Force), BART, SFMTA, DPH, Sup Ronen
- **Twice weekly testing-** morning or afternoon hours for **3 weeks in August**
- Bilingual staff
- VIP cards for business, transport workers, contacts
- Test to community care response
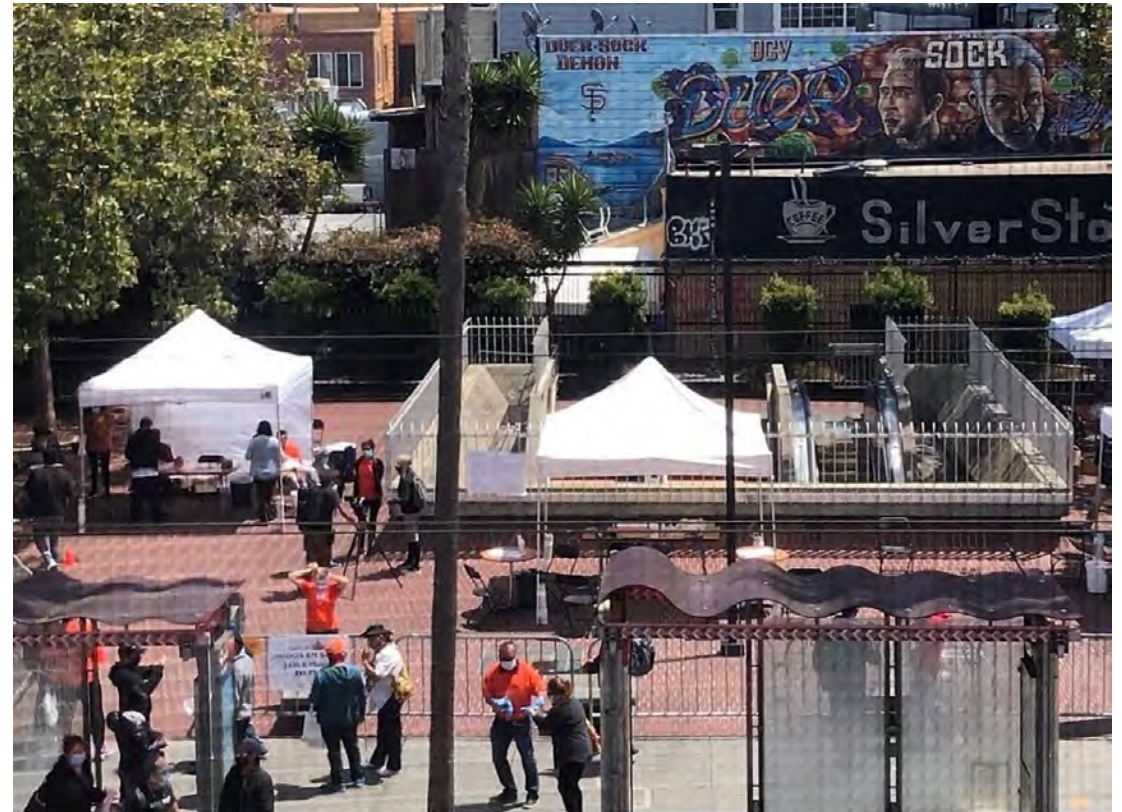
"Like I said son, survival is all about location, location, location!"

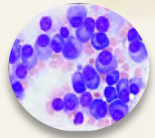# ASH Research Collaborative

- Non-profit

- Established by ASH in 2018

- Two programs:
  - Sickle Cell Disease Clinical Trials Network (SCD CTN)
  - Data Hub

- Improve **lives** of those affected by blood diseases

DATA → KNOWLEDGE → ACTION

Data Hub Programs

Sickle Cell Disease

Multiple Myeloma
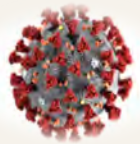
COVID-19 Registry for Hematology

Data Collection and Uses

Health Systems / Consortia

Genomic, molecular, other specialized data

Direct EHR integration at Sites

Closed Clinical Trial Datasets

Patient Reported Outcomes
Patient Generated Health Data

Data Hub
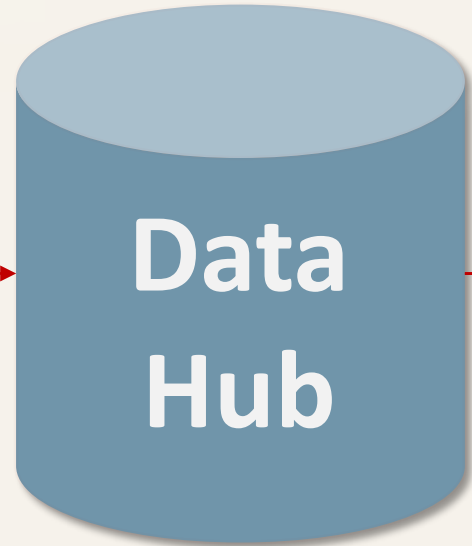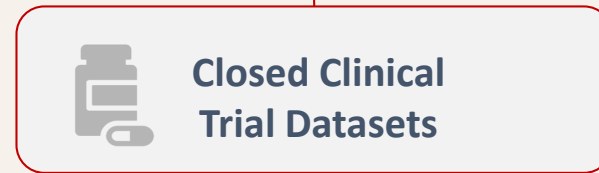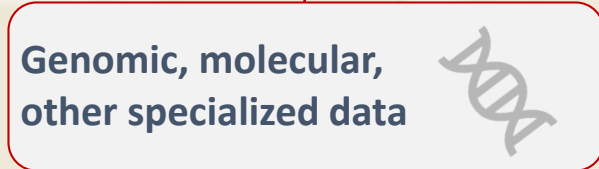
Improving Care and Outcomes

- ✔ Quality Improvement
- ✔ Clinical Guideline Implementation
- ✔ Personalized Analytics and Decision Support

Evidence Generation

- ✔ Cohort Selection
- ✔ Pre- and Post-Market Research
- ✔ Academic Research

ASH RESEARCH COLLABORATIVE
Accelerating Progress in Hematology

Addressing Disparities

- Ongoing engagement with the SCD and MM communities
  - SCD CTN Participation requirement includes implementing a community advisory board (CAB)

- Increasing awareness of clinical trials and reducing barriers to participation

- Creating learning networks

- Promoting shared decision making

- Generating real world evidence

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RESEARCH
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Accelerating Progress
in Hematology

Extending Our Reach

- ~110 sites expected in our SCD Data Hub (~50% US SCD pop.)
  - Academic institutions and community centers
- Data obtained from all patients
- Patient portal for longitudinal engagement
- Patient-reported outcomes

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Accelerating Progress
in Hematology

Goals and Opportunities

- COVID-19 and computable phenotypes
- Social determinants of health
- Consider interventions (e.g. testing, pragmatic studies)
- Additional hematologic conditions
- Continue community engagement

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Accelerating Progress
in Hematology

COVID-19 Registry for Hematology

Purpose
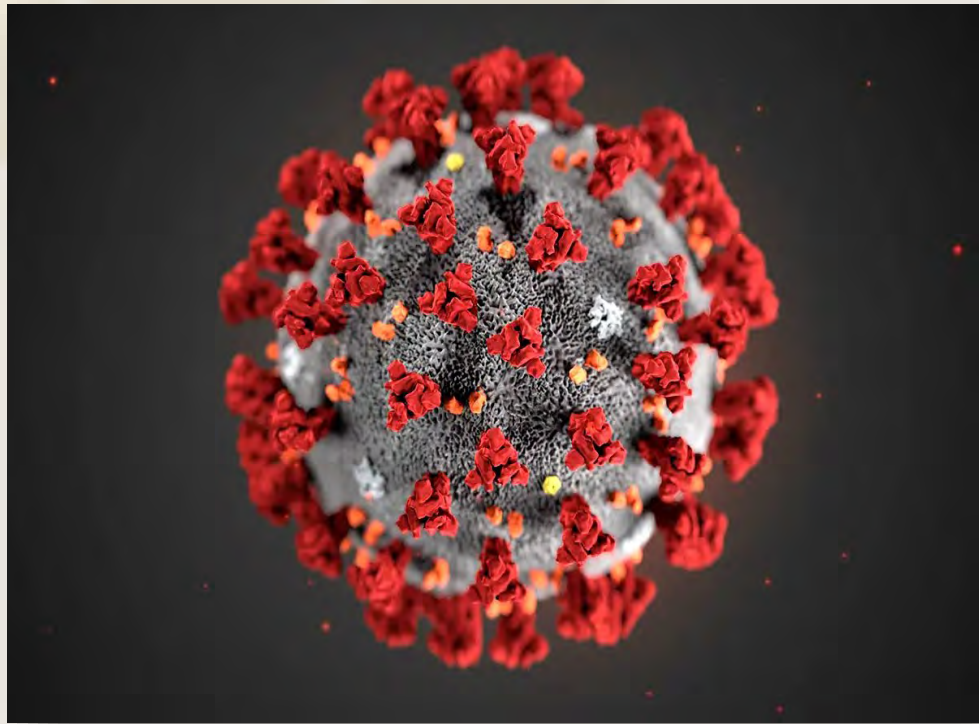
To provide hematologists on the front lines of the **COVID-19 pandemic** with near real-time information using **data** collected around from **around the world**.

ASH RESEARCH COLLABORATIVE
Accelerating Progress in Hematology

Registry Overview

- Launched on April 1, 2020
- Inclusion criteria:
  - COVID-19 positive **and**
  - Past or present malignant or non-malignant hematologic condition **or**
  - COVID-19 related hematologic complication

- De-identified data
- Research exempt under 45 CFR § 46.104(d)(4) and approved for a waiver of authorization
- Publicly available real-time observational summaries

Data Summaries

- Real-time summaries
- Filters for hematologic conditions
- Publicly available
- New metrics added as case number increases

Race/Ethnicity

Race/Ethnicity	Count
Asian	103
Hispanic/Latino/Latina	46
White/Caucasian	238
Other	39
Unknown	30
Black/African American	69

% of Total Number of Cases

COVID−19 Outcomes

Outcome	Count
Recovered	399
Death	114
Unknown	30

% of Total Number of Cases

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Accelerating Progress in Hematology
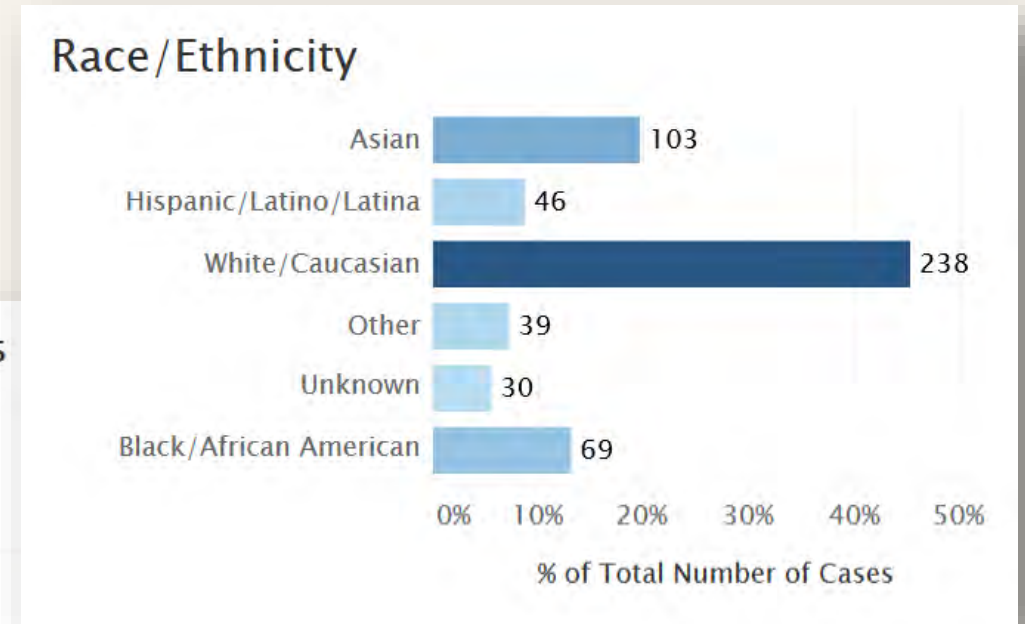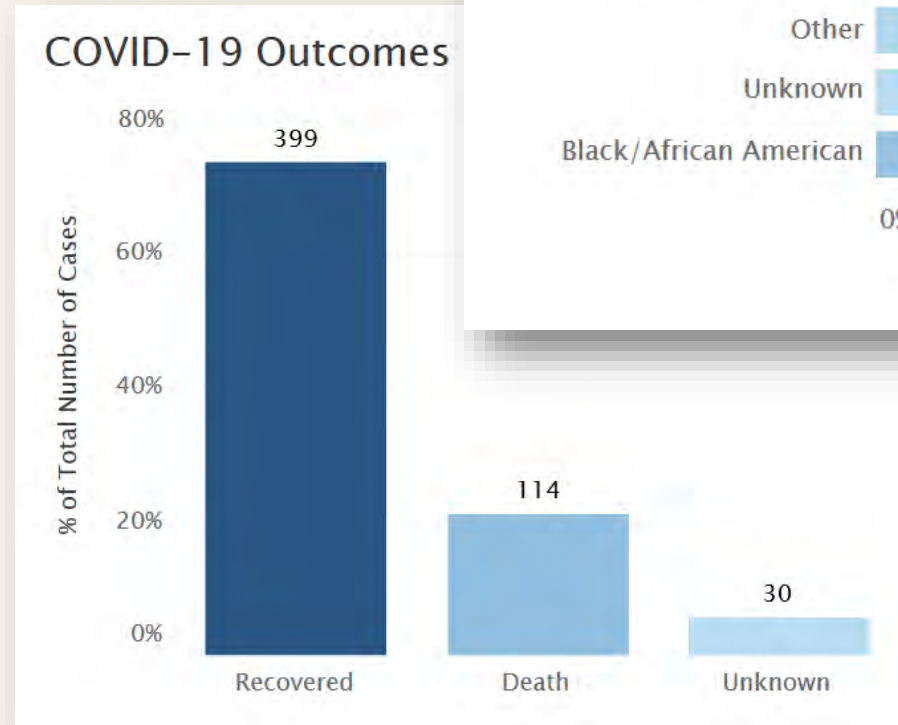
Questions?

info@ashrc.org

NIH-Designated Populations with Health Disparities

- Racial/ethnic minorities defined by OMB/Census

- Less privileged socio-economic status

- Underserved rural residents

- Sexual gender minorities

- A health outcome that is worse in one of these populations in comparison to a reference group defines a health disparity

- Social disadvantage resulting in part from being subject to discrimination and being underserved in health care, contributes to health disparities in all

Race/Ethnicity and Socioeconomic Status Affect Health Outcomes

- **Fundamental importance in human research**

- **Race/ethnicity predict life expectancy and mortality that are not fully explained**

- **African Americans have more strokes when compared to Whites for same SBP level**

- **Among persons with diabetes, all race/ethnic minorities have less heart disease and more ESRD when compared to Whites**

- **Race/ethnicity is a social construct with biological and other components**

Relative Risk of All-Cause Mortality by US Annual Household Income Level in 2016
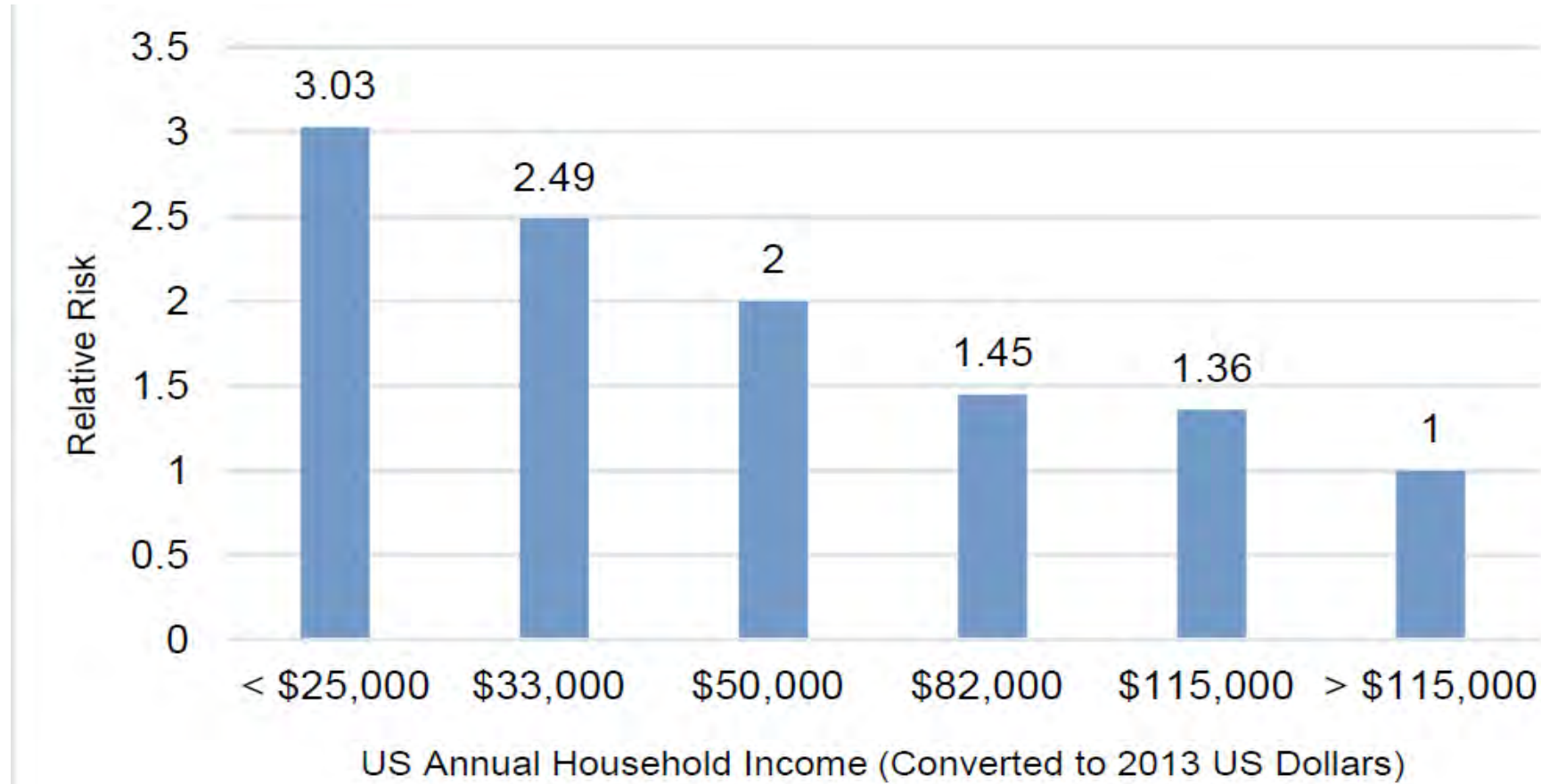
Wyatt R, et al., Achieving health equity: A guide for health care organizations. IHI White Paper. Institute for Healthcare Improvement, 2016

National Institute on Minority Health and Health Disparities Research Framework

		Levels of Influence*			
		Individual	**Interpersonal**	**Community**	**Societal**
Domains of Influence *(Over the Lifecourse)*	**Biological**	Biological Vulnerability and Mechanisms	Caregiver–Child Interaction Family Microbiome	Community Illness Exposure Herd Immunity	Sanitation Immunization Pathogen Exposure
	Behavioral	Health Behaviors Coping Strategies	Family Functioning School/Work Functioning	Community Functioning	Policies and Laws
	Physical/Built Environment	Personal Environment	Household Environment School/Work Environment	Community Environment Community Resources	Societal Structure
	Sociocultural Environment	Sociodemographics Limited English Cultural Identity Response to Discrimination	Social Networks Family/Peer Norms Interpersonal Discrimination	Community Norms Local Structural Discrimination	Social Norms Societal Structural Discrimination
	Health Care System	Insurance Coverage Health Literacy Treatment Preferences	Patient–Clinician Relationship Medical Decision-Making	Availability of Services Safety Net Services	Quality of Care Health Care Policies
Health Outcomes		Individual Health	Family/ Organizational Health	Community Health	Population Health

Social Determinants of Health

- **Demographics including family background**

- **Urban or rural residence or geographic region**

- **Cultural identity, religiosity, spirituality**

- **Language proficiency, Literacy, numeracy**

- **Structural determinants: housing, green space, broadband, economic opportunity, transportation, schools, healthy food access, public safety**

- **PhenX Toolkit on Social Determinants of Health:**
https://www.phenxtoolkit.org/collections/view/6

Perception of Unfair Treatment: 2015

In past 30 days were you treated unfairly because of racial or ethnic background in store, work, entertainment place, dealing with police, or getting healthcare?		
	Percent Agree	
	All	**Health**
Latinos	36%	14%
African Americans	53%	12%
Whites	15%	5%

Trust in clinician/institution? Role of Unconscious Bias?

National Institute on Minority Health and Health Disparities

Racism as Research Construct

- *Interpersonal*: Most work done, excellent measures developed, associations established

- ***Structural*: History, culture, institutions, and codified practices that perpetuate inequity; how do we incorporate into research?**

- *Internalized*: How discrimination (as above) effects individuals who are not aware or sublimate; accept cultural or biological inferiority

- Perceived societal discrimination and second-hand effects of racism

Clinical Registries Research to Address Covid-19 Disparities: What is Needed?

- **Standardized measurement of demographics and social determinants of health**

- **Address structural SDOH — incorporate into clinical management**

- **Track test results, symptoms, clinical cases**

- **Emphasis on participation in trials and promoting a science-based response**

- **Recognize and manage structural and interpersonal discrimination**

NIH Programs to Address Covid-19 Disparities

- Social, behavioral, and economic consequences — funding 52 supplements to existing grants (NIMHD, NIMH, NIA, OBSSR, plus other ICs)

- Rapid Acceleration of Diagnostics for Underserved Populations (RADx-UP): supplements to promote testing (NIMHD, NIA, OD)

- Coordination and Data Collection Center RADx-UP

- Data harmonization and effort to "require" use of Common Data Elements

- Community Engagement Alliance against Covid-19 Disparities Initiative: 11 State Consortiums

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Future Research Directions

- **Linkage of clinical registries to population-based data through census imputation**

- **Unique personal identifiers maintained in a confidential manner**

- **Leverage the data in CMS (Medicare and State-Medicaid), Social Security death index with clinical data (SEER-Medicare linked data as example)**

- **Standard consent for future use of de-identified data and data sharing for science**

- **Editor's choice by Eliseo J. Pérez-Stable and Francis S. Collins**

- **Definitions for minority health, health disparities, and NIMHD Research Framework**

- **30 research strategies in methods, measurement, etiology, and interventions**

- **Multi-year process with more than 100 authors, from NIH and academic scientists**

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National Institute
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Questions & Answers

Please submit all questions through the question box.

Summary & Evaluation

- Thank you to all our panelists.

- A recording of the webinar will be available on the CMSS website in the coming weeks.

- Please compete a short evaluation following the webinar.

- For more information, contact info@cmss.org.

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Join Us

The Council of Medical Specialty Societies invites you to join us for the

CMSS Virtual Annual Meeting, October 28 - 30, 2020

CMSS | Council of Medical Specialty Societies

Covid-19 and Beyond:
Digital Transformation of Healthcare, Research, and Education

Program Tracks:

Healthcare Transformation: focusing on telehealth and remote patient monitoring

Research Transformation: focusing on clinical registries, cloud-based computing, and digital research tools

Education Transformation: focusing on lessons learned and future opportunities for virtual meetings

Key Details:

- October 28: CMSS Members Only
- October 29-30: Open to All (Members and Non-Members)
- Registration Available mid-September
- Industry Partner and Exhibit Opportunities Available
- Visit www.cmss.org or follow @CMSSMed for frequent updates