A national framework to improve mortality, morbidity, and disparities data for COVID-19 and other large-scale disasters

Michael A. Stoto, PhD

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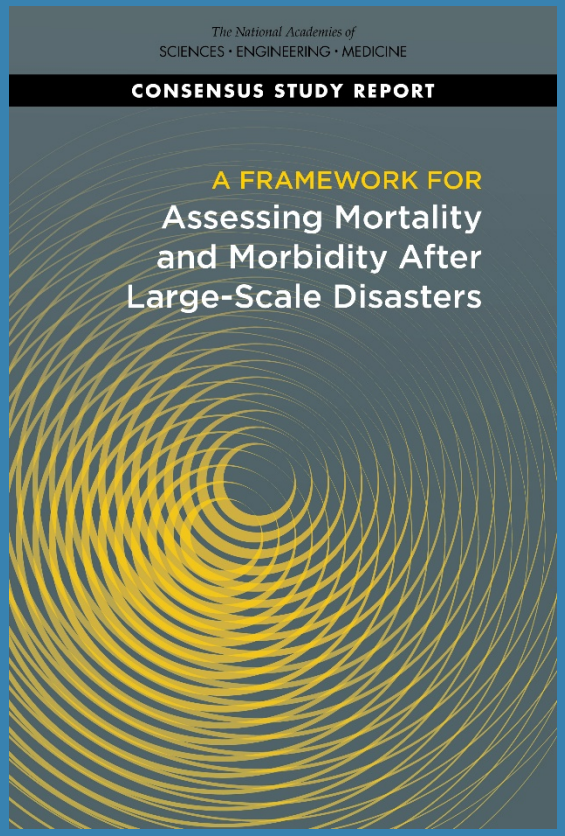
The National Academies of SCIENCES ENGINEERING MEDICINE



A Framework for Assessing Mortality and Morbidity After Large-Scale Disasters

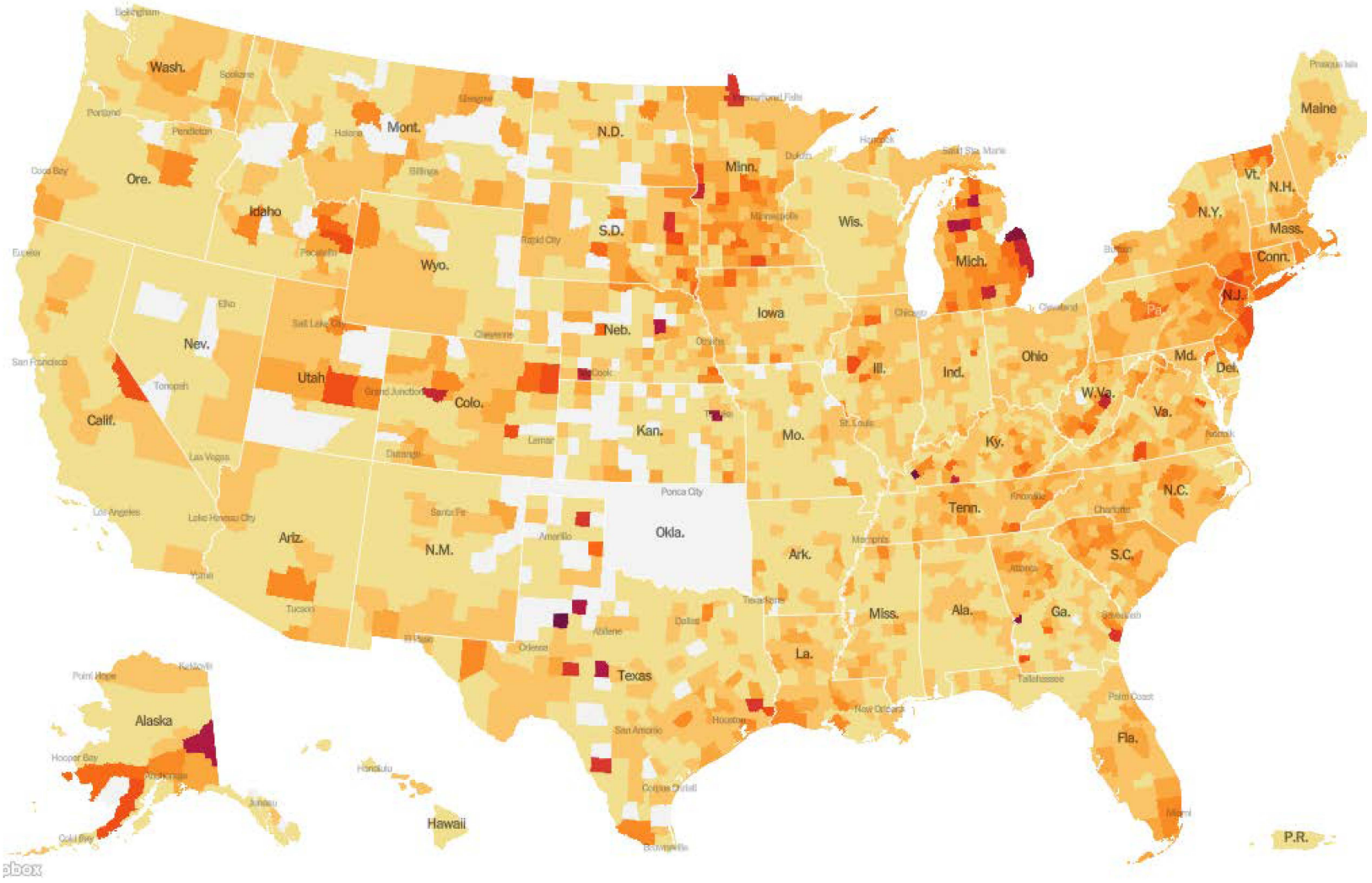
Report Highlights

Overview of Recommendations

Better metrics for controlling COVID-19

- As communities adjust their policies to prevent the spread of COVID-19, the focus is on restoring trust with science-based and objective “metrics”
- Data are published by many different government health agencies, universities, and the media
  - Vary in terms of metrics included, how defined
    - definitions change over time
  - Many also have well-known problems such as “uncounted deaths”
  - Despite all of these data, we seem to be “flying blind” in the fight against COVID-19
- President Biden’s executive order to ensure data-driven response to COVID-19 and other disasters

U.S. COVID-19 situation – March 23, 2021

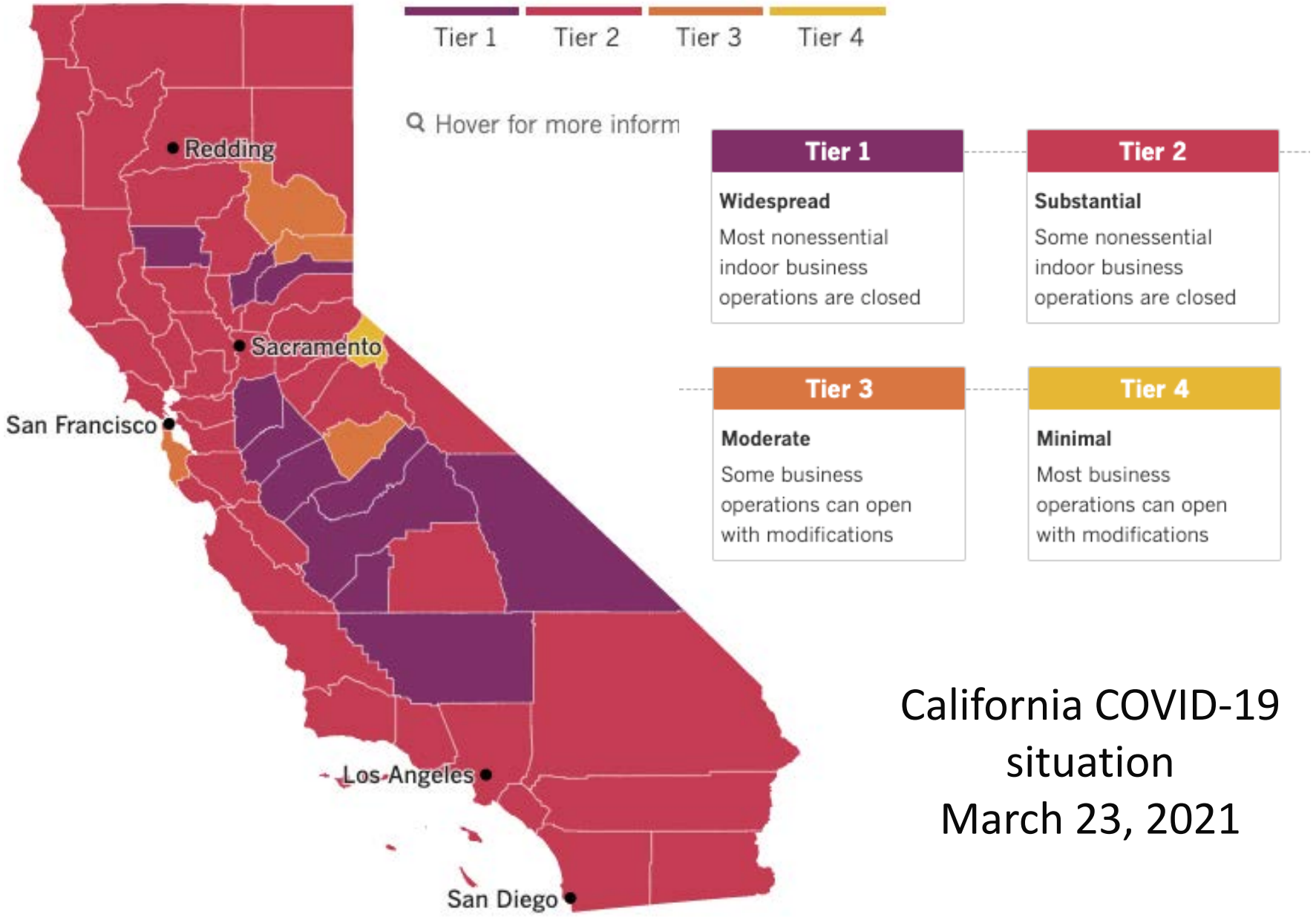


Average daily cases per 100,000 people in past week

10 30 50 70 100 250 Fev c

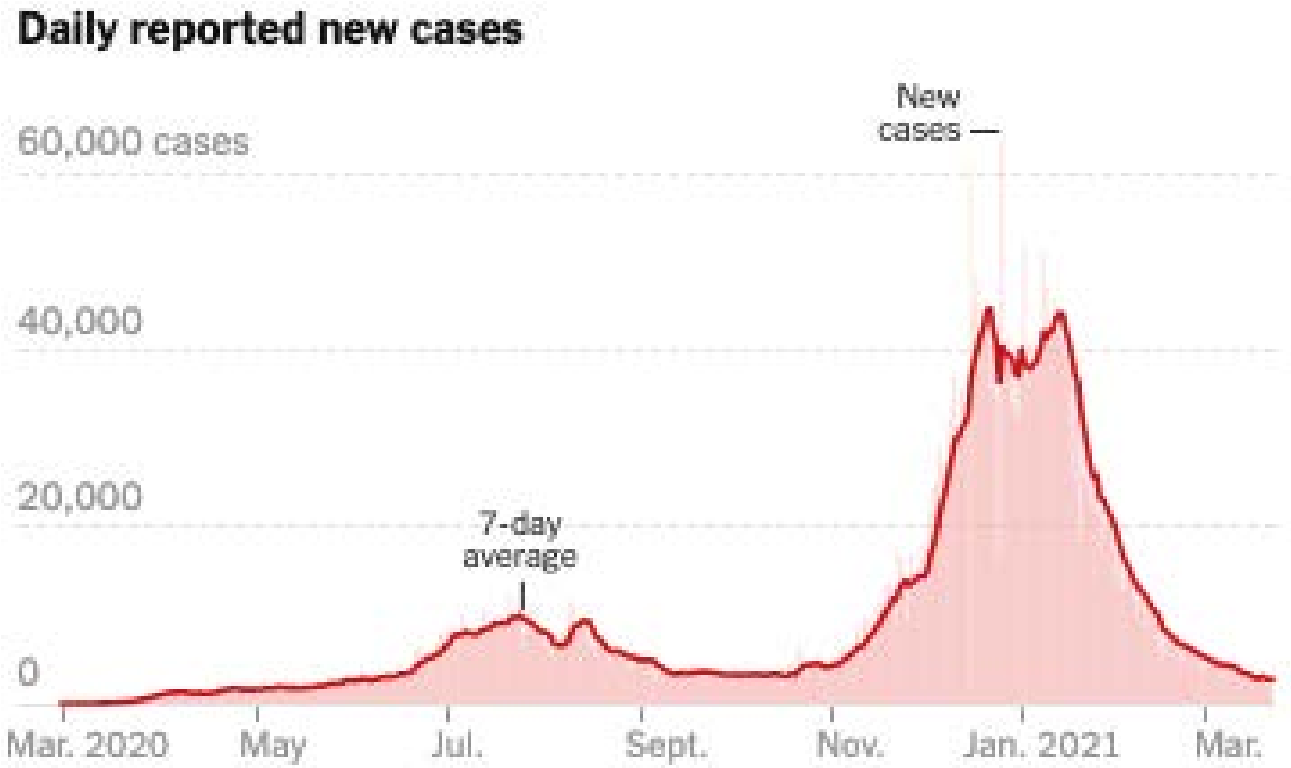
	TOTAL REPORTED	ON MARCH 22	14-DAY CHANGE
Cases	29.8 million+	55,621	-8% →
Deaths	542,587	650	-35% ↘
Hospitalized		38,969	-16% →

California Blueprint

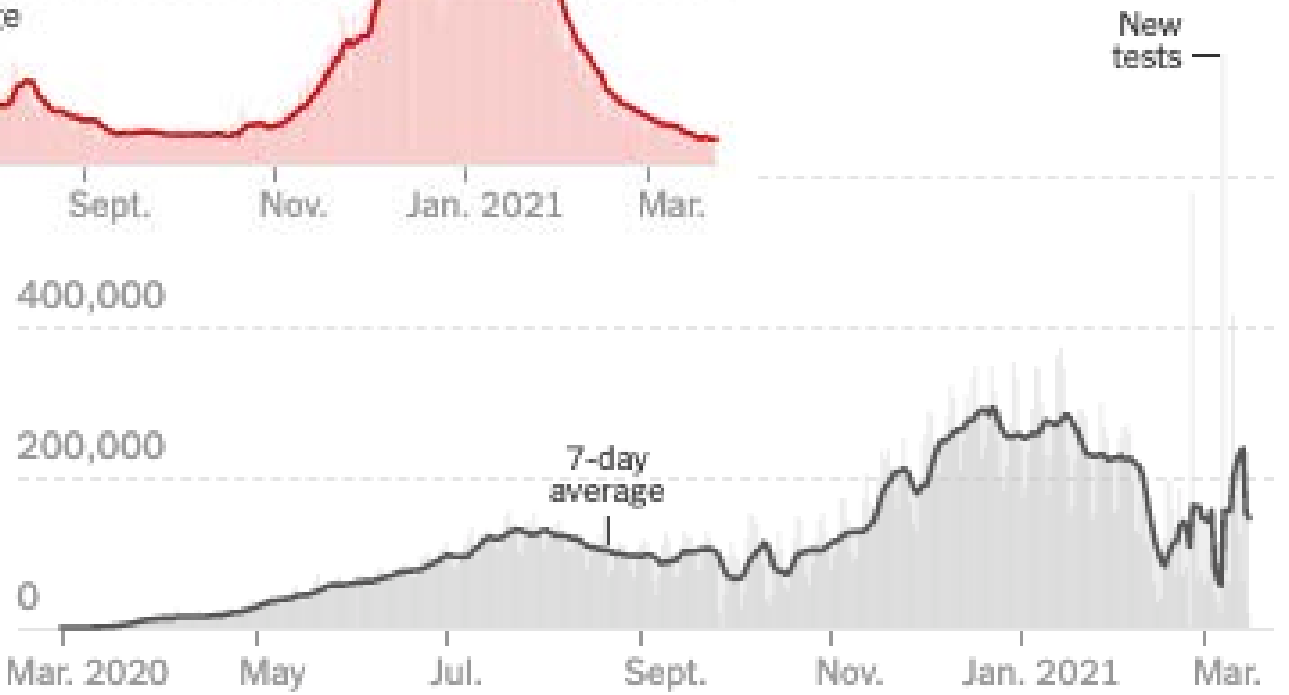


California COVID-19 situation
March 23, 2021

California COVID-19 situation – March 23, 2021



Daily reported specimens tested



Test positivity rate

- Introduced as an *ad hoc* solution to the problem that cases were being missed
  - testing capacity was limited, so likely cases were prioritized
  - < 5% target adopted from another use, i.e. whether a wide enough net was being thrown in contact tracing
- Through the summer and fall, testing options expanded, increasing the number of people tested (denominator)
  - population tested changed
    - from mostly people with symptoms or close contact
    - to include back-to-work testing, travelers seeking to avoid quarantine, people living with at-risk relatives & worried well
  - universities, schools, workplaces began frequent screening
  - test types (serum/antibodies, rapid antigen) expanded
- ➔ both numerator and denominator change in ways that don't reflect transmission of COVID-19 in the population

Where do the data come from?

- Mostly from “case surveillance”
  - doctors who diagnose a “case” notify health department
  - which then takes steps to control it
- Contact tracing requires identifying specific individuals who have the disease
  - cases who are symptomatic and/or test positive
  - their contacts while they were infectious
- These data facilitate epidemiologic investigations
  - characterize clinical disease course and factors influencing risk of transmission, including socio-demographic factors
  - identify local transmission risks (e.g. specific locations such as bars where super-spreader events may occur)
  - health officials take action, either focused on the specific location, or changing policy, e.g. delay reopening bars
- But case-based surveillance data have problems

Problems with reliance on reported cases

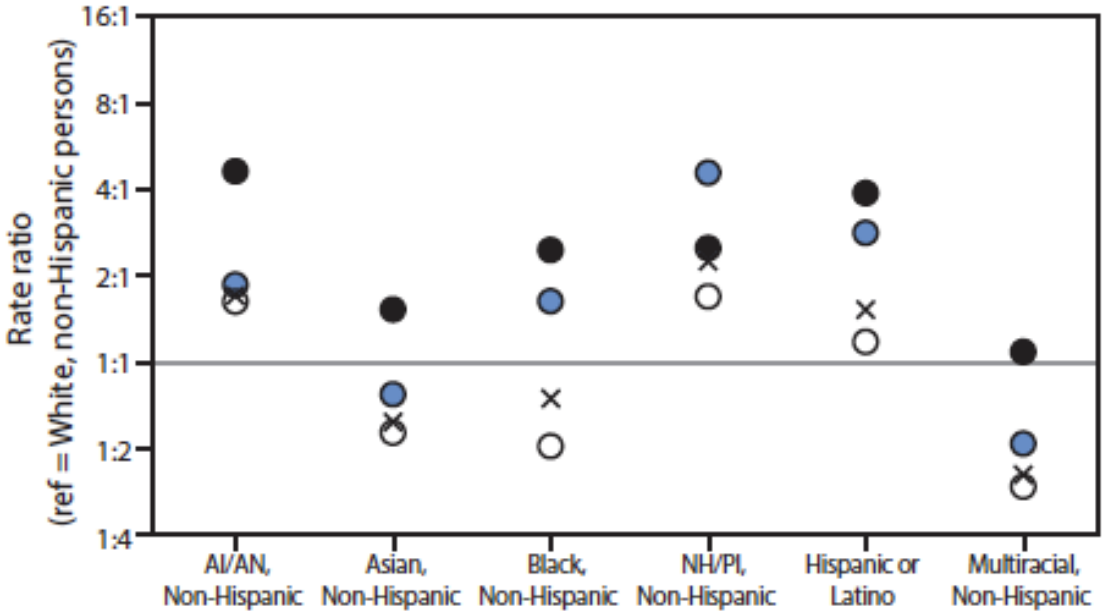
- Iceberg effect: # reported cases < # infected
  - individuals with mild or no symptoms
    - whether they seek care & referred to testing
    - test availability
  - proportion of cases reported varies
    - over time (changing test availability, etc.)
    - between states based on differences in definitions, policies, systems for reporting, etc.
      - do symptomatic cases “count” if never tested?
  - similar problems for reported deaths

Problems with reliance on reported cases

- Socio-demographic data not needed for operational purposes (e.g. contact tracing)
  - *so often not available for statistical purposes*

Centers for Disease Control and Prevention
MMWR
Morbidity and Mortality Weekly Report
Early Release / Vol. 70
March 10, 2021

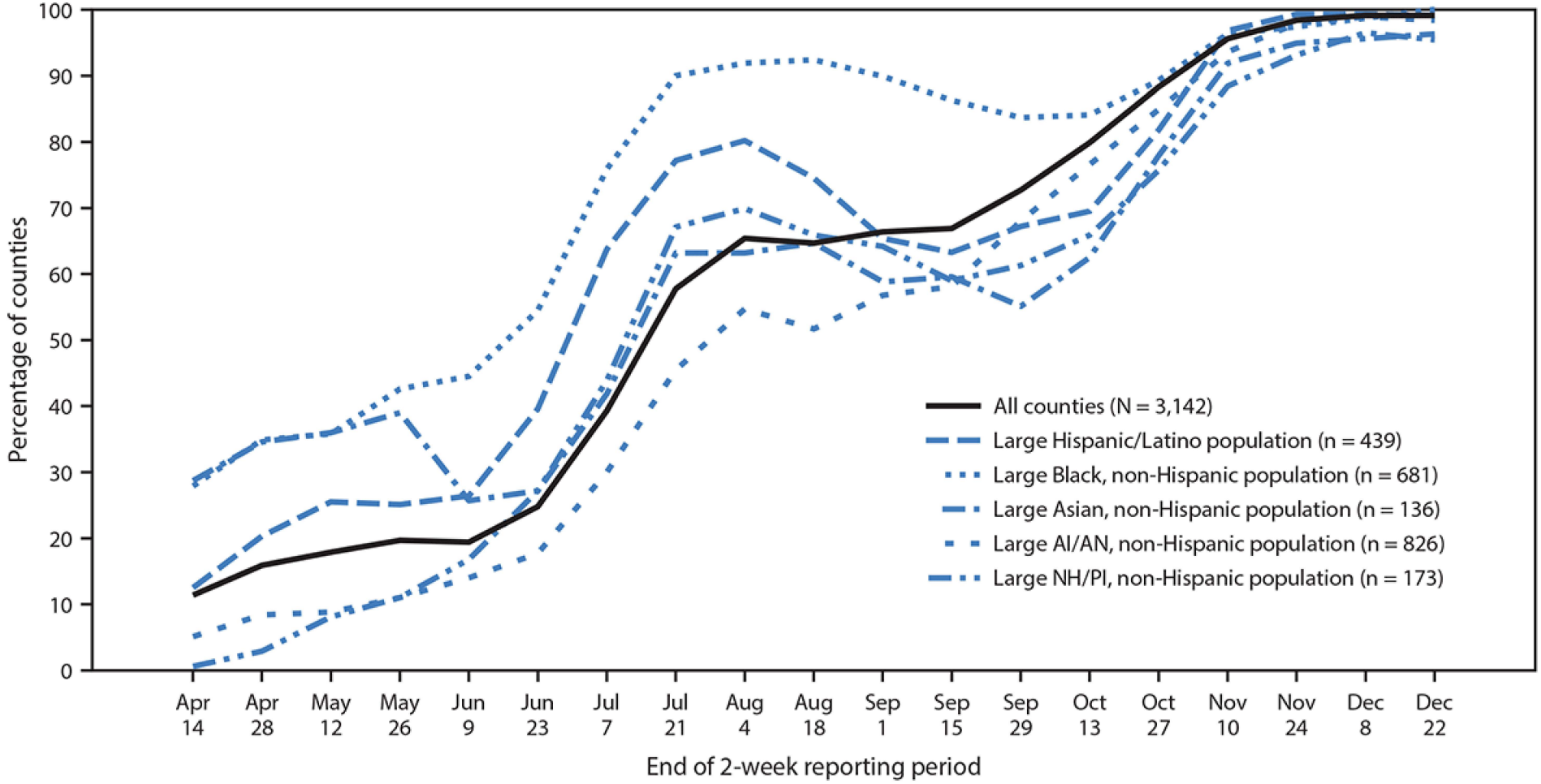
Racial and Ethnic Disparities in COVID-19 Incidence by Age, Sex, and Period Among Persons Aged <25 Years — 16 U.S. Jurisdictions, January 1–December 31, 2020



- Based on 16 jurisdictions with >70% completeness of race and ethnicity information
- only 30% of U.S. population

Percentage of counties with high COVID-19 incidence* among U.S. counties with large population percentages of five racial and ethnic minority groups† — United States, April 1–December 22, 2020 Source: Lee et al., *MMWR*, March 24, 2021

* >100 new cases per 100,000 persons in the 2-week period



AI/AN = American Indian/Alaska Native; NH/PI = Native Hawaiian or other Pacific Islander.

Recommendations

- Starting with current reported cases and deaths, CDC should standardize
  - case definitions (as already done)
  - measurement processes, e.g.
    - how to handle cases tested in one jurisdiction who live in another
    - electronic death registration systems, dropdown menus, etc.
  - metric definitions
    - including which tests to count (PCR, antibody, screening programs; pooled tests; first test only?; …)
  - time periods for averaging
  - and so on …

Strengthening Systems, Practices, and Approaches

- U.S. disaster management composed of a diverse and often disjointed network of
  - federal and SLTT actors and systems
  - stakeholders ranging from health care, government agencies, the general public, policy makers, public and private sectors, …
- Diversity in practices for collecting and recording data and methods for developing estimates compound these administrative challenges
- Extracting maximum value from data on morbidity and mortality requires these stakeholders and systems coordinate efforts effectively and uniformly across the disaster management enterprise

Developing a Mortality and Morbidity Framework

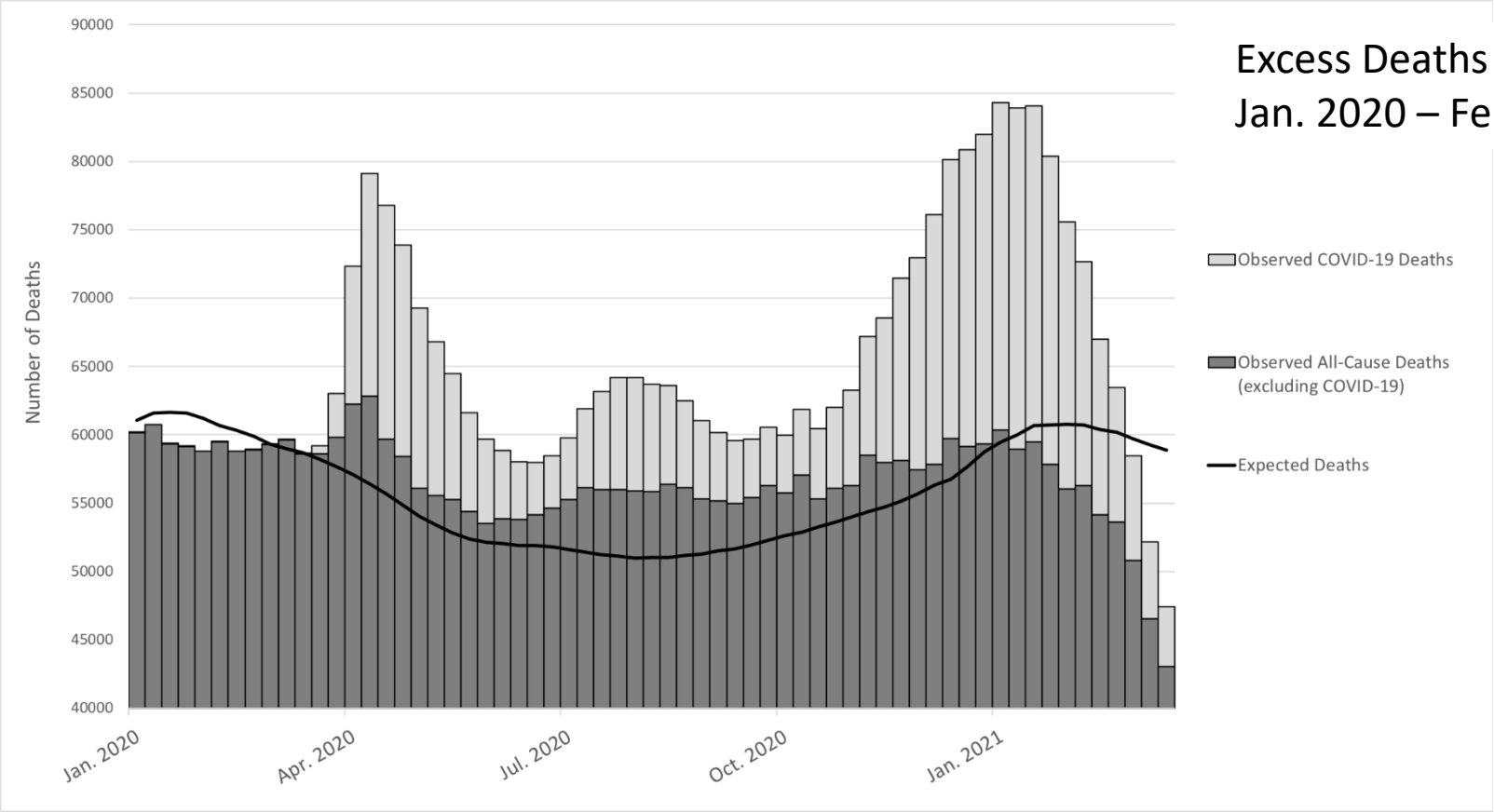
- Develop a uniform approach for conceptualizing and assessing mortality and morbidity data that
  - clarifies case definitions to uniformly characterize how an individual death or morbidity can be attributed to a disaster
  - incorporates the two primary methodological approaches for estimating mortality and morbidity—individual counts and population estimates
    - each has strengths, weaknesses, appropriate uses, methodologies
- Federal & SLTT agencies adopt & support stakeholders in applying this framework in practice, including
  - uniform case definitions and data collection, recording, and reporting practices
  - training

Beyond the current metrics

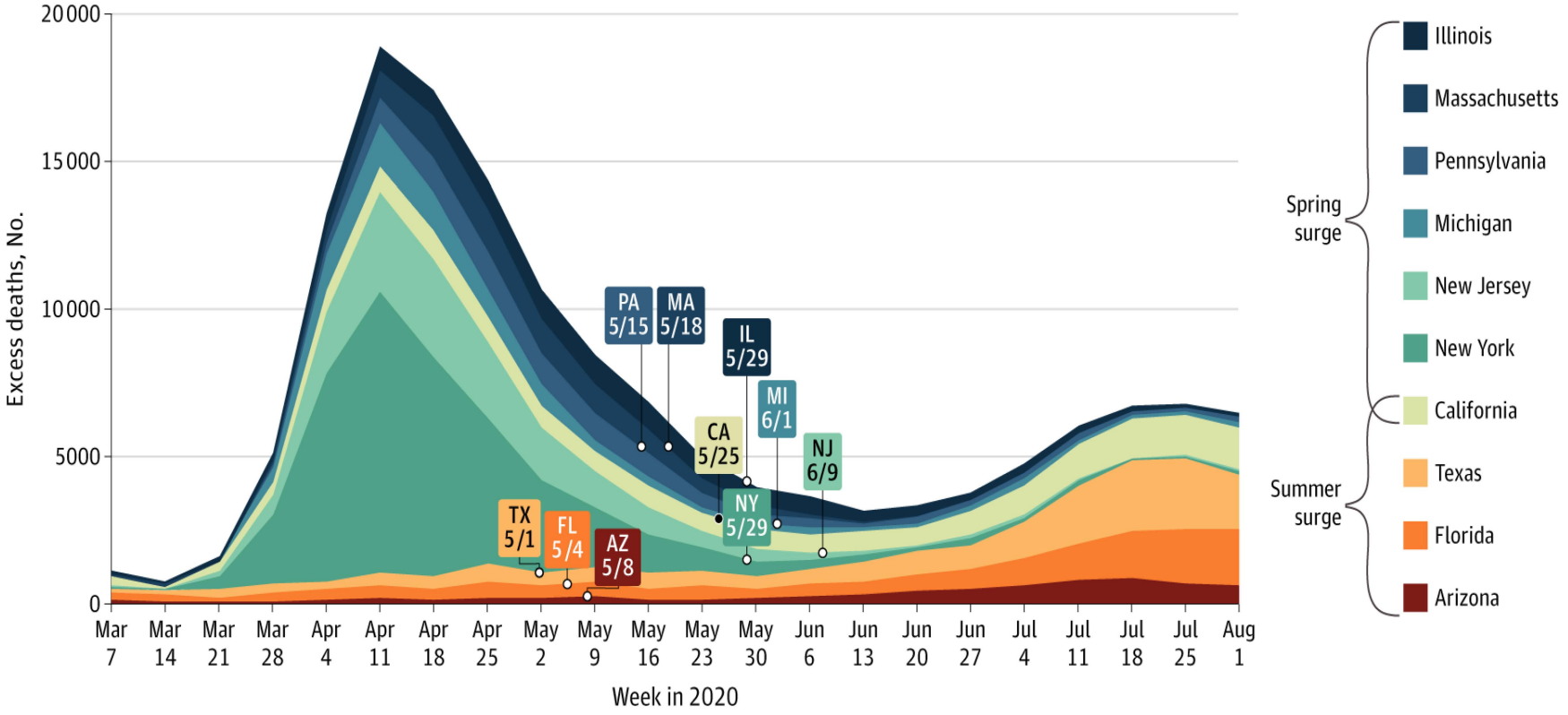
- Early in outbreak we go with the best we have
  - as the pandemic presses on, we must do better
  - trying to *count* all cases is not necessarily best
- Going forward, a new NASEM report suggests three statistical *estimation* methods to complement counts
  - excess mortality methods
  - syndromic surveillance
  - surveys based on representative samples
- Shift focus
  - from tracking day-to-day changes
  - to long-term trends and patterns & better understanding

Excess mortality methods

- Excess Mortality = actual deaths - predicted deaths
  - includes deaths
    - caused by COVID-19 infection
      - including those not attributed to it
    - indirectly caused by COVID-19



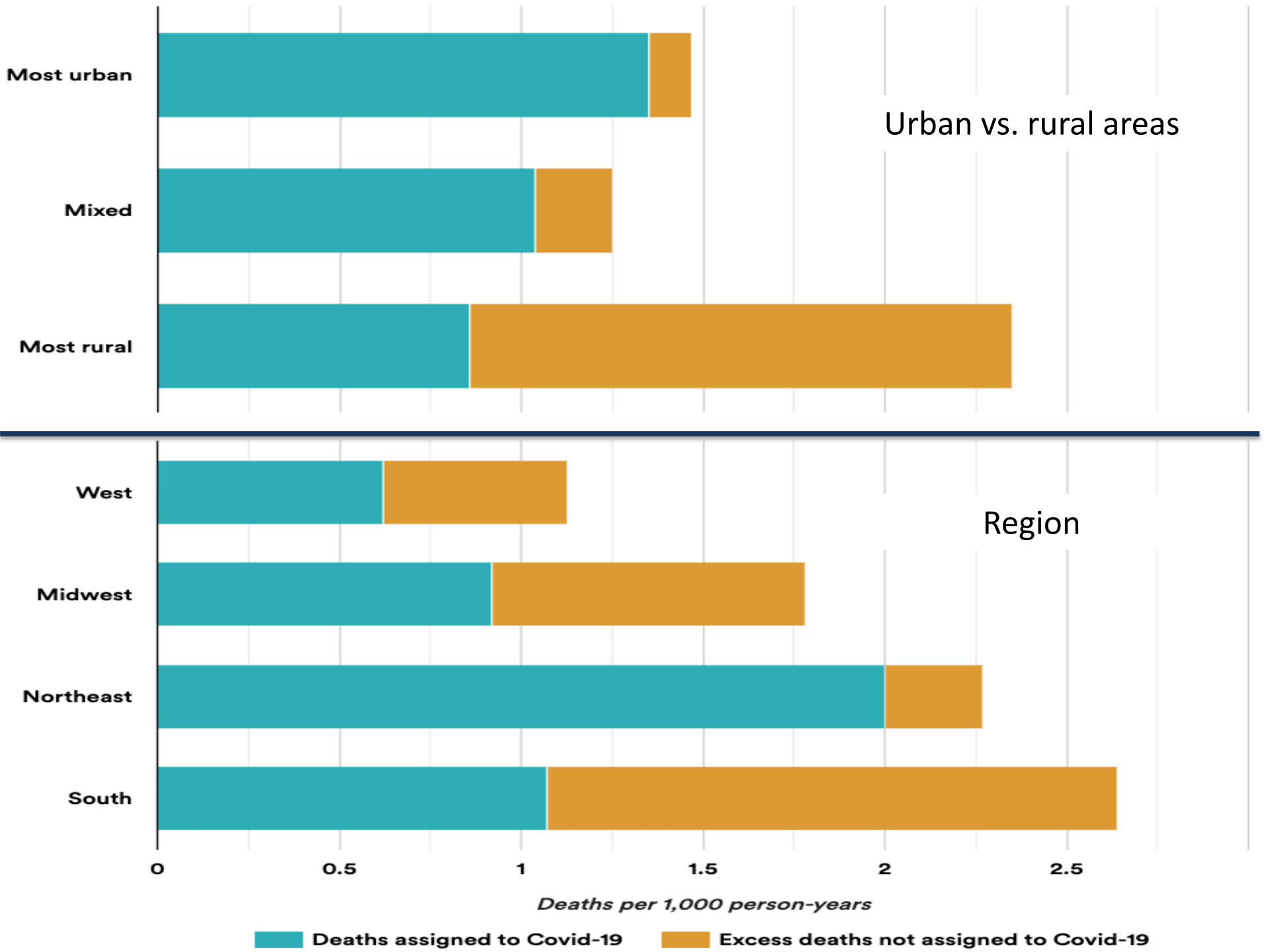
Excess Deaths in the U.S.
Jan. 2020 – Feb. 2021



Excess deaths from March to July 2020 in Selected States. The figure plots weekly excess deaths for the 10 states with the largest number of excess deaths during March-July 2020. Reopening dates refer to the lifting of broad coronavirus disease 2019 restrictions, as reported by the *New York Times*. Woolf *et al, JAMA*, October 12, 2020

Excess mortality differentials

- Age
  - U.S. March-July, 2020 - 25-44 age group
  - 12,000 excess deaths
  - only 38% attributed to COVID-19
  - relative increase of 26.5% greater than any other age
- Race and Ethnicity
  - relative excess mortality (11.9% for Whites)
    - vs. Latinxs 53.6%, Blacks 32.9%, Asians 36.6%
  - If these groups died at the same rate as Asians or Whites
    - 19,500 Black, 8,400 Latinx & 600 Indigenous people would still be alive
    - attributable to (consistent with existing inequities)
      - more likely to have "essential" jobs
      - more comorbidities


Most urban
Mixed
Most rural
Urban vs. rural areas
West
Midwest
Northeast
South
Region
0
0.5
1
1.5
2
2.5
Deaths per 1,000 person-years
Deaths assigned to Covid-19
Excess deaths not assigned to Covid-19

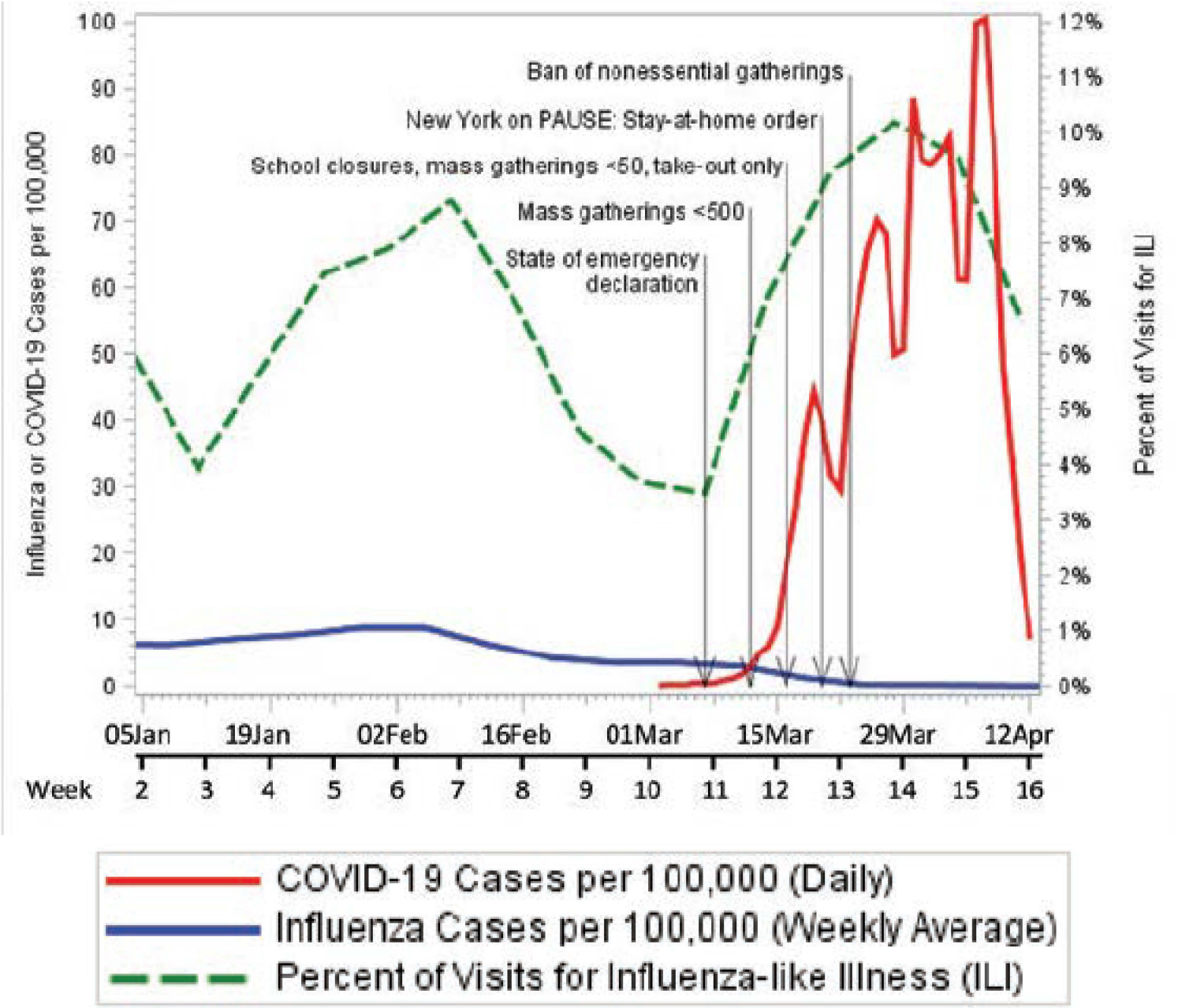
Excess mortality methods

- Compare deaths to similar period in the past
  - can look at cause of death, demographic and socioeconomic characteristics, etc.
  - research still needed, e.g. on
    - how to estimate expected deaths
      - e.g. the proper base period with which to compare
    - how to deal with people who moved because of the pandemic

Syndromic surveillance

- Don’t wait for a formal diagnosis and case reporting processes, but rather track existing data that might indicate when people are having symptoms consistent with COVID-19 (“COVID-19-like illness”)
  - Builds on an approach health officials have been using for years for influenza-like-illness (ILI)
  - based on
    - hospital ED visits (NSSP)
    - outpatient visits (ILINet)

New York City Metro Region. Jan. 1–April 12, 2020, Rosenberg *et al.*, 2020



Surveys based on representative samples

- Don’t need to count every case, or be sure that every case is “valid”
  - but do want a consistent reference population (denominator)
  - can sometimes adjust to be more representative
- Seroprevalence surveys
  - population-based
  - blood donations
  - clinic-based (dialysis, OB-GYN)

Prevalence of SARS-CoV-2 antibodies in a large nationwide sample of patients on dialysis in the USA: a cross-sectional study Anand *et al.*, *Lancet*, 2020

Seroprevalence substantially higher in Zip codes with

- Black & Hispanic populations
- high levels of poverty
- high population density

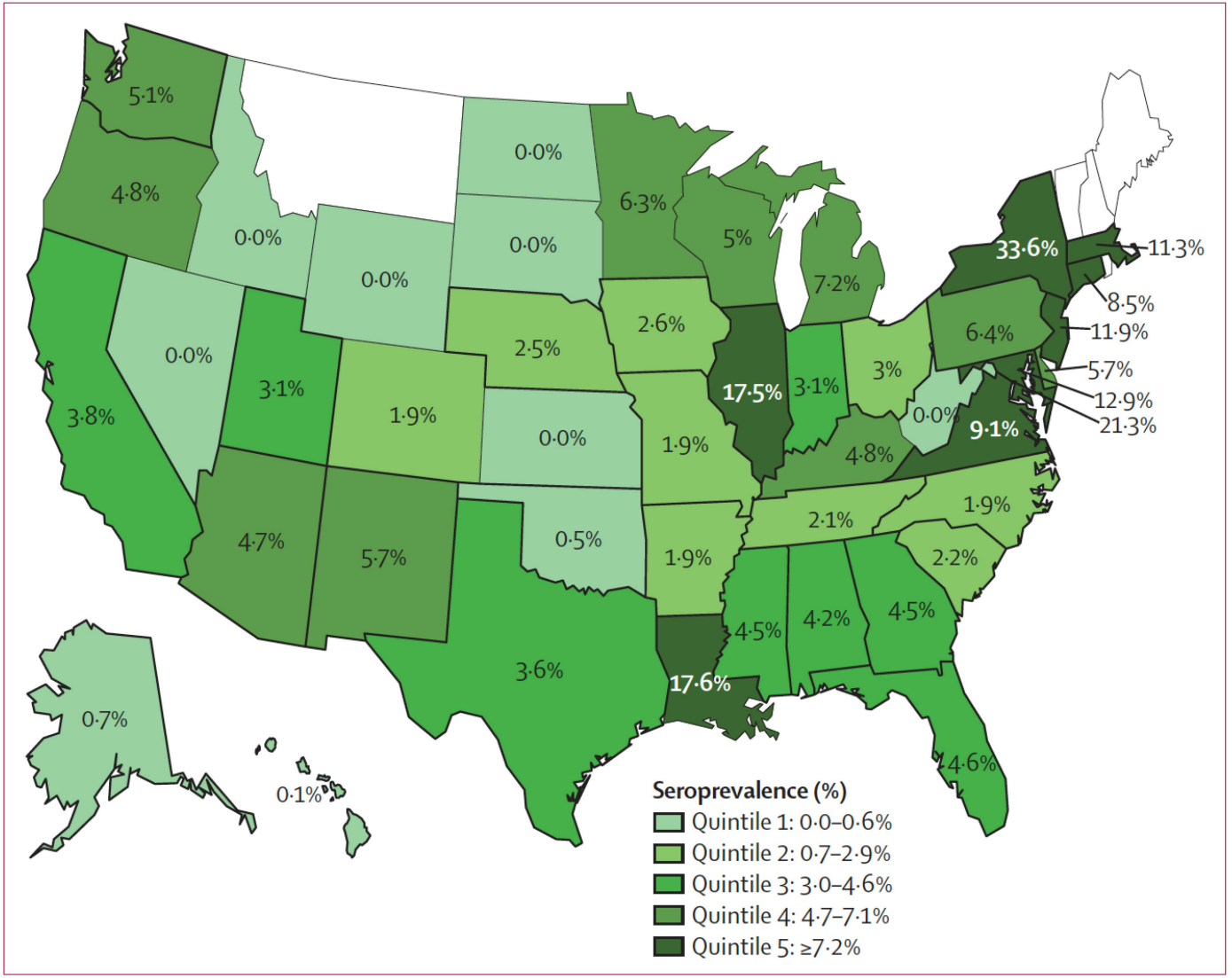


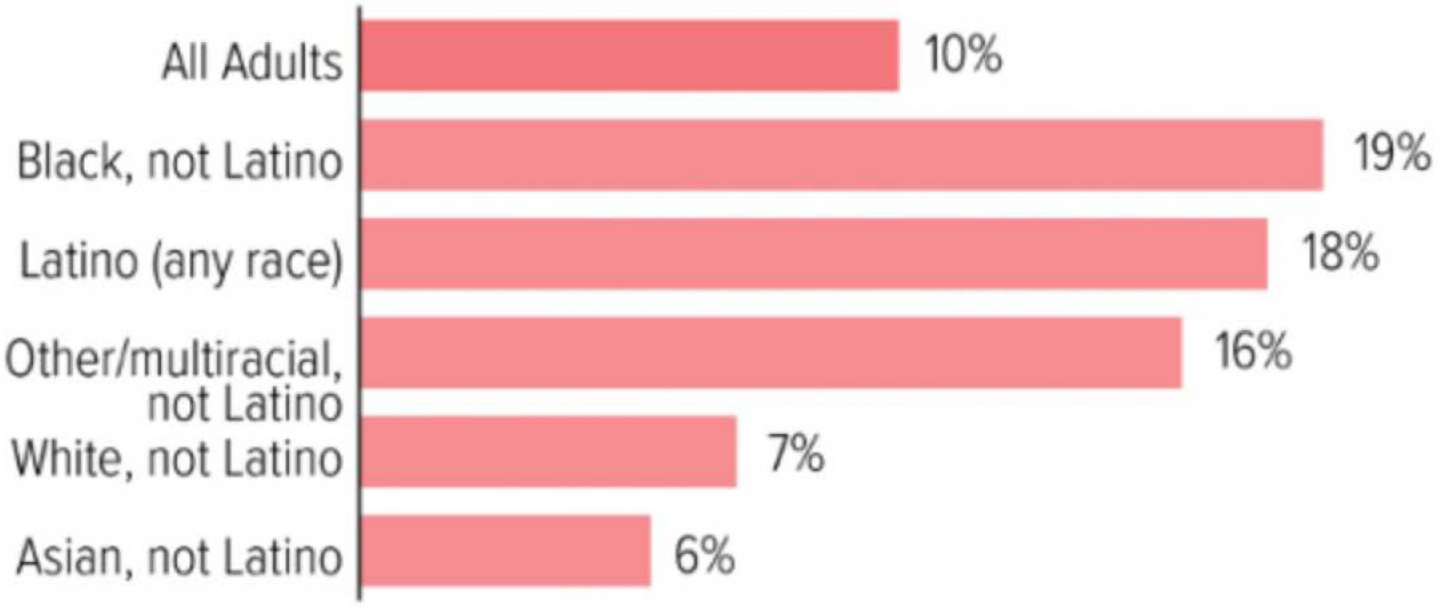
Figure 2: **Prevalence of SARS-CoV-2 antibodies in sampled population, by state**
Bolded borders represent states with more than 100 patients in the sample. The median number of patients sampled by state was 176 (IQR 83–536). States in white were not sampled. SARS-CoV-2=severe acute respiratory syndrome coronavirus 2.

Surveys based on representative samples

- Surveys can also be use to estimate mental health and social consequences of COVID-19
- Example: Census Bureau Pulse survey
  - designed to deploy quickly and efficiently, collecting data to measure household experiences during the coronavirus pandemic
  - Food insufficiency (share of households that sometimes or often did not have enough to eat in the last 7 days) concentrated in
    - the South and Southwest
    - Blacks and Latinos

Black and Latino Households Likelier to Experience Food Insufficiency During Pandemic

Share of adults saying that their household sometimes or often did not have enough to eat in the last 7 days, as of September 2-14, 2020



Note: Other/Multiracial not Latino = people identifying as American Indian, Alaska Native, Native Hawaiian or Pacific Islander, or more than one race. Percentages are based on reporting distributions and do not include the populations that did not respond to the question.

Source: CBPP analysis of Census Bureau Household Pulse Survey

Conclusions

- Managing the COVID-19 pandemic
  - requires detailed, objective data on the level and rate of increase in new infections
- Better information starts with standardizing current case definitions, measurement processes, and metric definitions (i.e. good research methods)
  - constant reference population
- Research-based *estimation* methods can supplement and complement *counts* of cases and deaths
  - excess mortality
  - syndromic surveillance
  - surveys based on representative samples
- Estimation is still largely experimental, so research needed into best methods, standardization, etc.

Guiding System Precepts for a Mortality and Morbidity Framework

- Collect and use data for community health protection as an essential component across all phases of disaster management
- Incorporate both individual counts and population estimates to better understand a disaster's true effect
- Leverage morbidity data as well as mortality data to support response, recovery, mitigation, preparedness, and prevention
- Build on and use existing systems, capacities, and methodologies
- Commit to the continuous improvement of systems over time
- Adopt an enterprise approach to activate stakeholders and systems in times of crisis as well as during the inter-disaster period
- Support the resilience and strengths of historically disadvantaged populations by using data to understand, mitigate, and eliminate inequalities in disaster impacts

Recommended immediate actions

1. Adopt and use a uniform framework for collecting, recording, and reporting mortality and morbidity data (Recs. 2-1 & 2)
2. Invest in improvements to data systems & tools for collecting, recording & reporting individual count data at SLTT levels (3-1 & 2)
3. Update Model State Vital Statistics Act and Regulations to facilitate more robust and uniform mortality data collection (3-2)
4. Create process to develop, validate, and promulgate national standards for reporting on a core set of morbidity impacts specific to the common types of major disasters (3-3)
5. Invest in and develop capacity to collect and analyze the data necessary for population estimates of mortality and morbidity (4-2)
6. Implement new tools and approaches to share and use mortality and morbidity data (4-3)
7. Create a separate Emergency Support Function dedicated to mortality management (3-5)

Future priorities to prepare for and respond to disasters and emergencies enhanced assessment of individual counts and population estimates

1. Integrate new technologies, as these become available, into existing electronic data systems and tools (3-1)
2. Invest in research to advance the science of mortality and morbidity assessment (3-1, 4-1, & 4-2)
3. Develop and disseminate resources for training professionals in the medicolegal death investigation system and for inclusion in state, local, tribal, and territorial disaster management (3-4 and 3-5)