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American Journal of
**PUBLIC
HEALTH**

A PUBLICATION OF
AMERICAN PUBLIC HEALTH ASSOCIATION

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AJPH

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COVER: Yoshia Uomoto, 98, looks up at her son Mark Uomoto as they visit in person for the first time in a year after indoor visitation restrictions because of COVID-19 were lifted at Nikkei Manor, an assisted living facility primarily serving Japanese-American seniors, in Seattle, WA, March 30, 2021. Residents, who have all been fully vaccinated, can visit with family for an hour at a time.

Cover concept and selection by Aleisha Kropf. Photo by REUTERS/Lindsey Wasson. Printed with permission.

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


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
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


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



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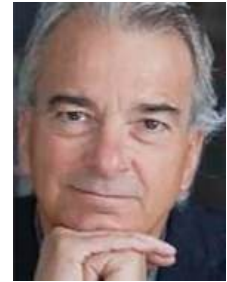
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Piloting Public Health



The paralysis of the surveillance system in 2020 is by no means the greatest failure of the public health response to COVID-19. The record is damning. In "Inside America's COVID-reporting breakdown," *Politico* health care reporter Erin Banco wrote:

Covid-19 was spreading rapidly throughout the United States, as cold winter weather began to drive people indoors, but the Centers for Disease Control and Prevention was flying blind: The state agencies that it relied on were way behind in their tracking, with numbers trickling in from labs by fax or even snail mail. (<https://politi.co/3Oo82iz>)

In an interview with the *Wall Street Journal*, Centers for Disease Control and Prevention (CDC) director Rochelle Walensky acknowledged the underfunding of the data collection system:

Fewer than 200 health facilities across the U.S. had their electronic-health records linked to CDC data-collection systems before the pandemic. . . . At the start of the pandemic, some states that were unable to electronically report positive COVID-19 cases had to fax PCR [polymerase chain reaction] results to the CDC. . . . Some states were entering positive results first because they didn't have the capacity to enter all the negative ones . . . so the CDC initially received a skewed view of what fraction of the population was positive. (<https://on.wsj.com/3RMgeMd>)

The CDC was "flying blind!" To track the progress of a pandemic and whether countermeasures are slowing it down, there is no substitute for collecting data specifically for that purpose. Instead, the government, the public, and the press had to interpret hospital and health center numbers of people who decided to test themselves or were so sick that they ended up in a hospital, where their case was recorded. These samples were highly selective, providing a distorted image of the pandemic's progression. The sociodemographic data often lacked information on ethnicity and race. The exact picture of the proportion of the population infected, and of the communities most affected, was never assessed. Today, reported counts of home test results substantially underestimate the true numbers of infected.

The absence of a national population-based surveillance system forced hasty decisions on lockdowns and school and business closures and delayed the identification of some of the most affected communities. It must have contributed to the grim side of the pandemic response. The United States has suffered the highest death rate of any wealthy country. Altogether, the impact was unfair and unjust. However, crises reveal failures in the public health system, and immediately after a crisis is typically a good time to remediate and prepare.

What is the state of the US surveillance system? The December 2021 issue of *AJPH* reviewed it along with ways to prepare for and effectively respond to this and future emergencies (<https://ajph.apha.org/toc/ajph/111/12>). The set of reports showed that, collectively, federal, state, and city surveillance and survey programs had begun to remedy the defective structures and improved collection, processing, and dissemination plans. Still, despite good intentions and expertise, we are still missing accurate estimates of incidence and fatality rates and comparisons of them across time, people, and places.

The June 2022 issue of *AJPH* (<https://ajph.apha.org/toc/ajph/112/6>) reviewed the current state of city dashboards, which have been established to remediate or complement the gaps in existing federal surveillance. They are works in progress, needing sustainable funding and geographical integration.

In this issue we document the gaps in the surveillance systems that are hiding the real inequities in COVID-19's impact and that jeopardize appropriate responses. The reports add empirical evidence to the theoretical guidance from the recent "Charting a Course for an Equity-Centered Data System" (<https://rwjf.ws/3RQHRUo>).

AJPH will continue to publish work that addresses the following key questions: (1) Which data are needed? (2) What purpose are they for? (3) Who collected and produced them? Modernizing the public health data infrastructure for the US federal government and state and local health departments has a high cost, but no price is too high for building a foundational tool indispensable for piloting public health.



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AJPH Editor-in-Chief
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DOI: <https://doi.org/10.2105/AJPH.2022.307065>

12 Years Ago

Customizing Survey Instruments and Data Collection to Reach Hispanic/Latino Adults

[T]he attitudes, behaviors, knowledge, and experience of Hispanic and Latino persons residing in the United States regarding tobacco use may differ from those of persons in non-Hispanic groups, which may warrant customized approaches to smoking prevention and cessation programs. . . . [We] examined available survey methods, tobacco-related instruments, and their utility for obtaining information from Hispanic populations. . . . The results support the conclusion that culturally sensitive modifications to survey procedures used to locate and contact specific population groups can result in response rates that far exceed those common in survey work today. . . . Developing instruments for specific population subgroups requires consideration of culture and language, cognitive demands, and potential response errors. Collecting information from specific subpopulations requires community knowledge and specialized training.

From *AJPH*, Supplement 1, 2010, pp. S159–S162, *passim*

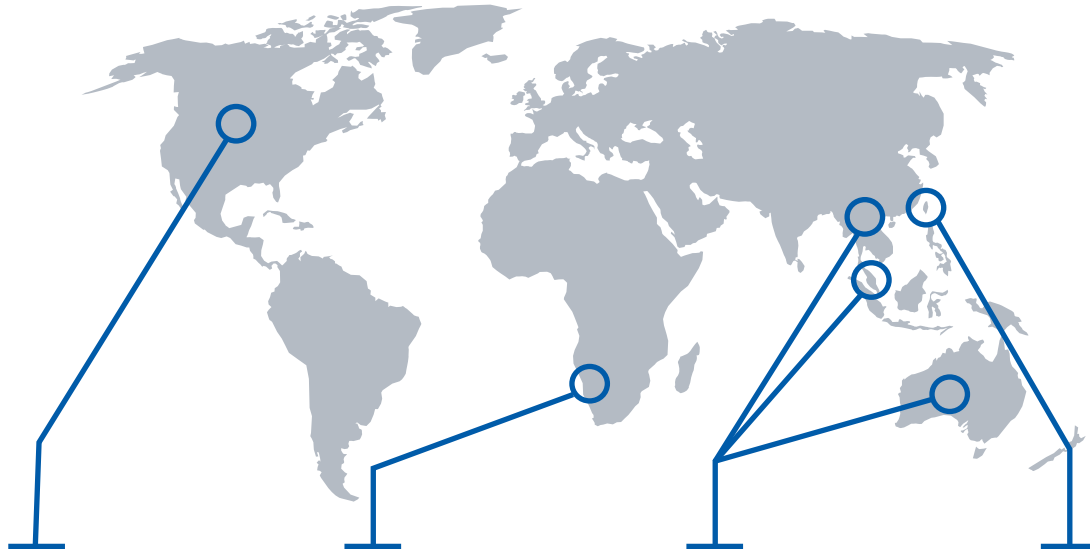
13 Years Ago

Monitoring Inequities in Self-Rated Health Over the Life Course in Population Surveillance Systems

It is necessary to monitor health inequities in terms of socioeconomic position (SEP), gender, ethnicity, and other indicators to determine whether they are widening or decreasing over time and to design and evaluate policies aimed at reducing these inequities. . . . It is widely acknowledged that SEP across the life course influences health and that observational studies of socially patterned exposures and outcomes should adjust for measures of SEP across the life course, but indicators of early-life SEP have not yet been included in population survey monitoring systems. . . . These results for housing tenure and family financial situation over the life course support the theory that SEP effects accumulate across childhood and adulthood.

From *AJPH*, April 2009, pp. 680–684, *passim*

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The Impact of the COVID-19 Pandemic on Drug Overdose-Related Deaths in the United States and Canada

Canada and United States

Imtiaz et al. evaluated the effect of the COVID-19 pandemic on drug overdose-related deaths in the United States and Canada using surveillance data. From 10 studies (9 from the US and 1 from Canada), the drug overdose-related deaths after the onset of COVID-19 were higher in the months leading up to the pandemic in 2020 compared with the months in 2019. Drug overdose-related deaths increased by 2% to 60% in US jurisdictions and by 58% in the Canadian study when comparing the second quarter of 2020 to the first quarter of 2020. A multidisciplinary approach should be used during a pandemic, including expansion of access to substance use disorder treatment and access to harm reduction services.

Citation. Imtiaz S, Nafeh F, Russell C, Ali F, Elton-Marshall T, Rehm J. The impact of the novel coronavirus disease (COVID-19) pandemic on drug overdose-related deaths in the United States and Canada: a systematic review of observational studies and analysis of public health surveillance data. *Subst Abuse Treat Prev Policy.* 2021;16(1):87. <https://doi.org/10.1186/s13011-021-00423-5>

Monitoring Population-Level Physical Activity in Adolescents and Adults

Namibia

Nashandi et al. validated a self-report questionnaire by comparing it to an accurate device-based method to assess moderate to vigorous physical activity (MVPA) among adolescent girls (n = 52) and women (n = 51) in Namibia. In adolescents, the questionnaire data had a nonsignificant positive correlation with the device, and in adults there was a significant positive correlation between the questionnaire and the device. In both groups, there was fair agreement between the self-report and device-assessed tertiles of MVPA. Device-assessed high MVPA was significantly higher in individuals self-reporting high MVPA compared to those reporting low MVPA. The questionnaire has high validity for application in population-level assessment of physical activity among adolescent girls and women in Namibia.

Citation. Nashandi HL, Reilly JJ, Janssen X. Public health surveillance of habitual physical activity in adolescents and adults in Namibia: a cross-sectional validation of activity questionnaires against accelerometry. *J Public Health (Oxf).* 2021;43(4):e706-e712. <https://doi.org/10.1093/pubmed/fdaa067>

Comparison of Influenza Surveillance Systems in Australia, China, and Malaysia

Malaysia, China, and Australia

El Guerche-Séblain et al. compared national influenza surveillance systems in China, Malaysia, and Australia and evaluated their adherence to World Health Organization guidance. Across all subsystems in Australia, across 4 subsystems in China, and across 2 subsystems in Malaysia there were disparities, particularly in regard to data granularity, data representativeness, and data communication. There were no publicly available influenza epidemiological reports in Malaysia. The results of the comparison suggest that influenza monitoring in all 3 countries can benefit from surveillance sentinel programs, expanded use of laboratory confirmation, and use of excess mortality modeling.

Citation. El Guerche-Séblain C, Rigoine De Fougerolles T, et al. Comparison of influenza surveillance systems in Australia, China, Malaysia and expert recommendations for influenza control. *BMC Public Health.* 2021;21(1):1750. <https://doi.org/10.1186/s12889-021-11765-x>

Automated Syndromic Surveillance in Communities

Taiwan

Chan et al. describe a surveillance system to serve as a sentinel for infectious disease outbreaks in Taipei City, Taiwan, using data from primary care clinics and community hospitals and incorporating spatiotemporal information. Meteorological factors were associated with 2 syndromic groups: influenza-like and enteroviral-like syndromes reported from July 2018 to October 2019. Daily average temperature was negatively associated with number of influenza-like syndrome. Daily minimum temperature, ozone, and concentration of particulate matter less than 2.5 micrometers in diameter were negatively associated with enteroviral-like syndromes. The system can provide warning signals to the local public health department and primary care physicians.

Citation. Chan TC, Tang JH, Hsieh CY, Chen KJ, Yu TH, Tsai YT. Approaching precision public health by automated syndromic surveillance in communities. *PLoS One.* 2021;16(8):e0254479. <https://doi.org/10.1371/journal.pone.0254479>

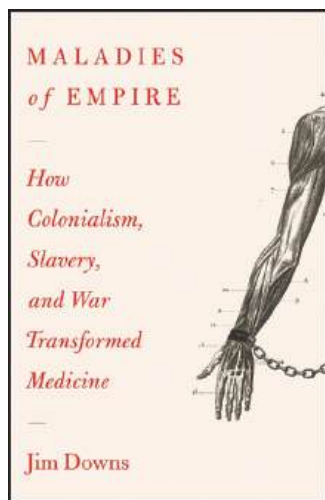
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How Violence Contributed to Medicine in the 19th Century

Daniel M. Fox, PhD, and Alfredo Morabia, MD, PhD

ABOUT THE AUTHORS

Daniel M. Fox is an Associate Editor of AJPH and is President Emeritus of the Milbank Memorial Fund. Alfredo Morabia is the Editor in Chief of AJPH and is with City University of New York and Columbia University, New York, NY (@AlfredoMorabia).



Maladies of Empire: How Colonialism, Slavery, and War Transformed Medicine
By Jim Downs, PhD

Cambridge, MA: The Belknap Press of Harvard University Press; 2021
262 pp.; \$29.95 (hardcover)
ISBN: 978067491721

Downs's subject is how, beginning in the mid-18th century, violence associated with colonialism, slavery, and war influenced the theory and practice of medicine and, allegedly, of epidemiology. In eight chapters, an introduction, and a conclusion, he presents some well-known and some less-known evidence to justify his argument.

Each chapter is a case study of one or several episodes in the relationship between violence and the history of medicine. Downs begins by presenting the speculations of doctors on slave ships and prisons about the effects of bad air in "crowded places" (pp. 17–18). There is a chapter on the "decline of contagion theory and the rise of epidemiology." The next chapter is a detailed study of "tracing fever in Cape Verde." Downs then generalizes from this study to describe "epidemiological practices in the British Empire," emphasizing the centrality of "recordkeeping" in imperial bureaucracies.

Moving away from medicine, he then focuses on the contributions of Florence Nightingale, commonly considered to be the founder of modern nursing and hospital epidemiology,¹ whom he calls the "unrecognized epidemiologist of the Crimean War and India" (p. 88). The book summarizes

Nightingale's contribution to the conceptualization and analysis of data about populations experiencing severe infectious diseases. He follows this chapter with studies of the history of the US Sanitary Commission during the American Civil War and the subsequent influence of its work, a history he summarizes as "from benevolence to bigotry." His cases conclude with a study of the "narrative maps" devised to document the interaction of Black troops and Muslim pilgrims during the cholera pandemic of 1865–1866.

Downs offers many examples of clinical observations made by doctors in captive populations, but the weakness of Downs's thesis is his attempt to link these episodes that belong to the history of medicine, as the title of the book clearly indicates, to the history of epidemiology. Downs seems to believe that doctors practice epidemiology when they examine their cases within large-scale "captive" populations such as military hospitals and camps, slave ships, prisons, and so on (p. 6). But doctors have attended large numbers of people since antiquity—that is, thousands of years before the emergence of epidemiology in the 17th century. Downs does not seem to realize that a clinical practice, even within a ship, a prison, or a concentration camp, remains a medical act as long as the multitude of individual cases itself does not become the new dimension of analysis—that is, assessed as a population, divided into groups, and compared.

Consider the example of Robert Dundas Thompson and Pierre Louis. Thompson who, in 1839, observed an enslaved African man refusing food and dying after nine days and a captured woman refusing to eat and dying after "about a week," concluded that "inhabitants of Africa can only live

without food for ten days” (p. 2). Thompson speculated on the basis of clinical observations. There is no epidemiological approach. In contrast, a decade before Thompson, Louis, the French physician, assessed the efficacy of bloodletting in the treatment of pneumonia comparing patients bled at different times after the onset of the pneumonia. Louis concluded that those bled early did not survive more frequently.² Louis was performing population studies and was a pioneer of clinical epidemiology.

A similar contrast can be made between Nightingale and the other Parisian clinicians who worked concurrently in the same large Parisian hospitals as Louis and speculated based on extrapolations from their multiple individual clinical observations.³ They were not even aware of the insights that a population approach can provide. In contrast, Nightingale’s epidemiological (sometimes referred to as statistical) work has been described by many authors,^{1,4,5} including in *AJPH*.⁶ In the studies during the Crimean War that Downs reports, she counted the deaths from different causes by month and compared them across time in an indisputable epidemiological approach.

The other surprising aspect of the book, which undermines its novelty, is that it ignores the role of violence and racism in many other cases of alleged medical research. The infamous Tuskegee study was conducted on African American sharecroppers of Alabama to learn about the natural history of syphilis.⁷ Concentration camp prisoners were used as subjects of the experiments on typhus treatment,⁸ the Dachau hypothermia experiments,⁹ the twin studies,¹⁰ or to illustrate medical anatomy books.¹¹ None of these examples are mentioned by Downs even though they stem from the same susceptibility of Western

medicine to abusing captive populations under the protection of dominant biases, of a racist, xenophobic, or chauvinistic nature, to accrue clinical observations. Most of the results, if not all, from research carried out in these unethical conditions for medicine have proved to be of no scientific value.¹²

Altogether, the claim that the episodes reported have constituted the “DNA of epidemiology” (p. 196) is not supported by the evidence and therefore is unwarranted. Except for the case of Nightingale, who strove to reduce violence against wounded and sick military, epidemiologists will not recognize in the book’s examples the foundations of their discipline. This does not mean that genuine epidemiology has not been carried out in similar unethical conditions, but the evidence of that will not be found in Downs’s book. This book is, nevertheless, an informed contribution to the history of medicine in conditions of colonialism, slavery, and war. **AJPH**

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CONFLICTS OF INTEREST

The authors have no conflict of interest with the contents of the book review to report.

REFERENCES

1. Winkelstein W. Florence Nightingale: founder of modern nursing and hospital epidemiology.

Epidemiology. 2009;20(2):311. <https://doi.org/10.1097/EDE.0b013e3181935ad6>

2. Louis PCA. *Researches on the Effects of Bloodletting in Some Inflammatory Diseases*. Boston, MA: Hilliard, Gray, and Co; 1836: 1–14.
3. Ackerknecht EH. *Medicine at the Paris Hospital, 1794–1848*. Baltimore, MD: The Johns Hopkins Press; 1967.
4. Keith JM. Florence Nightingale: statistician and consultant epidemiologist. *Int Nurs Rev*. 1988; 35(5):147–150.
5. McDonald L. Florence Nightingale, statistics and the Crimean War. *J R Stat Soc Ser A Stat Soc*. 2013;177(3):569–586. <https://doi.org/10.1111/rssa.12026>
6. Fee E, Garofalo ME. Florence Nightingale and the Crimean War. *Am J Public Health*. 2010;100(9): 1591. <https://doi.org/10.2105/AJPH.2009.188607>
7. Jones JH. *Bad Blood: The Tuskegee Syphilis Experiment, New and Expanded Edition*. Rev ed. New York, NY: Free Press; 1993.
8. Baumslag N. *Murderous Medicine: Nazi Doctors, Human Experimentation, and Typhus*. Westport, CT: Greenwood; 2005.
9. Berger RL. Nazi science—the Dachau hypothermia experiments. *N Engl J Med*. 1990;322(20): 1435–1440. <https://doi.org/10.1056/NEJM199005173222006>
10. Seidelman WE. Mengele medicus: medicine’s Nazi heritage. *Milbank Q*. 1988;66(2):221–239. <https://doi.org/10.2307/3350031>
11. Hildebrandt S. Anatomy in the Third Reich: an outline, part 1. National Socialist politics, anatomical institutions, and anatomists. *Clin Anat*. 2009; 22(8):883–893. <https://doi.org/10.1002/ca.20872>
12. Weindling P. *Health, Race, and German Politics Between National Unification and Nazism, 1870–1945*. New York, NY: Cambridge University Press; 1989.

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Advancing Public Health and Preventive Medicine

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Maxcy-Rosenau-Last Public Health and Preventive Medicine: 16th Edition
Matthew L. Boulton and Robert H. Wallace (Editors)
 2073 Pages, \$249.00 (hardcover)
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The timeliness and importance of the 16th edition of *Maxcy-Rosenau-Last Public Health and Preventive Medicine* cannot be overstated. The first edition of this landmark book was published more than 100 years ago; over this time period, we have witnessed remarkable scientific advances that form the foundations of public health and preventive medicine. These advances include translation of discoveries from basic sciences into medical and public health practice (e.g., antibiotics, vaccines), policies to address multiple risk behaviors (e.g., tobacco, alcohol), bigger and better surveillance systems, and a vast toolkit of evidence-based interventions. Application of these innovations has contributed to significant health gains. For example, from 1920 to 2020, Americans experienced a 43% increase in life expectancy. Over this same period, global life expectancy more than doubled.

Yet along with these developments in preventive technologies and health improvement strategies, there are many remaining challenges. Largely because of the COVID-19 pandemic, the United States experienced a decrease in life expectancy from 2019 to 2020, with a disproportionate burden among Hispanic and non-Hispanic Black populations.¹ COVID-19 has also illustrated and continues to show the

“fault lines” in public health, including inadequate surveillance systems, underfunding of public health and primary care, structural inequities, mis- and disinformation, and the intrusion of partisan politics into public health practice.^{2,3}

In addressing the many opportunities and challenges for public health and preventive medicine, Matthew Boulton and Robert Wallace have assembled an impressive set of 186 chapters across 11 sections, authored by world-class experts on each topic. This edition has four entirely new sections: Global Health, Health Disparities & Vulnerable Populations, Nutrition & Physical Activity, and Mental Health & Substance Use.

Many of the chapters could be books themselves; therefore, the editors and authors have appropriately chosen breadth over depth. Each chapter is a resource that provides entry points into additional readings and tools on each subject. In this book review, a few cross-cutting themes from this volume are highlighted.

BRIDGING DISCIPLINES

Medicine and public health are often described as distinct and complementary disciplines.⁴ Medicine focuses mainly on individuals, including early detection and treatment of risk behaviors and diseases. Public health, in turn, focuses on the community (population health, disparities), with emphasis on primary prevention and early detection via delivery of evidence-based interventions along with environmental, systems, and policy changes. As vividly illustrated in multiple sections and chapters in *Maxcy-Rosenau-Last Public Health and Preventive Medicine*, the application of transdisciplinary, team science provides a foundation for

solving many public health challenges.⁵ The use of principles of team science and systems science can lead to strong, complex, and adaptive public health systems.⁶

TRAINING THE NEXT GENERATION

A key consideration involves how the many principles and lessons in this textbook can be translated into the training of medical and public health professionals. In part, training of the next generation should be grounded in competency-based education—a norm for many research and practice-oriented training programs. The use of competencies allows for objective parameters on which to base achievement and gauge the growth of the researcher.⁷ Competencies can also provide direction and support for overall professional development and growth. Across the many sections and chapters in this book, competencies can be mapped to academic course work, clinical rotations, short courses, practica, and on-the-job training programs for professionals in public health and preventive medicine.^{8,9}

IMPLEMENTING KNOWN SOLUTIONS

As described in multiple chapters, but particularly in the chapter on implementation science, the decades of scientific progress in medicine and public health have too often not been translated into equitable improvements in population health.¹⁰ By influencing how scientific evidence is scaled up into practice, implementation science has great potential to accelerate progress toward achieving public health goals by seeking to understand and influence

how scientific evidence is put into practice.¹¹ Evidence in multiple forms, but particularly evidence-based interventions, is the foundation of implementation science and progress in public health.¹²

FOCUSING ON HEALTH EQUITY

Concepts of health disparities and health equity are more prominently featured in this new edition, across many chapters but particularly in section 3 on health disparities and vulnerable populations. Health equity is a framing that moves away from a deficit mindset of what society is doing poorly (disparities) to one that is positive about what society can achieve.¹³ Inequities are addressed through a range of approaches involving social determinants of health (e.g., structural racism, inequitable allocation of resources and opportunities). To fully address health equity, we need to continue to grow the evidence base, build political will, and better break down disease and risk factor “silos.”⁶

In summary, this classic text is a must-read for anyone seeking to deepen knowledge in public health and preventive medicine. It should be embraced and studied by multiple audiences as it brings us the latest information for learning from the past but, even more importantly, forging new paths forward to address a multitude of public health issues. *AJPH*

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REFERENCES

1. Woolf SH, Masters RK, Aron LY. Changes in life expectancy between 2019 and 2020 in the US and 21 peer countries. *JAMA Netw Open*. 2022; 5(4):e227067. <https://doi.org/10.1001/jamanetworkopen.2022.7067>
2. Brownson RC, Burke TA, Colditz GA, Samet JM. Reimagining public health in the aftermath of a pandemic. *Am J Public Health*. 2020;110(11):1605–1610. <https://doi.org/10.2105/AJPH.2020.305861>
3. Narayan KMV, Curran JW, Foegen WH. The COVID-19 pandemic as an opportunity to ensure a more successful future for science and public health. *JAMA*. 2021;325(6):525–526. <https://doi.org/10.1001/jama.2020.23479>
4. Fineberg HV. Public health and medicine: where the twain shall meet. *Am J Prev Med*. 2011;41(4 suppl 3):S149–S151. <https://doi.org/10.1016/j.amepre.2011.07.013>
5. Stokols D, Harvey R, Gress J, Fuqua J, Phillips K. In vivo studies of transdisciplinary scientific collaboration: lessons learned and implications for active living research. *Am J Prev Med*. 2005;28(2 suppl 2):202–213. <https://doi.org/10.1016/j.amepre.2004.10.016>
6. Leischow SJ, Best A, Trochim WM, et al. Systems thinking to improve the public's health. *Am J Prev Med*. 2008;35(2 suppl):S196–S203. <https://doi.org/10.1016/j.amepre.2008.05.014>
7. Leung WC. Competency based medical training: review. *BMJ*. 2002;325(7366):693–696. <https://doi.org/10.1136/bmj.325.7366.693>
8. Brownson RC, Samet JM, Chavez GF, et al. Charting a future for epidemiologic training. *Ann Epidemiol*. 2015;25(6):458–465. <https://doi.org/10.1016/j.annepidem.2015.03.002>
9. Wells EV, Benn RK, Warber SL. Public health and preventive medicine meet integrative health: applications of competency mapping to curriculum education at the University of Michigan. *Am J Prev Med*. 2015;49(5 suppl 3):S270–S277. <https://doi.org/10.1016/j.amepre.2015.07.009>
10. Lenfant C. Shattuck lecture—clinical research to clinical practice—lost in translation? *N Engl J Med*. 2003;349(9):868–874. <https://doi.org/10.1056/NEJMsa035507>
11. Peters DH, Adam T, Alonge O, Agyepong IA, Tran N. Implementation research: what it is and how to do it. *BMJ*. 2013;347:f6753.
12. Brownson RC, Shelton RC, Geng EH, Glasgow RE. Revisiting concepts of evidence in implementation science. *Implement Sci*. 2022;17(1):26. <https://doi.org/10.1186/s13012-022-01201-y>
13. Kumanyika SK. Health equity is the issue we have been waiting for. *J Public Health Manag Pract*. 2016;22(suppl 1):S8–S10. <https://doi.org/10.1097/PHH.0000000000000363>

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Using Administrative Data to Assess Transgender Health and Mortality Disparities

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🔗 See also Hughes et al., p. 1507.

Because of societal stigma,¹ transgender, nonbinary, and other gender-diverse people (hereafter trans people) experience health and well-being disadvantages compared with cisgender (cis) people,²⁻⁴ including, as shown by Hughes et al. in this issue of *AJPH* (p. 1507), greater mortality risks. These disparities are more pronounced for some groups of trans people than for others. Using an innovative approach, identifying trans and cis enrollees in claims data from the Optum Clinformatics Data Mart database, Hughes et al.'s landmark study provides clear evidence that mortality disadvantages experienced by trans people are profound and heterogeneous. Most strikingly, they estimate that only half of the Black trans feminine people and nonbinary people assigned male sex at birth (TFN) within the study survived to age 67 years. This aligns with conclusions from decades of public health research emphasizing how various structural disadvantages intersect to differentially shape life chances.^{4,5}

Better science regarding the health burdens experienced by trans people is needed to improve the well-being of

trans people. As we elaborate below, this science needs to include studies of trans people's health in which the trans sample is large and diverse, as made possible through administrative data, but also studies in which definitions of trans populations are not dependent on medical experiences, gender is self-identified, and there are multiple gender categories, currently not possible with most administrative data approaches.

THE PROMISE OF ADMINISTRATIVE CLAIMS DATA

In a social science era with increasingly low survey response rates and concerns about survey response validity, administrative claims data offer researchers a unique opportunity to document health disparities among large, diverse, and hard-to-reach populations.⁶ Understanding health burdens experienced by trans people is difficult because (1) most federal surveys historically only ask respondents if they are male or female, (2) most surveys identify only a few trans respondents, and (3) trans people may not self-identify on surveys because of

discrimination concerns.⁷ These limitations prevent within-group comparisons and hinder the generalizability of analysis from these surveys to the broader trans population.

By using administrative data, Hughes et al.'s study includes an unprecedented number of trans people, and, given the size of this group, they distinguish between groups of trans people by race/ethnicity and gender. Because of data access restrictions, Hughes et al. are not able to look beyond Black and White groups, but future studies using administrative data could build on their work and provide a closer look at trans health disparities across multiple racial/ethnic groups because we currently know very little about health in Asian and Latinx trans groups, among others. Given the large sample sizes potentially available with administrative data, less restricted access also offers researchers future opportunities to identify heterogeneity in health and mortality among trans groups by socioeconomic status, across geographic regions, and in different historical periods (e.g., before and after specific policies or events). The use of administrative data should be considered an important tool to help improve knowledge gaps regarding trans people with the goal of reducing health inequity.

THE PITFALLS OF ADMINISTRATIVE CLAIMS DATA

Yet, use of administrative data as a tool to study health disparities for trans compared with cis people is overly reliant on medical records to identify gender, a major limitation. We highlight two issues that must be considered when interpreting the results of Hughes et al.'s study and similar administrative data studies. First, this method relies too much on

records from a medical system that historically has been biased toward binary understanding of gender,⁸ contributing to an institutional and informational erasure of trans people without these medical experiences. There are multiple reasons why people who would self-identify as trans would be misidentified as cis within administrative records. As Cruz and Paine note in a recent study, electronic health records' emphasis on data standardization provides an inaccurate impression of these processes as "unbiased" and "objective" while missing the variation in care provision across medical environments.⁹ This has implications for who is "counted" as trans in administrative data. Additionally, trans people's access to affordable gender-affirming care is limited and uneven, with the most impacted being trans people in the South and Midwest, those who are lower-class and working-class individuals, and those who are part of racial/ethnic minoritized groups, meaning these groups are most likely to be miscategorized as cis using administrative data methods.²⁻⁴ As states pass anti-trans legislation with direct impacts on the availability of gender-affirming care,¹⁰ the misidentification of gender for these groups will likely be exacerbated.

Second, administrative data from insurance claims are limited in their ability to distinguish groups of trans people based on their "gender expression," given a reliance on specific medical procedures and diagnostic codes and the use of the "sex assigned at birth" label. Within the Hughes et al. study, TFN serves as shorthand for "trans feminine and nonbinary people assigned male sex at birth," and TMN serves as shorthand for "trans masculine and nonbinary people assigned female sex at birth." These labels rightly identify the wide range of genders within these categories

because the methods do not allow the researchers to distinguish between people with trans identities, nonbinary identities, or other gender identities. But by using sex assigned at birth within the label, there is a concern of biological essentialism. We echo critiques from Young and Meyer about the labels of MSM (men who have sex with men) and WSW (women who have sex with women) undermining the social dimensions of sexuality.¹¹ Similarly, the TFN and TMN labels risk obscuring the social dimensions of gender in favor of biomedical understandings. Affixing "assigned female sex at birth" to nonbinary people hinders recognition of gender *and* sex as social constructs and limits understanding of mortality disparities across sex/gender groups. Although TFN and TMN designations may make sense given the data limitations, and although Hughes et al. recognize the within-group heterogeneity, we caution against wide use of this shorthand because of issues with combining trans binary and nonbinary groups and because of the overreliance of sex assigned at birth within the label.

CONCLUSION

Ultimately, we appreciate the gains in public health knowledge in using administrative data to examine trans health disparities. Yet, we suggest, in line with the recent National Academies of Sciences, Engineering, and Medicine report,⁷ that the "gold standard" of research into gender-minoritized groups and health disparities should continue to be measures of gender that allow all respondents to self-identify and provide multiple gender options.⁴ An old expression continues to resonate: "If you aren't counted, then you don't count." Sometimes this has meant considering "LGBT" health

disparities broadly, with little attention to the concerns of trans people. Increasingly, though, public health research has specifically examined the health of trans people,²⁻⁴ but typically as a homogeneous category without attention to gender diversity. This contributes to an erasure of nonbinary, agender, genderfluid, and other gender-diverse groups, directly affecting our knowledge of the health disparities trans people face, especially as related to different sociopolitical environments. There is an urgent need to assess the health and well-being impacts of anti-trans legislation throughout the United States and to work to counter these policies and their harms^{10,12}; yet, this goal is hampered if not able to distinguish between groups of trans people based on accurate measures of gender. We advocate continued access to and analysis of administrative claims data while also prioritizing self-identified measures of gender rather than biomedically oriented measures. **AJPH**

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M. B. Thomeer wrote the initial draft of this editorial, and B. Patterson provided edits. Both authors approved the final draft.

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REFERENCES

1. King WM, Hughto JM, Operario D. Transgender stigma: a critical scoping review of definitions, domains, and measures used in empirical research. *Soc Sci Med*. 2020;250:112867. <https://doi.org/10.1016/j.socscimed.2020.112867>
2. Scheim AI, Baker KE, Restar AJ, Sell RL. Health and health care among transgender adults in the United States. *Annu Rev Public Health*. 2022;43(1):503–523. <https://doi.org/10.1146/annurev-publhealth-052620-100313>
3. Hsieh N, Shuster SM. Health and health care of sexual and gender minorities. *J Health Soc Behav*. 2021;62(3):318–333. <https://doi.org/10.1177/00221465211016436>
4. Feldman JL, Luhur WE, Herman JL, Poteat T, Meyer IH. Health and health care access in the US transgender population health (TransPop) survey. *Andrology*. 2021;9(6):1707–1718. <https://doi.org/10.1111/andr.13052>
5. Bowleg L. Evolving intersectionality within public health: from analysis to action. *Am J Public Health*. 2021;111(1):88–90. <https://doi.org/10.2105/AJPH.2020.306031>
6. National Research Council. *Nonresponse in Social Science Surveys: A Research Agenda*. Washington, DC: National Academies Press; 2013.
7. National Academies of Sciences, Engineering, and Medicine. *Measuring Sex, Gender, Identity, and Sexual Orientation*. Washington, DC: National Academies Press; 2022.
8. Shuster SM. Uncertain expertise and the limitations of clinical guidelines in transgender health care. *J Health Soc Behav*. 2016;57(3):319–332. <https://doi.org/10.1177/0022146516660343>
9. Cruz TM, Paine EA. Capturing patients, missing inequities: data standardization on sexual orientation and gender identity across unequal clinical contexts. *Soc Sci Med*. 2021;285:114295. <https://doi.org/10.1016/j.socscimed.2021.114295>
10. Jones A II, Navarro A. This year on pace to see record anti-transgender bills passed by states, says Human Rights Campaign. CBS News. April 22, 2022. Available at: <https://www.cbsnews.com/news/2022-anti-transgender-legislation-record-human-rights-campaign/>. Accessed on July 1, 2022.
11. Young RM, Meyer IH. The trouble with “MSM” and “WSW”: erasure of the sexual-minority person in public health discourse. *Am J Public Health*. 2005;95(7):1144–1149. <https://doi.org/10.2105/AJPH.2004.046714>
12. Barbee H, Deal C, Gonzales G. Anti-transgender legislation—a public health concern for transgender youth. *JAMA Pediatr*. 2022;176(2):125–126. <https://doi.org/10.1001/jamapediatrics.2021.4483>



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Are State-Level Policies Supporting Community Health Worker Employment? The Jury Is Still Out

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🔗 See also Jones et al., p. 1480.

In *AJPH* and elsewhere, a steady stream of research articles, blogs, and opinion pieces have been published supporting the expansion of the community health worker (CHW) workforce.¹ As frontline public health workers, CHWs have played an important role in COVID-19 response and prevention.² Moreover, there is ever-increasing evidence of their effectiveness in promoting access to primary and preventive care, building bridges between communities and health care systems, and improving health outcomes for chronic conditions, particularly in underserved communities.³ Workforce growth is predicated upon sustainable, dedicated financing mechanisms. Yet, CHW programs worldwide are underfunded. In the United States, CHW employment often relies on grants and other short-term resources.^{1,4} Long-term flexible funding models are important for both workforce development and program continuity.⁵ Medicaid coverage for CHW services has been identified as a potential solution for the constraints to CHW program sustainability.⁴ Similarly, occupational certification for CHWs provides a pathway for

career development and higher earning potential while encouraging workforce growth and integration.⁶

Although Medicaid coverage and certification are commonly touted as enablers of workforce growth, we actually know very little about how these two policies affect the CHW labor force. Jones et al., in this issue of *AJPH* (p. 1480), seek to address this gap in the literature. Their study examines how state-level policies for CHW certification and Medicaid reimbursement affect CHW employment, namely changes in hourly wages and occupational turnover. Using data from the US Census Bureau's Current Population Survey from 2010 to 2021, Jones et al. created two models to assess changes in hourly wages and turnover in (1) states with CHW certification compared with states without certification and (2) states with Medicaid reimbursement for CHW services compared with states without reimbursement. Jones et al. are to be applauded for embarking on this study and inspiring further inquiry toward determining effective policy strategies for advancing the CHW workforce.

WAGE GAPS PERSIST

The study's results indicate that wages were higher in states with certification, increasing by \$2.42 per hour. At first glance, this observed wage growth is encouraging. Improved wages would bolster the benefits of certification, which include role and competency standardization (at least at the state level), career development, and professional credibility.⁶ Unsurprisingly, wage increases were not distributed evenly in the study sample.

In those states with certification programs, hourly wages were significantly higher for male CHWs (\$5.16 more per hour) and for White CHWs (\$2.72 more per hour). Here we have more evidence of the persistent race and sex wage gap in the health workforce.⁷ Hourly wages for male CHWs of color (\$5.10 more per hour), however, were just higher than those of White men (\$5.06 more per hour). Data on how women of color fared is not reported in the study. Overall, CHWs of color earned 98 cents less per hour than White CHWs, a difference of \$2038 less per year for a full-time job. Female CHWs earned \$3.84 less per hour than men, approximately \$8000 less per year for a full-time job. Wage gaps have pernicious effects on the income and lifetime financial stability of women and people of color, especially for low-wage workers.⁸

DATA GRANULARITY MATTERS

In the study, Medicaid coverage did not affect wages. As Jones et al. point out, the dataset does not distinguish among the multiple options for Medicaid coverage (e.g., state plan authority, health homes, Section 1115 demonstration projects, managed

care), nor does it specify participation in Medicaid reimbursement for the study sample. Treatment states consisted simply of those that allowed some sort of Medicaid coverage for CHW services.

Neither Medicaid coverage nor certification affected turnover in this study. Jones et al. state that low wages are the main predictor of resignations among frontline health workers, but they did not examine how wages affect turnover. Because of data limitations, turnover in this study was narrowly defined as leaving the CHW workforce altogether; job transitions within the field were not captured. There is no differentiation between resignations (voluntary turnover) and layoffs or terminations (involuntary turnover). Voluntary turnover may indicate career progression or professional growth, a desired outcome of certification. Involuntary turnover, especially layoffs, could signal financial instability. Certainly, the turnover rate for the sample is high at approximately 25%, double what Jones et al. cite as the workforce average in 2021.

On the basis of this study, the jury's still out on the effectiveness of Medicaid reimbursement as a strategy for CHW workforce development. Considering the heterogeneity in Medicaid reimbursement programs, the field would benefit from state-based studies using granular data about program types and participation rates. We also cannot draw conclusions from this study on CHW turnover. Future research requires data that capture the nuances of job departures, specifically voluntary and involuntary job changes and transfers from one CHW job to another.

WORKFORCE EXPANSION MUST BE EQUITABLE

CHW workforce expansion will be successful only if it is equitable and does not perpetuate structural racism and sexism. Pay equity for women and people of color must be a priority for all CHW employers. If certification policies are indeed beneficial for wage growth, removing barriers to voluntary CHW certification is also in order. Otherwise, there is risk of reinforcing the very social determinants of health that CHWs seek to address in their work.⁷ **AJPH**

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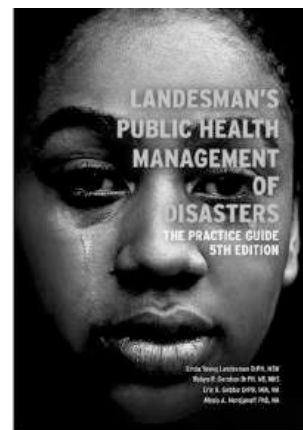
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REFERENCES

- Rodriguez NM. Community health workers in the United States: time to expand a critical workforce. *Am J Public Health*. 2022;112(5):697–699. <https://doi.org/10.2105/AJPH.2022.306775>
- Peretz PJ, Islam N, Matiz LA. Community health workers and Covid-19—addressing social determinants of health in times of crisis and beyond. *N Engl J Med*. 2020;383(19):e108. <https://doi.org/10.1056/NEJMp2022641>
- Landers S, Levinson M. Mounting evidence of the effectiveness and versatility of community health workers. *Am J Public Health*. 2016;106(4):591–592. <https://doi.org/10.2105/AJPH.2016.303099>
- Lapidos A, Lapedis J, Heisler M. Realizing the value of community health workers—new opportunities for sustainable financing. *N Engl J Med*. 2019;380(21):1990–1992. <https://doi.org/10.1056/NEJMp1815382>
- Sherman M, Covert HH, Lichtveld MY. "The more we know, the more we're able to help":

participatory development of an evaluation framework for community health worker programs. *J Public Health Manag Pract*. 2022;28(5):E734–E742. <https://doi.org/10.1097/PHH.0000000000001528>

- Coffinbargar M, Damian AJ, Westfall JM. Risks and benefits to community health worker certification. *Health Affairs Forefront*. July 7, 2022. Available at: <https://www.healthaffairs.org/doi/10.1377/forefront.20220705.856203>. Accessed July 12, 2022.
- Treadwell HM. Wages and women in health care: the race and gender gap. *Am J Public Health*. 2019;109(2):208–209. <https://doi.org/10.2105/AJPH.2018.304866>
- Delivered by Women, Led by Men: A Gender and Equity Analysis of the Global Health and Social Workforce. Geneva, Switzerland: World Health Organization; 2019.



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SNAP: The Most Important Component of Our Efforts to End Food Insecurity in the United States

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See also Insolera et al., p. 1498.

Food insecurity, the leading indicator of well-being among vulnerable Americans, remains a daunting challenge for our country. In 2020, 38 million persons in the United States lived in food-insecure households.¹ This is lower than the record highs of 50 million in 2009 and 2011 but remains unacceptably high.

SUPPLEMENTAL NUTRITION ASSISTANCE PROGRAM

These food insecurity rates would have been far higher were it not for the primary component of the social safety net against food insecurity, the Supplemental Nutrition Assistance Program (SNAP). The success of this program has been demonstrated in multiple studies insofar as SNAP recipients are up to 45% less likely to be food insecure than eligible nonparticipants once nonrandom selection into the program is addressed in econometric models.^{2,3} Insofar as food insecurity is tied to a wide array of negative health

outcomes,⁴ by reducing food insecurity, SNAP also leads to lower health care costs among recipients. These reductions in health care costs as a result of SNAP are, not surprisingly, very large. For example, a recent study found that SNAP leads to reductions in health care costs through Medicaid of \$2360 per person per year.⁵

The results of the study by Insolera et al. (p. 1498) provide critical further evidence of the success of SNAP. Using data from the Panel Study of Income Dynamics, they find substantial evidence of reductions in food insecurity years after receipt of SNAP. Namely, adults who received SNAP during childhood were more than three times more likely to be food secure than adults who did not participate as children despite being eligible. The results of the study by Insolera et al. are part of a broader set of articles that demonstrate the longer-term positive impacts of SNAP on health and other outcomes.⁶ We are able to say that SNAP leads to not only immediate improvements in well-being but also improvements years later.

The success of SNAP is attributable to five main factors. First, it reaches those who are most in need. Only those with access to resources so limited that they are not able to purchase a food-secure quantity of food with their current incomes are eligible for the program. Second, it leverages the traditional retail sector in the United States. It does so by allowing SNAP recipients to use their benefits in more than 260 000 stores.⁷ Third, SNAP is funded as an entitlement program. As such, there is no need for explicit authorization by policymakers to expand or contract during changing economic conditions. This is particularly important during times of increased economic need such as the Great Recession or the COVID-19 pandemic. Fourth, SNAP is also an entitlement program at the individual level. Although the average length of time on SNAP is slightly less than one year, there are persons who need assistance for longer time periods and, in some cases, much longer time periods. With a few minor exceptions, these particularly vulnerable individuals can stay on SNAP for as long as needed. The fifth and most important reason SNAP works is that it gives dignity and autonomy to recipients.⁸ SNAP recipients are given the dignity of being able to shop alongside their friends and neighbors at the food store, and, when shopping, they are given the autonomy of being able to make their own food choices that are consistent with their preferences, religious beliefs, dietary requirements, culture, and so forth. This differs from some other programs that sharply delineate what recipients can and cannot obtain. Consequently, it is not surprising that SNAP participation rates are very high, especially in comparison with other food assistance

programs that do not afford households the same levels of dignity and autonomy.

OPPORTUNITIES FOR AND THREATS TO SNAP

Any comprehensive effort to eradicate food insecurity in the United States, then, must have SNAP at its center. The US Department of Agriculture emphasized this importance in their recent momentous decision to raise the value of the maximum SNAP benefit by approximately 20%. This was done to reflect the high proportion of SNAP recipients who, although better off because of receiving SNAP, were still food insecure. It is estimated that this increase in benefits will lead to a decline of approximately 40% in food insecurity among SNAP recipients.⁹

One further step would be to expand eligibility and make enrollment more seamless. A possible path would be to have SNAP reconstructed as a modified universal basic income program whereby all households with incomes below 400% of the poverty line (approximately \$100 000 for a family of four) would receive the maximum SNAP benefit. If this were implemented, there would be an estimated 98% decline in food insecurity in the United States at a cost of \$564 billion.¹⁰ Although this is not an inexpensive proposal, any comprehensive cost-benefit calculation should account for the subsequent reductions in near-term and long-term health care costs.

Unfortunately, although support for the dignity and autonomy of SNAP recipients and recognition of the importance of food insecurity is strong in many circles, this is not universal. A recent manifestation of this is a belief among some that we should no longer be concerned with food insecurity and instead

should concentrate on “nutrition security.” From a research perspective, this is problematic,¹¹ and we already know that reducing food insecurity improves nutrient intakes and reduces health disparities. I’m much more concerned, though, about the explicit and implicit encouragement by some “nutrition security” advocates to make changes in the structure of SNAP such that restrictions would be imposed on what can and cannot be purchased by SNAP recipients. In essence, these advocates for changes to SNAP are saying vulnerable Americans do not have the capacity to make decisions about what is best for their families, and, instead, outside “experts” should be dictating these choices. This, of course, is stigmatizing to an already vulnerable population and would lead to declines in SNAP participation, subsequent increases in food insecurity (both short term and long term), declines in health outcomes, and widening of health disparities. Considering the evidence found in the study by Insolera et al. and in multiple other studies about the profound positive impacts of SNAP, we should resist the efforts of those who seek to infantilize SNAP recipients. **AJPH**

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REFERENCES

1. Coleman-Jensen A, Rabbitt M, Gregory C, Singh A. Household Food Security in the United States in 2020. Report Number 298. Washington, DC: US Department of Agriculture, Economic Research Service; 2021.
2. McKernan SM, Ratcliffe C, Braga B. The effect of the US safety net on material hardship over two decades. *J Public Econ*. 2021;197:104403. <https://doi.org/10.1016/j.jpubeco.2021.104403>
3. Gundersen C, Kreider B, Pepper J. Partial identification methods for evaluating food assistance programs: a case study of the causal impact of SNAP on food insecurity. *Am J Agric Econ*. 2017; 99(4):875–893. <https://doi.org/10.1093/ajae/aax026>
4. Gundersen C, Ziliak J. Food insecurity and health outcomes. *Health Aff (Millwood)*. 2015;34(11): 1830–1839. <https://doi.org/10.1377/hlthaff.2015.0645>
5. Berkowitz SA, Palakshappa D, Rigdon J, et al. Supplemental Nutrition Assistance Program participation and health care use in older adults: a cohort study. *Ann Intern Med*. 2021;174(12): 1674–1682. <https://doi.org/10.7326/M21-1588>
6. Almond D, Hoynes H, Schanzenbach D. Inside the war on poverty: the impact of food stamps on birth outcomes. *Rev Econ Stat*. 2011;93(2): 387–403. https://doi.org/10.1162/REST_a_00089
7. Center on Budget and Policy Priorities. SNAP Retailers Database. Available at: <https://www.cbpp.org/snap-retailers-database>. Accessed July 27, 2022.
8. Gundersen C. Ensuring the dignity and autonomy of SNAP recipients. *Physiol Behav*. 2020; 221:112909. <https://doi.org/10.1016/j.physbeh.2020.112909>
9. Gundersen C, Kreider B, Pepper J. Reconstructing the Supplemental Nutrition Assistance Program to more effectively alleviate food insecurity in the United States. *RSF*. 2018;4(2):113–130. <https://doi.org/10.7758/rsf.2018.4.2.06>
10. Gundersen C. Viewpoint: a proposal to reconstruct the Supplemental Nutrition Assistance Program (SNAP) into a universal basic income program for food. *Food Policy*. 2021;101:102096. <https://doi.org/10.1016/j.foodpol.2021.102096>
11. Poblacion A, Ettinger de Cuba S, Cook JT. For 25 years, food security has included a nutrition domain: Is a new measure of nutrition security needed? *J Acad Nutr Diet*. 2022; E-pub ahead of print. <https://doi.org/10.1016/j.jand.2022.04.009>

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Extreme Overcrowding and Extreme Lethality During the 1918 Influenza Pandemic

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 See also Aligne, p. 1454.

Reviewing a rich set of studies from history, biology, and the social sciences published from 1918 to date, Aligne (p. 1454) concludes that extreme congestion created by the First World War is one “essential cause” of the high lethality during the 1918 influenza in military camps, trenches, and especially among soldiers on troopships. The author claims that this conclusion holds well even after discussing several arguments against the role of virulence enhancement during extreme overcrowding.

EXTREME DISEASE BURDEN ON ACTIVE FLEETS

Two particularly relevant studies that cast light on the extreme overcrowding hypothesis were not included in the review by Aligne.^{1,2} These studies deal with the Brazilian and New Zealand fleets, both active during the war. The average mortality rate among eight ships in the Brazilian fleet was especially high at 8.2%, with even up to 13% to 14% mortality on two of the ships. Mortality on the New Zealand

troopships was lower, but morbidity was extremely high at 90%.² Both articles proposed explanations for the high mortality, including the crew's lack of immunity (due to less exposure to H1-like viruses before 1918 or during the first wave) and the typical young age of the crew, which was among the most vulnerable young adult age groups globally (ages 20–40 years). However, the close living conditions, poor ventilation, and a high number of people gathered in enclosed spaces were also possible causes of the high mortality rates.

NEW RESEARCH ON NAVY RECRUITS IN A NEUTRAL COUNTRY

A recently written thesis by the first author of this editorial³ is an important contribution to the literature because it uses high-level qualitative and quantitative archival data about soldiers in the Norwegian navy, which remained neutral during the war. The data show that one naval training ship, Kong Sverre, which was stationed along the coast of the city of Horten with 517 soldiers on

board, had a morbidity rate in the fall of 1918 of 31%, with 46% of the cases developing pneumonia and requiring hospitalization. Mortality was 8.1%, and lethality was 27%, which were more than 10 times higher than in similar, presumably healthy male age groups among Norwegian civilians.

Mortality and lethality for the generally healthy young soldiers on Kong Sverre (8.1% and 27%) was even higher than 1918 influenza fall mortality and lethality among persons with serious comorbidities, such as patients at six Norwegian psychiatric asylums (2.3% and 9.8%) and two Norwegian tuberculosis sanatoriums (0.74% and 17.8%).^{4,5} Although there were nine other vessels in the Norwegian navy, no ships were as large (in terms of size and number of soldiers on board) and as crowded as Kong Sverre, and mortality rates in the other ships were on par with what was seen among presumably healthy males of the same age in average civilian settings. Torjussen concluded that extreme overcrowding was the main reason that so many contracted severe disease and died on Kong Sverre, a ship that was nicknamed locally “The Ship of Death” and had one of the highest mortality rates of any ships internationally during the 1918 influenza pandemic.³

We agree with Aligne that extreme crowding is a major risk factor for severe disease enhancement during the 1918 influenza pandemic and that avoiding such a setting is key to reducing extreme mortality and lethality during pandemics. [AJPH](#)

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REFERENCES

- Schuck-Paim C, Shanks GD, Almeida FEA, Alonso WJ. Exceptionally high mortality rate of the 1918 influenza pandemic in the Brazilian naval fleet. *Influenza Other Respir Viruses*. 2013;7(1):27–34. <https://doi.org/10.1111/ir.12509>
- Summers JA, Wilson N, Baker MG, Shanks GD. Mortality risk factors for pandemic influenza on New Zealand troop ship, 1918. *Emerg Infect Dis*. 2010;16(12):1931–1937. <https://doi.org/10.3201/eid1612.100429>
- Torjussen C. «Dødsseileren» - losjiskipet i Horten. *En kvalitativ og kvantitativ analyse av årsakene til den høye dødeligheten på MS «Kong Sverre» under spanskesyken i 1918*. Borre, Norway: Universitetet i Sør-Øst Norge; 2022.
- Mamelund S-E, Dimka J. Tuberculosis as a Risk factor for 1918 influenza pandemic outcomes. *Trop Med Infect Dis*. 2019;4(2):74. <https://doi.org/10.3390/tropicalmed4020074>
- Dimka J, Mamelund S-E. 1918 Influenza outcomes among institutionalized Norwegian populations: implications for disability-inclusive pandemic preparedness. *Scand J Disabil Res*. 2020;22(1):175–186. <https://doi.org/10.16993/sjdr.725>



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Public Health Under Siege: Improving Policy in Turbulent Times

Edited by: Brian C. Castrucci, DrPH, Georges C. Benjamin, MD, Grace Guerrero Ramirez, MSPH, Grace Castillo, MPH

This new book focuses on the importance of health policy through a variety of perspectives, and addresses how policy benefits society, evidently through increased life expectancy and improved health. The book describes how detrimental social determinants can be to the overall population health and emphasizes how the nation is centered on policy change to create equal health care opportunities for all sectors of health.

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Being Accountable for Capability—Getting Public Health Reform Right This Time

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Underinvestment in our nation’s public health system continues to diminish COVID-19 control efforts.¹ Successive waves of the COVID-19 pandemic are a Sisyphean nightmare proving that we do not have a public health system that has the capacity to learn and improve through time and experience. Budget data and workforce capability assessments from local public health agencies do not allow for a detailed assessment of public health capabilities. Top-down efforts to gather these assessments have to date not resulted in robust data to assess and track the capabilities of our public health system.

Public health’s intransigent unreadiness stems in part from chronic underfunding. State and local health departments have seen little to no real growth in per capita spending for decades.^{2,3} Underfunding has led to capability gaps at both state and county levels. This article highlights past spending levels on foundational capabilities in state and county public health departments to inform efforts to rebuild a

responsive and accountable public health system.

STATE HEALTH DEPARTMENT SPENDING

Census of Governments data on state public health spending permit a breakdown of public health activity spending into three categories: public health areas, public health foundational capabilities, and clinical services (Box 1).⁴ The first category, public health areas, includes activities to control and prevent specific diseases or to undertake specific functions (e.g., restaurant inspections) through services that must be carried out by state or local health departments. The second category, public health foundational capabilities, covers state health department infrastructure, including competence to administer, to budget, and to conduct surveillance, communications, and community partnership functions as well as IT infrastructure. Capabilities are critical to a health department’s

capacity to meet non-disease-specific local needs and are the most relevant to address equity, structural health determinants, and readiness for current and future pandemics and other public health emergencies. The third category comprises the clinical services that state and local health departments deliver to close gaps in the safety net and serve vulnerable populations. These direct services are remunerative for health departments via a patchwork of state and federal grants as well as through billing Medicaid and private insurance.^{5,6}

BOX 1— Total State Health Department Spending in Clinical Services, Foundational Areas, and Foundational Capabilities of Public Health: United States, 2008–2013

Public health areas: \$101.4 billion
• Communicable disease control
• Preventing chronic disease and injury
• Environmental public health
• Maternal child and family health
• Linkage with primary care
Public health capabilities: \$28.6 billion
• Assessment
• Preparedness
• Policy support
• Communications
• Community partnerships
• Organization competence (hiring, budgets)
• IT Infrastructure
Clinical services: \$236 billion
• Behavioral health
• Home health care
• Medical transport
• Dental clinics
• Primary care
• Emergency medical services

Source. Resnick et al.⁴

It is understandable why clinical service provision supports the financial viability of health departments. However, when one considers what is needed to ensure pandemic preparedness, government public health spending priorities are reversed. According to a detailed analysis of state health spending over five years,⁷ US states devoted \$236 billion (60%) of their health budgets to clinical services (Box 1).⁴ Only \$28.6 billion (7%) of the public health spending activity of states was in foundational capabilities, whereas \$101.4 billion (28%) was spent on public health areas.⁴

Because we know more about what states—as opposed to counties—spend their money on, we can assess how specific types of spending are associated with capacity to control the spread of the pandemic. States varied widely in government public health spending in 2018, with a mean of \$71.92 per capita in Michigan and ranging from a minimum of \$27.81 per capita in South Dakota to a maximum of \$271.72 per capita in Delaware.³ Geographical variability in spending prior to the pandemic permits one to ask whether it was associated with the speed of controlling the pandemic in each county. Our analysis found that states that had spent more specifically on preparedness prior to the pandemic showed a more rapid ability to bend the COVID-19 curve.⁸

COUNTY HEALTH DEPARTMENT SPENDING

Because we know little about the activities directly supported by county government spending, it is hard to assess the association of county-level spending with capacity for pandemic control. The Census of Governments offers information on aggregated health

spending for each county.⁹ Disaggregated spending data by category at the county level are scarce. One study showed that foundational capabilities accounted for less than one third of county health department spending in Ohio in 2019.¹⁰ Detailed county health department budget data from 2015 showed that public health foundational capabilities accounted for only 21% of the average \$55 per capita local dollars spent on public health.¹¹

PAST COUNTY HEALTH SPENDING'S RELEVANCE TO PANDEMIC CONTROL

In the first weeks and months of the COVID-19 pandemic, an effective local response required states and counties to rapidly surge into new activities in epidemiology, contact tracing, communication, and partnership formation. Because funding for clinical service personnel was contractually tied to specific services, program officers for the contracts had to agree to release workers tied to prior grants (e.g., grants for behavioral health services). New pandemic funding in the immediacy of the crisis required a surge in administrative capacity and effort to hire new people. Government hiring and procurement rules¹² can limit flexibility and speed. Counties with better organizational capacity in human resources, procurement, finance, and contracting would have been better able to access and mount a staffing and retraining surge.

However, evidence from the United States showed no relationship between historical levels of county government health spending and the ability to bend the initial COVID-19 epidemic curves in the first half of 2020.⁸ The null effect of county-level health spending was

unchanged after controlling for county racial and age composition, population density, urbanicity, median county income, and strength of the medical sector. The United States is not alone in showing no impact of prior local health investments on the ability to control COVID-19. An examination of prepandemic borough-level public health spending in the United Kingdom also showed no correlation with COVID-19 control in 2020.¹³

The best explanation for this lack of a relationship is that the overall amount of money a county spends on health is often not reflective of the capability of its public health department. This decoupling of public health capability from overall spending on health explains enduring deficits in local delivery of essential public health services and a disproportionate focus on health care as the de facto allocation of a given jurisdiction's health "investment."^{14,15} De-evolution is how organizations survive financial starvation, by sloughing off functions that are not explicitly paid for by grants or fees for services. Thus, starving health departments have no choice but to eliminate their local epidemiologists, policy analysts, and community organizers unless these roles can be justified as line items in an earmarked program. The dire state of de-evolution and structural unfitness in local health departments is a legacy of survivalism born of a boom–bust funding cycle. When funding streams don't support capabilities like local surveillance and community partnerships, these skillsets are shed. Foundational capabilities gain meager support only in the short-term immediacy of a crisis. The default equilibrium is fragmented funding for earmarked programs tied to special issues, diseases, and populations and to health department staff

losing the capability to do anything else.¹⁶

BUILDING PUBLIC HEALTH CAPABILITY FROM THE BOTTOM UP

Improvement requires good data about the current status of local public health capability (foundational capabilities) and where the gaps are. Despite decades of calls for reform, we still know very little about local public health capability. Data are typically not collected, and communities being served are typically unaware of gaps in capability.

In 1988 and 2003 the Institute of Medicine (IOM) asked national, state, and local governments to gather systematic data on state and local public health activity as the basis for quality improvement.^{17,18} These efforts were not funded at the national level. Neither the Centers for Disease Control and Prevention (CDC) nor the National Institutes of Health (NIH) offer programmatic research funding to support the systematic study of public health functions and foundational capacity in localities across the United States. The CDC's Center for State, Tribal, Local, and Territorial Support would have the remit to support local efforts to measure capability, but it has seen no growth in its budget for five years. So, although another national commission asking for an assessment of public health infrastructure is welcome,¹⁹ history says we will need a backup plan to assess public health capacity if Congress continues to ignore the advice of expert panels like the IOM or any forthcoming pandemic commissions. One way to drive change is to mobilize ownership and advocacy from the bottom up.

The task of improving a local health department's functional capability requires establishing permanent local public health capability teams (PHCTs) that would acquire explicit and protected funding in each local health department. Their mission would be to undertake community participatory assessments of public health capability. These efforts could push us beyond the past limitations of the Public Health Accreditation (PHAB) because the PHCTs would have permanent funding as opposed to waxing and waning with the five-year accreditation cycle. Fewer than 10% of America's local health departments have been accredited under the PHAB.¹⁶ A national survey showed that a typical local health department has no consistent resources dedicated to quality improvement.¹⁴ Institutionalized PHCTs would be charged with continuous improvement and could rely on preexisting tools from the PHAB, CDC, and the Public Health Foundation.²⁰⁻²²

A participatory capability assessment would start with a transparent, standardized, and public inventory of the public health workforce, including their activities and financing. The PHCTs would set up multisector stakeholder consortia to examine the local public health capability portfolio in the light of other local strengths, assets, and needs. Achieving local community engagement in the work of the health department is difficult in general, but it is especially necessary in the work of capability improvement. The PHCT would give specific attention to equity, social determinants, and readiness for coming health threats. In the second phase, the consortium led by the PHCTs could propose and execute a costed investment plan to build capabilities in the community. These investments

would include training and retooling for current workers, new hiring, and deliberate complementary investments by local partners. Communities should integrate public health capability strengthening with hospitals' plans to spend their community benefit dollars in response to the cycle of Community Health Needs Assessments. School systems could integrate their Title I investments in conformity with this broad assessment of public health capability. Other units of local government—including law enforcement, transportation, aging, and parks—could interface to achieve synergy and win-win cooperation. Private sector partners like local pharmacies, medical practices, senior living centers, food retailers, and exercise clubs would be invited to participate. PHCTs could help assess and plan investments to correct local gaps in data technology and utilization that have been a long-neglected priority.²³

Costed plans for public health capability investment would give state legislatures, federal agencies, and Congress a more realistic idea of the investment needed to achieve a public health system rooted in community aspirations, strengths, and needs. Natural advocates for change would be the newly empowered citizen coauthors of their community assessments of public health capability. With transparency and public accessibility, the local planning units could take advantage of mutual exchange and learning. State health departments, universities, the CDC, and national professional societies could conduct systematic evaluation and research about best practices. The NIH and the Patient-Centered Outcomes Research Institute should be asked to support integrative research on the population health impacts of the improvements in public health infrastructure.

IMPLEMENTATION

Modern public health efforts require broad public support from citizens at the grassroots level whose trust is founded on co-designing public health agencies that are “by the people and for the people.” The root cause of local health departments’ capability gap is a fragmented, starved, upside-down federalized system. Money (and power) are at the national and state level; execution and community trust and buy-in are at the local level. Conducting the work of a PHCT via community participatory methods would help to generate sustaining political support from local county government, but it does not solve the problem of getting them started and financing them.

We propose a system of empowerment grants to local public health agencies. Federal or state government contributions would be necessary. Although the federal government could not require that counties maintain quality improvement units, states could. Federal, state, and local governments are all beneficiaries of the health and safety of places.²⁴ Higher real estate prices (and more local tax revenue) have been shown to occur following small area improvements in life expectancy.²⁵

The funds required for a 21st century public health system can be expected to be extremely modest compared with the future lives lost and economic cost if public health capability is not put into place. The Public Health Leadership Forum estimates that \$4.5 billion would be needed to support core public health foundational capabilities.²⁶ The cost of PHCTs would be a small fraction of \$4.5 billion. These costs are indeed modest compared with total national curative health expenditure, which stands at \$4 trillion.²⁷ PHCTs that take

a participatory approach to plan and cost out performance improvement plans would generate in-kind contributions to local public health activities from other government branches and the private sector that would offset their direct cost.

Internal politics in the existing vertical programs that dominate state and local health departments can be expected to resist change if they see the PHCT as an alien force of outside inspectors. However, any health department’s capability team would naturally include people from these programs, who would be drawn into quality improvement conversations designed to achieve preexisting goals. Better capabilities of local health departments are complementary to each programmatic public health area.²⁸ Unlike the introduction of a new program area, a quality improvement initiative that involves stakeholders is not competing for resources but making resources more available and efficient.

Ultimately, the goal is for each county in America to have a local public health agency that has the capability to address ongoing and emerging public health threats and health inequities through a co-designed community-based social compact. Local public health agencies will be able to say, “We worked with you, listened to you, and now we are offering to co-deliver the public health responses that we all agreed on as priorities for our community. Please keep us accountable.” The politics of local control and local inclusion, combined with the low price tag, make this approach appealing to America’s communities, which do not want to be caught off guard for the next challenge. The risk of facing the 21st century without a capable and accountable network of local public health agencies makes this approach an absolute necessity. **AJPH**

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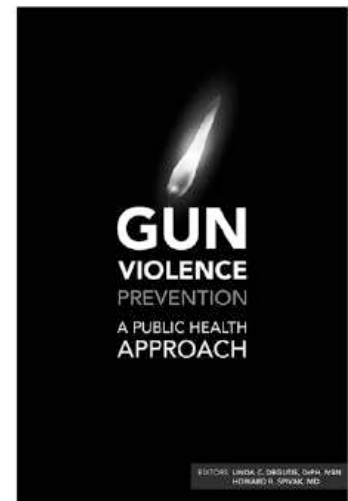
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REFERENCES

1. Maani N, Galea S. COVID-19 and underinvestment in the public health infrastructure of the United States. *Milbank Q*. 2020;98(2):250–259. <https://doi.org/10.1111/1468-0009.12463>
2. Trust for America’s Health. The impact of chronic underfunding on America’s public health system: trends, risks, and recommendations, 2021. Available at: https://www.tfah.org/wp-content/uploads/2021/05/2021_PHFunding_Fnl.pdf. Accessed June 1, 2022.
3. Alfonso YN, Leider JP, Resnick B, McCullough JM, Bishai D. US public health neglected: flat or declining spending left states ill equipped to respond to COVID-19. *Health Aff (Millwood)*. 2021;40(4):664–671. <https://doi.org/10.1377/hlthaff.2020.01084>
4. Resnick BA, Fisher JS, Colrick IP, Leider JP. The foundational public health services as a framework for estimating spending. *Am J Prev Med*. 2017;53(5):646–651. <https://doi.org/10.1016/j.amepre.2017.04.015>
5. Public Health Leadership Forum. Defining and constituting foundational “capabilities” and “areas.” 2014. Available at: http://www.resolve.org/site-healthleadershipforum/files/2014/03/Articulation-of-Foundational-Capabilities-and-Foundational-Areas.v1.May_.pdf. Accessed June 1, 2022.
6. Public Health Leadership Forum. Developing a financing system to support public health infrastructure. 2014. Available at: https://www.resolve.org/docs/phlf_developingafinancingsystemtosupportpublichealth636869439688663025.pdf. Accessed June 1, 2022.

7. Leider JP, Resnick B, Bishai D, Scutchfield FD. How much do we spend? Creating historical estimates of public health expenditures in the United States at the federal, state, and local levels. *Annu Rev Public Health*. 2018;39(1):471–487. <https://doi.org/10.1146/annurev-publhealth-040617-013455>
8. Lamba S, Wolfson C, Cardona C, et al. Past local government health spending was not correlated with COVID-19 control in US counties. *SSM Popul Health*. 2022;17:101027. <https://doi.org/10.1016/j.ssmph.2022.101027>
9. Sensenig AL, Resnick BA, Leider JP, Bishai DM. The who, what, how, and why of estimating public health activity spending. *J Public Health Manag Pract*. 2017;23(6):556–559. <https://doi.org/10.1097/PHH.0000000000000568>
10. Singh SR, Leider JP, Orcena JE. The cost of providing the foundational public health services in Ohio. *J Public Health Manag Pract*. 2021;27(5):492–500. <https://doi.org/10.1097/PHH.0000000000001233>
11. Public Health Activities and Services Tracking. Uniform chart of accounts. Data from 2015. Available at: <https://phastdata.org/viz/coa-dashboard> Accessed February 1, 2022.
12. Mays GP, Smith SA. Geographic variation in public health spending: correlates and consequences. *Health Serv Res*. 2009;44(5 pt 2):1796–1817. <https://doi.org/10.1111/j.1475-6773.2009.01014.x>
13. Acharya A, Wolfson C, Matta S, Cardona C, Lamba S, Bishai D. The role of public health expenditures in COVID-19 control: evidence from local governments in England. *SSM Popul Health*. 2021;15:100861. <https://doi.org/10.1016/j.ssmph.2021.100861>
14. Wallace M, Sharfstein J, Lessler J. Performance and priorities: a cross-sectional study of local health department approaches to essential public health services. *Public Health Rep*. 2020;135(1):97–106. <https://doi.org/10.1177/0033354919890862>
15. Robin N, Castrucci BC, McGinty MD, Edmiston A, Bogaert K. The first nationally representative benchmark of the local governmental public health workforce: findings from the 2017 Public Health Workforce Interests and Needs Survey. *J Public Health Manag Pract*. 2019;25(2 suppl):S26–S37. <https://doi.org/10.1097/PHH.0000000000000939>
16. Wallace M, Sharfstein JM. The patchwork US public health system. *N Engl J Med*. 2022;386(1):1–4. <https://doi.org/10.1056/NEJMp2104881>
17. Institute of Medicine (US) Committee for the Study of the Future of Public Health. *The Future of Public Health*. Washington, DC: National Academies Press; 1988.
18. Boufford JL, Cassel C, Bender K, Berkman L, Bigby J, Burke T. *The Future of the Public's Health in the 21st Century*. Washington, DC: Institute of Medicine of the National Academies; 2003.
19. Sullivan P. Bipartisan senators unveil bill to improve pandemic preparedness. *The Hill*. January 25, 2022. Available at: <https://thehill.com/policy/healthcare/591318-bipartisan-senators-unveil-bill-to-improve-pandemic-preparedness>. Accessed June 1, 2022.
20. *PHAB Guide to Initial Accreditation*. Alexandria, VA: Public Health Accreditation Board; 2016.
21. Corso LC, Lenaway D, Beitsch LM, Landrum LB, Deutsch H. The national public health performance standards: driving quality improvement in public health systems. *J Public Health Manag Pract*. 2010;16(1):19–23. <https://doi.org/10.1097/PHH.0b013e3181c02800>
22. Moran J, Duffy G. *Public Health Quality Improvement Encyclopedia*. Washington, DC: Public Health Foundation; 2012.
23. Frieden T, Gerberding J, Koplan J, Roper WL, Satcher D. Former CDC directors: coordinating our nation's health data will save lives. *The Hill*. March 10, 2022. Available at: <https://thehill.com/opinion/healthcare/597494-former-cdc-directors-coordinating-our-nations-health-data-will-save-lives>. Accessed June 1, 2022.
24. Mays GP, Mamaril CB. Public health spending and Medicare resource use: a longitudinal analysis of US communities. *Health Serv Res*. 2017;52(suppl 2):2357–2377.
25. Nau C, Bishai D. Green pastures: do US real estate prices respond to population health? *Health Place*. 2018;49:59–67. <https://doi.org/10.1016/j.healthplace.2017.11.008>
26. *The Impact of Chronic Underfunding on America's Public Health System: Trends, Risks, and Recommendations, 2020*. Washington, DC: Trust for America's Health; 2020.
27. *National Health Expenditure Fact Sheet*. Washington, DC: Center for Medicaid and Medicare; 2021.
28. Gunzenhauser JD, Eggena ZP, Fielding JE, Smith KN, Jacobson DM, Bazini-Barakat N. The quality improvement experience in a high-performing local health department: Los Angeles County. *J Public Health Manag Pract*. 2010;16(1):39–48. <https://doi.org/10.1097/PHH.0b013e3181bedc1f>



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Gun Violence Prevention: A Public Health Approach

Edited By: Linda C. Degutis, DrPH, MSN, and Howard R. Spivak, MD

Gun Violence Prevention: A Public Health Approach acknowledges that guns are a part of the environment and culture. This book focuses on how to make society safer, not how to eliminate guns. Using the conceptual model for injury prevention, the book explores the factors contributing to gun violence and considers risk and protective factors in developing strategies to prevent gun violence and decrease its toll. It guides you with science and policy that make communities safer.

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Adapting by Their Bootstraps: State and Territorial Public Health Agencies Struggle to Meet the Mounting Challenge of Climate Change

Nicole A. Errett, PhD, MSPH, Kathleen Dolan, MSPH, Cat Hartwell, MPH, Jamie Vickery, PhD, and Jeremy J. Hess, MD, MPH

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As heat waves, storms, wildfires, droughts, and floods mount and the pressure builds for serious engagement on climate change—the greatest public health challenge of our time—cracks in the foundations of US state and territorial health agencies (STHAs) are widening. Chronic underinvestment since the 2008 “Great Recession” resulted in a decimated US public health system at the start of the COVID-19 pandemic.^{1,2} Before the pandemic, 24% of the state and local public health workforce was scheduled to retire in 2020.³ This scheduled attrition, combined with pandemic burnout, is likely to lead to countless years of lost experience that cannot be swiftly replaced. Congress has responded to the COVID-19

pandemic with appropriations aimed at bolstering public health agency capacity; however, if similar event-specific “disaster” appropriations (e.g., Ebola, Hurricane Sandy) are guides, these investments are unlikely to be sustained.

PREPAREDNESS GAPS IN THE PUBLIC HEALTH SYSTEM

Concomitantly, the health effects of climate change and the need for public health system engagement are increasingly apparent. Although health impact pathways will vary, all regions of the country are at risk for effects such as injury, illness, and health care facility damage associated with extreme weather events,

changes to the geographic and seasonal range of disease-carrying vectors, and shifts in regional allergen exposures.⁴ Our most vulnerable populations, including children, older adults, people with underlying health conditions, and those living in communities historically affected by environmental injustice, are at increased risk.

While the world rapidly warms, our preparedness gap appears to have grown. The morbidity and mortality effects of climate change that are now being widely observed have been anticipated for more than 20 years, and the United States and other high-income countries have engaged in national-level preparedness efforts.^{5–8} Nevertheless, although the mantra of preparedness is that “all disasters are local,” efforts to engage frontline state, territorial, and local governments in climate change adaptation activities have been minimal and erratic.

The primary federal effort to build state and local climate and health capacity has been the Centers for Disease Control and Prevention (CDC) Climate-Ready States and Cities Initiative, which has funded a handful of jurisdictions to implement its Building Resilience Against Climate Effects framework.⁸ Through its preparedness mandate, the CDC established this framework to provide guidance for state, territorial, and local health agencies in developing and implementing climate change adaptation activities. However, CDC support has been limited, with only 16 STHA grants awarded in 2010 and just nine grants awarded in 2021.⁹ Although the CDC has also funded the Association of State and Territorial Health Officials to provide technical assistance and limited funding for STHAs to implement components of the framework, these efforts are far from sufficient to support all 59 STHAs,

let alone the hundreds of local jurisdictions with large populations at risk.

CLIMATE AND HEALTH PROGRAMS AND ACTIVITIES

To better characterize the level of adaptation activity among STHAs, we administered an online survey in 2021 in partnership with the Association of State and Territorial Health Officials to determine whether STHAs had developed climate and health programs (CHPs) and inventory the climate-related activities they were implementing. Areas of focus included interagency coordination, surveillance, mitigation policies, internal education, external education, state agency coordination, technical assistance, federal agency coordination, adaptation implementation, and adaptation evaluation.

Given the aforementioned lack of federal investment, we intentionally set the bar for programming very low,

defining a formal program as one that has at least one staff person designated to spend their time on climate and health programming (i.e., one full-time equivalent). Yet, only 19 of the 41 STHAs that responded to our survey reported having such a program at the time (16 of the 36 responding state health departments and three of five territories).

We found that STHAs were “adapting by their bootstraps” and engaging in a variety of climate and health activities even in the absence of formal programs and dedicated funds. All responding jurisdictions reported some level of engagement in climate and health activities, demonstrating widespread concern about climate change health effects.

However, jurisdictions with CHPs reported higher rates of almost all of the activities surveyed (Table 1). The only activity in which there was not a statistically significant difference was surveillance of climate-sensitive conditions, reported by 58% of respondents with a CHP and 57% of respondents without a program.

Certain activities were common to almost all agencies reporting CHPs, including linking the STHA with other state or territorial government agencies working on climate change, providing internal education about climate- and health-related activities, and providing external education promoting awareness of climate change and health. STHAs with CHPs also reported engagement in a suite of other program activities, including developing and maintaining data indicators and Web-based tools for vulnerability assessments, seeking outside sources of technical and financial assistance to support the CHP and its activities, and participating in interstate agency groups aimed at coordinating and elevating climate adaptation planning and investments (e.g., the Interagency Climate Adaptation Network).

Ninety-five percent of STHAs with CHPs reported partnerships with nongovernmental organizations that focused on climate and health adaptation, and STHAs with CHPs reported significantly larger numbers of partnerships, with the majority engaging in more than three. In contrast, 45% of respondents without CHPs reported no partnerships, and only 14% reported more than three.

TABLE 1— Climate Change Adaptation Activities in US State and Territorial Health Departments With and Without Climate and Health Programs (CHPs): 2021

	Has CHP, %	No CHP, %
Coordinates climate change activities between programs or departments across the agency	84.21	19.05
Conducts or coordinates surveillance of climate-sensitive diseases	57.89	57.14
Informs climate mitigation policy and planning with health data	78.95	19.05
Provides internal education about climate- and health-related activities to other programs	94.74	28.57
Provides external education to promote awareness of climate change and health	94.74	33.33
Links the health department with other state government agencies working on climate change	94.74	33.33
Provides technical assistance to local or regional health agencies assessing or addressing climate effects on health	78.95	38.10
Acts as a liaison with federal agencies involved in climate change and health	84.21	28.57
Implements climate and health adaptation interventions	73.68	23.81
Evaluates climate and health adaptation interventions	73.68	23.81

RECOMMENDATIONS

Our results demonstrate that even modest investments in CHPs—a single full-time equivalent—can have profound effects on STHA activities addressing the health effects of climate change. A lack of sufficient and sustained investments has forced STHAs to master the art of doing more with less; we can only begin to imagine what these agencies could do to prepare for and respond to the health effects of climate change with investments proportional to the magnitude of the threat.

A substantial and sustained funding increase is needed to ensure that STHAs are adequately prepared to protect the public's health from climate change effects. As we have learned from other threats, investment in prevention will yield significant returns and reduce the outlays required when disaster inevitably strikes. Despite the efforts of the Biden administration,¹⁰ the 2022 federal budget ultimately did not include appropriations to support the proposed level of substantive Department of Health and Human Services engagement in climate and health activities, including the Climate-Ready States and Cities Initiative.

Without immediate federal investments, STHAs lacking CHPs can incorporate climate change readiness into broader public health programming through a "climate in all policies" approach. Preparing for climate hazards in the context of all-hazards disaster planning, integrating climate-sensitive diseases into existing surveillance systems, and communicating the risks of climate change and the health benefits of climate mitigation are a few opportunities to start. STHAs can also engage across sectors with other state and local agencies, academic partners, and nongovernmental and community organizations.

CONCLUSION

Climate change is stressing our public health system, which is already on the precipice, by exacerbating health disparities, damaging health care facilities and resources, and stretching personnel and capabilities to their limits. Worse is in store. It is critical to build capacity now, expanding the public health workforce and strengthening preparedness so that

STHAs can collaboratively and effectively deal with the challenges to come. *AJPH*

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K. Dolan contributed to study conceptualization and design, data collection, and data interpretation and reviewed and provided critical revisions to content. C. Hartwell contributed to data collection, analysis and interpretation, and reviewed and provided critical revisions to content. J. Vickery contributed to data collection, and reviewed and provided critical revisions to content. J.J. Hess contributed to study conceptualization and design, data collection, and data interpretation; led the data analysis; and reviewed and provided critical revisions to content.

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The University of Washington Human Subjects Division determined that this project qualified for exempt status.

REFERENCES

1. Trust for America's Health. The impact of chronic underfunding on America's public health system: trends, risks, and recommendations. Available at:

<https://www.tfah.org/report-details/publichealthfunding2020>. Accessed May 28, 2020.

2. Maani N, Galea S. COVID-19 and underinvestment in the public health infrastructure of the United States. *Milbank Q*. 2020;98(2):250–259. <https://doi.org/10.1111/1468-0009.12463>
3. Leider JP, Coronado F, Beck AJ, Harper E. Reconciling supply and demand for state and local public health staff in an era of retiring baby boomers. *Am J Prev Med*. 2018;54(3):334–340. <https://doi.org/10.1016/j.amepre.2017.10.026>
4. Cissé G, McLeman R, Adams H, et al. Health, well-being, and the changing structure of communities. In: Pörtner H-O, Roberts DC, Tignor M, et al., eds. *Climate Change 2022: Impacts, Adaptation, and Vulnerability*. Cambridge, England: Cambridge University Press.
5. Austin SE, Biesbroek R, Berrang-Ford L, Ford JD, Parker S, Fleury MD. Public health adaptation to climate change in OECD countries. *Int J Environ Res Public Health*. 2016;13(9):889. <https://doi.org/10.3390/ijerph13090889>
6. Ebi KL, Mills DM, Smith JB, Grambsch A. Climate change and human health impacts in the United States: an update on the results of the US national assessment. *Environ Health Perspect*. 2006;114(9):1318–1324. <https://doi.org/10.1289/ehp.8880>
7. Hess JJ, Schramm PJ, Luber G. Public health and climate change adaptation at the federal level: one agency's response to Executive Order 13514. *Am J Public Health*. 2014;104(3):e22–e30. <https://doi.org/10.2105/AJPH.2013.301796>
8. Marinucci GD, Luber G, Uejio CK, Saha S, Hess JJ. Building resilience against climate effects—a novel framework to facilitate climate readiness in public health agencies. *Int J Environ Res Public Health*. 2014;11(6):6433–6458. <https://doi.org/10.3390/ijerph110606433>
9. Centers for Disease Control and Prevention. Climate-Ready States and Cities Initiative grant recipients. Available at: https://www.cdc.gov/climateandhealth/crsci_grantees.htm. Accessed April 4, 2022.
10. White House. Executive order on tackling the climate crisis at home and abroad. Available at: <https://www.whitehouse.gov/briefing-room/presidential-actions/2021/01/27/executive-order-on-tackling-the-climate-crisis-at-home-and-abroad>. Accessed April 4, 2022.

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Where Do You Go When Your Prison Cell Floods? Inadequacy of Current Climate Disaster Plans of US Departments of Correction

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The global climate crisis is the most significant, potentially irreversible environmental threat to humanity we face.¹ In the last three years, we have experienced the warmest years on global record, and the number of extreme climate-related events is projected to increase.² The negative impacts of these events are disproportionate across different populations: Black individuals are 40% more likely than White people to reside in areas with the highest projected increases in extreme temperature-related deaths.³

One understudied factor that may exacerbate the impact of climate disaster events on individuals is incarceration status. Incarceration is a key facet of structural racism in the United States. The United States contains 25% of the world's incarcerated population despite making up less than 5% of the world's overall population, and

marginalized individuals are overrepresented in these settings.⁴ Carceral systems have historically experienced heightened morbidity and mortality from climate disasters when systems have not evacuated facilities or taken other preventative actions; this was evident in the aftermath of Hurricane Katrina, where residents of Orleans Parish, Louisiana prisons were left in their cells without water, food, and ventilation for days while correctional staff left their posts.⁵ In addition, jails and prisons themselves present environmental risk. Prisons contribute to greenhouse gas emissions, and people inside are regularly exposed to contaminated water, hazardous waste, and food insecurity.⁶

Despite this, there is currently no unified federal plan to provide oversight or relief to incarcerated people during climate disaster events. As a result, states are responsible for developing and

enacting emergency management (EM) plans that cover the entire state, including those living in congregate settings. The design and implementation of these plans vary state to state, with specific tasks delegated to relevant state agencies, departments, and sometimes nongovernmental organizations. To identify how incarcerated people are represented in climate disaster response, we reviewed state and department of correction (DOC) policies on disaster planning.

DISASTER RESPONSE IN CARCERAL SETTINGS

To characterize the inclusion of incarcerated people in statewide protocols for disaster response, we performed a content analysis of each state's EM plan. These plans were identified by searching state government Web sites with the terms "emergency management plan" and "disaster response plan." Using an inductive approach, we qualitatively coded state plans for mentions of incarcerated people and DOC system-level guidance. We also coded DOC-specific EM plans for all 50 states; these plans were searched for on DOC Web sites. Searches for both DOC and state-level plans were performed in February of 2022. After all coding was complete, a thematic analysis was performed to identify consistent findings across state and DOC EM plans.

We identified 40 states with publicly shared EM plans on their government Web site. Of these 40 states, 30 (75%) mentioned incarcerated people in some capacity. Six states (15%) included protocols around DOC resident safety and evacuation. The most common mentions of incarcerated individuals were in the context of labor: 24 states (60%) mentioned DOC resident

labor for disaster mitigation; 14 states (35%) mentioned *only* DOC resident labor for disaster mitigation, with no other references to incarcerated people or the DOC; 10 states (25%) did not mention the DOC or incarcerated people in their published EM plans (Table 1).

Overall, 33 DOCs (66%) did not have EM plans published on their Web site at the time of this analysis. Of the 17 DOCs that did have published EM plans, seven systems (41%) discussed resident labor. Twenty-four percent (n = 4) of DOCs only discussed labor, with no other references to resident safety or DOC provision of resources. Six DOCs (35%) discussed protocols to promote resident safety during disasters. Full references for state and DOC EM plans can be found in the Appendix (available as a supplement to the online version of this article at <http://www.ajph.org>).

IMPLICATIONS AND SOLUTIONS

Most state and DOC EM plans do not outline how to protect the safety of incarcerated populations and carceral staff. Common themes across state and DOC-level EM plans include resident labor and use of materials from DOCs, with few mentions of resident safety. Because

carceral settings are often situated in areas that are disparately affected by climate disasters, this lack of guidance may result in excess negative impact during public health emergencies.

More than half of the EM plans that indicate the use of incarcerated labor to mitigate climate disasters do not provide any insight into other procedures to prioritize the health and well-being of incarcerated people. Where EM policies indicate tasks delegated to those in the custody of the DOC, safety precautions are notably absent; only one DOC (Colorado) indicated that the medical needs of incarcerated work crews would be assessed on an ongoing basis in the event of a disaster. Overall, only six states outlined protocols to keep incarcerated individuals safe in the event of a disaster.

Carceral institutions follow policies developed by the American Correctional Association (ACA). The ACA states that all staff must be trained in the facility's emergency management plans but does not specify any standards of care during these emergencies.^{7(p198)} Whereas carceral standards for disaster risk management and response are lacking in the United States, other nations maintain robust guidelines. Indonesia provides comprehensive

protocols for staff training, resident evacuation, risk assessment, and contingency planning. Jails in the Philippines are required to maintain and update emergency operational plans. Staff and detainees must routinely participate in drills designed to respond to climate disasters.⁶

To ensure that DOCs adequately prepare for these emergencies, federal funding could be contingent on creating these essential features of operation. Eligibility requirements or post-award audits for federal emergency relief and preparedness funds could be changed to include precise requirements for the presence of robust operations plans. Incentivizing the creation of these programs promotes a system wherein state emergency response agencies, with the support of the ACA, routinely audit and evaluate carceral emergency operations plans. Crucially, this avoids the lengthy process of rewriting federal statutes and delivers flexible solutions in the shortest time frame.

Longer-term solutions include creating policies that explicitly require the protection and well-being of prison residents. EM plans should include an evacuation policy and plan to provide food, water, clothing, and shelter. If incarcerated labor is mentioned in these policies, there should be protocols in place to ensure that people are appropriately compensated with money or sentence reduction. Visits with health care staff should be prioritized, as the labor can be mentally and physically demanding. Ultimately, systems can also actively work to reduce carceral populations to minimize the number of individuals affected by a climate disaster.

The infrastructure of carceral facilities, overcrowding, and higher rates of chronic medical conditions all contribute to the likelihood that climate-related

TABLE 1— Content Analysis of State and Department of Corrections (DOC) Emergency Management (EM) Plans: United States, 2022

	No. (%) of State EM Plans (n = 40)	No. (%) of DOC EM Plans (n = 17)
Mentioned DOC resident labor	24 (60)	7 (41)
Only mentioned DOC resident labor	14 (35)	4 (24)
Mentioned DOC resident evacuation or safety	6 (15)	6 (35)
Mentioned DOC provision of resources	9 (23)	0 (0)
No mention of incarcerated people or DOC	10 (25)	NA

Note. NA = not applicable.

disasters significantly affect the health of incarcerated people.⁵ However, few state or DOC EM plans indicate how this increased risk will be mitigated. These findings add to the growing evidence that there is a lack of transparency with respect to climate disaster response and little accountability regarding this population. There must be significantly greater oversight of policies and procedures to protect incarcerated people in the event of climate disasters, particularly as the world faces a global climate crisis of increasing severity. **AJPH**

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CONFLICTS OF INTEREST

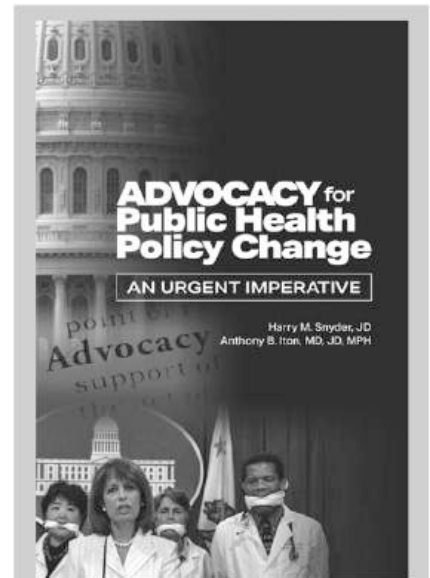
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REFERENCES

1. World Health Organization. Climate change and health. Available at: <https://www.who.int/news-room/fact-sheets/detail/climate-change-and-health>. Accessed June 15, 2022.
2. US Global Change Research Program. Highlights of the findings of the US Global Change Research Program Climate Science Special Report. Available at: <https://science2017.globalchange.gov/chapter/executive-summary>. Accessed June 15, 2022.
3. US Environmental Protection Agency. EPA report shows disproportionate impacts of climate change on socially vulnerable populations in the United States. September 2021. Available at: <https://www.epa.gov/newsreleases/epa-report-shows-disproportionate-impacts-climate-change-socially-vulnerable>. Accessed June 15, 2022.
4. LeMasters K, Brinkley-Rubinstein L, Maner M, Peterson M, Nowotny K, Bailey Z. Carceral epidemiology: mass incarceration and structural racism during the COVID-19 pandemic. *Lancet Public Health*. 2022;7(3):e287–e290. [https://doi.org/10.1016/S2468-2667\(22\)00005-6](https://doi.org/10.1016/S2468-2667(22)00005-6)
5. Motanya NC, Valera P. Climate change and its impact on the incarcerated population: a descriptive review. *Soc Work Public Health*. 2016;31(5):348–357. <https://doi.org/10.1080/19371918.2015.1137513>
6. Penal Reform International. Natural hazards and prisons. December 2021. Available at: https://cdn.penalreform.org/wp-content/uploads/2021/12/PRI_Natural_hazards_and_prisons_WEB.pdf. Accessed June 15, 2022.
7. American Correctional Association. Performance-based standards and expected practices for adult correctional institutions. 2021. Available at: <https://user-3imepyw.cld.bz/Perf-Based-Stds-Adult-Corr-Inst-5th-ed-March-2021/79>. Accessed June 15, 2022.



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Violence and Injury Curricula Still Inadequate in Public Health Schools and Programs—A Call to Action

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Unintentional injury (e.g., poisonings or overdoses, motor vehicle crashes, fires, falls, sports injuries, occupational injuries) and violence (e.g., suicide, homicide, child maltreatment, partner violence) have long been among the leading causes of death in the United States and around the globe (<https://bit.ly/3PiAjHw>; <https://bit.ly/3JRUtY0>). As with any health issue, injury prevention hinges on whether public health professionals recognize the importance of these problems and have the capability to respond effectively. Ensuring that there are opportunities to learn about injury and violence in schools and programs of public health is critical, but training opportunities are woefully inadequate. We urge immediate action to expand public health training addressing injury and violence.

Until the 1979 *Healthy People: The Surgeon General's Report on Health Pro-*

motion and Disease Prevention, injury and violence issues were not consistently recognized in the domain of public health.¹ Attention accelerated after 1985, when the Institute of Medicine published *Injury in America: A Continuing Public Health Problem*, which called for the Centers for Disease Control and Prevention (CDC) to provide leadership.²

As a result, the CDC developed an initial injury program, funded five injury control research centers in 1987, and created the National Center for Injury Prevention and Control (NCIPC) in 1992.³ Injury control research centers are required to have training components and have made progress in preparing both researchers and practitioners, although funding has never been adequate or proportional to the size of the problem. As of 2022, the NCIPC budget is a mere \$715 million, with only \$9 million devoted to nine

injury control research centers.⁴ The CDC's National Institute for Occupational Safety and Health (NIOSH), with a budget of less than \$352 million, supports 11 agricultural safety and health centers, 18 education and research centers, and 10 total worker health centers.⁴ In stark contrast, the CDC's National Center for Chronic Disease Prevention and Health Promotion has a \$1.3 billion budget that includes nearly \$27 million for 26 university-based prevention research centers focused on chronic disease, having grown from the original three centers funded in 1986.^{4,5}

INJURY AND VIOLENCE CURRICULA

A 2006 study concluded that schools of public health “have limited capacity to conduct training on injury prevention and control.”^{6(p350)} A 2019 Web site scan for course offerings in all 178 accredited US schools and programs of public health reported that just 24% listed at least one course in injury and violence.⁷

We conducted a 2021 national survey of leaders in accredited schools and programs of public health in the United States to document current training in injury and violence (full report available from the authors). We examined course offerings, topics covered in courses, other training opportunities (e.g., seminars and training grants), and barriers to enhancing training.

Our sample (n = 77) included 37 of 68 accredited schools and 40 of 159 accredited programs. Results indicate that at least 32% of schools and 60% of programs offered no credit-bearing course in injury or violence. Because of our efforts to ask colleagues with injury prevention expertise to urge their

institutional leaders to participate, we suspect this is an overestimate, with schools responding to the survey being more likely to have offerings than non-responding schools. If none of the non-responding institutions offer injury or violence prevention courses, the proportion of courses across all schools and programs would total only 18%. If half of nonresponding institutions offer injury and violence prevention courses, the overall figure still would be only 51%. Among the 41 institutions indicating they offer courses, violence and overdose are the topics covered most often (Figure 1).

A third of respondents acknowledged that their institution’s coverage of injury and violence was more limited than

coverage of chronic or infectious diseases. Overall, slightly more than a third (36%) of responding institutions reported having no faculty specifically trained in injury and violence. Lack of funding and absence of an accreditation requirement were noted as limiting factors. Not surprisingly, institutions indicating they had one or more injury-related centers reported more coverage of these topics in their curricula.

In 1999, the Institute of Medicine endorsed a 1993 publication calling for “development of a national injury control training plan.”^{3(p195)} Such a plan still does not exist.

The Institute of Medicine report argued that advances in injury and violence prevention depend on the “continued

development of the infrastructure of the field,”^{3(p14)} and multiple calls to action have made similar pleas.⁸⁻¹¹ Efforts have been made to strengthen training for workers already in the field—led by the Society for Advancement of Violence and Injury Research (SAVIR) and the Safe States Alliance—including the development of core competencies for practitioners (Songer et al.¹²; <https://bit.ly/3parvsB>). Although helpful, these efforts do not address the need for strong training in degree programs.

Given that injury and violence collectively are the fourth leading cause of death in the United States (<https://bit.ly/3PIAjHw>), it should be unfathomable and unacceptable that in 2022 an accredited school or program of public

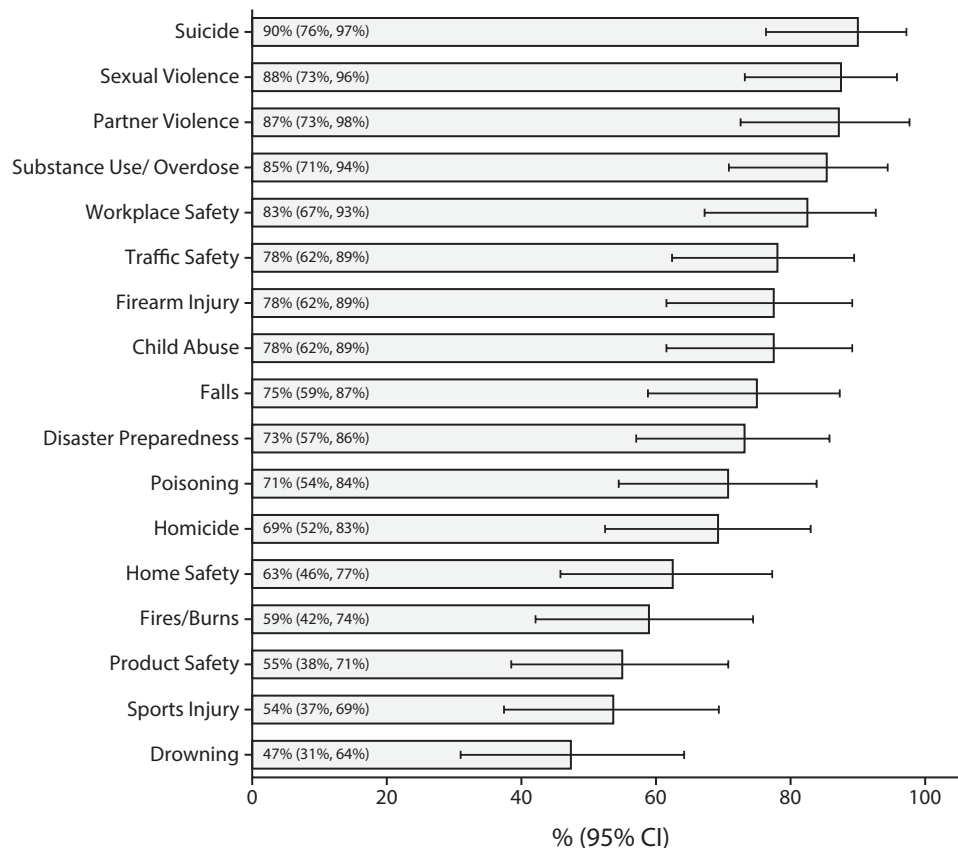


FIGURE 1— Percentage of Accredited Schools and Programs of Public Health Offering Credit-Bearing Courses That Cover Injury and Violence Topics (n = 41): United States, 2021

Note. CI = confidence interval.

health fails to provide training on this problem. But that is the reality.

Our recommendations amplify and expand earlier calls to action. It is imperative that institutions training public health professionals ensure that our future infrastructure has the capacity to address prevention of high-priority issues, such as gun violence, overdoses, suicides, falls in the elderly, traumatic brain injuries in sports, traffic crashes, workplace injury, and family violence, and be prepared to tackle emerging injury issues, such as those associated with climate change.

OUR CALL TO ACTION

We strongly urge the following:

1. NCIPC and NIOSH prioritize working together and with other organizations (e.g., SAVIR) to create a national plan for training injury and violence prevention researchers and practitioners, with attention to published core competencies¹² and the role of upstream social determinants of injury and violence;
2. the National Institutes of Health (NIH) and the CDC (a) support individual and institutional training grants that focus on injury and violence prevention at all training levels for those planning careers both in practice and research; (b) encourage the inclusion of training in injury and violence in relevant training grants; (c) ensure funding for academic research centers that focus on injury and violence prevention, with incentives to assist other institutions with less capacity; and (d) encourage research on injury and violence in existing relevant NIH research center programs;
3. the Council on Education in Public Health (www.ceph.org) devise

ways to encourage the inclusion of all major public health problems in the curriculum with a focus on both research and practice capacity building;

4. SAVIR and the Association of Schools and Programs of Public Health (<https://aspph.org>) partner to ensure that teaching resources (e.g., model syllabi, recorded lectures, and experienced mentors) are available to institutions in developing their capacities in injury and violence prevention education; and
5. public health schools and programs (a) recruit faculty trained in injury and violence prevention; (b) ensure the development of injury- and violence-specific coursework; (c) incorporate content on injury and violence prevention into core courses that reach all degree-seeking public health students; and (d) offer continuing education opportunities focused on core competencies¹² for injury and violence prevention tailored for those specializing in the topic.

Finally, we urge our public health colleagues to join us in advocating for these recommendations vigorously through all channels possible. *AJPH*

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CONTRIBUTORS

C. W. Runyan provided project oversight, sent solicitation to participants who are not from Association of Schools and Programs of Public Health member schools and programs, and drafted the editorial. K. F. Carlson and R. M. Johnson performed data cleaning and analyses. R. M. Johnson prepared the human participants application. All authors participated in conceptualizing the study, developing the data collection instrument, interpreting results, and preparing the editorial; all take responsibility for the work.

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CONFLICTS OF INTEREST

The authors have no conflicts of interest to declare.


REFERENCES

1. US Office of the Assistant Secretary for Health. *Healthy People: The Surgeon General's Report on Health Promotion and Disease Prevention*. Rockville, MD: Department of Health, Education, and Welfare; 1979. DHHS publication PHS 79-55071.
2. US Committee on Trauma Research. *Injury in America: A Continuing Public Health Problem*. Washington, DC: National Academies Press; 1985.
3. Institute of Medicine. *Reducing the Burden of Injury: Advancing Prevention and Treatment*. Washington, DC: National Academies Press; 1999.
4. Centers for Disease Control and Prevention. FY 2022 operating plan. Available at: <https://www.cdc.gov/budget/documents/fy2022/FY-2022-CDC-Operating-Plan.pdf>. Accessed July 2, 2022.
5. Centers for Disease Control and Prevention. Prevention Research Centers history. February 28, 2022. Available at: <https://www.cdc.gov/prc/about-prc-program/history.htm>. Accessed 2022, July 2, 2022.
6. Hemenway D, Aglipay GS, Helsing KL, Raskob GE. Injury prevention and control research and training in accredited schools of public health: a CDC/ASPH assessment. *Public Health Rep*. 2006;121(3):349–351. doi: [10.1177/003335490612100321](https://doi.org/10.1177/003335490612100321)

7. Carlson K, Wu T, Gilbert T. 196 The availability of injury curricula across accredited schools and programs of public health: a needs assessment. *Inj Prev*. 2020;26(suppl 1): A33.1. DOI: [10.1136/injuryprev-2020-savir.82](https://doi.org/10.1136/injuryprev-2020-savir.82)
8. Runyan CW, Villaveces A, Stephens-Stidham S. Improving infrastructure for injury control: a call for policy action. *Inj Prev*. 2008;14(4):272–273. doi: [10.1136/ip.2008.018804](https://doi.org/10.1136/ip.2008.018804)
9. Garrettson M, Runyan CW, Schiff M, Ramirez M. Injury control training in the USA: meeting the challenge. *Inj Prev*. 2012;18(4):278. doi: [10.1136/injuryprev-2012-040419](https://doi.org/10.1136/injuryprev-2012-040419)
10. Runyan CW, Hargarten S, Hemenway D, et al. An urgent call to action in support of injury control research centers. *Am J Prev Med*. 2010;39(1): 89–92. doi: [10.1016/j.amepre.2010.03.012](https://doi.org/10.1016/j.amepre.2010.03.012)
11. Browne A, Barber CW, Stone DM, Meyer AL. Public health training on the prevention of youth violence and suicide: an overview. *Am J Prev Med*. 2005;29(5 suppl 2):233–239. doi: [10.1016/j.amepre.2005.08.024](https://doi.org/10.1016/j.amepre.2005.08.024)
12. Songer T, Stephens-Stidham S, Peek-Asa C, et al.; National Training Initiative for Injury and Violence Prevention. Core competencies for injury and violence prevention. *Am J Public Health*. 2009; 99(4):600–606. doi: [10.2105/AJPH.2008.137331](https://doi.org/10.2105/AJPH.2008.137331)



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Healthy Aging Through The Social Determinants of Health

Edited by Elaine T. Jurkowski, PhD, MSW
and M. Aaron Guest, PhD, MPH, MSW

This new book examines the link between social determinants of health and the process of healthy aging. It provides public health practitioners and others interacting with the older population with best practices to encourage healthy aging and enhance the lives of people growing older.

Healthy Aging: Through The Social Determinants of Health gives insight into the role each of these plays in the healthy aging process: health and health care; neighborhood and built environment; social support; education; and economics and policy.

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Integrated Multicultural Media Campaign to Increase COVID-19 Education and Vaccination Among Californians, 2021

Martha Eugenia Dominguez, PhD, MPH, MCHES, MA, CLC, Dayanna Macias-Carlos, MPA, Jorge A. Montoya, PhD, Aaron Plant, MPH, and Deborah Neffa-Creech, PhD

Despite the availability of safe, effective COVID-19 vaccines, many remain unvaccinated or partially vaccinated. In 2021, the California Department of Public Health launched a California-wide integrated multicultural vaccine media campaign. The campaign was evaluated in two waves through online surveys with adults (n = 1594; n = 1575). Campaign exposure was associated with looking for vaccine information, visiting a state vaccine Web site, and becoming fully vaccinated during the campaign. Higher campaign exposure was associated with greater odds of vaccine engagement. (*Am J Public Health*. 2022;112(10):1389–1393. <https://doi.org/10.2105/AJPH.2022.306974>)

C COVID-19 vaccines are safe and effective at reducing the risk of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) infection and related hospitalization and death.¹ Despite this, nearly one third of the US population aged 5 years or older (32.1%) is not fully vaccinated.² In California, 27.1% of residents aged 5 years or older were not fully vaccinated as of January 2022.³

COVID-19 vaccine hesitancy is associated with several factors, including demographics, trust in government, and misinformation.⁴ Solutions to overcome vaccine hesitancy are urgently needed.^{4,5} Integrated multicultural media campaigns (i.e., campaigns that coordinate creative, messaging, and media plans to optimize reach and impact) can be used to help overcome vaccine hesitancy and increase COVID-19 vaccination rates on a population scale. Effective media campaigns should be grounded in research

to understand the drivers of vaccine hesitancy among different population segments.⁵ Messages that are tailored to address barriers and motivators to vaccine uptake among specific groups are more likely to succeed.⁶

INTERVENTION AND IMPLEMENTATION

The California Department of Public Health launched a statewide multicultural campaign, Let's Get to Immunity, in 2021 to help Californians in racial/ethnic groups experiencing higher rates of COVID-19 cases and deaths^{7,8} overcome vaccine hesitancy and become fully vaccinated (i.e., two doses of Pfizer or Moderna or one dose of Johnson & Johnson vaccine). The campaign aimed to achieve this by providing science-based vaccine information and education, meeting residents where they are in terms of vaccine readiness based on formative research,

and providing culturally tailored motivational messaging (i.e., messaging incorporating values and concerns deemed important to Californians in racial/ethnic groups prioritized in the campaign, per formative research) about the COVID-19 vaccine as the greatest tool to minimize the impact of the pandemic.

The campaign was designed using extensive research that explored facilitators and barriers to vaccine uptake among diverse groups of Californians by gathering a broad range of beliefs and attitudes across multicultural and multigenerational populations throughout the state. Campaign advertisements addressed concerns and questions (e.g., vaccine safety and side effects and how many others have been vaccinated) and spoke to values and feelings (e.g., family and community health, and hopes for the end of the pandemic) shared during formative research. Advertisements and messages were created for specific

racial/ethnic groups based on these research findings (e.g., “COVID-19 vaccine side effects are normal and a sign that your body is building the protection needed against the virus”; “Join the millions of Californians who have already been vaccinated for COVID-19”; and “For the future of our families and our community, the COVID-19 vaccine is our best tool”). Formative research demonstrated that multicultural communities needed timely, culturally congruent, and science-based information from credible, trusted sources to actively combat misinformation and increase trust in vaccines. The total cost of the campaign, including planning and implementation, was \$40 million.

Two waves of cross-sectional online surveys—May 1–28, 2021 (n = 1594) and August 30–September 14, 2021 (n = 1575)—were conducted to evaluate the campaign. Each survey began several months after initial planned media placements. Californians at least 18 years of age were recruited using a mix of an online marketing research panel with more than 1.5 million Californians who had opted in to be solicited for research questionnaires (49% of wave-1 responses/85% of wave-2 responses), and a random selection from databases of California voter rolls (28%/13% of responses) and one of the three largest US credit-reporting companies (23%/2% of responses).

Panel members were recruited via e-mail, and those recruited via voter rolls and the credit reporting company received text messages to phones with a link to the survey and a mailing with an invitation to complete the survey online. Response rates for text messages and mailings were 6% and 3%, respectively. Recruitment materials named the sponsor organization, included basic information about a

survey regarding COVID-19, and mentioned a \$5 to \$10 incentive (amount depended on source of recruitment).

Quotas were imposed to recruit close to 100 respondents who identified as Asian/Pacific Islander, Native American, Black/African American, or Hispanic/Latinx, and were Spanish-language, Vietnamese-language, or Chinese-language dominant. Those who were fully vaccinated before campaign media placements were ineligible to participate.

Campaign exposure was measured by asking participants about both unaided and aided campaign awareness (i.e., had they listened to or viewed radio, video, and print campaign ads in the last three months). Participants who were aware of the campaign were asked about the frequency of exposure (“About how many times per week did you see or hear a Let’s Get to Immunity ad?”). A three-tiered variable was created using a median split: no exposure, lower-level exposure (saw or heard an ad one time per week or less), and higher-level exposure (saw or heard an ad two or more times per week).

The main outcomes measured were whether participants had looked for information in the past three months to learn about the COVID-19 vaccine or how to get vaccinated, visited the state’s vaccination Web site (<https://www.vaccinateall58.com>), and became fully vaccinated during the campaign wave evaluated. For the vaccination outcome, participants were asked if they had received a COVID-19 vaccine and, if yes, which vaccine (i.e., Pfizer, Moderna, or Johnson & Johnson) and how many doses. Participants who had been fully vaccinated were asked, “About how many weeks ago did you get the second dose (or a single dose for Johnson & Johnson) of the COVID-19 vaccine?”

Those who had received only one dose of Pfizer or Moderna vaccines were categorized as not becoming fully vaccinated during the campaign. Participant characteristics (e.g., age, gender, race/ethnicity, household income, political ideology, and trust in government) and experiences with COVID-19 (e.g., knows someone who has been hospitalized or has died as a result of COVID-19) were also captured.

We used SPSS version 27 (IBM, Somers, NY) to run descriptive statistics for each sample, as well as binary logistic regression models to test associations between campaign exposure and the three outcomes while controlling for other potential predictors. We performed analyses using a 95% confidence interval (two-tailed).

PLACE, TIME, AND PERSONS

Let’s Get to Immunity ran statewide from March 10 through September 30, 2021, and included different strategies and messaging tailored to diverse population segments. Media placements included social media, television, radio, print, and billboard advertising, with a focus on multicultural and multilingual media outlets (see Appendix A: campaign advertisements, available as a supplement to the online version of this article at <https://ajph.org>).

The campaign primarily targeted adults and secondarily families in the state by providing multicultural and multigenerational education and information. As California is very diverse with large populations of non-English speakers, the campaigns ran in 13 languages including Spanish, Cantonese, Mandarin, and Vietnamese, in addition to English.

PURPOSE

The campaign aimed to educate and motivate Californians to become fully vaccinated against COVID-19 by providing science-based information and education about the vaccine, as well as culturally tailored, research-informed motivational messaging about the vaccine's potential to end the pandemic.

EVALUATION AND ADVERSE EFFECTS

In each wave, most participants were non-White (69.1%/59%), and about one fifth took the survey in Spanish, Vietnamese, or Chinese (23.9%/16.8%; Table 1). More than half reported

campaign awareness (61%/53.7%), with most of these individuals reporting higher-level exposure. Many became fully vaccinated during the campaign wave (54.1%/44.6%) and recently looked for COVID-19 vaccine information (71.1%/63.4%). Some reported having visited the California vaccination Web site (10.5%/17.8%). There were significant differences in participant characteristics, experiences with COVID-19, and outcomes by campaign exposure level (Table A, available as a supplement to the online version of this article at <https://ajph.org>). All were included as covariates in the binary logistic regression models.

Across all logistic regression models, campaign exposure was significantly

related to outcomes after controlling for multiple additional potential predictors (Table B, available as a supplement to the online version of this article at <https://ajph.org>). An exposure dose effect was present throughout—those with higher-level exposure had greater odds of looking for COVID-19 vaccine information, visiting the California vaccination Web site, and becoming fully vaccinated than those with lower-level exposure. Those with lower-level campaign exposure were about 40% more likely than those with no campaign exposure to have become fully vaccinated during the campaign wave (wave 1: odds ratio [OR] = 1.47; 95% confidence interval [CI] = 1.07, 2.02; wave 2: OR = 1.45; 95% CI = 1.07, 1.97). Those

TABLE 1— Participant Characteristics, Campaign Exposure, and COVID-19-Related Variables by Evaluation Wave of the Let's Get to Immunity Campaign: California, March–September 2021

	Wave 1, Mean \pm SD or No. (% of Total)	Wave 2, Mean \pm SD or No. (% of Total)
Total	1594	1575
Age, y	43.7 \pm 16.3	40.9 \pm 14.7
Gender		
Male	708 (44.4)	734 (46.6)
Female	859 (53.9)	825 (52.4)
Other ^a	27 (1.7)	16 (1.0)
Race/ethnicity (mutually exclusive)		
White	492 (30.9)	646 (41.0)
Asian/Pacific Islander	460 (28.9)	293 (18.6)
Black/African American	127 (8.0)	162 (10.3)
Hispanic/Latinx	295 (18.5)	296 (18.8)
Mixed/biracial	178 (11.2)	124 (7.9)
Native American/Alaska Native	36 (2.3)	45 (2.9)
Other	6 (0.4)	9 (0.6)
Survey language preferred		
English	1213 (76.1)	1310 (83.2)
Spanish	141 (8.8)	120 (7.6)
Vietnamese	102 (6.4)	44 (2.8)
Chinese (traditional)	69 (4.3)	59 (3.7)
Chinese (simplified)	69 (4.3)	42 (2.7)
Education level ^b		
\leq high school degree/GED	385 (24.2)	385 (24.7)

Continued

TABLE 1— Continued

	Wave 1, Mean ±SD or No. (% of Total)	Wave 2, Mean ±SD or No. (% of Total)
Some college or trade school	366 (23.0)	365 (23.4)
Associate’s degree (2 y)	165 (10.4)	194 (12.4)
College graduate (4 y)	392 (24.6)	416 (26.7)
Graduate work/degree	251 (15.7)	180 (11.6)
Prefer not to answer	35 (2.2)	19 (1.2)
Annual household income,^b \$		
≤ 30 000	459 (28.8)	410 (26.3)
30 001–60 000	369 (23.1)	360 (23.1)
60 001–90 000	271 (17.0)	311 (19.9)
> 90 000	368 (23.1)	395 (25.3)
Don’t know or prefer not to say	127 (8.0)	83 (5.3)
Area of residence^{b,c}		
Urban	792 (50.9)	810 (52.0)
Suburban	709 (45.6)	591 (37.9)
Rural	54 (3.5)	158 (10.1)
Views in most political matters^b		
Liberal	505 (31.7)	453 (29.1)
Moderate	557 (34.9)	528 (33.9)
Conservative	297 (18.6)	383 (24.6)
Prefer not to answer	235 (14.7)	195 (12.5)
Trusts the US government to look out for the interests of “people like you”^b		
Not at all	354 (22.2)	495 (31.8)
Some	910 (57.1)	753 (48.3)
A lot	330 (20.7)	311 (19.9)
Campaign exposure		
No exposure	622 (39.0)	729 (46.3)
Exposure (unaided or aided awareness)	972 (61.0)	846 (53.7)
Lower-level exposure (1 time per week or less)	398 (40.9)	356 (42.1)
Higher-level exposure (2 times per week or more)	574 (59.1)	490 (57.9)
Experiences with COVID-19 and outcome variables		
Knows someone who has been hospitalized or has died as a result of having COVID-19	676 (42.4)	703 (44.6)
Has a household member who has received a COVID-19 vaccine	842 (52.8)	772 (49.0)
Has looked for information in the past 3 mo to learn about the COVID-19 vaccine or how to get vaccinated	1133 (71.1)	998 (63.4)
Has visited the California vaccination Web site (https://www.vaccinateall58.com)	168 (10.5)	281 (17.8)
COVID-19 vaccination status		
No vaccine doses received (unvaccinated)	545 (34.2)	704 (44.7)
Did not become fully vaccinated during the campaign (received first dose only)	186 (11.7)	169 (10.7)
Became fully vaccinated during the campaign wave	863 (54.1)	702 (44.6)

Note. GED = general educational development.

^aOther gender includes transgender, gender nonbinary/nonconforming, or prefer not to say.

^bData missing (n = 16) for wave 2 sample.

^cData missing (n = 39) for wave 1 sample.

with higher-level exposure were between 60% (OR = 1.63; 95% CI = 1.21, 2.18) and 100% (OR = 2.01; 95% CI = 1.50, 2.68) more likely to do so. The analyses also revealed other factors associated with higher or lower odds of becoming fully vaccinated.

We did not observe adverse effects.

SUSTAINABILITY

Integrated multicultural media campaigns with evaluations can be an efficient, effective way to help improve behaviors on a wide scale. The California Department of Public Health will build on lessons learned from these evaluation waves for future public health behavior campaigns.

PUBLIC HEALTH SIGNIFICANCE

These results strongly indicate that multicultural campaign efforts designed to educate, inform, and motivate Californians to become fully vaccinated for COVID-19 were effective. Results from each evaluation wave clearly and consistently produced significant associations between campaign exposure and vaccination-related behaviors among a diverse sample of residents. Our study also found evidence of a dose-response relationship between campaign exposure and outcomes, including becoming fully vaccinated during the campaign wave. This study adds to the limited literature on the impact of an integrated multicultural media campaign on vaccination uptake, including a discussion of a dose-response effect.^{9,10}

The analyses also found that specific participant characteristics were related to vaccine uptake and engaging in vaccination-related behaviors. These factors, including race/ethnicity,

urbanicity, political ideology, and trust in government, should be further explored in formative research and considered when creating tailored ads for future integrated multicultural media communication efforts. It should be noted that while we controlled for various factors in our models, other unmeasured, omitted confounders could exist and help to better explain differences among participants with varying levels of exposure to the campaign. *AJPH*

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CONTRIBUTORS

M. E. Dominguez contributed to campaign formative research, development, implementation, media evaluation, and original draft preparation. D. Macias-Carlos contributed to campaign development and implementation. A. Plant contributed to study design, study implementation, and original draft preparation. D. Neffa-Creech contributed to study design and analysis. J. A. Montoya contributed to conceptualization, study design, data analysis, and original draft preparation. All authors reviewed and edited the draft manuscript and approved the version to be published.

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CONFLICTS OF INTEREST

The authors have no conflicts of interest to declare.

HUMAN PARTICIPANT PROTECTION

Sterling institutional review board designated this study as non-human participant research.

REFERENCES

- Johnson AG, Amin AB, Ali AR, et al. COVID-19 incidence and death rates among unvaccinated and fully vaccinated adults with and without booster doses during periods of Delta and Omicron variant emergence—25 US jurisdictions, April 4–December 25, 2021. *MMWR Morb Mortal Wkly Rep*. 2022;71(4):132–138. <http://dx.doi.org/10.15585/mmwr.mm7104e2>
- Centers for Disease Control and Prevention. COVID-19 vaccinations in the United States. Available at: https://covid.cdc.gov/covid-data-tracker/#vaccinations_vacc-total-admin-rate-total. Accessed January 28, 2022.
- California ALL. California statewide vaccination data. 2022. Available at: <https://covid19.ca.gov/vaccination-progress-data/#overview>. Accessed January 28, 2022.
- Daly M, Jones A, Robinson E. Public trust and willingness to vaccinate against COVID-19 in the US from October 14, 2020, to March 29, 2021. *JAMA*. 2021;325(23):2397–2399. <https://doi.org/10.1001/jama.2021.8246>
- Evans WD, French J. Demand creation for COVID-19 vaccination: overcoming vaccine hesitancy through social marketing. *Vaccines (Basel)*. 2021;9(4):319. <https://doi.org/10.3390/vaccines9040319>
- French J, Deshpande S, Evans W, Obregon R. Key guidelines in developing a pre-emptive COVID-19 vaccination uptake promotion strategy. *Int J Environ Res Public Health*. 2020;17(16):5893. <https://doi.org/10.3390/ijerph17165893>
- California Health and Human Services Agency. COVID-19 time-series metrics by county and state. Available at: <https://data.chhs.ca.gov/dataset/covid-19-time-series-metrics-by-county-and-state>. Accessed December 1, 2020.
- California Department of Public Health. COVID-19 age, race and ethnicity data. Available at: <https://www.cdph.ca.gov/Programs/CID/DCDC/Pages/COVID-19/Age-Race-Ethnicity.aspx>. Accessed December 1, 2020.
- Farrelly MC, Davis KC, Haviland ML, Messeri P, Heaton CG. Evidence of a dose-response relationship between "truth" antismoking ads and youth smoking prevalence. *Am J Public Health*. 2005;95(3):425–431. <https://doi.org/10.2105/AJPH.2004.049692>
- McAfee T, Davis KC, Shafer P, Patel D, Alexander R, Bunnell R. Increasing the dose of television advertising in a national antismoking media campaign: results from a randomised field trial. *Tob Control*. 2017;26(1):19–28. <https://doi.org/10.1136/tobaccocontrol-2015-052517>

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Feed1st, No Questions Asked: How a Hospital-Based Food Pantry Program Grew Its Impact During the COVID-19 Pandemic

Cristianne R. M. Frazier, PhD, El A. Pinkerton, MPH, Mellissa Grana, BA, Meryl Davis, BA, Spencer Asay, BS, Jennifer A. Makelarski, PhD, MPH, and Stacy Tessler Lindau, MD, MAPP

Feed1st, a no-questions-asked, self-serve food pantry program at a Chicago, Illinois, medical center, increased its impact during the COVID-19 pandemic, adding five new pantries and distributing 124% more food in March 2020 to November 2021 (42 970 pounds or 36 000 meals) than in the same period of 2018 to 2019 (19 220 pounds or 16 000 meals). Of 11 locations, distribution was highest in a phlebotomy waiting area and a cafeteria pantry. The community-engaged model enabled Feed1st to increase food access for patients, caregivers, and workers during the pandemic. (*Am J Public Health.* 2022;112(10):1394–1398. <https://doi.org/10.2105/AJPH.2022.306984>)

We describe the Feed1st hunger mitigation program, established in 2010, and its rapid expansion during the COVID-19 pandemic. The impact of this open-access model is compared with the only other hospital-based food pantry reporting its impact during the same period, which uses the prevalent questions-asked, limited-access approach.

INTERVENTION AND IMPLEMENTATION

Feed1st addresses food insecurity at the point of care using open-access pantries located in a medical center.^{1,2} Self-serve, no-questions-asked pantries are open 24 hours a day, seven days a week, 365 days a year, to everyone in the medical center. There are no eligibility requirements, and signage invites people to take as much food as they need for themselves and others.

People are also invited to participate with donations, volunteer time, suggestions, and by receiving a newsletter. Information about community-based food supports is available at each pantry. Operations are guided by an advisory board comprising community members and partners, patients, hospital administrators, nurses, doctors, researchers, and medical students.

Prepandemic Operations

Feed1st opened its first pantry in a children's hospital chapel closet in 2010.¹ In the following decade, Feed1st added five pantries in the children's hospital family lounges, including in the emergency department, and one in an adult oncology clinic waiting area. Pantries were regularly stocked by Feed1st staff and volunteers with shelf-stable food purchased at-cost from a regional food depository. Food was delivered

from the depository to a central storage location at the medical center, then distributed to pantries and satellite storage closets near pantries. Between distributions, trained volunteers stocked pantries from satellite storage. The amount of food procured for a pantry was based on the previous month's usage. Space was supported by the medical center's community benefit program.³ Anonymous, entirely voluntary sign-in data were collected at each pantry site (Table A, available as a supplement to the online version of this article at <https://ajph.org>). Patrons learned about pantries through referrals from clinicians, hospital admissions materials, signage, social media, and word of mouth.

Pandemic Operations

In March 2020, all children's hospital pantries closed because of infection

control requirements. The oncology pantry remained open. In response to the closures, and with support from partners, Feed1st rapidly opened five new pantries located in a hospital cafeteria (April 2020; [Figure 1](#)), the children's hospital lobby (May 2020), a staff meeting room (June 2020), the adult emergency department (September 2020), and the phlebotomy waiting area (March 2021) (Table B, available as a supplement to the online version of this article at <https://ajph.org>). Pantries in the children's hospital family lounges reopened between January and May 2021.

All pantries operated according to the prepandemic open-access model. Supply chain operations were modified

when the hospital volunteer program shut down for infection control purposes. Medical students and nurses increased their volunteer hours. Hand sanitizer and signage to reduce COVID-19 transmission were introduced (i.e., “touch only what you will take,” and “maintain 6 feet of social distancing”). Signage in the oncology clinic directed nononcology patient patrons to other Feed1st pantries to reduce risk to immunocompromised patients. A QR code linked to an anonymous, voluntary, electronic sign-in questionnaire temporarily replaced, then supplemented, pen-and-paper sign-ins (Table A).

New marketing and communications strategies were implemented to

improve access. Pantry locations were featured in hospital incident command system messages to all staff in April 2020 and June 2020. In May 2020, a physician assistant created and published a digital order for the electronic medical record that enabled clinicians to easily share pantry locations with patients. Feed1st was invited by the chief operating officer of the medical center to share its pandemic response effort with 500 hospital leaders (including its new president) in November 2020, multiplying community champions. Location information was added to most in-patient TV screens in March 2021, and nine news stories (internal and external) appeared in print, online,

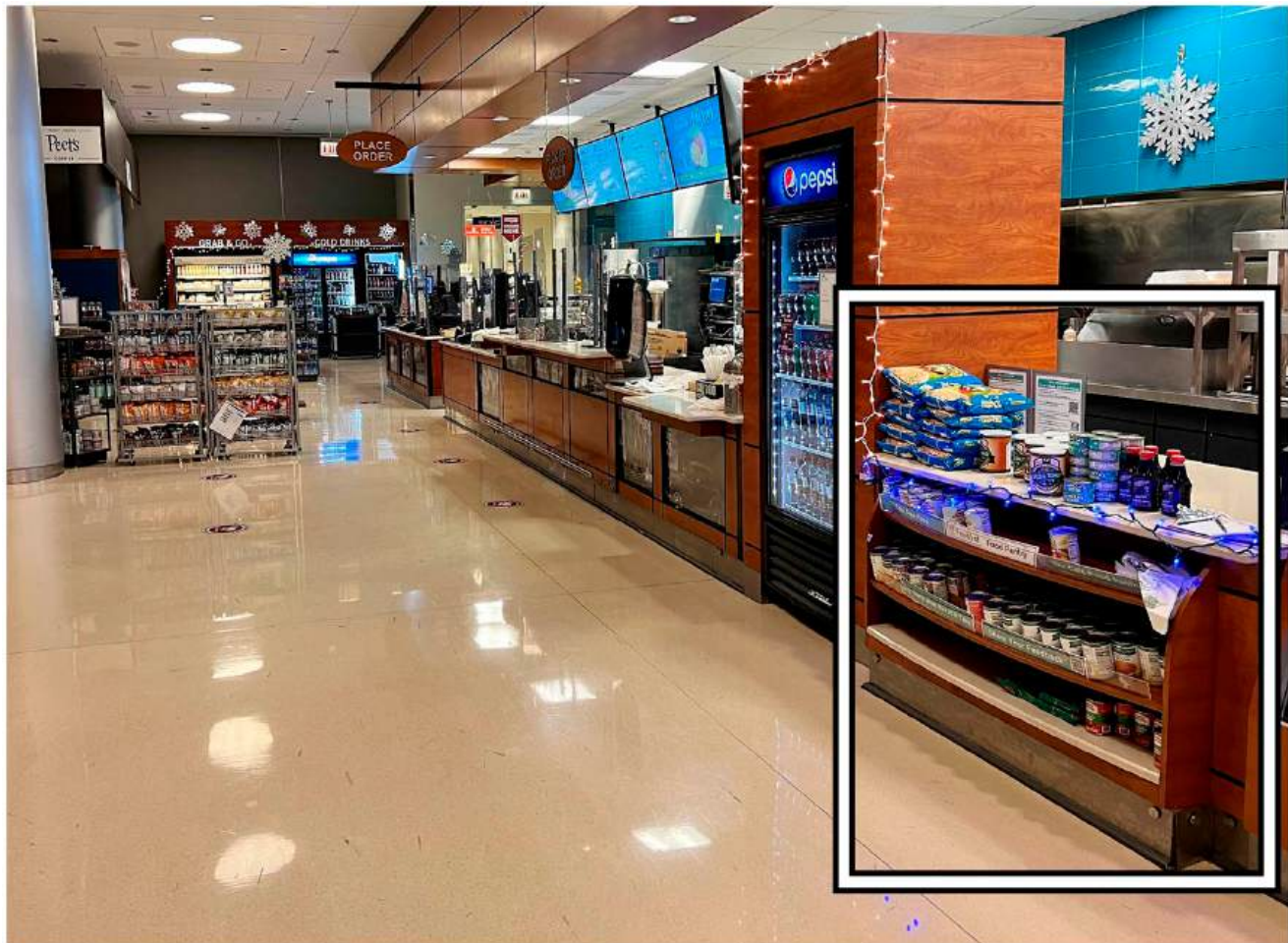


FIGURE 1— Placement of Feed1st Food Pantry in a Hospital Food Retail Location: Chicago, IL

or both, including one that interviewed a Feed1st patron.⁴

PLACE, TIME, AND PERSONS

Feed1st currently operates 11 pantries across the University of Chicago Medicine campus located on Chicago's South Side, including in the children's hospital, emergency departments, outpatient clinics, a hospital cafeteria, and a staff meeting room. This study describes the impact of Feed1st in the 21 months since the start of the COVID-19 pandemic (March 2020–November 2021) compared with a prepandemic reference period (March 2018–November 2019).

Seventy-six percent of residents in the hospital's primary service area are

African American or Black, 13% are Hispanic, and 49% have an annual household income below 200% of the federal poverty level.⁵

PURPOSE

The purpose of Feed1st is to mitigate food insecurity among patients, families, and staff at an urban medical center.

EVALUATION AND ADVERSE EFFECTS

Pounds of food procured for and distributed from each pantry location were tracked monthly (collectively referred to as "distributed").

Prepandemic Operations

Feed1st distributed 19 220 pounds of food (16 000 meals) to at least 3077 households and 8718 individuals from March 2018 to November 2019 (Figure 2). Pounds of food distributed is a common impact metric reported by food banks.⁶ The total number of households and individuals were sums of actual, voluntary sign-in data and represent the minimum number served.

Pandemic Operations

Feed1st distributed 42 970 pounds of shelf-stable food (36 000 meals) March 2020 to November 2021, a 124% increase relative to the prepandemic

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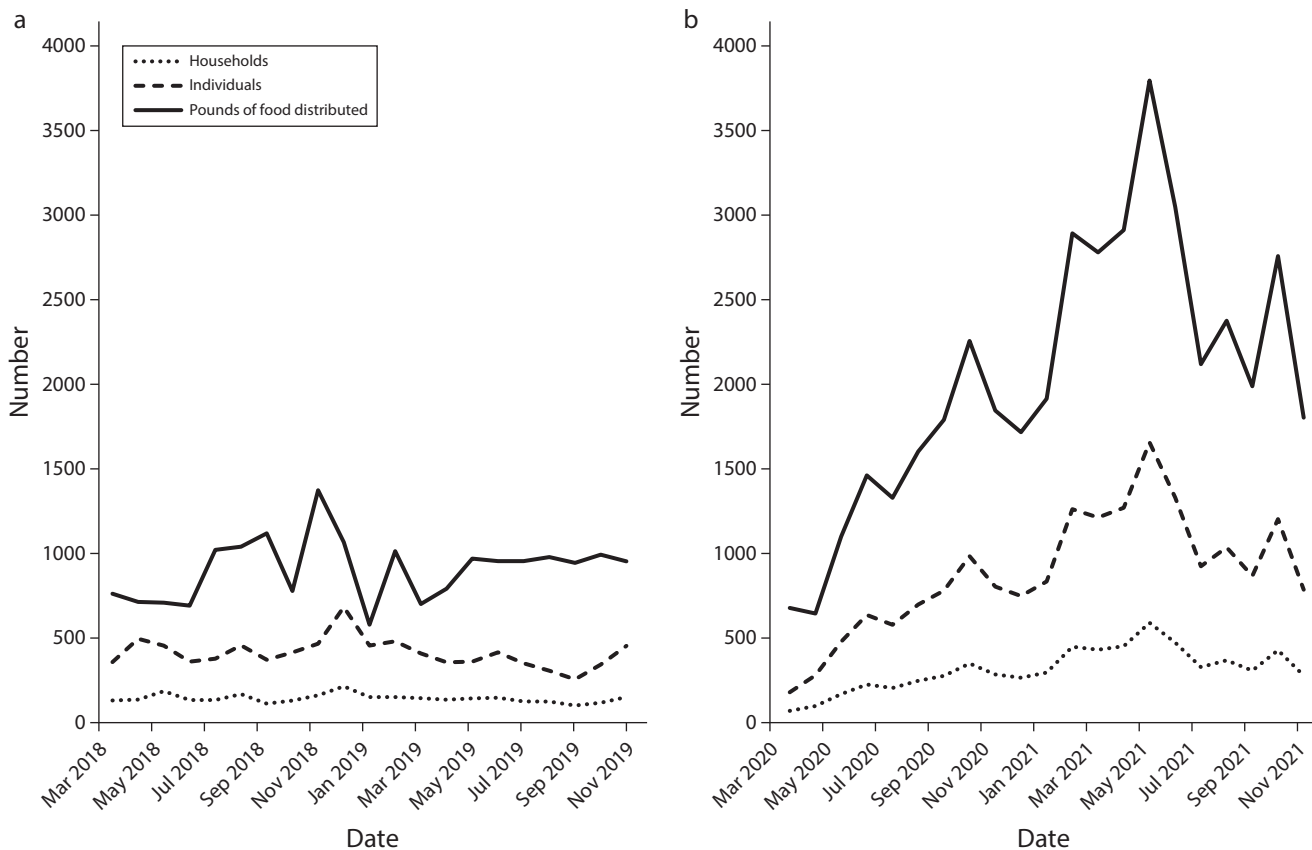


FIGURE 2— Monthly Pounds of Food Distributed and Usage (a) Before (March 2018–November 2019) and (b) During (March 2020–November 2021) the COVID-19 Pandemic: Chicago, IL

reference period (Figure 2). Average monthly usage was highest in the phlebotomy waiting area (606 pounds), followed by the hospital cafeteria (471 pounds), and was lowest in the staff pantry (218 pounds; Table B). Cafeteria management reported that the pantry in that location had no negative or positive impact on sales. Surprisingly, usage did not decrease at the children's hospital despite closure over 10 to 14 months of five of six pantries located in closed family lounges; distribution from the new lobby pantry compensated for these closures. Usage decreased in the oncology clinic by 12.7%, reflecting a redirection of nononcology patient patrons to alternate locations.

The electronic sign-in was rarely utilized ($n = 21$). After a pen was added back to each clipboard, paper sign-ins were higher, but, as expected, also very low ($n = 1310$) because of ongoing COVID-19 infection control practices and concerns (Appendix B, available as a supplement to the online version of this article at <https://ajph.org>). Therefore, based on monthly food distribution (in pounds) and mean prepandemic pantry usage (6.4 pounds per household or 2.3 pounds per individual during the period March 2018–November 2019), we estimated monthly and total households (6600) and individuals (18 600) served for the period March 2020 to November 2021 (Figure 2; Appendix B, available as a supplement to the online version of this article at <https://ajph.org>).

Pantry use could be stigmatizing, a concern we addressed by requiring no permission or documentation; posting a highly visible invitation to take as much food as needed for anyone in need; promoting opportunities to contribute back to Feed1st through volunteerism, giving feedback, and receiving our

newsletter; and by making available a variety of access points (Figure A, available as a supplement to the online version of this article at <https://ajph.org>).

SUSTAINABILITY

Feed1st is sustained through the hospital's operating budget and community benefit program, community engagement,⁷ volunteer programs, donations, and grants. At-cost or free food from the local food depository is also key to sustainability.

PUBLIC HEALTH SIGNIFICANCE

Nearly all food pantries require patrons to answer questions about their identity, income, or both.⁸ This practice enables tracking but can deter use. By contrast, the Feed1st model minimizes stigma and facilitates use by requiring no permission. This model delivered an increase in short-term food assistance during a massive public health and socioeconomic emergency. Increased impact was facilitated by the successful introduction of a first-of-its-kind food pantry in a hospital cafeteria. By contrast, a more traditional hospital food pantry (referral or ID required, not self-serve, limited hours and food access) serving a similar population, including staff, reported a decrease in food procured and families served March 2020 to August 2020, compared with before the pandemic (Olivia Weinstein and Ashley McCarthy, e-mail communications, February 17 and 25, 2022).⁹ During the same period, Feed1st's open-access model delivered a 27% increase in food distribution. In addition, at least two other hospitals used the Feed1st toolkit¹⁰ to rapidly launch new open-access pantries during the

pandemic.^{11,12} Increased impact of the Feed1st open-access, no-barriers model during a major public health crisis suggests that food pantry systems might re-examine structural barriers to access and the consequences for public health. **AJPH**

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S. T. Lindau conceptualized and supervised the study, contributed writing and editing for critical content, and provided material support. C. R. M. Frazier led the writing and assisted with the study and analyses. E. A. Pinkerton and J. A. Makelarski led analyses and assisted with writing. M. Grana, M. Davis, and S. Asay assisted with the study, analyses, and writing.

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CONFLICTS OF INTEREST

S. T. Lindau discloses that she is founder and co-owner of NowPow LLC, a company acquired in September 2021 by Unite Us LLC, where she is a paid advisor and a stockholder. She is president of MAPSCorps, a 501c3 nonprofit organization, and serves on other nonprofit boards. Neither the University of Chicago nor the University of Chicago Medicine endorses or promotes any NowPow, Unite Us, or MAPSCorps product or service. S. T. Lindau holds debt in Glenbervie Health LLC and health care–related investments managed by third parties. S. T. Lindau is a contributor to UpToDate Inc. The University of Chicago receives royalties from UpToDate Inc. All other authors have no competing interests to disclose.

HUMAN PARTICIPANT PROTECTION

Data presented are not human participant research data.

REFERENCES

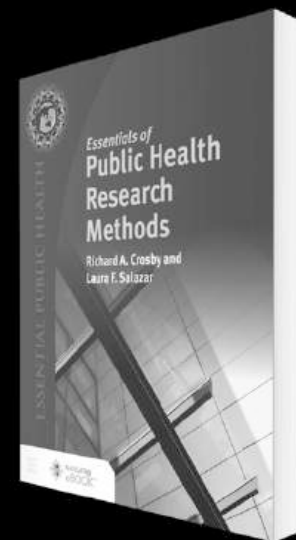
1. Makelarski JA, Thorngren D, Lindau ST. Feed first, ask questions later: alleviating and understanding caregiver food insecurity in an urban children's hospital. *Am J Public Health*. 2015;105(8):e98–e104. <https://doi.org/10.2105/AJPH.2015.302719>
2. Makelarski JA, Abramssohn E, Benjamin JH, Du S, Lindau ST. Diagnostic accuracy of two food insecurity screeners recommended for use in health care settings. *Am J Public Health*. 2017;107(11):1812–1817. <https://doi.org/10.2105/AJPH.2017.304033>
3. Community Benefit Connect. What is community benefit? Available at: https://www.communitybenefitconnect.org/about-us/about_what-is. Accessed February 9, 2022.
4. Levine L. Hospital food pantries serve staff, patients, caregivers, and family. *South Side Weekly*. January 2021. Available at: <https://southsideweekly.com/hospital-food-pantries-serve-staff-patients-caregivers-and-family>. Accessed February 9, 2022.
5. US Census Bureau. 2015–2019 American Community Survey 5-year estimates. 2020. Available at: <https://www.census.gov/data/developers/data-sets/acs-5year.html>. Accessed December 2, 2021.
6. Food bank use down, but need still far above pre-pandemic levels. *PBS NewsHour*. October 12, 2021. Available at: <https://www.pbs.org/newshour/economy/food-bank-use-down-but-need-still-far-above-pre-pandemic-levels>. Accessed February 11, 2022.
7. Lindau ST, Makelarski JA, Chin MH, et al. Building community-engaged health research and

discovery infrastructure on the South Side of Chicago: science in service to community priorities. *Prev Med*. 2011;52(3-4):200–207. <https://doi.org/10.1016/j.ypmed.2011.01.001>

8. US Department of Agriculture. The Emergency Food Assistance Program. January 2020. Available at: https://fns-prod.azureedge.us/sites/default/files/resource-files/tefap-program-fact-sheet-2019_1.6.20.pdf. Accessed February 10, 2022.
9. Weinstein O, Donovan K, McCarthy AC, et al. Nourishing underserved populations despite scarcer resources: adaptations of an urban safety net hospital during the COVID-19 pandemic. *Am J Public Health*. 2021;111(4):663–666. <https://doi.org/10.2105/AJPH.2020.306132>
10. Feed1st by the Lindau Laboratory at The University of Chicago. Feed1st food pantry toolkit. May 2019. Available at: https://d1xwl80c5c04ho.cloudfront.net/sites/obgyn/files/2019-09/Feed1st%20Toolkit_EDITION%201.0%2009132019.pdf. Accessed February 9, 2022.
11. Mead S. As always, supporting families. *Hopkins Children's: The John Hopkins Children's Center Magazine*. Fall 2021. Available at: https://www.hopkinsmedicine.org/johns-hopkins-childrens-center/_documents/_publications/hopkins-childrens-magazine-fall-2021.pdf. Accessed February 9, 2022.
12. Swedish Hospital. The Cupboard. Available at: <https://swedishcovenant.org/community/food-connections-program/pop-up-food-pantry>. Accessed February 9, 2022.

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COVID Community-Engaged Testing in Alabama: Reaching Underserved Rural Populations Through Collaboration

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Rural communities are often underserved by public health testing initiatives in Alabama. As part of the National Institutes of Health's Rapid Acceleration of Diagnostics–Underserved Populations initiative, the University of Alabama at Birmingham, along with community partners, sought to address this inequity in COVID-19 testing. We describe the participatory assessment, selection, and implementation phases of this project, which administered more than 23 000 COVID-19 tests throughout the state, including nearly 4000 tests among incarcerated populations. (*Am J Public Health*. 2022;112(10):1399–1403. <https://doi.org/10.2105/AJPH.2022.306985>)

Funded as part of the National Institutes of Health's Rapid Acceleration of Diagnostics–Underserved Populations initiative (RADx-UP),¹ COVID Community-Engaged Testing in Alabama (COVID COMET AL) is a partnership between the University of Alabama at Birmingham (UAB) Center for AIDS Research and community partners, including ConnectionHealth, a community health worker (CHW) organization; Acclinate, an organization that promotes diversity within health care and clinical trials; and five Area Health Education Centers (AHEC) that are geographically distributed to serve rural communities in Alabama's 67 counties.

INTERVENTION AND IMPLEMENTATION

Grounded in the Adopting and Demonstrating the Adaptation of Prevention Techniques (ADAPT) framework² and informed by a precision public health

approach,³ descriptive epidemiology was used to identify the rural counties most impacted by COVID-19 for prioritization of a testing intervention delivered locally by community partners. In addition to providing test kits and access to a centralized laboratory, the COVID COMET AL intervention included peer health advocates,⁴ CHWs,⁵ and venue-based testing^{6,7} deployed in local rural counties by AHEC and ConnectionHealth, with Acclinate providing communications and marketing support.

PLACE, TIME, AND PERSONS

We planned to deploy the COVID COMET AL combination intervention program in six highly impacted rural Alabama counties in two successive waves of three counties each. As a community-engaged testing program, we adjusted this strategy in response

to feedback from community partners, the Human Subjects Unit, and the Community and Scientific Advisory Board. In reviewing epidemiological data, these groups felt that the widespread impact of COVID-19 on all rural communities statewide was so substantial that the testing program should not be limited to only six of Alabama's 67 counties.

Accordingly, the investigative team and community partners opted to leverage local resources and relationships to deploy the testing initiative across the entire state, while prioritizing rural counties most severely impacted by COVID-19 as determined by epidemiology. CHWs from the partner organizations, as well as nurses and other personnel in venues such as jails and schools that were working with AHEC, provided testing services. These testing services included Aptima polymerase chain reaction (PCR) testing⁸ with 48-hour return of results and Visby

point-of-care PCR testing⁹ with on-site results in 30 minutes.

PURPOSE

The overarching vision for the RADx-UP program is “one consortium of inter-linked community-engaged research projects across the United States [working] to understand COVID-19 health disparities and to deploy implementation strategies to improve the reach, acceptance, uptake, and sustainability of COVID-19 testing.”¹⁰ As part of this consortium, the purpose of COVID COMET AL was to empower community partners to deploy testing and mitigation services in rural communities across Alabama that are

disproportionately impacted by COVID-19 to attenuate intersectional health inequities.

EVALUATION AND ADVERSE EFFECTS

From October 2020 through February 2022, testing was conducted in myriad rural community settings spearheaded by regional AHEC offices (Figure 1), with high uptake in rural jails, particularly with the point-of-care Visby PCR test (Figure 2). A total of 23 394 tests were conducted via COVID COMET AL, including 18 503 Aptima PCR tests and 4891 Visby point-of-care PCR tests. Using the definition from the Alabama Rural Health Association, we conducted

14 667 tests (62%) in rural counties.¹¹ Tests were conducted in 55 of Alabama’s 67 counties, and they were sent to a central laboratory at the UAB Heersink School of Medicine for analysis. As part of standard COVID-19 testing protocol, CHWs would collect participant demographic data via a standardized form to submit with each test.

Of the total, 12% (n = 2708) returned positive results, while 88% (n = 20 632) were negative. We were unable to analyze less than 1% (n = 54) of tests. Of those individuals tested, 54% (n = 12 701) were Black, 35% (n = 8104) were White, 5% (n = 1283) were Hispanic, 2% (n = 578) were Asian, and less than 1% (n = 12) were American Indian or Alaskan Native or Native Hawaiian or other

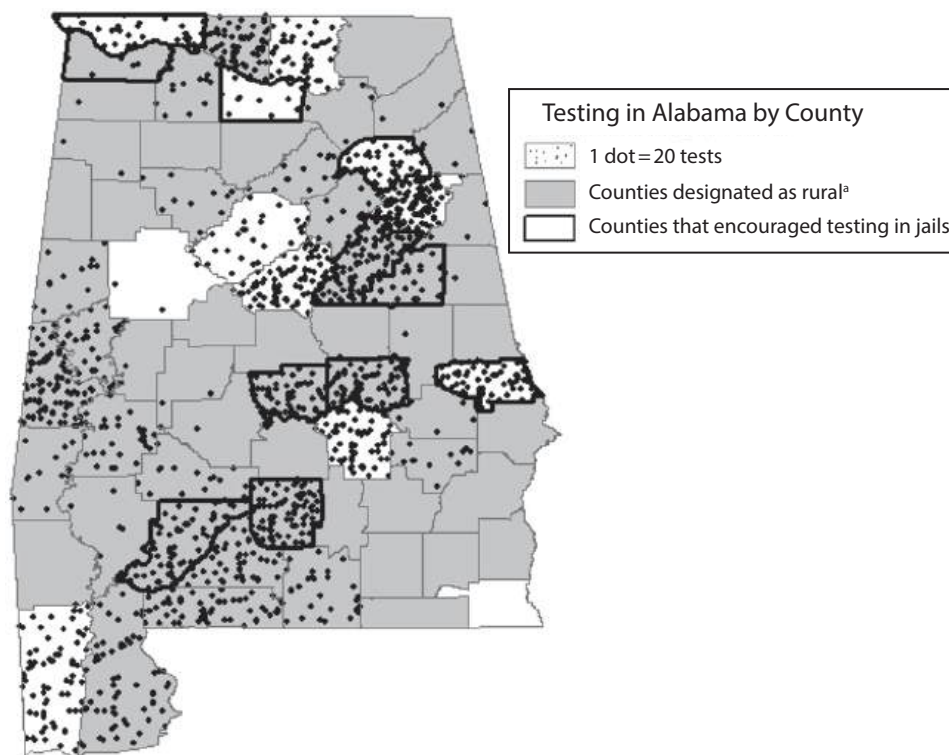


FIGURE 1— COVID COMET AL Testing Density in Alabama: October 2020–February 2022

Note. COVID COMET AL = COVID Community-Engaged Testing in Alabama. The map was created in Esri’s desktop geospatial processing program, ArcMap. ArcMap randomly places dots within a polygon—in this case, counties—with each dot representing 20 tests conducted in a county.

^aRurality, designated by the Alabama Rural Health Association,¹¹ is indicated with gray shading, and a darker outline is used to indicate counties that encouraged testing in jails.

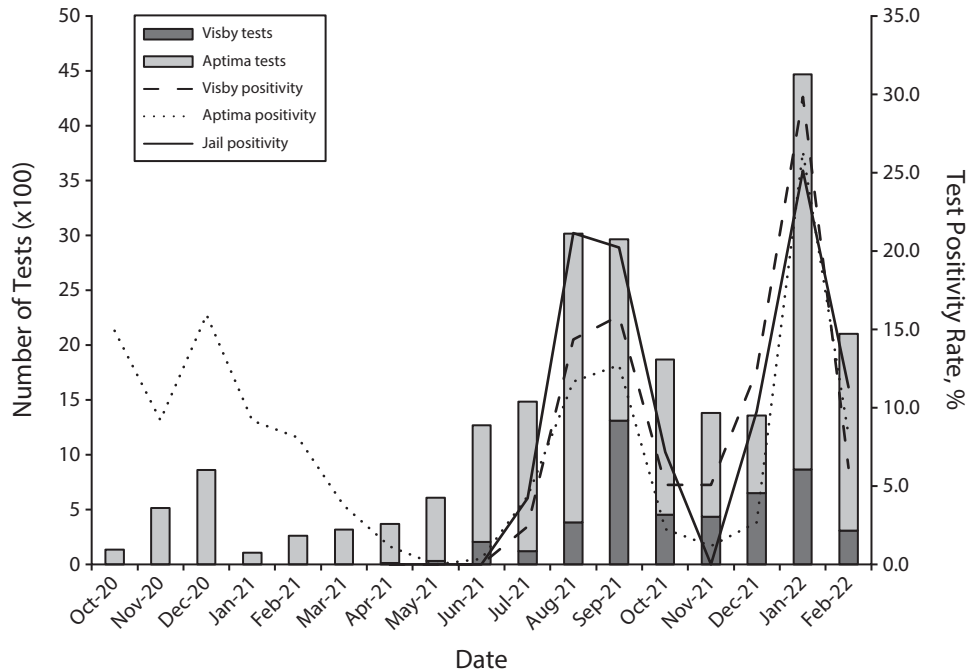


FIGURE 2— COVID COMET AL Testing Numbers and Percent Positivity in Alabama: October 2020–February 2022

Note. COVID COMET AL = COVID Community-Engaged Testing in Alabama.

Pacific Islander. Less than 1% (n = 195) identified as “some other race,” and we did not capture racial data for 2% (n = 521) of tests. As a note, following reporting guidance from the US Centers for Disease Control and Prevention, “Hispanic” was captured as a racial, instead of an ethnic, category.

Fifty-three percent (n = 12 505) of those tested identified as female, and 45% (n = 10 492) identified as male. Less than 1% (n = 10) identified as another gender, and we were unable to capture gender data for 2% (n = 387) of those tested. Nearly 13% (n = 2992) of those tested were minors (aged < 18 years), 36% (n = 8331) were aged between 18 and 40 years, 39% (n = 9031) were aged between 41 and 65 years, 12% (n = 2841) were aged between 66 and 85 years, and nearly 1% (n = 198) were aged older than 85 years. We were unable to capture the age of one participant.

Leveraging local partnerships within each AHEC service area, the COVID COMET AL team was consistently able to provide testing services within jails and other congregate living facilities throughout the state. The team conducted 3852 tests in jails, 11% (n = 382) of which were positive. The majority of these tests were the Visby point-of-care PCR test (n = 3168), which allowed jails to test new inmates for COVID-19 and receive results in 30 minutes, obviating the need for mandatory isolation in the case of a negative result and informing quarantine measures in a timely manner when indicated.

Notably, testing procedures established with AHEC community partners and their existing relationships with local entities in their catchment areas proved valuable in scaling up testing services to meet local demand in the face of the Delta and Omicron surges (Figure 2). Between July 25 and

September 25, 2021, 669 people were tested weekly, on average, with a 13.9% average weekly positivity rate marking a significant increase in both testing volume and positivity rate ($P < .01$; 8.8% higher positivity rate; 95% confidence interval [CI] = 7.7%, 9.8%) during the Delta wave when compared with a weekly average of 137 tests and total positivity rate of 5.1% between October 2, 2020, and July 24, 2021. These numbers increased further during the Omicron wave, between December 25, 2021, and February 11, 2022, with a weekly average of 842 tests and a 25.8% positivity rate, reflecting a significant change from the baseline 5.1% positivity rate ($P < .01$; 20.7% higher positivity rate; 95% CI = 19.4%, 21.9%).

SUSTAINABILITY

Although RADx-UP funding for direct testing services ended February 28,

2022, the COVID COMET AL infrastructure at UAB continues to support community partners providing community-based testing. Alabama AHEC provides ongoing COVID-19 testing in rural counties statewide via a multicomponent intervention strategy including peer health advocates, CHWs, and venue-based testing, largely funded by the Alabama Department of Public Health. The centralized UAB laboratory and the data management cores continue to provide services, including data reporting and visualization, for ongoing COVID-19 testing initiatives led by community partners. They plan to continue these roles indefinitely because AHEC continues to request them and because they bring value to other community partners.

PUBLIC HEALTH SIGNIFICANCE

We report on an academic–community partnership funded via a federal initiative and adapted to meet local needs by providing 23 394 COVID-19 tests to Alabamians statewide. Notably, testing services reached several underserved populations, including individuals experiencing incarceration and people living in rural counties, who have not historically been reached by screening and testing initiatives for both communicable and noncommunicable diseases. Building upon these relationships and testing successes, the UAB Center for AIDS Research is pursuing opportunities to provide testing services for sexually transmitted infections, including HIV, and vaccine-preventable diseases, like influenza, to rural Alabamians facing intersectional inequities. The inroads made with local rural jails hold the potential to broaden public health screening and prevention programs

for a largely underreached population, a promising legacy of the COVID COMET AL project. *AJPH*

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CONFLICTS OF INTEREST

All authors report no conflicts of interest.

HUMAN PARTICIPANT PROTECTION

This project received expedited approval from the institutional review board at the University of Alabama at Birmingham, protocol number IRB-300006055, on September 16, 2020.

REFERENCES

1. Tromberg BJ, Schwetz T, Pérez-Stable E, et al. Rapid scaling up of Covid-19 diagnostic testing in the United States—the NIH RADx Initiative. *N Engl J Med*. 2020;383(11):1071–1077. <https://doi.org/10.1056/NEJMsr2022263>
2. McLeroy VS, Galbraith J, Cummings B, et al. Adapting evidence-based behavioral interventions for new settings and target populations. *AIDS Educ Prev*. 2006;18(suppl A):59–73. <https://doi.org/10.1521/aeap.2006.18.supp.59>
3. Khoury MJ, Iademarco M, Riley W. Precision public health for the era of precision medicine. *Am J Prev Med*. 2016;50(3):398–401. <https://doi.org/10.1016/j.amepre.2015.08.031>
4. Marquez C, Kerkhoff A, Naso J, et al. A multi-component, community-based strategy to facilitate COVID-19 vaccine uptake among Latinx populations: from theory to practice. *PLoS One*. 2021;16(9):e0257111. <https://doi.org/10.1371/journal.pone.0257111>
5. Ballard M, Bancroft E, Nesbit J, et al. Prioritising the role of community health workers in the COVID-19 response. *BMJ Glob Health*. 2020;5(6):ce002550. <https://doi.org/10.1136/bmjgh-2020-002550>
6. English K, Lei U, Shipman-Amuwo F, et al. Community-based testing for SARS-CoV-2—Chicago, Illinois, May–November 2020. *MMWR Morb Mortal Wkly Rep*. 2021;70(19):707–711. <https://doi.org/10.15585/mmwr.mm7019a4>
7. Kerkhoff AD, Sachdev D, Mizany S, et al. Evaluation of a novel community-based COVID-19 “test-to-care” model for low-income populations. *PLoS One*. 2020;15(10):e0239400. <https://doi.org/10.1371/journal.pone.0239400>
8. Newsom K, Zhang Y, Chamala S, Martinez K, Clare-Salzler M, Starostik P. The Hologic Aptima SARS-CoV-2 assay enables high ratio pooling saving reagents and improving turnaround time. *J Clin Lab Anal*. 2021;35(9):e23888. <https://doi.org/10.1002/jcla.23888>
9. Renzoni A, Perez F, Ngo Nsoga M, et al. Analytical evaluation of Visby Medical RT-PCR portable

device for rapid detection of SARS-CoV-2. *Diagnos- tics (Basel)*. 2021;11(5):813. <https://doi.org/10.3390/diagnostics11050813>

10. National Institutes of Health. NOT-OD-20-120: Notice of Special Interest (NOSI): Emergency competitive revisions for community-engaged research on COVID-19 testing among under- served and/or vulnerable populations. 2020. Available at: [https://grants.nih.gov/grants/guide/ notice-files/not-od-20-120.html](https://grants.nih.gov/grants/guide/notice-files/not-od-20-120.html). Accessed April 29, 2022.
11. Alabama Rural Health Association. Analysis of urban vs. rural. Available at: [https://arhaonline. org/analysis-of-urban-vs-rural](https://arhaonline.org/analysis-of-urban-vs-rural). Accessed May 2, 2022.



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Cannabis: Moving Forward, Protecting Health

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This new book addresses the ongoing debate on cannabis policy and provides guidance on how to regulate its sale and distribution. Instead of taking a stance for or against cannabis use, the book:

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Disparate Impact of the COVID-19 Pandemic and Health Equity Data Gaps

Denys T. Lau, PhD, and Paulina Sosa, MPH

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🔗 See also **COVID-19 and Health Equity Data Gaps**, pp. 1404–1453.

The COVID-19 pandemic has had disproportionate effect on marginalized populations, especially among racial and ethnic minorities and older adults with complex needs, putting them at significantly high risk for COVID-19–related severe illness, hospitalization, and mortality.^{1,2} These disparate impacts have shone a spotlight on the structural racism and pervasive socioeconomic inequities that persistently disadvantage certain communities, particularly by race, ethnicity, and age.

COVID-19 SHARED EXPERIENCES

Information about marginalized communities and their shared COVID-19 experiences has been documented throughout the pandemic. For example, Black communities, even before COVID-19, were more likely to have high rates of underlying health conditions, lower levels of health insurance, and more individuals working in front-line jobs, therefore putting individuals in these communities at elevated risk for infection, poorer health outcomes, and death during the pandemic. Compared with White individuals, COVID-19 mortality rates were 3.8

times higher among Black individuals.³ With such a high death toll, many Black children disproportionately lost their primary—and often sole—caregiver to COVID-19. Compared with White children, Black children were 2.4 times more likely to have experienced death of a parent or grandparent because of COVID-19.⁴

Latinx/Hispanic people accounted for 24.7% of COVID-19 infection cases, second only to White people (53.6%).⁵ In addition, Latinx/Hispanic communities had the greatest number of COVID-19–related deaths among all racial and ethnic minority groups. Social distancing policies were especially challenging for Latinx/Hispanic communities because individuals were more likely to reside in households with higher numbers of people, travel via mass transit, and be part of the essential workforce that must work outside of their home in food, hospitality, agriculture, and other service-based industries.⁶ Much of these circumstances were concentrated among Latinx/Hispanic immigrants.

Several US states, including California, Hawaii, Oregon, and Utah, with large numbers of Asian American, Native Hawaiian, and Pacific Islander (AANHPI) residents have reported significantly

higher rates of COVID-19–positive cases among NHPIs than other racial and ethnic groups, including Black and American Indian residents.⁷ Furthermore, throughout the pandemic, AANHPI communities across the United States experienced a rise in hate crimes and xenophobia. The Federal Bureau of Investigation documented a 77% increase in hate crimes against Asian American people from 2019 to 2020.⁸

For American Indian and Alaska Native (AI/AN) persons, COVID-19 incidence rates in 23 states with adequate race/ethnicity data were 3.5 times higher than for their White counterparts in the first seven months of the pandemic.⁹ Recent data showed that one in 475 AI/AN individuals had died from COVID-19, compared with one in 825 for White individuals and one in 645 for Black individuals.¹⁰ Compared with White children, AI/AN children were 4.5 times more likely to lose a parent or grandparent caregiver to COVID-19–related death.⁴ The loss of many elders in AI/AN tribes has been particularly profound given their wisdom and status as cultural tradition and unwritten language keepers.

Older adults, especially those of racial and ethnic minority descent, were severely impacted by COVID-19, with more than 95% of COVID-19–related deaths occurring in people aged 50 years and older, despite that fact that most infections occurred in people younger than 50 years.¹¹ Social distancing policies aimed to prevent COVID-19 infection were particularly challenging for many older adults who needed functional, health, and social support from family, friends, community services like adult day services centers (ADSCs), or residential care settings like nursing homes. Many older adults need community-based daily support and social services to remain

aging in place, but almost three quarters of ADSCs across the country had to limit hours or close temporarily during the first year of the pandemic.¹²

HEALTH EQUITY DATA GAPS

Despite the availability of descriptive statistics noted previously, understanding the disparate impact of COVID-19 and advancing health equity require consistent, high-quality, and timely health data from communities disproportionately affected by the pandemic. In this issue, *AJPH* has several invited articles that discuss our current understanding of COVID-19's inequitable effect on selected marginalized populations, describe existing data gaps that persistently hinder our ability to effectively monitor and reduce health disparities in these populations, and propose recommendations to close the data gaps to support decision-making and advance health equity science:

- Black children and adolescents: Mays et al. (p. 1407) discuss the lack of data collection and accuracy needed to monitor and predict COVID-19 in Black children and adolescents. Besides race/ethnicity data, they argue that data are also needed on the social context and social vulnerabilities of racial/ethnic minorities that decrease their opportunity for optimal health. Finally, they discuss the need for continuous data on the long-term, multigenerational impact of COVID-19 on educational attainment, mental health, and social well-being of Black children.
- Latinx/Hispanic language and data gaps: Lemos et al. (p. 1412) discuss the importance and power of narrative, language, and data needs in

Latinx/Hispanic communities. They first provide an overview of the health data gaps in our understanding of COVID-19's impact on Latinx/Hispanic communities. They then describe the recently formed Health Access for Communities in Emergency Response Campaign and their ongoing efforts to improve Latinx/Hispanic community health data quality in terms of adequacy, accuracy, and consistency. Such efforts would provide more and better information about Latinx/Hispanic communities to be able to advocate for sustainable political actions to meet their health and social needs. Finally, the article discusses the importance of community engagement in data collection, as well as some best practices and lessons learned from their efforts in addressing data gaps.

- AANHPI hate incidents: Shimkhada and Ponce (p. 1446) first provide an inventory of salient national and local data sources on anti-AANHPI hate incidents, building the mosaic of evidence on the effect of COVID-19 on AANHPI persons. They then present findings from the California Health Interview Survey on the experience with hate within different AANHPI subgroups and the impact of hate incidents on their mental health, delays in care, and perceived neighborhood safety in California. Finally, the article discusses where gaps remain and where investments in data collection may help move health equity science and public health actions forward.
- Meaningful and usable data on AI/AN persons: Mays et al. (p. 1416) discuss the importance of including indigenous principles in obtaining health

equity data for AI/AN persons while advancing indigenous innovation and governance that stem from sovereignty and self-determination. They argue that public health data need to be respectful and meaningful to AI/AN sovereign tribes, as well as sharable, usable, and congruent with federal, state, and local authorities for the purpose of ensuring well-being in these populations. In addition, they advocated that AI/AN persons and other indigenous people need to be active partners in the data and intervention planning to protect against unanticipated exploitation and harm.

- Older adults in ADSCs: Sadarangani et al. (p. 1421) describe the disproportionate effect of COVID-19 on older adults who rely on essential daily services from ADSCs. They highlight the experiences and vulnerabilities of diverse older adults with complex health and social needs when their access to community-based services was abruptly cut off during the pandemic. In addition, they discuss potential underdocumentation of unmet needs in older adults attributable to the lack of systematic data collection on social determinants of health and health outcomes in community service settings, undermining efforts to achieve health equity.

This collection of articles is intended to further the discourse on how to address health equity data to better understand, track, and improve the experiences of racial and ethnic minorities and older adults who have been disproportionately affected by the COVID-19 pandemic. As articulated in President Biden's Executive Order 13985, "a first step to promoting equity in Government action is to gather

the data necessary to inform that effort” (<https://bit.ly/3b1aKg9>). High-quality health data that are collected in a culturally competent way and disseminated in a timely and useful manner are fundamental to informing public health actions toward achieving health equity. Accurate, reliable, adequate, and meaningful data are essential for identifying where health disparities lie, informing efforts to reduce disparities, monitoring progress toward achieving health equity, and establishing accountability for achieving progress. More importantly, public health data collection, analysis, and reporting that incorporate authentic community engagement with marginalized populations would help prevent misuse of such data and avoid unintended stigmatization and mistreatment (<https://bit.ly/3vbUEXM>). Without such data and process, health inequities would persist.

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REFERENCES

1. Centers for Disease Control and Prevention. Health equity considerations and racial and ethnic minority groups. July 24, 2020. Available at: <https://stacks.cdc.gov/view/cdc/91049>. Accessed July 5, 2022.

2. Centers for Disease Control and Prevention. Risk for COVID-19 infection, hospitalization, and death by age group. April 29, 2022. Available at: <https://www.cdc.gov/coronavirus/2019-ncov/covid-data/investigations-discovery/hospitalization-death-by-age.html#print>. Accessed July 5, 2022.

3. Barrett NJ. Race and COVID 19: outcomes that matter to the Black community. Engagement Award final summary report. Patient-Centered Outcomes Research Institute. Available at: <https://www.pcori.org/sites/default/files/EA-Barrett057-Final-Summary-Report.pdf>. Accessed July 5, 2022.

4. Hillis SD, Blenkinsop A, Villaveces A, et al. COVID-19-associated orphanhood and caregiver death in the United States. *Pediatrics*. 2021;148(6):e2021053760. <https://doi.org/10.1542/peds.2021-053760>

5. Despres C. Update: coronavirus case rates and death rates for Latinos in the United States. *Salud America!* May 20, 2022. Available at: <https://salud-america.org/coronavirus-case-rates-and-death-rates-for-latinos-in-the-united-states>. Accessed July 5, 2022.

6. Riley AR, Chen Y-H, Matthay EC, et al. Excess deaths among Latino people in California during the COVID-19 pandemic. *SSM Popul Health*. 2021;15:100860. <https://doi.org/10.1016/j.ssmph.2021.100860>

7. Kaholokula JK, Samoa PA, Miyamoto RES, et al. COVID-19 special column: COVID-19 hits Native Hawaiian and Pacific Islander communities the hardest. *Hawaii J Health Soc Welf*. 2020;79(5):144–146.

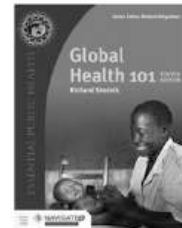
8. US Department of Justice. 2020 FBI hate crime statistics. May 5, 2022. Available at: <https://www.justice.gov/crs/highlights/2020-hate-crimes-statistics>. Accessed July 5, 2022.

9. Hatcher SM, Agnew-Brune C, Anderson M, et al. COVID-19 among American Indian and Alaska Native Persons—23 States, January 31–July 3, 2020. *MMWR Morb Mortal Wkly Rep*. 2020;69(34):1166–1169. <https://doi.org/10.15585/mmwr.mm6934e1>

10. Lakhani N. Exclusive: Indigenous Americans dying from COVID at twice the rate of White Americans. *The Guardian*. February 4, 2021. Available at: https://www.theguardian.com/us-news/2021/feb/04/native-americans-coronavirus-covid-death-rate?CMP=Share_iOSApp_Other. Accessed July 5, 2022.

11. Efflein J. Number of coronavirus disease 2019 (COVID-19) deaths in the U.S. as of June 2, 2022, by age. Statista. Available at: <https://www.statista.com/statistics/1191568/reported-deaths-from-covid-by-age-us>. Accessed July 5, 2022.

12. Centers for Disease Control and Prevention, National Center for Health Statistics. Adult day services centers. Long-term care and COVID-19. August 10, 2021. Available at: <https://www.cdc.gov/nchs/covid19/npals/adsc.htm>. Accessed July 5, 2022.



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The Accumulation of Disadvantage: Black Children, Adolescents, and COVID-19 Data Inequity

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 See also **COVID-19 and Health Equity Data Gaps**, pp. **1404–1453**.

A core truth during the COVID-19 pandemic is that, no matter the variant, no matter the public health response, some racial/ethnic minorities, especially Black Americans, suffered a disproportionate impact from COVID-19 compared with others.¹ This is true not only for individual morbidity and mortality risks but also for the well-being of Black families and communities. These effects reflect, at least in part, preexisting socioeconomic inequities and patterns of structural racism that persistently disadvantage Black lives.² However, it also represents preventable mortality and morbidity from what has been described as “America’s broken health data system—built on unconnected, aggregated, and time-lagged information.”³

COVID-19 has had a particularly deleterious effect on Black children and adolescents.^{4,5} Their COVID-19 mortality rates are twice as high as those seen in White children and adolescents.⁶

Black children and adolescents are also far more likely to have family members with blue collar, service, or retail sales jobs that cannot be performed remotely, thus increasing COVID-19 risk for the whole family. Indeed, adults with low socioeconomic position have suffered the highest death rates among all non-elderly Americans.^{7,8} Thus, it is no surprise that Black children also have been heavily affected by the death of a primary caregiver from COVID-19.^{7,9} Often these children are aged younger than 14 years. For a sizable minority, this is the loss of a sole caregiver during a time in which child welfare worsened for Black children. Reflecting the higher rates of single motherhood in the Black community, the life-transforming loss of a sole caregiver falls hard on Black children.^{10,11}

At the start of the pandemic, public health practitioners geared up rapidly to employ both traditional and novel outbreak tool kits in the hopes of creating data-driven insights to mitigate

pandemic-related harm. But preexisting challenges quickly undermined efforts to achieve full data equity for Black Americans. As articulated in President Biden’s Executive Order 13985,¹² data equity involves embedding into data systems the capacity to make health and well-being decisions that are fair and just for all. Key aspects of data equity are the constructs of meaningfulness and accessibility that allow individuals, public health professionals, and communities to make informed choices that reduce health risks. In this regard, data equity is essential to ultimately deriving equitable benefits from research. We address two data equity challenges as they affect Black children’s lives.

UNDERMINING DATA EQUITY: MISSING DATA

Many federal data sets, as noted in the Executive Order, are currently missing key demographic and social disadvantage measurements essential for equitable data-driven health decisions. This occurs for numerous reasons (e.g., resource limitations, limitations in data sharing, patchy data completion standards).¹³ As a consequence, early efforts in COVID-19 data collection were greatly limited by either the absence of race and ethnicity from the list of included data elements or, even when they were included as data elements, a significant proportion of missing values for race and ethnicity. Much has been written about this,¹⁴ including its impact on predictive modeling of transmission, estimating mortality burden, and tracking hospitalizations in Black and other minority populations. However, there has been less focus on the root causes of these missing data because of the lack of regulations for timeliness,

completeness, and standardization of the reporting among various data systems, which are essential in making policy and offering guidance at the local, state, and federal levels. Missing as well was an appreciation of the need to measure and model social determinants of health.¹⁵

As an example, Coronavirus in Kids (COVKID) Project investigators (E. B. P., J. L. S.) visited state COVID-19 dashboards weekly to manually extract data on cases, hospitalizations, vaccinations, and deaths in children. Comparing those data counts to the Centers for Disease Control and Prevention's (CDC's) COVID-19 Case Surveillance Restricted Access Detailed Data for children revealed that a large proportion of the COVID-19 case data reported to the CDC by state health departments were missing race and ethnicity (Table 1). The official case data displayed on the CDC COVID Tracker Web site were missing more than 50% of Black child and adolescent cases at the end of January 2022. After correction using an imputation method,⁸ the COVID-19 incidence data revealed that, in many states, the number of Black children diagnosed with COVID-19 during the first two years of the pandemic was substantially higher than current data suggest. Yet these are the data that were used at the federal level for guidance on school reopenings and other child-related risk assessments. Moreover, with the pronounced viral spread of the Omicron variant, closing of testing centers, increased use of at-home antigen testing, and asymptomatic illness in children, reported pediatric cases are likely only a small fraction of all infections for all children. A recent study reported that the seroprevalence of antibodies to infection-induced SARS-CoV-2 (the causative agent of COVID-19) is higher than 70% among children aged 17 years and younger who had blood

tests ordered for reasons other than COVID-19. Incomplete surveillance of cases, particularly among higher-risk populations, undermines the potential contributions of public health surveillance to risk mitigation.¹⁶

Unfortunately, the national COVID-19 hospitalization surveillance system, overseen by the Department of Health and Human Services (DHHS), does not include any race/ethnicity data.¹⁴ There are possible solutions to this oversight. For example, hospitals already record patient race/ethnicity in their own electronic medical records; merging this key variable with the DHHS COVID-19 hospitalization surveillance system would close the gap, but to do so would require incentives to lessen the financial impact on hospitals and perhaps a federal mandate. Other approaches could involve coordinated improvements in data collection across a wide variety of local and state health departments. A commitment to data equity will be expensive and require the federal government to invest in annual financing of the public health surveillance system, which emphasizes near-time data with interoperability among multisectoral federal, state, and local agencies and governments.

GENERATIONAL EFFECTS OF DATA INEQUITIES ON BLACK CHILDREN

Systems constructed for data equity require more than the measurement of race/ethnicity. Critical markers of social disadvantage are also essential to create effective and informative surveillance systems.¹⁵ The limited race-specific data that we do have on COVID-19 vaccinations suggest that the plight of Black children and adolescents follows much the same path as that of Black adults: disadvantaging social determinants

result in greater social vulnerability to risk exposures. Black children, like Black adults, may be less likely to be vaccinated and more likely to live in dense, often multigenerational housing with unvaccinated persons and attend schools where vaccination rates are lower. Reflecting this, the Kaiser Family Foundation reported that, compared with White children, Black children had lower rates of testing but were more likely to be infected, hospitalized, and to suffer from multisystem inflammatory syndrome.²

Such data systems must accommodate data disaggregation for income, education, occupation, and geography, among other factors.¹⁵ Although public health emergencies compel us to pay attention at the moment, true public health surveillance requires that we do all that is possible to look ahead and mitigate long-term sequelae. This requires vigilance in our data collection and analyses that both monitor and evaluate health outcomes, as well as identifying opportunity costs that could be reduced. Nationally, we must begin to address the long-term family disruptions of the pandemic, including large numbers of Black children who find themselves orphaned, in the foster care system, needing to move to new households, or living without adequate parental supervision. This, too, is a form of "long COVID" that has an impact on social and individual well-being; it demands data-informed sequelae mitigation efforts. The US surgeon general has already cautioned us to be vigilant about long-term pandemic effects on educational attainment and mental health among children (<https://bit.ly/3QJxtNu>).

As we move into the third year of this pandemic, it is critical that we finance and create an interoperable multisector data infrastructure that will measure,

TABLE 1— Estimates of State-Level COVID-19 Cumulative Incidence Among Non-Hispanic Black Children and Adolescents Aged 0 to 19 Years as of January 28, 2022

State	Source ^a	Reporting Age Range, Years ^b	Cumulative Cases in Age Range ^c	Proportion Non-Hispanic Black ^d	Cumulative Non-Hispanic Black Cases ^e	Census Population in Age Range ^f	Estimated Cumulative Incidence Rate ^g	Cumulative COVID-19 Cases, Blacks ^h	CDC Case Count as % of Estimated Cumulative Cases	% of Cases for Non-Hispanic Blacks Missing From CDC File ⁱ
Alabama	COVKID	0-17	182 605	0.2992	54 635	314 403	17.4	18 927	34.6	65.4
Alaska	COVKID	0-19	53 932	0.0215	1 160	5 724	20.3	612	52.8	47.2
Arizona	CDC	0-19	395 812	0.0485	19 197	93 781	20.5	13 067	68.1	31.9
Arkansas	CDC	0-19	183 583	0.1949	35 780	138 564	25.8	27 715	77.5	22.5
California	CDC	0-19	1 884 272	0.0479	90 257	491 818	18.4	65 731	72.8	27.2
Colorado	CDC	0-19	249 679	0.0282	7 041	60 223	11.7	3 686	52.4	47.6
Connecticut	COVKID	0-19	152 176	0.1463	22 263	94 343	23.6	2 760	12.4	87.6
Delaware	CDC	0-19	60 719	0.2591	15 732	58 594	26.8	10 843	68.9	31.1
District of Columbia	COVKID	0-19	27 244	0.6667	18 164	75 472	24.1	14 445	79.5	20.5
Florida	COVKID	0-19	1 057 162	0.1759	185 955	942 354	19.7	86 779	46.7	53.3
Georgia	CDC	0-19	401 175	0.3818	153 169	944 637	16.2	74 271	48.5	51.5
Hawaii	COVKID	0-17	40 865	0.0092	376	5 099	7.4	130	34.6	65.4
Idaho	CDC	0-19	58 617	0.0075	440	4 434	9.9	237	53.9	46.1
Illinois	CDC	0-19	664 721	0.1365	90 734	473 699	19.2	57 112	62.9	37.1
Indiana	CDC	0-19	319 162	0.0937	29 905	197 709	15.1	20 132	67.3	32.7
Iowa	COVKID	0-17	108 688	0.0529	5 750	40 488	14.2	2 759	48.0	52.0
Kansas	CDC	0-19	168 529	0.0638	10 752	48 127	22.3	8 190	76.2	23.8
Kentucky	COVKID	0-19	249 691	0.0615	15 356	105 251	14.6	6 183	40.3	59.7
Louisiana	CDC	0-19	240 406	0.4044	97 220	437 209	22.2	68 882	70.9	29.1
Maine	CDC	0-19	42 903	0.0380	1 630	8 395	19.4	1 226	75.2	24.8
Maryland	COVKID	0-19	206 798	0.3180	65 762	454 631	14.5	22 592	34.4	65.6
Massachusetts	COVKID	0-19	404 399	0.0765	30 937	135 072	22.9	19 974	64.6	35.4
Michigan	COVKID	0-19	451 475	0.1073	48 443	378 433	12.8	19 523	40.3	59.7
Minnesota	CDC	0-19	302 393	0.0996	30 118	147 696	20.4	22 458	74.6	25.4
Mississippi	COVKID	0-17	133 428	0.6275	83 726	288 165	29.1	2 997	3.6	96.4
Missouri	CDC	0-19	248 996	0.1371	34 137	204 646	16.7	23 979	70.2	29.8
Montana	CDC	0-19	44 271	0.0068	301	1 667	18.1	197	65.4	34.6
Nebraska	COVKID	0-19	90 347	0.0431	3 894	31 618	12.3	905	23.2	76.8
Nevada	COVKID	0-19	104 991	0.0981	10 300	81 010	12.7	7 541	73.2	26.8
New Hampshire	COVKID	0-19	68 054	0.0157	1 068	5 795	18.4	228	21.3	78.7
New Jersey	CDC	0-19	439 305	0.1370	60 185	287 924	20.9	35 822	59.5	40.5
New Mexico	COVKID	0-19	110 197	0.0109	1 201	9 809	12.2	823	68.5	31.5

(continued)

TABLE 1— Continued

State	Source ^a	Reporting Age Range, Years ^b	Cumulative Cases in Age Range ^c	Proportion Non-Hispanic Black ^d	Cumulative Non-Hispanic Black Cases ^e	Census Population in Age Range ^f	Estimated Cumulative Incidence Rate ^g	Cumulative COVID-19 Cases, Blacks ^h	CDC Case Count as % of Estimated Cumulative Cases	% of Cases for Non-Hispanic Blacks Missing From CDC File ⁱ
New York	CDC	0–19	949 789	0.1470	139 619	657 844	21.2	64 925	46.5	53.5
North Carolina	CDC	0–19	557 398	0.2259	125 916	586 396	21.5	87 866	69.8	30.2
North Dakota	COVKID	0–19	46 501	0.0426	1 981	8 624	23.0	0	0.0	100.0
Ohio	COVKID	0–19	469 227	0.1576	73 950	431 964	17.1	51 913	70.2	29.8
Oklahoma	COVKID	0–17	143 791	0.0703	10 109	72 660	13.9	6 364	63.0	37.0
Oregon	CDC	0–19	136 322	0.0347	4 730	22 037	21.5	2 575	54.4	45.6
Pennsylvania	CDC	0–19	506 956	0.0834	42 280	378 864	11.2	25 274	59.8	40.2
Rhode Island	COVKID	0–18	76 299	0.0597	4 555	15 932	28.6	1 632	35.8	64.2
South Carolina	CDC	0–19	304 447	0.2873	87 468	365 633	23.9	54 387	62.2	37.8
South Dakota	COVKID	0–19	42 133	0.0271	1 142	7 302	15.6	708	62.0	38.0
Tennessee	CDC	0–19	401 910	0.1847	74 233	318 413	23.3	50 790	68.4	31.6
Texas	COVKID	0–19	1 354 361	0.1068	144 646	1 002 565	14.4	7 944	5.5	94.5
Utah	CDC	0–19	173 302	0.0144	2 496	12 593	19.8	2 247	90.0	10.0
Vermont	COVKID	0–19	28 513	0.0301	858	2 473	34.7	629	73.3	26.7
Virginia	COVKID	0–19	315 911	0.2380	75 187	417 449	18.0	46 559	61.9	38.1
Washington	CDC	0–19	317 001	0.0449	14 233	79 276	18.0	4 716	33.1	66.9
West Virginia	COVKID	0–20	102 173	0.0723	7 387	16 188	45.6	53	0.7	99.3
Wisconsin	COVKID	0–19	326 593	0.0560	18 289	122 502	14.9	9 727	53.2	46.8
Wyoming	CDC	0–19	28 890	0.0079	228	1 410	16.2	159	69.7	30.3

Note. CDC = Centers for Disease Control and Prevention; COVKID = Coronavirus in Kids Tracking and Education Project. Black = non-Hispanic Black. The age range of cases in the CDC file is 0 to 19 years for every state. Age range for the COVKID data varies by state. When COVKID data for ages 0 to 17 years were chosen as the most complete (i.e., AL, HI, IA, MS, OK), it means that the CDC case count for ages 0 to 19 years was lower than the COVKID case count for 0 to 17 years.

Source. Data source for CDC restricted access COVID-19 Caseline Datafile: <https://data.cdc.gov/Case-Surveillance/COVID-19-Case-Surveillance-Restricted-Access-Detail/mbd7-r32t>. Source for COVKID Project data: <https://www.covkidproject.org/technical-notes>.

^aSource of most complete COVID-19 case counts for those aged 0–19 years.

^bThe age range of cases in the CDC file is 0–19 years for every state. Age range for the COVKID data varies by state. When COVKID data for ages 0–17 years were chosen as the most complete (i.e., AL, HI, IA, MS, OK), it means that the CDC case count for ages 0–19 years was lower than the COVKID case count for ages 0–17 years.

^cMost complete estimate for total cumulative cases as of January 28, 2022.

^dProportion of those aged 0–19 years who were non-Hispanic Black in the CDC caseline data file.

^eImputed cumulative non-Hispanic Black cases in reporting age range (percentage non-Hispanic Black in CDC file multiplied by most complete total cumulative cases aged 0–19 years as of January 28, 2022, per this method: <https://www.covkidproject.org/post/simple-method-race-ethnicity-imputation>).

^fCensus 2020 population for non-Hispanic blacks in age range.

^gCumulative cases divided by the 2020 population of non-Hispanic blacks for the state-specific age range.

^hAll CDC cumulative cases are for those aged 0–19 years.

ⁱThe percentage of the most complete estimate of cumulative COVID-19 cases in non-Hispanic Blacks who were missing (not reported) in the CDC caseline file.

link, and utilize disaggregated race/ethnicity classification combined with linkages to social risk and vulnerability to mitigate what are sure to be accumulating COVID-related disadvantages for Black children and adolescents. Our search for measures of social risk and vulnerability must be broad but also population and place specific. What COVID-19 underscored is that health risks are not just about how healthy or sick we are but what job we work, how we live with our families, and other non-health-specific characteristics. Our data infrastructure must also have the capacity to link health and social determinant data together to detect and respond to the accumulating negative consequences on the horizon for Black children and adolescents.

Although we recognize that optimized data systems by themselves will not eliminate the harmful health effects of cumulative social disadvantage, they nevertheless represent an important step in providing the armamentarium needed for action in guiding our public health infrastructure toward the goal of health equity. It is also imperative to ask and monitor who controls and produces data.¹⁷ What we have shown is the critical need for a COVID-19 public health data governance structure in which data produced at the state and federal levels can better serve as the roadmap for risk reduction. If the well-being of Black children matters, then data equity requires “sense making” as a part of that public health data governance that allows us all to interpret the data “in the context of the lives, risks and stories of those whom the data are meant to help” (Mays et al., p. 1419). *AJPH*

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REFERENCES

- Ahmad FB, Cisewski JA, Anderson RN. Provisional mortality data—United States, 2021. *MMWR Morb Mortal Wkly Rep*. 2022;71(17):597–600. <https://doi.org/10.15585/mmwr.mm7117e1>
- Artiga S, Hill L, Ndugga N. Racial disparities in COVID-19 impacts and vaccinations for children. Kaiser Family Foundation. 2021. Available at: <https://www.kff.org/racial-equity-and-health-policy/issue-brief/racial-disparities-in-covid-19-impacts-and-vaccinations-for-children>. Accessed April 28, 2022.
- Plough A, Christopher GC. Equity-centered public health data demands new voices at the table. *Health Affairs Forefront*. <https://doi.org/10.1377/forefront.20220427.865970>
- Hamel L, Lopes L, Kearney A, et al. KFF COVID-19 vaccine monitor: winter 2021 update on parents' views of vaccines for kids. Kaiser Family Foundation. 2021. Available at: [https://www.kff.org/coronavirus-covid-19/poll-finding/kff-covid-19-vaccine-monitor-winter-2021-update-on-parents-views-of-vaccines/#:~:text=While%20about%20six%20in%20ten,5%20to%2011%20\(43%25\)](https://www.kff.org/coronavirus-covid-19/poll-finding/kff-covid-19-vaccine-monitor-winter-2021-update-on-parents-views-of-vaccines/#:~:text=While%20about%20six%20in%20ten,5%20to%2011%20(43%25)). Accessed April 28, 2022.
- Ho S. Child abuse report: deaths of black children up in pandemic. *AP News*. 2022. Available at: <https://apnews.com/article/coronavirus-pandemic-health-child-abuse-child-welfare-us-department-of-health-and-human-services-f58c5bff8232329ac78ac69ee8e8074e>. Accessed May 6, 2022.
- Women's Institute for Independent Social Enquiry. The COVKID Project National Dashboard. 2021. Available at: <https://www.covkidproject.org>. Accessed January 21, 2021.
- Pathak EB, Menard JM, Garcia RB, Salemi JL. Joint effects of socioeconomic position, race/ethnicity, and gender on COVID-19 mortality among working-age adults in the United States. *Int J Environ Res Public Health*. 2022;19(9):5479. <https://doi.org/10.3390/ijerph19095479>
- Bixler D, Miller AD, Mattison CP, et al. SARS-CoV-2-associated deaths among persons aged <21 years—United States, February 12–July 31, 2020. *MMWR Morb Mortal Wkly Rep*. 2020;69(37):1324–1329. <https://doi.org/10.15585/mmwr.mm6937e4>
- Hillis SD, Blenkinsop A, Villaveces A, et al. COVID-19-associated orphanhood and caregiver death in the United States. *Pediatrics*. 2021;148(6):e2021053760. <https://doi.org/10.1542/peds.2021-053760>
- Treglia D, Cutuli JJ, Arasteh KJ, et al. Hidden pain: children who lost a parent or caregiver to COVID-19 and what the nation can do to help them. COVID Collaborative. 2021. Available at: <https://www.covidcollaborative.us/assets/uploads/img/HIDDEN-PAIN-FINAL.pdf>. Accessed May 6, 2022.
- Kramer S. US has world's highest rate of children living in single-parent households. 2019. Available at: <https://www.pewresearch.org/fact-tank/2019/12/12/u-s-children-more-likely-than-children-in-other-countries-to-live-with-just-one-parent>. Accessed May 6, 2022.
- The White House. The release of the Equitable Data Working Group Report [press release]. April 22, 2022. Available at: <https://www.whitehouse.gov/ostp/news-updates/2022/04/22/the-release-of-the-equitable-data-working-group-report>. Accessed May 6, 2022.
- Krieger N, Gonsalves G, Bassett MT, Hanage WP, Krumholz HM. The fierce urgency of now: closing glaring gaps in US surveillance data on COVID-19. *Health Affairs Blog*. April 14, 2020. Available at: <https://www.healthaffairs.org/doi/10.1377/forefront.20200414.238084/full>. Accessed August 11, 2022.
- Goldfarb A. Federal COVID data 101: what we know about race and ethnicity data. COVID Tracking Project. 2021. Available at: <https://covidtracking.com/analysis-updates/federal-covid-data-101-race-ethnicity-data>. Accessed May 6, 2022.
- Ong PM, Pech C, Gutierrez NR, Mays VM. COVID-19 medical vulnerability indicators: a predictive, local data model for equity in public health decision making. *Int J Environ Res Public Health*. 2021;18(9):4829. <https://doi.org/10.3390/ijerph18094829>
- Clarke KEN, Jones JM, Deng Y, et al. Seroprevalence of infection-induced SARS-CoV-2 antibodies—United States, September 2021–February 2022. *MMWR Morb Mortal Wkly Rep*. 2022;71(17):606–608. <https://doi.org/10.15585/mmwr.mm7117e3>
- Krieger N. Structural racism, health inequities, and the two-edged sword of data: structural problems require structural solutions. *Front Public Health*. 2021;9:655447. <https://doi.org/10.3389/fpubh.2021.655447>

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Latinx Race and Ethnicity Data Gaps: The HACER Campaign and a Call to Action

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Note. The thoughts expressed in this article are those of the authors and do not necessarily represent official AMA policy.

 See also [COVID-19 and Health Equity Data Gaps](#), pp. 1404–1453.

As of July 1, 2022, more than 87 million reported cases and one million deaths were attributed to COVID-19 in the United States.¹ The COVID-19 pandemic continues to illuminate health, social, and institutional inequities nationally.

LATINX IMPACT

As of July 1, 2022, 126 891 Latinx people in the United States have died from COVID-19, representing the greatest number of deaths for any minoritized or marginalized race or ethnic group for which data are available.¹ Latinx people comprise a quarter of all US COVID-19 cases ($n = 12\,808\,026$).¹ These numbers are likely an undercount, as the data issues raised in this article show. Latinx children also have been inequitably affected by the loss of a primary or secondary caregiver and other adverse childhood experiences because of the pandemic.² Despite these devastating impacts and likely undercounts, the true impact of the COVID-19 pandemic on Latinx people will not be fully understood

until emerging inequities in mortality for specific Latinx subpopulations—including younger adults and children—and inequities in long COVID-19 and other associated disabilities are illuminated.

In 2021, the Centers for Disease Control and Prevention declared racism a public health crisis.³ Building on this awareness of structural racism, we recognize that the Latinx community was made vulnerable to COVID-19 because of limited essential worker protections, decades of systemic exclusion and institutional racism, and inequitable access to health care services, public health interventions, personal protective equipment, and other key resources.^{4–8} This resulted in disproportionately high rates of infection, hospitalization, and mortality in Latinx communities.^{7,8}

The pandemic also highlighted the fundamental need to identify and address the gaps and limitations in the public health data infrastructure, which inhibit our ability to address the needs of the Latinx community.

Our work builds on previous efforts that illuminate how the public health data infrastructure fails the Latinx communities by rendering the population invisible and limiting scientific and public discourse on Latinx health.^{4,9}

In the following sections, we highlight three key data issues that were salient for the Latinx community during the COVID-19 pandemic (Table 1).

DATA ISSUE 1: LACK OF ACCURATE DATA COLLECTION

Data collection is essential for accurately representing the health impact and equitably supporting each community during a public health emergency.

Although the Office of Management and Budget (OMB) defines a Hispanic/Latino ethnic data collection category (Table A, available as a supplement to the online version of this article at <http://www.ajph.org>), this category is not captured systematically across local, state, or other non-federally funded data collection systems.¹⁰ For example, although Hispanic or Latino is an ethnic category, per OMB definition, other demographic surveys may capture this as a race category. This results in the inaccurate categorization of race and ethnicity data and can result in difficulties when Hispanic or Latino data are reconciled with other relevant public health or health data sets. Given that race and ethnicity data collection is not mandated, significant amounts of Hispanic/Latino ethnicity data fields are missing.¹¹ Additionally, ethnicity data are not accurately categorized or reconciled, often resulting in the Latinx community being undercounted or miscategorized. Lastly, the lack of culturally responsive data collection has raised concerns about confidentiality and its impact on the accuracy of the data collected.¹²

TABLE 1— Critical Data Gaps in Latinx Communities, and HACER Recommendations

Issue	Standard Definition	Health Equity Implication in Latinx Community	HACER Solution to Counter Data Gap
Lack of accurate data collection	Data collection does not accurately capture all Latinx data because 1. Not capturing Hispanic/Latino ethnicity data; 2. Ethnicity data are not reconciled with cumulative data; 3. Lack of culturally responsive data collection methods.	If Latinx data are missing, then this will lead to undercounts and underrepresentation in reporting and decision-making.	Standardize collection and reporting of • Race and ethnicity; • Preferred language; • Industry and occupation data.
Lack of accurate data reporting	Data reporting does not capture the full scope of Latinx infection and mortality rates due to COVID-19 and other diseases.	The underreporting of ethnicity surveillance data does not provide decision-makers with the most accurate picture to make the best decisions for Latinx communities.	Ensure that data collection and reporting tools are multicultural and multilingual, particularly in the Spanish language.
Lack of data standardization	The lack of data standardization of the word used to identify ethnicity categories, “country of origin,” and “ancestry.”	With the lack of standardization of words, classifications, and categories, there is an underrepresentation of the Latinx community in data and reporting.	Develop and share a plan for classifying LHS+ and other ethnic minorities that are not being properly categorized to data collection agencies.

Note. HACER = Health Access for Communities in Emergency Response; LHS+ = Latina/e/o/x, Hispanic, and Spanish origin.

DATA ISSUE 2: LACK OF TIMELY DATA REPORTING FOR DECISION-MAKERS

Gaps in the quality of race and ethnicity data reporting raised an alarm for data collection and surveillance agencies around the country. The data inform priorities made by decision-makers around public health, economics, funding allocation, and education. The American Medical Association (AMA) and the Latinx Task Force urged the government to prioritize efforts to collect and report on race and ethnicity related to COVID-19 testing, hospitalization, mortality,¹³ and vaccinations.¹⁴ Furthermore, in an effort to accurately visualize Latinx data, the AMA compiled the COVID-19 Health Equity data collection mapping tool and a compendium of resources to draw attention to complexities associated with data inequities.¹⁵ Ethnicity data need to be reported quickly and accurately to public health officials and communicated effectively to communities and leaders. There is

existing synergy¹⁶ to improve the COVID-19 data issues around race and ethnicity data quality and reporting, but Latinx considerations need to be integrated as part of these ongoing efforts.

DATA ISSUE 3: LACK OF DATA STANDARDIZATION FOR RACE AND ETHNICITY

Scholars and community members have pointed out the lack of consistency and standardization in data reporting when defining pan-ethnic identities and Latinx communities.¹⁷ Identity categorization is complicated for this population given that there are long-standing debates about the terminology. Furthermore, more recently, in several national polls, the majority of survey respondents did not indicate a preference between the pan-ethnic terms.^{18–21} Nevertheless, each of these terms has its own distinctions, and the official use of any of these terms has implications for purposes of diversity, equity, and inclusion related to data

standardization (online Table A). This example demonstrates how the current national data standards still lack a true understanding of, and hence representation of, the Latinx communities in the United States.

Another missing data collection element is the lack of specificity of subethnic Latinx categories in the United States, such as “country of origin” or “ancestry.” It is important to include this in data collection to appropriately showcase the diverse identities, cultures, needs, and health gaps that shape Latinx communities in different parts of the country.¹² The Health Access for Communities in Emergency Response (HACER) document calls for a plan to standardize these data and ensure that they are regularly collected.

EMERGENCE OF THE LATINX TASK FORCE

The gaps and inequities faced by the Latinx community during the pandemic amplified the urgency for concerted

efforts. Because there were limited, synergistic efforts supporting Latinx communities around the country,²⁰ the Latinx Task Force (hereafter, “Task Force”) developed at a critical time (<https://latinxtaskforce.org/partners/network>). The Task Force brought together public health, community organizations and leaders, and community health workers and *promotores* from the Latinx community to discuss health and data gaps in their communities and, more importantly, solutions to fill these gaps. This effort culminated with the launch of the HACER Campaign in October 2020 during Latinx Heritage Month.

OVERVIEW OF HACER CAMPAIGN

HACER primarily focused on the gaps in data collection, reporting, and representation of the Latinx community. The Task Force launched HACER with the release of a national statement to raise awareness of Latinx health inequities and data gaps (<https://latinxtaskforce.org/hacer-campaign/statement>). This campaign soon evolved into a larger initiative in which members prioritized issues related to policy and funding (Figure A, available as a supplement to the online version of this article at <http://www.ajph.org>). Ultimately, the Task Force, along with local, state, and national partners, identified community needs, solutions, and recommendations (Table 1). One noteworthy long-term multisectoral solution emerged around building a more comprehensive, culturally and linguistically responsive public health infrastructure inclusive of Spanish-speaking surveyors, forms, and leaders to ensure representation in data collection and reporting.

BEST PRACTICES AND LESSONS LEARNED

The main goal of HACER is to raise awareness of the data gaps and inequities that directly affect Latinx communities nationally. In the following sections, the best practices and lessons learned that can inform the next steps are presented.

Partnership and Collaboration

Best practice. Forming an intentional understanding of the needs, perspectives, and roles that every partner has in a collaborative effort of this capacity helped embed a holistic lens in the vision behind developing and launching the campaign. The Task Force made an explicit effort to invite every partner to submit suggestions, edits, and recommendations across every step of this effort. Additionally, by being intentional about language, diversity, and race and ethnicity when describing the Latinx community, we were able to integrate this holistic and diversity, equity, and inclusion lens for the data infrastructure initiative. HACER initially garnished volunteer-driven contributions and endorsements from over 75 national, state, and local Latinx-focused partners. This network has grown to over 250 partners.

Lesson learned. Inclusive and transparent planning processes for transforming public health data systems, with input from communities, require extensive expertise and resources, including staffing, time, and communication. These efforts require coordination and resources from federal and national sources to maximize impact and ensure strategic uptake among key public health and health surveillance systems.

Awareness, Monitoring, and Evaluation

Best practice. A campaign needs considerable time and resources to raise awareness and increase reach. The Task Force has been invited to present to federal, state, and local agencies at over 12 meetings to garner support. Additionally, over 1000 organizations and leaders have learned about HACER and the recommendations through national events and townhalls.

Lessons learned. To ensure that widespread support leads to action, there is a need to embed monitoring and evaluation efforts to strengthen accountability. Priorities for the next iteration of the campaign, HACER 2.0, include a tailored call to action for Task Force members and community decision-makers and a visual map that shows the breadth of collaboration across the country.

Storytelling and Data Visualizations

Best practice. Transformative efforts like the Satcher Health Leadership Institute’s Health Equity Tracker (<https://satcherinstitute.org/research/health-equity-tracker-project>), which highlight how structural racism not only harms health but also shapes our data systems, have recently been launched, but there remains a distinct lack of data accessibility and transferability of insights to marginalized and minoritized communities.

Lessons learned. Public health maps and surveillance reports often remain inaccessible to the Latinx community. Key examples of how data are cocreated and translated into accessible communications using dashboards or story maps are sorely needed.

CONCLUSION AND CALL TO ACTION

The COVID-19 pandemic brought to light many issues faced by our current public health systems in data collection, analysis, and reporting, but it also brought together new and nontraditional partners. The pandemic taught us that there is power in synergy and partnership. It is critical to amplify and value the voices and expertise of local community leaders to address data and other equity-based issues and to address the historical and present injustices Latinx communities face. The Latinx Task Force continues to center the needs of families, communities, and partners in its work. This also must be done at the federal, state, local, and corporate level to ensure that communities receive holistic, culturally and linguistically appropriate efforts and attention to address these persistent inequities.

As the Task Force strives for health equity, we invite all public health and health leaders to visit latinxtaskforce.org to integrate the HACER recommendations to appropriately address these data gaps. HACER recommendations remain critical as we strengthen our community health and public health systems. *AJPH*

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REFERENCES

- Centers for Disease Control and Prevention. COVID data tracker. 2022. Available at: <https://covid.cdc.gov/covid-data-tracker/#demographics>. Accessed July 4, 2022.
- Hillis SD, Blenkinsop A, Villaveces A, et al. COVID-19-associated orphanhood and caregiver death in the United States. *Pediatrics*. 2021;148(6):e2021053760. <https://doi.org/10.1542/peds.2021-053760>
- Walensky RP. Racism and health [press release]. Media statement from CDC director. Updated April 8, 2021. Available at: <https://www.cdc.gov/media/releases/2021/s0408-racism-health.html>. Accessed July 2022.
- Del Rios M, Puente S, Vergara-Rodriguez P, Sugrue N. Latino invisibility in the pandemic. *AMA J Ethics*. 2022;24(4):E289–E295. <https://doi.org/10.1001/amajethics.2022.289>
- Avila A. Essential or expendable during the COVID-19 pandemic? A student-lived experience on grieving the unjust and early deaths of vulnerable populations. *Am J Public Health*. 2021;111(1):66–68. <https://doi.org/10.2105/AJPH.2020.306001>
- Gwynn RC. Health inequity and the unfair impact of the COVID-19 pandemic on essential workers. *Am J Public Health*. 2021;111(8):1459–1461. <https://doi.org/10.2105/AJPH.2021.306386>
- Martinez ME, Nodora JN, Carvajal-Carmona LG. The dual pandemic of COVID-19 and systemic inequities in US Latino communities. *Cancer*. 2021;127(10):1548–1550. <https://doi.org/10.1002/ncr.33401>
- Tai DBG, Sia IG, Doubeni CA, Wieland ML. Disproportionate impact of COVID-19 on racial and ethnic minority groups in the United States: a 2021 update. *J Racial Ethn Health Disparities*. 2021;1–6. <https://doi.org/10.1007/s40615-021-01170-w>
- Amaro H, Zambrana RE. Criollo, Mestizo, Mulato, LatiNegro, Indigena, White, or Black? The US Hispanic/Latino population and multiple responses in the 2000 census. *Am J Public Health*. 2000;90(11):1724–1727. <https://doi.org/10.2105/AJPH.90.11.1724>
- Rodriguez-Lainz A, McDonald M, Fonseca-Ford M, et al. Collection of data on race, ethnicity, language, and nativity by US public health surveillance and monitoring systems: gaps and opportunities. *Public Health Rep*. 2018;133(1):45–54. <https://doi.org/10.1177/0033354917745503>
- Flynn MA, Check P, Steege AL, Sívén JM, Syron LN. Health equity and a paradigm shift in occupational safety and health. *Int J Environ Res Public Health*. 2021;19(1):349. <https://doi.org/10.3390/ijerph19010349>
- Rodriguez-Lainz A, McDonald M, Penman-Aguilar A, Barrett DH. Getting data right—and righteous to improve Hispanic or Latino health. *J Healthc Sci Humanit*. 2016;6(3):60–83.
- American Medical Association. Top physician orgs urge COVID-19 mortality data by race, ethnicity [press release]. 2020. Available at: <https://www.ama-assn.org/press-center/press-releases/top-physician-orgs-urge-covid-19-mortality-data-race-ethnicity>. Accessed March 2022.
- American Medical Association. Health care groups urge more race, ethnicity data for COVID vaccinations [press release]. 2021. Available at: <https://www.ama-assn.org/press-center/press-releases/health-care-groups-urge-more-race-ethnicity-data-covid-vaccinations>. Accessed March 2022.
- American Medical Association. The role of data collection in the COVID-19 pandemic. Updated July 28, 2020. Available at: <https://www.ama-assn.org/delivering-care/health-equity/role-data-collection-covid-19-pandemic>. Accessed March 2022.
- Orvis K. Briefing room: reviewing and revising standards for maintaining, collecting, and presenting federal data on race and ethnicity. The White House. 2022. Available at: <https://www.whitehouse.gov/omb/briefing-room/2022/06/15/reviewing-and-revising-standards-for-maintaining-collecting-and-presenting-federal-data-on-race-and-ethnicity>. Accessed July 2022.
- Zambrana RE, Amaro G, Butler C, DuPont-Reyes M, Parra-Medina D. Analysis of Latina/o sociodemographic and health data sets in the United States from 1960 to 2019: findings suggest improvements to future data collection efforts. *Health Educ Behav*. 2021;48(3):320–331. <https://doi.org/10.1177/10901981211011047>
- Lopez MH, Krogstad JM, Passel JS. Who is Hispanic? Pew Research Center. 2021. Available at: <https://www.pewresearch.org/fact-tank/2021/09/23/who-is-hispanic>. Accessed March 2022.
- Mccarthy J, Dupree W. No preferred racial term among most black, Hispanic adults. Gallup. 2021. Available at: <https://news.gallup.com/poll/353000/no-preferred-racial-term-among-black-hispanic-adults.aspx>. Accessed March 2022.
- Noe-Bustamante L, Mora L, Lopez MH. About one-in-four US Hispanics have heard of Latinx, but just 3% use it. Pew Research Center. 2020. Available at: <https://www.pewresearch.org/hispanic/2020/08/11/about-one-in-four-u-s-hispanics-have-heard-of-latinx-but-just-3-use-it>. Accessed March 2022.
- Taylor P, Lopez MH, Martinez J, Velasco G. When labels don't fit: Hispanics and their views of identity. Pew Research Center. Updated April 4, 2012. Available at: <https://www.pewresearch.org/hispanic/2012/04/04/when-labels-dont-fit-hispanics-and-their-views-of-identity>. Accessed March 2022.

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Data Equity in American Indian/Alaska Native Populations: Respecting Sovereign Nations' Right to Meaningful and Usable COVID-19 Data

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 See also [COVID-19 and Health Equity Data Gaps](#), pp. 1404–1453.

Precision public health offers the promise of improving health equity by delivering the “right intervention at the right time, every time to the right population.”¹ But the COVID-19 pandemic underscored how far the United States is from meeting that promise, especially for marginalized urban and rural American Indian/Alaska Native (AI/AN) populations. The reasons for this are many, including failure to collect relevant data, barriers to data dissemination, and less than optimal use of data to effectively inform public policy. In [Table 1](#), we present a report card on COVID-19 data availability compiled by the Urban Indian Health Institute in 2021. This exposes some of the reporting limitations as experienced by the AI/AN populations.² However, this report card does not begin to capture the long-term consequences for AI/AN

persons deriving from the loss of so many elders. Gone are key leaders, including the keepers of unwritten language, and enduring are disruptions of tribes, nations, bands, pueblos, communities, native villages, and families who face complicated waves of grieving. For AI/AN populations, who are especially sensitive to threats of genocide, COVID-19 reawakens awareness of structural racism as a weapon for their destruction.

PROBLEMS WITH DATA COLLECTION AND COMPILATION

At the beginning of the COVID-19 pandemic, there could be no doubt that the AI/AN community would be a highly vulnerable population for whom accurate data could drive effective policy

interventions. Two factors were already known. One is that AI/AN populations are often made invisible in data collection efforts—for example, AI/AN persons are sometimes classified as other or White race.³ This is especially problematic for the 71% of AI/AN persons who live in urban areas and access services within mainstream health systems.⁴ The second is that, in the service of federal, state, and local laws related to data privacy and protection, results for small populations are often suppressed or aggregated with others. This reduces capacity to provide policy-setting predictions.^{2,3} But a third factor was also missing data on race completely—early efforts at COVID-19 tracking failed to either measure or report the race of infected individuals.⁵

A fourth challenge for public health planning lies in the creation of an appropriate social vulnerability index (SVI). In a recent study of COVID-19 rates among AI/AN persons,⁶ the authors combined the Centers for Disease Control and Prevention's (CDC) SVI with a set of risk conditions unique to tribal conditions within New Mexico. Using census and other data sources, the study added new vulnerability measures (e.g., absence of telephone service or Internet, incomplete plumbing, presence of abandoned uranium mines) to demonstrate that expanded SVI measures are highly correlated with COVID-19 infection rates at the zip code level. These authors also showed that higher levels of racial segregation and density of racial/ethnic minority populations are predictive of higher COVID-19 infection rates. Finally, using data from 23 states, Hatcher et al.⁷ found that underlying conditions for the AI/AN population may explain why early pandemic infection rates among the AI/AN community were 3.5 times

TABLE 1— Report Card on the Centers for Disease Control and Prevention (CDC) and State COVID-19 Surveillance Data for American Indians/Alaska Natives: United States, January 2020–January 2021

State Information		State-Reported COVID-19 Information		CDC COVID-19 National Surveillance Data		Overall Grade
State	AI/AN Population ^a	Is AI/AN Population Included on State Dashboard?	Grade (% of Cases With Complete Racial Information Reported on Dashboard)	Grade (% of Confirmed Cases From the State Reported to CDC)	Grade (% of Confirmed Cases With Complete Racial Information Reported on CDC Database)	
Alabama	69 283	No	F (49)	D- (62)	D- (62)	F (43)
Alaska	148 222	Yes	D- (62)	.. ^b	F (59)	C (74)
Arizona	458 422	Yes	C- (72)	A (95)	D (63)	B (83)
Arkansas	61 824	Yes	B- (82)	A (95)	B (85)	A- (91)
California	1 089 251	Yes	D (65)	A+ (99)	F (37)	C (75)
Colorado	159 162	Yes	C (73)	C (76)	F (38)	C- (72)
Connecticut	43 195	Yes	F (53)	B (84)	F (40)	D+ (69)
Delaware	13 516	No	B+ (89)	A (96)	F (0)	F (46)
Florida	219 895	No	C (76)	F (50)	D (65)	F (48)
Georgia	122 051	Yes	C (76)	C+ (77)	F (43)	C (74)
Hawaii	37 751	No	D (65)	B (83)	F (50)	F (49)
Idaho	51 467	Yes	F (59)	A- (92)	F (59)	C+ (77)
Illinois	141 473	Yes	D+ (67)	A- (92)	F (52)	C+ (78)
Indiana	66 617	No	C (75)	D (66)	D- (61)	F (50)
Iowa	33 753	Yes	D (65)	B+ (89)	D+ (69)	B- (81)
Kansas	69 645	Yes	C+ (77)	B- (82)	C+ (78)	B (84)
Kentucky	38 568	No	C (74)	F (40)	B- (80)	F (48)
Louisiana	65 461	Yes	B (85)	F (6)	F (59)	D (63)
Maine	20 865	Yes	B (84)	A (94)	B (85)	A- (91)
Maryland	81 228	No	B- (81)	F (41)	F (35)	F (39)
Massachusetts	75 027	Yes	D+ (67)	A+ (98)	F (59)	B- (81)
Michigan	158 391	Yes	C- (70)	F (59)	B- (80)	C+ (77)
Minnesota	124 345	Yes	B+ (88)	A+ (100)	B (83)	A (93)
Mississippi	31 669	Yes	B (83)	F (29)	B (84)	C (74)
Missouri	87 760	Yes	D- (60)	F (13)	C- (70)	D- (61)
Montana	90 472	Yes	C- (70)	A (96)	C- (72)	B (84)
Nebraska	43 760	Yes	F (58)	F (27)	C+ (78)	D (66)
Nevada	85 953	Yes	B+ (87)	B+ (89)	F (53)	B- (82)
New Hampshire	12 534	No	F (57)	F (20)	B- (81)	F (39)
New Jersey	102 441	No	D (63)	A+ (98)	F (48)	F (52)
New Mexico	257 858	Yes	C (76)	F (35)	D (64)	D+ (69)
New York	318 858	No	F (0)	D+ (69)	F (39)	F (27)
North Carolina	245 724	Yes	C- (70)	A+ (99)	C- (70)	B (85)
North Dakota	51 664	Yes	D (63)	F (50)	F (6)	F (55)
Ohio	107 899	Yes	C- (70)	.. ^b	C (73)	B- (81)
Oklahoma	553 509	Yes	C (74)	B- (80)	C+ (77)	B (83)
Oregon	146 851	Yes	F (56)	A (94)	F (57)	C+ (77)
Pennsylvania	117 073	No	F (59)	A+ (99)	D (63)	F (55)

(continued)

TABLE 1— Continued

State Information		State-Reported COVID-19 Information		CDC COVID-19 National Surveillance Data		Overall Grade
State	AI/AN Population ^a	Is AI/AN Population Included on State Dashboard?	Grade (% of Cases With Complete Racial Information Reported on Dashboard)	Grade (% of Confirmed Cases From the State Reported to CDC)	Grade (% of Confirmed Cases With Complete Racial Information Reported on CDC Database)	
Rhode Island	20 190	Yes	C (75)	F (27)	F (27)	F (57)
South Carolina	58 171	No	D (66)	A+ (99)	D+ (67)	F (58)
South Dakota	92 686	Yes	B+ (89)	B (84)	B (84)	B+ (89)
Tennessee	76 883	Yes	C (73)	A+ (99)	C- (71)	B (86)
Texas	485 363	No	F (3)	F (3)	C- (72)	F (20)
Utah	73 697	Yes	B (83)	. . . ^b	B- (82)	B+ (88)
Vermont	8 088	Yes	B+ (88)	A- (92)	A- (90)	A (93)
Virginia	109 216	Yes	C (74)	B- (81)	D (64)	B- (80)
Washington	264 596	Yes	F (54)	A+ (100)	F (43)	C (74)
West Virginia	15 137	No	D (64)	F (8)	A- (92)	F (41)
Wisconsin	106 202	Yes	B (86)	B- (82)	B+ (87)	B+ (89)
Wyoming	22 024	Yes	F (57)	F (2)	B (83)	D- (61)
United States Overall ^c	6 935 690	C-	D+ (68)	D+ (69)	D (63)	D- (68)

Note. AI/AN = American Indian/Alaska Native, defined as American Indian/Alaska Native only + American Indian/Alaska Native in combination.

Source. Urban Indian Health Institute.²

^aPopulation numbers are believed to be an undercount and should not be interpreted to represent tribal enrollment numbers.

^bState reported a greater number of cases to the CDC than reported on dashboard; therefore, we were unable to identify the percentage of confirmed cases sent to the CDC.

^cUnited States overall grades averaged across states: 72% of states included AI/AN populations on their scoreboards; across states, 68% of state-reported cases included complete racial information reporting and 69% of confirmed state cases were reported to the CDC; 63% of confirmed cases in the CDC databases had complete racial information. Averaging these percentage-based grades is a score of 68, receiving a grade of D-.

that of Whites. They speculate that both underlying health conditions and reliance on shared transportation contributed to the early spread of the virus within AI/AN populations.

DATA DISSEMINATION BARRIERS

Even when appropriate data are collected, public health laws and policies can work to limit data sharing with the 12 tribal epidemiology centers (TECs), even though data are shared with states. TECs are the public health organizations of tribal and urban AI/AN

communities, serving similar roles as local public health departments. A recent US Government Accountability Office (GAO) report found that more than half of TECs experienced data access problems, as some CDC and Indian Health Service officials were unaware that the Department of Health and Human Services (DHHS) is required by federal law to provide data in its possession to TECs.⁸ Even when these requests were addressed, some took a year to fulfill. This is particularly problematic for smaller tribal communities that do not have the resources to track and update local community data in a

timely manner; the CDC and Indian Health Service are usually the only reliable and timely data source for these underresourced tribal nations.

Although the federal government's public health laws are designed to protect the security, privacy, and confidentiality of health data, less well-known is that the federal government also is bound by its trust doctrine to assist tribal groups, such as TECs, in matters of well-being. The trust doctrine reflects federal responsibility to Indian nations, requiring that it support tribal self-government and economic prosperity. Tribal nations, in turn, have the

responsibility to provide health care services and ensure the survival and welfare of Indian tribes and people.^{3,7,9} Consequently, the GAO report recommended that the DHHS work to resolve policy lapses and that both the CDC and Indian Health Service develop clear guidance for data sharing with TECs.

Although this is a necessary set of actions, COVID-19 data equity might be best achieved by also engaging the principles of the Global Indigenous Data Alliance, the voices of indigenous data warriors. CARE (Collective benefit, Authority to control, Responsibility, and Ethics) principles for indigenous data governance were developed as a framework for data management and sharing. These are complementary with FAIR (Findable, Accessible, Interoperable, Reusable) principles.¹⁰ TEC's requests for COVID-19 data are consistent with CARE principles and reflect that data equity is best served when it advances indigenous innovation and governance efforts that emanate from sovereignty and self-determination. Recognition of CARE principles is also needed for state and local data entities. Indeed, adhering to the Global Indigenous Data Alliance's FAIR and CARE principles is fundamental to data equity. How to apply these principles is well laid out in the Urban Indian Health Institute report.²

DATA USABILITY

Data equity requires that data be usable and meet clinically meaningful use standards for both public health entities and populations. CARE principles also underscore that data collection and its use must not bring unnecessary harm to those providing the data. In particular, identifying high infection rates for specific tribal nations

and other small communities could generate potential risks for targeted racism and violence. Data collection and surveillance methods must plan for this possibility and act to safeguard vulnerable populations.¹¹ It is also essential that AI/AN and other small and marginalized populations be included in this planning to ensure effective use and to protect against unanticipated harm.¹² County and local health and public health entities can optimize careful public messaging by not expecting data to speak for themselves, but rather helping people to have awareness of what the data mean. For example, when data are aggregated into personally unrecognizable categories (e.g., "other") or grouped where those within the group are heterogeneous for risks and resources,¹³ as is true of AI/AN groups, it is difficult to effectively use public health data for risk reduction. Data equity requires "sense making" by public health agencies in which numbers are interpreted in the context of the lives, risks, and stories of those whom the data are meant to help.

Finally, data equity also obligates us to plan for exceptions to the "average" case and to recognize the unique needs of small populations. At the start of the COVID-19 pandemic, when our public health knowledge base and armamentarium were sparse, enacting stay-at-home orders and public health advisories such as masking, hand washing, and physical distancing were reasonable strategies for the whole. But the viability of these strategies for communities that lack indoor plumbing, are isolated from public health messaging, experience water scarcities, and whose households lack isolating spaces were underappreciated challenges. We could have done better. For example, tribal

reservations could have been seen as warranting deliveries of personally protective equipment and water resources.¹⁴ An early study showed that initially high rates of COVID-19 infection in rural tribal groups were related to the prevalence of indoor plumbing on tribal reservations and English language use.¹⁵ These results illustrate that housing and general infrastructure information might be exceptionally predictive of infection rates for some AI/AN populations. Additionally, the prevalence of public health messaging and notices in a few languages may not have served certain populations well and may have left some with little to no information—at least at the early stages of a pandemic. However, AI/AN communities recognized the deficits of this messaging and quickly rallied scarce resources to successfully launch COVID-19 prevention campaigns that used regional context, language, and imagery, resulting in better-informed AI/AN communities nationwide.

We would be remiss to end this article without highlighting the incredible public health success, born of the principles of self-determination, that occurred when AI/AN tribal and urban groups asked the federal government to step aside and provide them with the COVID-19 vaccine.¹⁶ These groups engaged in consultation and education-first activities with AI/AN persons, which resulted in vaccination rates in some tribal groups as high as 80% to 90%. This is an achievement that many states cannot claim. FAIR and CARE principles are an effective public health tool for COVID-19 prevention, mitigation, and recovery that may be integral to protecting AI/AN and other racial/ethnic, rural, and low-income groups in the next pandemic. We cannot withstand another million deaths. [AJPH](#)

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CONFLICTS OF INTEREST

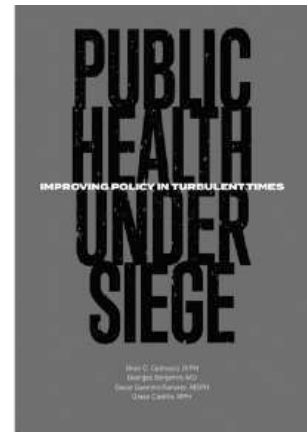
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REFERENCES

1. Khoury M. Precision public health: what is it? CDC blogs: genomics and precision health. 2018. Available at: <https://blogs.cdc.gov/genomics/2018/05/15/precision-public-health-2>. Accessed April 17, 2022.
2. Urban Indian Health Institute. Data genocide of American Indians and Alaska Natives in COVID-19 data. 2021. Available at: <https://www.uihi.org/projects/data-genocide-of-american-indians-and-alaska-natives-in-covid-19-data>. Accessed April 17, 2022.
3. Small-Rodriguez D, Akee R. Identifying disparities in health outcomes and mortality for American Indian and Alaska Native populations using tribally disaggregated vital statistics and health survey data. *Am J Public Health*. 2021;111(suppl 2):S126-S132. <https://doi.org/10.2105/AJPH.2021.306427>
4. Urban Indian Health Institute, Seattle Indian Health Board. Community health profile: national aggregate of urban Indian organization service areas. 2021. Available at: <https://www.uihi.org/resources/community-health-profile-national-aggregate-of-urban-indian-organization-service-areas>. Accessed July 6, 2022.
5. Krieger N, Testa C, Hanage W. US racial and ethnic data for COVID-19 cases: still missing in action. *Lancet*. 2020;396(10261):E81. [https://doi.org/10.1016/S0140-6736\(20\)32220-0](https://doi.org/10.1016/S0140-6736(20)32220-0)
6. Yellow Horse A, Yang T, Huyser K. Structural inequalities established the architecture for COVID-19 pandemic among Native Americans in

Arizona: a geographically weighted regression perspective. *J Racial Ethn Health Disparities*. 2022;9(1):165-175. <https://doi.org/10.1007/s40615-020-00940-2>

7. Hatcher S, Agnew-Brune C, Anderson M, et al. COVID-19 among American Indian and Alaska Native persons—23 states, January 31–July 3, 2020. *MMWR Morb Mortal Wkly Rep*. 2020; 69(34):1166-1169. <https://doi.org/10.15585/mmwr.mm6934e1d>
8. US Government Accountability Office. Tribal epidemiology centers: HHS action needed to enhance data access. 2022. Available at: <https://www.gao.gov/products/gao-22-104698>. Accessed April 17, 2022.
9. Hoss A. Federal Indian law as a structural determinant of health. *J Law Med Ethics*. 2020;47(S4):34-42.
10. GO FAIR. FAIR principles. 2016. Available at: <https://www.go-fair.org/fair-principles>. Accessed April 17, 2022.
11. Ford C, Amani B, Harawa N, et al. Adequacy of existing surveillance systems to monitor racism, social stigma and COVID inequities: a detailed assessment and recommendations. *Int J Environ Res Public Health*. 2021;18(24):13099. <https://doi.org/10.3390/ijerph182413099>
12. Carroll S, Akee R, Chung P, et al. Indigenous peoples' data during COVID-19: from external to internal. *Front Sociol*. 2021;6:617895. <https://doi.org/10.3389/fsoc.2021.617895>
13. Anderson T, Awan V, McDonnell D, Mousseau H. Foundations of data equity: learning from a workshop. Harder + Company. 2021. Available at: <https://harderco.com/foundations-of-data-equity-learning-from-a-workshop>. Accessed April 17, 2022.
14. US Government Accountability Office. Drinking water and wastewater infrastructure: opportunities exist to enhance federal agency needs assessment on tribal projects. 2018. Available at: <https://www.gao.gov/products/gao-18-309>. Accessed April 17, 2022.
15. Rodriguez-Lonebear D, Barceló N, Akee R, Carroll S. American Indian reservations and COVID-19: correlates of early infection rates in the pandemic. *J Public Health Manag Pract*. 2020;26(4):371-377. <https://doi.org/10.1097/PHH.0000000000001206>
16. Haroz E, Kemp C, O'Keefe V, et al. Nurturing innovation at the roots: the success of COVID-19 vaccination in American Indian and Alaska Native communities. *Am J Public Health*. 2022;112(3):383-387. <https://doi.org/10.2105/AJPH.2021.306635>



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Public Health Under Siege: Improving Policy in Turbulent Times

Edited by: Brian C. Castrucci, DrPH, Georges C. Benjamin, MD, Grace Guerrero Ramirez, MSPH, Grace Castillo, MPH

This new book focuses on the importance of health policy through a variety of perspectives, and addresses how policy benefits society, evidently through increased life expectancy and improved health. The book describes how detrimental social determinants can be to the overall population health and emphasizes how the nation is centered on policy change to create equal health care opportunities for all sectors of health.

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Adult Day Services, Health Equity for Older Adults With Complex Needs, and the COVID-19 Pandemic

Tina R. Sadarangani, RN, PhD, Joseph E. Gaugler, PhD, Holly Dabelko-Schoeny, PhD, and Katherine A. Marx, PhD, MPH

 See also **COVID-19 and Health Equity Data Gaps**, pp. 1404–1453.

Morbidity and mortality from COVID-19 have unduly affected older adults from racial and ethnic minority groups. In this article, we highlight the experiences and vulnerabilities of diverse older adults with complex health and social needs when their access to vital, but overlooked, community-based adult day service centers (ADSCs) was abruptly cut off during a pandemic.

Pandemic-related ADSC closures left vulnerable older adults and their care partners without essential daily support and services, such as health monitoring and socialization. However, the magnitude of the impact of ADSC closures on well-being, particularly among members of racial/ethnic minority groups, has yet to be measured with any form of “big data” because large-scale, nationally representative data sets consisting of participant-level information and outcomes associated with ADSC participation do not yet exist. Unmet needs of older adults resulting from pandemic-related ADSC closures are underrecognized because of a lack of systematic data collection, undermining efforts to achieve health equity.

We call on ADSCs to link rigorous collection of racial and ethnic data to quality measures of access to equitable “age-friendly” care as a means of better supporting diverse community-dwelling older adults beyond the COVID-19 pandemic. (*Am J Public Health*. 2022;112(10):1421–1428. <https://doi.org/10.2105/AJPH.2022.306968>)

C COVID-19, caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), had killed more than 865 000 people in the United States as of January 2022.¹ More than 630 000 COVID-19-linked deaths (nearly 75% of such deaths) have occurred among people older than 65 years.² This suggests that COVID-19 has taken the lives of nearly 1 in 100 older US adults in just over 2 years. Although cases of COVID-19 in the United States have fluctuated over time and between states since the beginning of the pandemic, adults aged 65 years and older continue to be affected disproportionately in terms of hospitalizations and deaths.³

Well-intentioned social distancing policies, such as avoiding crowded places and limiting contact with people outside of one’s household, were implemented at the beginning of the COVID-19 pandemic to protect people at high risk of severe illness from the virus, such as older adults. However, these measures also had unintended consequences for older adults’ health and well-being that have not been captured in public health data in the same way as morbidity and mortality.⁴ The purpose of this article is to describe the disproportionate, but understudied, effects of the COVID-19 pandemic on older adults receiving care through adult day service centers (ADSCs) in March 2020.

ADSCs are professional care settings designed for individuals who require supervised care during the day or those who are isolated and lonely.⁵ These centers enable older adults to socialize and enjoy planned activities in a peer group setting while still receiving needed health and social services. They simultaneously offer family caregivers respite from caregiving. Nearly 60% of ADSC users identify as members of racial/ethnic minority groups, and the majority of users live below federal poverty guidelines.⁶

In this analysis, we highlight the experiences and vulnerabilities of diverse older adults with complex health and social needs when their access to vital,

but overlooked, adult day services was abruptly cut off during a pandemic.⁷ We also explore the ways in which potential unmet needs of older adults resulting from the pandemic are underrecognized because of a lack of systematic data collection in community-based settings serving older adults, undermining efforts to achieve health equity. Finally, we call for a standardized approach to data collection in ADSCs that links data on race and ethnicity as well as social determinants of health to establish quality measures for age-friendly communities. As an essential first step, this would enable ADSCs to identify disparate outcomes exacerbated by the COVID-19 pandemic and to take eventual concrete and measurable actions to address the unmet health and social needs of diverse older adults.

STRUCTURAL FACTORS AND COVID-19 OUTCOMES

Morbidity and mortality from COVID-19 have unduly affected older adults from racial and ethnic minority groups, who have experienced higher COVID-19 case numbers and hospitalizations than their White counterparts.² Age, chronic conditions, and behavioral and social factors (e.g., crowded living conditions)⁸ contribute to the severity of COVID-19 symptoms as well as the likelihood of mortality. However, the pandemic has clearly exposed the role of structural racism in shaping COVID-19 disparities in outcomes among racial/ethnic minority populations.⁹ In a cross-sectional study involving multiple data sets, including the American Community Survey, the PULSE COVID survey,¹⁰ and the National Health Interview Survey,¹⁰ death rates among Black (472 deaths per 100 000 individuals) and

Latinx (545 deaths per 100 000) individuals aged 65 to 74 years were about 3 times higher than rates among non-Latinx White people (164 deaths per 100 000) in the same age bracket.

The “weathering” hypothesis suggests that increased exposure to social inequality throughout the life course results in physiological stress.¹¹ Racism contributes to increased stress, lower income, and barriers to health care access, which all contribute to chronic illnesses that increase the likelihood of poor outcomes from COVID-19.¹² For these reasons, COVID-19 has caused additional harm to racial/ethnic minority older adults who are already vulnerable to poor health outcomes.

However, it is important to note that the ramifications of COVID-19 for older adults from diverse communities should not only be viewed in terms of excess deaths. Racism, discrimination, language barriers, and weak social networks already predispose people from diverse racial/ethnic backgrounds to a higher vulnerability for social isolation.¹³ However, public health measures to mitigate infection spread may have unintentionally exacerbated loneliness and related health complications among older people. In general, social distancing has inadvertently led to social disconnection for many older adults, particularly those who live alone, functionally depend on family members, rely on support from community services, or live in residential long-term care facilities.¹⁴ Care partners, many of whom are the sole source of care for older individuals in the community, have also experienced undue stress while trying to protect their family members from COVID-19 and simultaneously facing a lack of options for support and respite.¹⁵

Many care partners have reported seeing declines in mental health and

physical and cognitive functioning in their loved ones.⁷ These reports are unsurprising. Older adults with medical, cognitive, or social frailty have difficulty compensating when their homeostasis¹⁶ is threatened. In other words, aging is associated with a diminished capacity to respond to varying physiological challenges. When faced with the added challenge of social isolation, older adults are particularly susceptible to rapid declines. Although older adults experienced high rates of loneliness and social isolation before the pandemic, many had social outlets that supported productive engagement and buffered depression and loneliness.¹⁶ These social outlets included congregate settings such as churches, senior centers, and ADSCs, many of which were deemed unessential and closed in-person services for extended periods, even after lockdowns were lifted.¹⁷

THE ROLE OF ADULT DAY SERVICES

In the early days of the COVID-19 pandemic, institutional long-term care facilities, which primarily serve older adults, were identified as high-risk settings for severe outcomes from outbreaks of COVID-19 because of the advanced age and multiple underlying conditions of the residents.¹⁸ Far less public health attention was paid to older adults in community-based long-term care settings, a majority of whom qualify for placement into skilled nursing facilities.⁷ Among these community settings were ADSCs, which serve more than 286 000 adults each day in the United States.¹⁹ ADSC staff provide people who have chronic illnesses or functionally disabling conditions with culturally congruent care, health monitoring, socialization opportunities, and

assistance with activities of daily living for up to 8 hours per day.²⁰ In addition, clinically trained staff provide vital sign monitoring, counseling, nutrition services, and medication administration.⁵ ADSC staff also deliver evidence-based care, including memory care programs, which supports aging in place.²¹

Although most ADSCs are independently owned and operated, in some cases they are embedded within the Program of All-Inclusive Care for the Elderly (PACE), which provides comprehensive integrated medical and social services to certain frail, elderly people (participants) still living in the community.²² Most of the program participants are dually eligible for Medicare and Medicaid, and health-related services are often delivered at the ADSC.

ADSC users are a medically complex population who also have unmet social needs: (1) 69.2% of users live with some combination of Alzheimer's disease and Alzheimer's disease-related dementias, diabetes, depression, or heart disease¹⁹; (2) 65.8% are Medicaid beneficiaries; and (3) 58% are members of racial/ethnic minority groups.⁶ Among ADSC users, chronic disease management is frequently complicated by poverty, disability, limited English proficiency, transportation barriers, and food insecurity.²³

The results of an integrative review²⁰ of the literature showed that ADSCs are a favorable and effective form of long-term care for members of racial/ethnic minority groups, namely immigrants. ADSCs successfully incorporate elements of immigrants' ethnic backgrounds and language into activities and programs that facilitate social connectedness, improve physical health and function, and preserve independence. Older adults in these centers experience a deep sense of camaraderie that supports well-being when spending time with peers who

share a common language or generational experience. The people, food, imagery, and social activities in ADSCs all offer reminders of "home" (i.e., their native country) to older immigrants, providing them with a familiar environment. Beyond their particular cultures, programs in ADSCs expose older immigrants to new experiences (e.g., current events or field trips to museums), providing an avenue for acculturation and making American culture and history more accessible to them.

The aforementioned integrative review²⁰ also revealed that bilingual and bicultural staff, especially nurses, played the role of cultural liaison between older immigrants and the health care system. More than 6000 registered nurses and licensed practical nurses work in ADSCs nationally.⁶ Nurses in particular promote health literacy by helping older adults process and understand health information so that they can make better health care decisions (e.g., adhering to their medication regimen).²⁴ They also transform directives from health care providers (e.g., dietary modifications) into culturally sensitive, actionable health care interventions (e.g., culturally tailored lunches at the ADSC).²⁴

EFFECT OF PANDEMIC CLOSURES ON "NONESSENTIAL" CENTERS

In March 2020, ADSC sites across the nation were forced to close congregate operations with little notice or direction, putting an abrupt end to in-person services.^{7,17} Although child care facilities were deemed essential during the pandemic,²⁵ ADSCs were not treated the same way. According to the National Center for Health Statistics, 72% of ADSCs reported limiting hours or closing temporarily between January 2020

and March 2021. Moreover, 28.9% of ADSCs reported shortages of personal protective equipment such as gloves or face masks in that same period. Lack of this equipment may have limited their ability to safely provide in-person services.²⁶ Closures left ADSC clients without essential daily support and services, such as meal preparation, health monitoring, and socialization. Care partners also had no source of respite.⁷

However, many ADSC sites demonstrated resilience and creativity, continuing to provide telephonic or remote services to clients, including virtual programming.⁷ They did so while receiving no promise of reimbursement from government programs such as Medicaid, which is the primary payer of ADSCs. The lack of revenue to pay employees and cover overhead costs led some sites to close permanently.¹⁷

In a study of 22 ADSCs,²⁷ 86.4% reported that they stopped providing in-center services as a result of COVID-19, with 52.6% nearly suspending services because of a state mandate. Nearly 64% needed to furlough or terminate staff, whereas other sites transferred employees to other facilities or reduced working hours. All 22 sites offered telephone support to clients, including regular wellness check-ins (42.9%) and care coordination (28.6%); however, only 54.5% received any kind of reimbursement for these services. Most sites reported providing clients with activity ideas (77.3%), 14 sites (63.6%) provided virtual activities using technology such as YouTube or Zoom, and 12 sites (54.5%) provided customized bags of activities to clients. Although the majority of the sites provided these services, they were rarely reimbursed for this support. Almost 2 years later, ADSCs that were able to reopen had to reduce capacity while simultaneously incurring

higher costs, workforce shortages, confusing and changing infection-control rules, and fears of new outbreaks.²⁷

Although ADSCs have clearly struggled to find ways to operate amid new variants and growing case counts,²⁸ a limited body of research has demonstrated the profound effects of ADSC closures on older adults and their care partners. Studies that have assessed the effects of ADSC closures on older adults and their care partners have consistently shown that pandemic-related closures of ADSCs have

1. Exacerbated isolation and caregiver strain,
2. Accelerated cognitive and functional declines,
3. Led to unsafe behaviors,
4. Increased the use of care in higher-cost settings (e.g., emergency rooms and skilled nursing facilities), and
5. Limited opportunities for productive engagement among the older adults they serve.^{7,29}

The experiences of ADSC staff in a qualitative descriptive study conducted by Sadarangani et al.⁷ highlight the effects of closures. For example, one staff member described increased health care use:

What I'm seeing is, I'm just looking at her hospitalizations, so we have had during this period of time 33 hospitalizations ... in the three months, and our average before that was maybe one to two a month.... Not only did we have 33 hospitalizations, we've had 43 [emergency room] visits as well.

Another staff member described the physical and emotional effects of ADSC closures in the words of a caregiver:

"Since you closed," and this was about a week and a half afterward, "I haven't been able to get him outta bed. He comes outta bed to eat. He goes back to bed. He hasn't been able to—he doesn't wanna do anything." She said, "I would say to him [prior to that], 'They're here to pick you up for the program.' He was up. He was showered. He was dressed. He was ready." She said, "He can't."

The consensus within this limited body of research on pandemic-related closures of ADSCs is that well-intentioned efforts to reduce the spread of COVID-19 among older adults by shuttering congregate settings inadvertently increased other health risks in this population by creating a gap in essential services. We lack data on exactly how many adult day programs have permanently closed since March 2020, although a Kaiser Family Foundation³⁰ survey of home- and community-based service providers showed that ADSCs were the most frequently reported types of such providers to have permanently closed during the pandemic. These closures also threaten the long-term viability of an increasingly important sector of care that predominantly serves vulnerable community-dwelling older racial/ethnic minorities.

LACK OF LARGE-SCALE STANDARDIZED DATA AFTER THE PANDEMIC

The scale and magnitude of the effects of ADSC closures on the well-being of users and their care partners, particularly those who identify as racial/ethnic minorities, have yet to be measured with any form of "big data" because large-scale, nationally representative data sets consisting of participant-level data and outcomes associated with ADSC participation do not yet exist.³¹

Notably, the National Postacute and Long-term Care Study, conducted by the Centers for Disease Control and Prevention, provides information on 7 major sectors of paid, regulated postacute and long-term care, including adult day services, but does not yet publicly share participant-level data.³²

Other studies examining the effects of ADSC use involve inconsistent outcome measures, do not incorporate physiological measures, include small sample sizes rather than large data sets, and rarely incorporate stakeholders into the study design process.^{33,34} Moreover, race and ethnicity data are not routinely collected by ADSCs. This is evidenced by results from a recent retrospective cohort analysis³⁴ of 3053 ADSC clients in California with dementia. The analysis showed that data on race and ethnicity were collected from only 53.4% of participants because these data fields are not required by the state at the program level.

Even before the COVID-19 pandemic, a lack of standardized, large-scale data³⁵ led to ADSCs remaining a largely overlooked community-based resource for supporting individuals with complex health and social needs. The lack of data on social determinants of health and health outcomes among ADSC users represents a major obstacle to improving the health and well-being of older adults in the wake of the COVID-19 pandemic and understanding the effects of isolation on this vulnerable population.

Data collection in adult day services is fundamental to public health. Without it, the public health importance of these programs remains hidden, even though most older adults with chronic health conditions prefer to be cared for in their communities.³⁶ From a health equity perspective, the lack of data is problematic because data are a

cornerstone of efforts to address disparities. Data are essential for identifying where disparities exist, directing efforts and resources to address disparities as they are identified, measuring progress toward achieving greater equity, and establishing accountability for achieving progress. ADSC data on race and ethnicity can also inform culturally relevant programming. Without adequate data, inequities remain unseen and unaddressed.

Efforts to conduct research in ADSCs have historically been disjointed; ADSCs lack rigorous, replicable, patient-level data that demonstrate their effects on the health and well-being of older adults and caregivers and their value for these individuals.³³ Investments in technology, such as electronic health record systems, telehealth portals, and data reporting and management systems,³⁷ have lagged far behind other health care providers. Now, ADSCs are further challenged to demonstrate the adverse effects of long-term closures or limited access to congregate care brought on by the pandemic.

A national survey of ADSC sites conducted just before the start of the pandemic examined which data, if any, ADSCs across the country were collecting. According to the survey results, 32% of ADSCs reported collecting data using standardized outcome measures.³¹ These ADSCs primarily collected data on activities of daily living (88.1%), cognition (57.5%), depression (48.7%), and loneliness (34.2%). These findings are promising because they demonstrate the capacity and capability of ADSCs to collect outcome data on clients and caregivers.

However, these measures, although important, do not fully reflect the services and benefits that ADSCs are known to provide (e.g., physical activity, cognitive stimulation, and socialization). Data

collection in other important domains, such as caregiver well-being and health care use, was either inadequate or nonexistent. For example, only 27.8% of ADSCs used an evidence-based tool to assess caregiver well-being, and few centers recorded numbers of falls, emergency department visits, or hospitalizations.³¹ The latter measures have all been strongly suggested by researchers³³ and may be critically important in demonstrating the potential of ADSCs to reduce health care use and costs and leverage funding.

The survey also suggested that although some ADSCs are mandated by their respective state bodies to collect such data, many ADSCs appear to be collecting the data of their own volition.³¹ ADSCs clearly have a desire to collect outcome data and use the power of data to influence programming, policy-making, and funding. However, many programs could now find themselves in limbo, made worse by the pandemic, and unable to collect outcome data because of limited resources or to leverage additional resources because of a lack of evidence of their effectiveness.

The fact that ADSCs generally do not have the capacity and resources to undertake research independently underscores the need for academic researchers to engage with centers using a community-based participatory action framework to identify ADSC strengths and opportunities.³⁵

FUTURE DIRECTIONS TO PROMOTE HEALTH EQUITY

As uncertainties about the viability of ADSC programs for frail older adults persist amid the ongoing pandemic, it is clear that ADSCs in particular would benefit from a roadmap clearly showing

ways to demonstrate for payers and policymakers the effects closures have had on the well-being of the individuals they serve and their care partners. With such information, ADSCs could demonstrate that they provide an essential service. This is particularly important with respect to members of racial/ethnic minority groups, who disproportionately receive care in ADSCs and have been profoundly affected by the COVID-19 pandemic. It is important to note that ADSCs are not the only segment of health care whose collection of data on race, ethnicity, and language is inadequate. In fact, historically data on race, ethnicity, and language were collected not for quality improvement purposes but to allow analyses ensuring compliance with civil rights provisions.³⁸

The COVID-19 pandemic has increased pressure for improvements in data collection across health care. However, it also represents an opportunity for community-based services, such as ADSCs, to highlight their abilities to address unmet health and social needs. This can be done not only by regulating and funding data collection but also by focusing on collecting information that is of importance to ADSC users and their families to inform care planning and quality of life.

Two initiatives may offer ADSCs guidance for approaches to data collection that emphasize equitable age-friendly health care with a focus on social determinants of health. The Centers for Disease Control and Prevention's Data Modernization Initiative³⁹ focuses on working toward equitable public health through identifying and promoting best practices for data collection that account for social factors. Improved, standardized data collection on social determinants of health

(e.g., discrimination and living arrangements) is needed to understand creative methods to leverage community-based programs such as ADSCs to meet people's urgent and basic needs and improve health in the face of future pandemics or natural disasters, as opposed to simply shutting off access.

The "4Ms" framework⁴⁰ set forth by the Age-Friendly Health Systems initiative of the Institute for Healthcare Improvement established 4 evidence-based contributors to high-quality, cost-effective care for older adults. The 4Ms refer to "what matters" (knowing, and aligning care with, older adults' health outcome goals and care preferences), "medication" (using age-friendly medication and screening for the use of specific high-risk medications), "mentation" (screening for and documenting depression, dementia, and delirium), and "mobility" (screening for the ability to move around safely).

In 2021, the Institute for Healthcare Improvement issued a directive for Age-Friendly Health Systems to apply the 4Ms equitably, by race and ethnicity, across their older adult patient populations. To date, more than 1000 care settings, including hospitals, clinics, and nursing homes, have joined this initiative. It is not clear how many ADSCs are part of the initiative. Participating organizations will be required to record the racial/ethnic breakdown of their patient populations. This is particularly important for ADSCs, where these data are not routinely collected and will represent a significant advance in data collection. Linking the quality measures within the 4Ms framework to the rigorous collection of racial and ethnic data in the initiative will help researchers and policymakers understand the effects they have on the individuals they serve. Analyzing data stratified by

race and ethnicity and taking concrete and measurable actions to address disparate outcomes would represent an evolutionary step forward toward health equity for community-dwelling older adults.

It is important to note that, to pursue or actualize any data collection efforts, ADSCs will require support and incentives. Currently, they do not have systematic requirements or structures across states to collect or use outcome data.³¹ Similar to many providers of long-term care services, ADSCs are facing critical staffing shortages and are struggling to keep their doors open.³⁰ Forcing additional data collection may be perceived as burdensome, particularly as centers struggle to make up for financial losses during periods of closure. One possible solution is improving their partnerships with managed care companies that administer Medicaid plans and offering financial incentives for improved outcomes.

CONCLUSIONS

The COVID-19 pandemic has seriously affected the health and well-being of older adults, particularly those who identify as members of racial/ethnic minority groups. We have summarized evidence suggesting that people who receive care in ADSCs and their care partners suffered disproportionately when their access to essential services and support was taken away with little or no notice in March 2020, and in many cases this access has yet to be fully restored 2 years later.

Lack of large-scale data on unmet health and social needs resulting from ADSC closures is a direct affront to health equity. More investment in and data from ADSCs that reflect evidence-based quality measures are needed to

demonstrate the benefits centers have for frail older adults and their care partners and strengthen programs that will benefit the physical and emotional health of older adults in the wake of the COVID-19 pandemic. Valid and reliable measures, such as those endorsed by the National Quality Forum,⁴¹ would enable fair comparisons and benchmarking between ADSCs and other long-term care settings. Incorporating the 4Ms framework and the Data Modernization Initiative into data collection and engaging managed care programs have the potential to garner the attention of payers and health systems, which will help bring their attention to the essential and successful work of ADSCs with frail older adults who have complex health and social needs. **AJPH**

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CONFLICTS OF INTEREST

The authors have no conflicts of interest to declare.

HUMAN PARTICIPANT PROTECTION

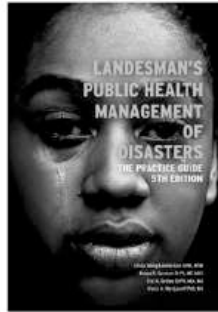
No protocol approval was needed for this study because no human participants were involved.

REFERENCES

- Johnson AG, Amin A, Ali A, et al. COVID-19 incidence and death rates among unvaccinated and fully vaccinated adults with and without booster doses during periods of Delta and Omicron variant emergence—25 U.S. jurisdictions, April 4–December 25, 2021. *MMWR Morb Mortal Wkly Rep.* 2022;71(4):132–138. <https://doi.org/10.15585/mmwr.mm7104e2>
- Centers for Disease Control and Prevention. Provisional death counts for COVID-19. Available at: <https://www.cdc.gov/nchs/covid19/mortality-overview.htm>. Accessed January 26, 2022.
- Yanez ND, Weiss NS, Romand JA, Treggiari MM. COVID-19 mortality risk for older men and women. *BMC Public Health.* 2020;20(1):1742. <https://doi.org/10.1186/s12889-020-09826-8>
- Bowling CB, Berkowitz TSZ, Smith B, et al. Unintended consequences of COVID-19 Social distancing among older adults with kidney disease. *J Gerontol A Bio Sci Med Sci.* 2022;77(4):e133–e137. <https://doi.org/10.1093/gerona/glab211>
- Oliver RE, Foster M. Adult day care: an important long-term care alternative & potential cost saver. *Mo Med.* 2013;110(3):227–230.
- National Center for Health Statistics. Long-term care providers and services users in the United States, 2015–2016. Available at: https://www.cdc.gov/nchs/data/series/sr_03/sr03_43-508.pdf. Accessed January 26, 2022.
- Sadarangani T, Zhong J, Vora P, Missaelides L. “Advocating every single day” so as not to be forgotten: factors supporting resiliency in adult day service centers amidst COVID-19-related closures. *J Gerontol Soc Work.* 2021;64(3):291–302. <https://doi.org/10.1080/01634372.2021.1879339>
- Centers for Disease Control and Prevention. Health equity considerations and racial and ethnic minority groups. Available at: <https://www.cdc.gov/coronavirus/2019-ncov/community/health-equity/race-ethnicity.html>. Accessed January 26, 2022.
- Ajllore O, Thames AD. The fire this time: the stress of racism, inflammation and COVID-19. *Brain Behav Immun.* 2020;88:66–67. <https://doi.org/10.1016/j.bbi.2020.06.003>
- Guerrero LR, Wallace SP. The impact of COVID-19 on diverse older adults and health equity in the United States. *Front Public Health.* 2021;9:661592. <https://doi.org/10.3389/fpubh.2021.661592>
- Geronimus AT, Hicken M, Keene D, Bound J. “Weathering” and age patterns of allostatic load scores among Blacks and Whites in the United States. *Am J Public Health.* 2006;96(5):826–833. <https://doi.org/10.2105/AJPH.2004.060749>
- Sadarangani TR. The nurse’s role in promoting health equity and improving racial justice in older adults through elimination of unconscious bias. *Geriatr Nurs.* 2020;41(6):1025–1027. <https://doi.org/10.1016/j.gerinurse.2020.10.011>
- Johnson S, Bacsu J, McIntosh T, Jeffery B, Novik N. Competing challenges for immigrant seniors: social isolation and the pandemic. *Healthc Manage Forum.* 2021;34(5):266–271. <https://doi.org/10.1177/08404704211009233>
- Smith ML, Steinman LE, Casey EA. Combatting social isolation among older adults in a time of physical distancing: the COVID-19 social connectivity paradox. *Front Public Health.* 2020;8:403. <https://doi.org/10.3389/fpubh.2020.00403>
- Sheth K, Lorig K, Stewart A, Parodi JF, Ritter PL. Effects of COVID-19 on informal caregivers and the development and validation of a scale in English and Spanish to measure the impact of COVID-19 on caregivers. *J Appl Gerontol.* 2021;40(3):235–243. <https://doi.org/10.1177/0733464820971511>
- Steinman MA, Perry L, Perissinotto CM. Meeting the care needs of older adults isolated at home during the COVID-19 pandemic. *JAMA Intern Med.* 2020;180(6):819–820. <https://doi.org/10.1001/jamainternmed.2020.1661>
- Gaugler JE, Marx K, Dabelko-Schoeny H, et al. COVID-19 and the need for adult day services. *J Am Med Dir Assoc.* 2021;22(7):1333–1337. <https://doi.org/10.1016/j.jamda.2021.04.025>
- Nanda A, Vura NVRK, Gravenstein S. COVID-19 in older adults. *Aging Clin Exp Res.* 2020;32(7):1199–1202. <https://doi.org/10.1007/s40520-020-01581-5>
- Caffrey C, Lendon JP. Service provision, hospitalizations, and chronic conditions in adult day services centers: findings from the 2016 National Study of Long-Term Care Providers. *Natl Health Stat Rep.* 2019;(124):1–9.
- Sadarangani TR, Murali KP. Service use, participation, experiences, and outcomes among older adult immigrants in American adult day service centers: an integrative review of the literature. *Res Gerontol Nurs.* 2018;11(6):317–328. <https://doi.org/10.3928/19404921-20180629-01>
- Sadarangani T, Chong S, Park S, et al. A qualitative analysis of the delivery of person-centered nutrition to Asian Americans with dementia in the adult day health care setting. *J Appl Gerontol.* 2021;40(2):179–188. <https://doi.org/10.1177/0733464820910030>
- Hirth V, Baskins J, Dever-Bumba M. Program of All-Inclusive Care (PACE): past, present, and future. *J Am Med Dir Assoc.* 2009;10(3):155–160. <https://doi.org/10.1016/j.jamda.2008.12.002>
- Sadarangani T, Missaelides L, Eilertsen E, Jaganathan H, Wu B. A mixed-methods evaluation of a nurse-led community-based health home for ethnically diverse older adults with multimorbidity in the adult day health setting. *Policy Polit Nurs Pract.* 2019;20(3):131–144. <https://doi.org/10.1177/1527154419864301>
- Jennings-Sanders A. Nurses in adult day care centers. *Geriatr Nurs.* 2004;25(4):227–232. <https://doi.org/10.1016/j.gerinurse.2004.06.021>
- Van Lancker W, Parolin Z. COVID-19, school closures, and child poverty: a social crisis in the making. *Lancet Public Health.* 2020;5(5):e243–e244. [https://doi.org/10.1016/S2468-2667\(20\)30084-0](https://doi.org/10.1016/S2468-2667(20)30084-0)
- Centers for Disease Control and Prevention. Long-term care and COVID-19 in adult day services. Available at: <https://www.cdc.gov/nchs/covid19/npals/adsc.htm>. Accessed April 26, 2022.
- Parker LJ, Marx K, Gaugler JE, Gitlin LN. Implications of the COVID-19 pandemic on adult day services and the families they serve. *Am J Alzheimers Dis Other Dement.* 2021;36:1–6. <https://doi.org/10.1177/15333175211050152>
- Zimmerman S, Gaugler JE, Nkimbeng M. COVID-19 vaccination and implementation science: how one can benefit the other. *J Am Med Dir Assoc.* 2021;22(11):2223–2224. <https://doi.org/10.1016/j.jamda.2021.09.018>
- Vervaecke D, Owaisi RB, Meisner BA. Adult day program directors’ experiences managing the COVID-19 pandemic. *Can J Aging.* 2021;40(4):639–650. <https://doi.org/10.1017/S0714980821000490>
- Watts MO. 2021. State Medicaid home and community-based services (HCBS) programs respond to COVID-19: early findings from a 50-state survey. Available at: <https://www.kff.org/coronavirus-covid-19/issue-brief/state-medicare-home-community-based-services-hcbs-programs-respond-to-covid-19-early-findings-from-a-50-state-survey>. Accessed January 26, 2022.
- Sadarangani T, Anderson K, Vora P, Missaelides L, Zagorski W. A national survey of data currently being collected by adult day service centers across the United States. *J Appl Gerontol.* 2022;41(3):729–735. <https://doi.org/10.1177/07334648211013974>
- Centers for Disease Control and Prevention. National Post-acute and Long-term Care Study homepage. Available at: <https://www.cdc.gov/nchs/npals/index.htm>. Accessed January 26, 2022.
- Anderson KA, Geboy L, Jarrott SE, et al. Developing a set of uniform outcome measures for adult day services. *J Appl Gerontol.* 2020;39(6):670–676. <https://doi.org/10.1177/0733464818782130>
- Sadarangani T, Parker L. Unpacking data from adult day centers in order to realize their untapped potential in dementia care. *Innov Aging.* 2021;5(suppl 1):83. <https://doi.org/10.1093/geroni/igab046.318>
- Sadarangani T, Zagorski W, Parker L, Missaelides L. Identifying research priorities in adult day centers to support evidence-based care of vulnerable older adults. *Prog Community Health Partnersh.* 2021;15(1):127–131. <https://doi.org/10.1353/cpr.2021.0012>
- Binette J, Vasold K. Home and community preferences: a national survey of adults ages 18-plus. Available at: <https://www.aarp.org/research/topics/community/info-2018/2018-home-community-preference.html>. Accessed January 26, 2022.
- Centers for Disease Control and Prevention. Tables on use of electronic health records and health information exchange among adult day services centers and residential care communities from the 2016 National Study of Long-Term Care Providers. Available at: <https://www.cdc.gov/>

[nchs/data/nsltcp/EHR-HIE-use-among-adsc-rcc-2016.pdf](https://nchs.data.nsltcp/EHR-HIE-use-among-adsc-rcc-2016.pdf). Accessed January 1, 2020.

38. Hahn RA, Truman BI, Williams DR. Civil rights as determinants of public health and racial and ethnic health equity: health care, education, employment, and housing in the United States. *SSM Popul Health*. 2017;4:17–24. <https://doi.org/10.1016/j.ssmph.2017.10.006>
39. Centers for Disease Control and Prevention. Data Modernization Initiative. Available at: <https://www.cdc.gov/surveillance/data-modernization/index.html>. Accessed January 26, 2022.
40. Institute for Healthcare Improvement. What is an age-friendly health system? Available at: <http://www.ihl.org:80/Engage/Initiatives/Age-Friendly-Health-Systems/Pages/default.aspx>. Accessed January 26, 2022.
41. Mor V, Angelelli J, Gifford D, Morris J, Moore T. Benchmarking and quality in residential and nursing homes: lessons from the US. *Int J Geriatr Psychiatry*. 2003;18(3):258–266. <https://doi.org/10.1002/gps.821>



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Trends in Collection of Disaggregated Asian American, Native Hawaiian, and Pacific Islander Data: Opportunities in Federal Health Surveys

Kevin H. Nguyen, PhD, Kaitlyn P. Lew, BS, and Amal N. Trivedi, MD, MPH

 See also COVID-19 and Health Equity Data Gaps, pp. 1404–1453.

Collection of data for Asian American, Native Hawaiian, and Pacific Islander (AANHPI) persons that is disaggregated by ethnic subgroup may identify disparities that are not apparent in aggregated data. Using content analysis, we identified national population surveys administered by the US Department of Health and Human Services (HHS) and evaluated trends in the collection of disaggregated AANHPI data between 2011 and 2021.

In 2011, 4 of 15 surveys (27%) collected disaggregated data for Asian American, 2 of 15 surveys (13%) collected data on Native Hawaiian, and 2 of 15 surveys (13%) collected disaggregated data for Pacific Islander people. By 2019, 14 of 21 HHS-administered surveys (67%) collected disaggregated data for Asian American (6 subgroups), 67% collected data on Native Hawaiian, and 67% collected disaggregated data on Pacific Islander (3 subgroups) people.

Collection of disaggregated AANHPI data in HHS-administered surveys increased from 2011 to 2021, but opportunities to expand collection and reporting remain. Strategies include outreach with community organizations, increased language assistance, and oversampling approaches. Increased availability and reporting of these data can inform health policies and mitigate disparities. (*Am J Public Health*. 2022;112(10):1429–1435. <https://doi.org/10.2105/AJPH.2022.306969>)

Approximately 7% of the US population self-identify as Asian American, Native Hawaiian, or Pacific Islander (AANHPI).¹ Though often treated as a monolith, the AANHPI population in the United States is diverse, with origins from 50 countries and speaking more than 100 languages.^{1,2} Disparities between non-Hispanic White and AANHPI people—which are the product of racism, xenophobia, and other structural inequities—are well documented, including higher prevalence of chronic conditions, higher cancer incidence rates, and worse access to care.^{3–5} While AANHPI people have historically

been aggregated as 1 race in many federal surveys, studies suggest that this amorphous category masks wide variation in access to medical resources and health outcomes by ethnic subgroup (e.g., Asian Indian, Chinese).^{3,6} For example, Filipinx, Asian Indian, and Korean adults have a high prevalence of diabetes; Chinese and Korean people have a higher prevalence of current smoking; and Pacific Islander people have higher rates of obesity.⁶

Disaggregation of health data for AANHPI people has been a priority of the US Department of Health and Human Services (HHS) for more than 20 years.⁷

Advocates argue that more granular data are a critical first step for identifying various experiences of care in ethnic subgroups and that this information may be used to inform robust targeted interventions, health policies, and resource allocation. Poor data quality (or failure to collect and report disaggregated data) can codify racist biases and mask health inequities among AANHPI people.⁸ Organizations such as the Robert Wood Johnson Foundation have announced renewed commitment to data disaggregation.⁹

Population health survey data can be leveraged for assessing disparities in patient-reported access to care, health

services utilization, and diagnoses.¹⁰ The extent to which disparities can be detected, however, depends on the data that are collected. As such, Section 4302 of the Affordable Care Act (ACA) of 2010 mandated that the HHS Secretary establish data collection standards for race, ethnicity, sex, primary language, and disability status for federally conducted or supported public health surveys by 2012.¹¹ Data collection standards were to be adopted to the extent practicable in all national population surveys.¹¹ The data collection standards, which were developed by the Office of Minority Health (OMH), required more granular data collection for some AANHPI subgroups.¹¹

In 2010, a review by Islam et al. indicated that 4 of 17 federal data sets collected limited AANHPI subgroup data: National Health Interview Survey (NHIS), National Survey on Drug Use and Health (NSDUH), Medical Expenditure Panel Survey (MEPS), and Early Childhood Longitudinal Survey.¹² We extended this work by examining how the landscape of disaggregated AANHPI data collection in population surveys has changed since 2010 and assessing the impact of the mandate on collection and reporting of disaggregated AANHPI data in HHS-administered surveys. We then discuss barriers to expanding data collection in other surveys and identify strategies to promote further adoption of disaggregated AANHPI data and advance AANHPI health equity.

METHODS

Considering the vast number of data systems and data collection activities at HHS, we included lists of HHS surveys and data systems developed by the HHS Assistant Secretary of Planning and Evaluation,^{13,14} the National Center for Health

Statistics,¹⁵ and the Centers for Medicare and Medicaid Services (CMS).¹⁶ We supplemented these lists with data sources from previous work examining disaggregated AANHPI data collection.^{1,12}

The scope of our study was to examine trends in disaggregated AANHPI health data among HHS-administered population surveys. Therefore, we excluded provider surveys or facility-level data sets, administrative data, vital records, disease surveillance systems, and area-level data sets (Table A, available as a supplement to the online version of this article at <https://ajph.org>). Though some non-HHS federally administered surveys (e.g., American Community Survey) collect health-related data for AANHPI people, we excluded them from our study.

Using content analysis, we reviewed the available documentation from each survey that met our inclusion criteria, such as questionnaires, codebooks, and result summaries. To extend previous work, we reviewed available documentation between 2011 and 2021.^{3,14} Our unit of analysis was the survey-year, as all surveys were collected on an annual or biennial basis. For each survey, we searched documents for the keywords of “race,” “ethnicity,” “Asian,” “Native Hawaiian,” and “Pacific Islander” to assess whether disaggregated AANHPI data were collected and, if so, for which subgroups. When documentation was not available publicly ($n = 5$), the study team directly contacted the corresponding agencies.

While we present collection of disaggregated AANHPI data in population surveys through 2021, we focused our examination of trends between 2011 and 2019, as many surveys and data collection systems were affected by the COVID-19 pandemic.¹⁴ Some HHS-administered surveys were introduced in our study period or were collected for only 1 year.

A total of 14 HHS surveys consistently collected data in our study period. Using those 14 surveys, we conducted a separate analysis examining trends in disaggregated AANHPI data collection.

RESULTS

Of 52 data systems administered by HHS in our study period, 26 (50%) were excluded because they were provider surveys, administrative data, disease surveillance systems, vital records, or area-level files (Table A). In Table A and Table B (available as a supplement to the online version of this article at <https://ajph.org>), we summarize collection of disaggregated AANHPI data by 6 HHS agencies (Agency for Healthcare Research and Quality, Centers for Disease Control and Prevention, CMS, Health Resources and Services Administration, National Institutes of Health, and Substance Abuse and Mental Health Services Administration) administered between 2011 and 2021. The total number of surveys in our sample ranged from 15 in 2011 to 21 in 2019. Four surveys (Health Center Patient Survey, Native Hawaiian and Pacific Islander National Health Interview Survey, Home and Community-Based Services Consumer Assessment of Healthcare Provider and Systems [CAHPS], and Nationwide Adult Medicaid CAHPS) were each collected for 1 year.

Among surveys that collected disaggregated AANHPI data in their most recent year of data collection, the number of Asian American subgroups ranged between 7 and 35, and the number of Pacific Islander subgroups ranged between 3 and 10. Some surveys—particularly CAHPS surveys—also documented the availability of linguistically inclusive survey materials, in which the most common languages were Cantonese, Mandarin, Korean, and Vietnamese.

Trends in Disaggregated Data Collection

In 2011, about one quarter of HHS-administered surveys (4 of 15, or 27%) collected disaggregated Asian American data, and fewer (2 of 15, or 13%) collected Native Hawaiian data and disaggregated Pacific Islander data. By 2019, two thirds of HHS-administered surveys (14 of 21, or 67%) collected disaggregated data for Asian American (6 subgroups), Native Hawaiian, and Pacific Islander (3 subgroups) people. There were 14 HHS surveys that consistently collected data in our study period. In 2011, of the 14 surveys, 4 surveys (29%; MEPS, NHIS, National Health and Nutrition Examination Survey [NHANES], and NSDUH) collected disaggregated Asian American data, 2 surveys (14%; NHIS and NHANES) collected Native Hawaiian data, and 2 surveys (14%; NHIS and NHANES) collected disaggregated Pacific Islander data (Figure 1).

Following the ACA mandate, the number of surveys collecting disaggregated data increased for AANHPI people, reaching a total of 9 (64%) by 2015, where it has since plateaued. Of surveys currently being collected, 8 do not collect disaggregated AANHPI data: Health and Retirement Survey, Home Health CAHPS, Hospital CAHPS, Medicare Fee-for-Service CAHPS, Medicare Advantage Health Plan Disenrollment Survey, Qualified Health Plan Enrollee Survey, National Youth Tobacco Survey, and Youth Risk Behavior Surveillance System (Table 1).

Commonly Collected Ethnic Subgroups

There were 7 commonly used ethnic subgroups among Asian American people (Asian Indian, Chinese, Filipino,

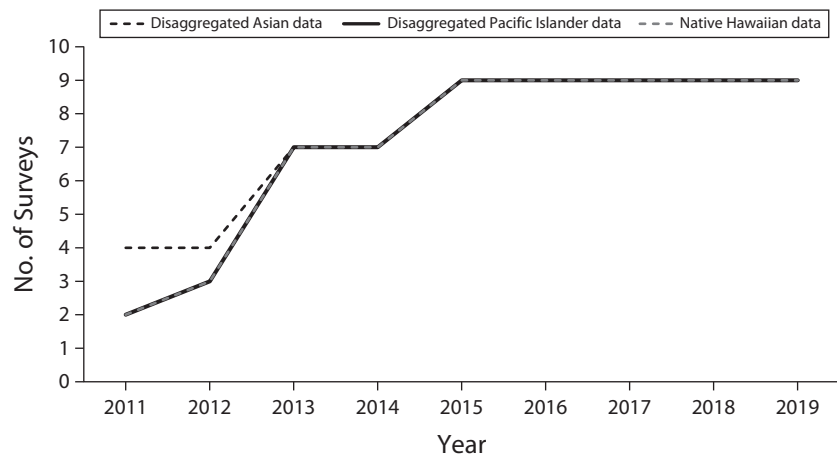


FIGURE 1— Trends in Collection of Disaggregated Asian American, Native Hawaiian, and Pacific Islander Data: US Department of Health and Human Services-Administered Surveys

Note. Limited to 14 surveys that consistently collected data between 2011 and 2019 (Behavioral Risk Factor Surveillance Survey, Fee for Service Consumer Assessment of Healthcare Provider and Systems, Health and Retirement Study, Health Outcomes Survey, Home Health Consumer Assessment of Healthcare Provider and Systems, Hospital Consumer Assessment of Healthcare Provider and Systems, Medical Expenditure Panel Survey, Medicare Current Beneficiary Survey, National Health and Nutrition Examination Survey [NHANES], National Health Interview Survey, National Immunization Survey [NIS], National Survey of Family Growth, National Survey on Drug Use and Health, National Youth Tobacco Survey). Disaggregated Asian American data for all surveys included Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, and other Asian. Disaggregated Pacific Islander data included Native Hawaiian, Guamanian or Chamorro, Samoan, and other Pacific Islander. NHANES collected data on 29 additional Asian American subgroups (Bangladeshi, Bengalese, Bharat, Bhutanese, Burmese, Cambodian, Cantonese, Dravidian, East Indian, Goanese, Hmong, Indochinese, Indonesian, Iwo Jiman, Lao-Hmong, Laotian, Madagascar/Malagasy, Malaysian, Maldivian, Mong, Nepalese, Nipponese, Okinawan, Pakistani, Siamese, Singaporean, Sri Lankan, Taiwanese, and Thai) and NIS collected data on 6 additional Pacific Islander subgroups (Chuukese, Pohnpeian, Palauan, Yapese, Kosraean, and Marshallese).

Japanese, Korean, Vietnamese, and other Asian) and 3 commonly collected subgroups for Pacific Islander people (Guamanian or Chamorro, Samoan, and other Pacific Islander; Table C, available as a supplement to the online version of this article at <https://ajph.org>). All surveys that collected disaggregated Pacific Islander data included a category for Native Hawaiians. The only surveys that included additional response options beyond these 11 subgroups was NHANES, which included a total of 35 response options for Asian Americans, and the National Immunization Survey, which included 10 response options for Pacific Islanders (Figure 1; Tables C and D, available as a supplement to the online version of this article at <https://ajph.org>).

DISCUSSION

In our examination of HHS-administered population surveys, we found that the number of surveys collecting disaggregated AANHPI data increased between 2011 and 2021. Following the ACA mandate, many surveys have aligned with OMH data collection standards to include 11 AANHPI subgroups: Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, other Asian, Native Hawaiian, Guamanian or Chamorro, Samoan, and other Pacific Islander. Many—but not all—HHS-administered surveys have expanded data collection since 2010.^{1,2,12} Importantly, few surveys expanded upon the OMH data collection standards,

TABLE 1— Collection of Disaggregated Data on Asian American, Native Hawaiian, and Pacific Islander Patients: US Department of Health and Human Services Patient Surveys, 2011–2021

Survey	Agency	Years of Data Collection	Disaggregated AANHPI Data Collected	Year Disaggregated AANHPI Data Collection Began
Medical Expenditure Panel Survey	AHRQ	2011–2018	Yes	2011 (Asian American), 2012 (NHPI)
Behavioral Risk Factor Surveillance System	CDC	2011–2020	Yes	2013
National Health and Nutrition Examination Survey	CDC	2011–2021	Yes	2011
National Health Interview Survey	CDC	2011–2021	Yes	2011
National Immunization Survey	CDC	2011–2021	Yes	2015
National Survey of Children's Health	CDC (2011–2012), HRSA (2016–2020)	2011–2012, 2016–2021	Yes	2016
National Survey of Family Growth	CDC	2011–2019	Yes	2013
National Youth Tobacco Survey	CDC	2011–2020	No	NA
Native Hawaiian and Pacific Islander National Health Interview Survey	CDC	2014	Yes	2014
Youth Risk Behavior Surveillance System	CDC	2011–2021	No	NA
CAHPS for Accountable Care Organizations Participating in Medicare Initiatives	CMS	2013–2021	Yes	2013
CAHPS for Merit-Based Incentive Payment System	CMS	2016–2021	Yes	2016
Fee for Service CAHPS	CMS	2011–2021	No	NA
Health Outcomes Survey	CMS	2011–2021	Yes	2013
Home and Community Based CAHPS	CMS	2017	Yes	2017
Home Health CAHPS	CMS	2011–2021	No	NA
Hospital CAHPS	CMS	2011–2019	No	NA
In-Center Hemodialysis CAHPS	CMS	2015–2021	Yes	2015
Medicare Advantage and Prescription Drug Plan Disenrollment Survey	CMS	2013–2021	No	NA
Medicare Current Beneficiary Survey	CMS	2011–2021	Yes	2015
Nationwide Adult Medicaid CAHPS	CMS	2014	Yes	2014
Outpatient and Ambulatory Surgery CAHPS	CMS	2016–2021	Yes	2016
Qualified Health Plan Enrollee Survey	CMS	2020–2021	No	NA
Health Center Patient Survey	HRSA	2014	No	NA
Health and Retirement Survey	NIH	2010–2021	No	NA
National Survey on Drug Use and Health	SAMHSA	2011–2019	Yes	2011 (Asian American), 2013 (NHPI)

Note. AANHPI = Asian American, Native Hawaiian, or Pacific Islander; AHRQ = Agency for Healthcare Research and Quality; CAHPS = Consumer Assessment of Healthcare Provider and Systems; CMS = Centers for Medicare and Medicaid Services; HRSA = Health Resources and Services Administration; NA = not applicable; NIH = National Institutes of Health; NHPI = Native Hawaiian and Pacific Islander; SAMHSA = Substance Abuse and Mental Health Services Administration. For all surveys that collected disaggregated Asian American data, the subgroups collected were Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, and other Asian. For all surveys that collected disaggregated Pacific Islander data, the subgroups collected were Guamanian or Chamorro, Samoan, and other Pacific Islander. NHANES and NIS were the only surveys that expanded upon these groups (see Table D, available as a supplement to the online version of this article at <https://ajph.org>).

suggesting additional disaggregation is still necessary for some groups (e.g., Pakistani, Sri Lankan, Burmese, and Nepalese people).^{2,10}

Barriers

Inclusion of subgroup questions on population-based surveys face several interconnected challenges, including limited translation to Asian languages, low response rates, small sample sizes, and variation in reporting.^{1,2,12} Small sample sizes, for example, can prevent federal agencies' ability to report statistics disaggregated by subgroup or release public-use files with disaggregated AANHPI categories because of potential confidentiality or data-security issues, and limit researchers' ability to access such data.^{2,9,17} Several of the publicly available data sets in our study do not make the disaggregated data publicly available. Though collection of disaggregated data is a critical step, gaps in reporting metrics by AANHPI subgroup and making disaggregated data publicly available remain.

We were unable to examine the reasons approximately one third of HHS surveys do not collect disaggregated AANHPI data. Though sample size could, in part, play a role, in Table B we show that several of the surveys that do not collect disaggregated data have comparable or larger annual sample sizes compared with other surveys. Another possible explanation is that—considering the mandate indicated that standards be adopted “to the extent practicable”—agencies did not prioritize or were unable to implement disaggregated data collection. Even among survey leaders who want to collect more granular subgroup data, administrative constraints have been cited as a barrier: increasing sample

sizes, developing approaches for more detailed enumeration, or attempting to implement new methodologies that sufficiently capture subpopulations (e.g., developing oversampling strategies, hiring bilingual interviewers, partnering with translation services) can be expensive and complex. Understanding the reasons and barriers to disaggregated data collection for HHS surveys warrants further exploration.

Opportunities to Expand

Researchers and advocates have proposed multiple potential solutions to increase collection of disaggregated AANHPI data. First, federal or state mandates that may encourage data disaggregation are necessary but insufficient. As our study findings suggest, more HHS-administered health surveys began collecting disaggregated AANHPI data following the ACA's mandate to develop and implement data collection standards.

Second, innovative and successful approaches to sampling—such as outreach with community organizations to encourage participation, language assistance for limited English proficiency, and data collection using multiple modes—may mitigate issues around small sample size.^{1,12} For example, the California Health Interview Survey uses multiple approaches to oversample certain ethnic subgroups, including interviewing in several Asian languages (Cantonese, Mandarin, Korean, Vietnamese, Khmer, and Tagalog), using a targeted surname list sample to oversample for Korean and Vietnamese people, and interviewing with both landline or cellphone survey modalities.¹ These efforts must be accompanied by increased funding or investments to support the resources

needed to successfully expand data collection.

Implications for Policy and Practice

The need for disaggregated AANHPI data has been particularly critical during the COVID-19 pandemic.^{18,19} The pandemic, subsequent economic recession, and waves of anti-AANHPI physical assaults and racism illustrated the persistent structural inequities faced by AANHPI people.^{18,20,21} Several studies have noted the lack of COVID-19 data for AANHPI communities, despite increased risk for infection because of disproportionate participation in essential workforce, structural inequities, and a higher likelihood of residing in multigenerational households.^{18,20,22} The disproportionate number of COVID-19–related deaths among Filipinx nurses underscores the importance of disaggregated data collection and reporting during the pandemic.²³

Studies suggest that poor data quality limited the ability to identify and mitigate COVID-19–related disparities nationwide for AANHPI subgroups, as well as to understand the mechanisms driving them.^{18,24} In New York City, there was variation in COVID-19 infection, hospitalization, and mortality rates across Asian American subgroups.²² Disaggregated AANHPI data also suggest heterogeneity in concern for physical assault and self-reported discrimination by subgroup during the COVID-19 pandemic.²¹ Despite national efforts to improve disaggregated AANHPI data collection and reporting, the COVID-19 pandemic underscored that these practices remain inconsistent and suboptimal. Importantly, recent state-level initiatives have emerged to collect disaggregated

AANHPI data (e.g., Hmong communities in Minnesota).

Population surveys have the unique opportunity to identify health disparities that would be otherwise masked with aggregate grouping.¹⁰ A critical first step to understanding the diversity of experiences among AANHPI people and eliminating AANHPI disparities is the collection and reporting of granular subgroup data. More broadly, advancing AANHPI health equity will require concurrent efforts to remove structural barriers, such as lack of funding for AANHPI-specific research, extrapolation of research findings to all AANHPI subgroups, and omission or limited representation in US clinical trials.^{17,25} Systems-level implicit and explicit AANHPI biases—including narratives of AANHPI exceptionalism and the perpetuation of the “model minority myth”—may hinder national progress in prioritizing AANHPI health disparities.^{12,25}

Limitations

Our study has several limitations. First, though we attempted to be comprehensive in our list of HHS-administered population surveys by using multiple data sources, it is possible that some were excluded.

Second, though we limited our study to HHS-administered surveys, many state health surveys and non-HHS-administered federal surveys have been collecting disaggregated AANHPI data and are considered some of the best sources of information on ethnic subgroups among AANHPI people.¹² In November 2021, the New York University Center for the Study of Asian American Health released the AA & NH/PI Web Hub, which provides additional research data sets related to AANHPI people.

Third, disaggregated data collection alone does not address other issues, such as respondents not recognizing or being fearful of self-reporting race or ethnic subgroup information when presented to them and higher likelihoods of Asian Americans reporting “other” or “unknown” race. Moreover, collection of disaggregated data does not necessarily guarantee reporting or availability of such data to researchers.

Lastly, despite inclusion of subgroup questions in national questionnaires, it is possible that there is variation by state as to whether these questions are asked for some surveys (e.g., Behavioral Risk Factor Surveillance System).¹

CONCLUSIONS

The growth in collection of disaggregated AANHPI data in HHS-administered population surveys is encouraging and a critical first step to identifying and addressing AANHPI health disparities across subgroups. As the United States becomes more diverse, it is important to be attentive to how subgroups are collected and defined in survey-based research and to ensure that survey data are comprehensive and inclusive. While there has been improvement in data collected in the past decade, some gaps remain. Failure to collect these data may prevent a detailed understanding of characteristics, health status, and health needs of AANHPI people, thereby affecting the development of policies and allocation of resources. *AJPH*

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CONTRIBUTORS

K. H. Nguyen originated the study, completed analyses, and led the writing. K. P. Lew assisted with analyses and substantially contributed to drafting and revision of the article. A. N. Trivedi supervised the study and substantially contributed to the drafting and revision of the article.

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CONFLICTS OF INTEREST

The authors have no conflicts of interest to report.

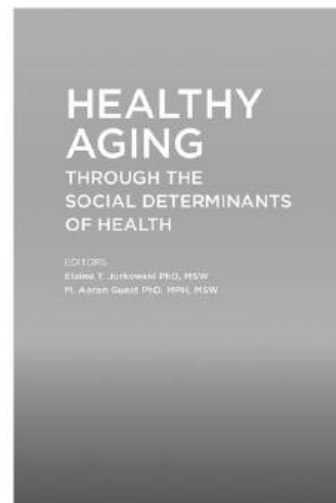
HUMAN PARTICIPANT PROTECTION

Institutional review board approval was not needed because this study did not use human participants. The unit of analysis was survey-year.

REFERENCES

- Shimkhada R, Scheitler A, Ponce NA. Capturing racial/ethnic diversity in population-based surveys: data disaggregation of health data for Asian American, Native Hawaiian, and Pacific Islanders (AANHPIs). *Popul Res Policy Rev*. 2021;40(1):81–102. <https://doi.org/10.1007/s11113-020-09634-3>
- Chin KK. Improving public health surveillance about Asian Americans, Native Hawaiians, and Pacific Islanders. *Am J Public Health*. 2017;107(6):827–828. <https://doi.org/10.2105/AJPH.2017.303802>
- Nguyen KH, Trivedi AN. Asian American access to care in the Affordable Care Act era: findings from a population-based survey in California. *J Gen Intern Med*. 2019;34(11):2660–2668. <https://doi.org/10.1007/s11606-019-05328-5>

4. Cheng YJ, Kanaya AM, Araneta MRG, et al. Prevalence of diabetes by race and ethnicity in the United States, 2011–2016. *JAMA*. 2019;322(24):2389–2398. <https://doi.org/10.1001/jama.2019.19365>
5. Torre LA, Sauer AMG, Chen MS Jr, Kagawa-Singer M, Jemal A, Siegel RL. Cancer statistics for Asian Americans, Native Hawaiians, and Pacific Islanders, 2016: converging incidence in males and females. *CA Cancer J Clin*. 2016;66(3):182–202. <https://doi.org/10.3322/caac.21335>
6. Wyatt L, Russo R, Kranick J, Elfassy T, Kwon S, Wong J. Health atlas for Asian Americans, Native Hawaiians, and Pacific Islanders: a comprehensive look at AA and NH&PI health in the US 2021. New York University. 2021. Available at: <https://med.nyu.edu/departments-institutes/population-health/divisions-sections-centers/health-behavior/sites/default/files/pdf/csaah-health-atlas.pdf>. Accessed July 19, 2022.
7. Waksberg J, Levine DB, Marker D. Assessment of major federal data sets for analyses of Hispanic and Asian or Pacific Islander subgroups and Native Americans: extending the utility of federal data bases: Human Services Policy. US Department of Health and Human Services, Assistant Secretary for Planning and Evaluation. 2000. Available at: <https://aspe.hhs.gov/reports/assessment-major-federal-data-sets-analyses-hispanic-asian-or-pacific-islander-subgroups-native>. Accessed July 20, 2022.
8. Yi SS, Kwon SC, Suss R, et al. The mutually reinforcing cycle of poor data quality and racialized stereotypes that shapes Asian American health. *Health Aff (Millwood)*. 2022;41(2):296–303. <https://doi.org/10.1377/hlthaff.2021.01417>
9. Farah K, Doan LN, Lee M, Chin MK, Kwon SC, Yi SS. Disaggregating race/ethnicity data categories: criticisms, dangers, and opposing viewpoints. *Health Affairs Forefront*. March 23, 2022. Available at: <https://www.healthaffairs.org/doi/10.1377/forefront.20220323.555023>. Accessed May 9, 2022. <https://doi.org/10.1377/forefront.20220323.555023>
10. Ponce NA. Centering health equity in population health surveys. *JAMA Health Forum*. 2020;1(12):e201429-e. <https://doi.org/10.1001/jamahealthforum.2020.1429>
11. US Department of Health and Human Services, Office of Minority Health. Final data collection standards for race, ethnicity, primary language, sex, and disability status required by section 4302 of the Affordable Care Act. October 31, 2011. Available at: <https://www.minorityhealth.hhs.gov/omh/browse.aspx?lvl=2&lvlid=23>. Accessed May 9, 2022.
12. Islam NS, Khan S, Kwon S, Jang D, Ro M, Trinh-Shevrin C. Methodological issues in the collection, analysis, and reporting of granular data in Asian American populations: historical challenges and potential solutions. *J Health Care Poor Underserved*. 2010;21(4):1354–1381. <https://doi.org/10.1353/hpu.2010.0939>
13. Office of the Assistant Secretary for Planning and Evaluation, US Department of Health and Human Services. Guide to HHS surveys and data resources. May 20, 2012. Available at: <https://aspe.hhs.gov/basic-report/guide-hhs-surveys-and-data-resources>. Accessed May 9, 2022.
14. Queen S, Mintz R, Cowling K. The impact of the COVID-19 pandemic on major HHS data systems. Washington, DC: US Office of the Assistant Secretary of Planning and Evaluation; 2021.
15. Centers for Disease Control and Prevention. Summary of current surveys and data collection systems. June 2019. Available at: https://www.cdc.gov/nchs/data/factsheets/survey_matrix_2017.pdf. Accessed May 9, 2022.
16. Centers for Medicare and Medicaid Services. Consumer Assessment of Healthcare Providers & Systems. 2020. Available at: <https://www.cms.gov/Research-Statistics-Data-and-Systems/Research/CAHPS>. Accessed May 9, 2022.
17. Doãn LN, Takata Y, Sakuma K-LK, Irvin VL. Trends in clinical research including Asian American, Native Hawaiian, and Pacific Islander participants funded by the US National Institutes of Health, 1992 to 2018. *JAMA Network Open*. 2019;2(7):e197432-e. <https://doi.org/10.1001/jamanetworkopen.2019.7432>
18. Chin M, Doãn L, Chong SK, Wong JA, Kwon SC, Yi S. Asian American subgroups and the COVID-19 experience: what we know and still don't know. *Health Affairs Blog*. May 24, 2021. Available at: <https://www.healthaffairs.org/doi/10.1377/forefront.20210519.651079>. Accessed May 9, 2022.
19. Wang K, Cullen T, Nunez-Smith M. Centering equity in the design and use of health information systems: partnering with communities on race, ethnicity, and language data. *Health Affairs Forefront*. May 19, 2021. Available at: <https://www.healthaffairs.org/doi/10.1377/forefront.20210514.126700>. Accessed May 9, 2022. <https://doi.org/10.1377/hblog20210514.126700>
20. Penaia CS, Morey BN, Thomas KB, et al. Disparities in Native Hawaiian and Pacific Islander COVID-19 mortality: a community-driven data response. *Am J Public Health*. 2021;111(suppl 2):S49–S52. <https://doi.org/10.2105/AJPH.2021.306370>
21. Ha SK, Nguyen AT, Sales C, et al. Increased self-reported discrimination and concern for physical assault due to the COVID-19 pandemic in Chinese, Vietnamese, Korean, Japanese, and Filipino Americans. *medRxiv*. 2020:2020.09.15.20194720. <https://doi.org/10.1101/2020.09.15.20194720>
22. Marcello RK, Dolle J, Tariq A, et al. Disaggregating Asian race reveals COVID-19 disparities among Asian Americans at New York City's public hospital system. *medRxiv*. 2020:2020.11.23.20233155. <https://doi.org/10.1101/2020.11.23.20233155>
23. Oronce CIA, Adia AC, Ponce NA. US health care relies on Filipinx while ignoring their health needs: disguised disparities and the COVID-19 pandemic. *JAMA Health Forum*. 2021;2(7):e211489-e. <https://doi.org/10.1001/jamahealthforum.2021.1489>
24. Quint JJ, Van Dyke ME, Maeda H, et al. Disaggregating data to measure racial disparities in COVID-19 outcomes and guide community response—Hawaii, March 1, 2020–February 28, 2021. *MMWR Morb Mortal Wkly Rep*. 2021;70(37):1267–1273. <https://doi.org/10.15585/mmwr.mm7037a1>
25. Obra J, Lin B, Doan LN, Palaniappan L, Srinivasan M. Achieving equity in Asian American health-care: critical issues and solutions. *J Asian Health*. 2021;1(1).



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Healthy Aging Through The Social Determinants of Health

Edited by Elaine T. Jurkowski, PhD, MSW
and M. Aaron Guest, PhD, MPH, MSW

This new book examines the link between social determinants of health and the process of healthy aging. It provides public health practitioners and others interacting with the older population with best practices to encourage healthy aging and enhance the lives of people growing older.

Healthy Aging: Through The Social Determinants of Health gives insight into the role each of these plays in the healthy aging process: health and health care; neighborhood and built environment; social support; education; and economics and policy.

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Building Public Health Surveillance 3.0: Emerging Timely Measures of Physical, Economic, and Social Environmental Conditions Affecting Health

Lorna E. Thorpe, PhD, Rumi Chunara, PhD, Tim Roberts, MLS, MPH, Nicholas Pantaleo, MPH, Caleb Irvine, MPH, Sarah Conderino, MS, Yuruo Li, PhD, Pei Yang Hsieh, MPH, Marc N. Gourevitch, MD, MPH, Shoshanna Levine, DrPH, Rebecca Ofrane, MPH, and Benjamin Spoer, PhD, MPH

 See also COVID-19 and Health Equity Data Gaps, pp. 1404–1453.

In response to rapidly changing societal conditions stemming from the COVID-19 pandemic, we summarize data sources with potential to produce timely and spatially granular measures of physical, economic, and social conditions relevant to public health surveillance, and we briefly describe emerging analytic methods to improve small-area estimation.

To inform this article, we reviewed published systematic review articles set in the United States from 2015 to 2020 and conducted unstructured interviews with senior content experts in public health practice, academia, and industry. We identified a modest number of data sources with high potential for generating timely and spatially granular measures of physical, economic, and social determinants of health.

We also summarized modeling and machine-learning techniques useful to support development of time-sensitive surveillance measures that may be critical for responding to future major events such as the COVID-19 pandemic. (*Am J Public Health.* 2022;112(10):1436–1445. <https://doi.org/10.2105/AJPH.2022.306917>)

Population health surveillance is a cornerstone of prevention, disease control, and disaster response.¹ In the early phase of the COVID-19 pandemic, the lack of reliable, granular COVID-19 data by demographic subgroup was a basic failure of the US surveillance infrastructure. The pandemic's wide-reaching impacts also underscored the need for timely surveillance of physical, economic, and social conditions, also known broadly as social determinants of health (SDOH), to enable early detection of vulnerable groups and

prompt action to mitigate health inequities.

The call for surveillance of SDOH is not new. In 2010, social determinants were formally introduced into the Healthy People 2020 framework.² In 2016, the Centers for Disease Control and Prevention issued a “Public Health 3.0 Call to Action” for local public health and political leaders to leverage resources to address SDOH and health equity.³ The Call to Action was endorsed by the American Public Health Association and included 5 broad recommendations.

One of the 5 recommendations focused on surveillance, stressing that

Timely, reliable, granular-level (ie, subcounty), and actionable data should be made accessible . . . including those targeting the social determinants of health and enhancing equity.^{4(p4)}

In response, the US Department of Health and Human Services established an SDOH workgroup within Healthy People 2030.⁵ The workgroup selected 7 primary SDOH objectives in 2018,

with surveillance measures to track them (Table A, available as a supplement to the online version of this article at <https://ajph.org>). National surveys were identified as data sources, and their probability sampling frames ensured representativeness of national and, in some instances, state-level estimates. Four of the data sources could generate county-level estimates for one third of US counties. Such data are valuable, yet they fall short of the Public Health 3.0 Call to Action for timely and granular (i.e., subcounty) data.

The goal of this article was to highlight large-volume data sources to monitor local physical, economic, and social conditions in a timely fashion while also meeting other public health surveillance data standards, including representativeness and temporal data quality consistency.⁶ The study was originally commissioned by the Robert Wood Johnson Foundation and led by researchers at New York University's (NYU's) Grossman School of Medicine and Global School of Public Health during January through April 2021 to inform the National Commission to Transform Public Health Data Systems. Because the science of small-area data has unique challenges, we also summarize state-of-science approaches for small-area estimation, including when data are of insufficient volume, as well as methods for analyzing unstructured data and for presenting data to meet needs of local stakeholders.

To inform our work, we conducted a rapid horizon scan to synthesize information on resources that could be harnessed for public health surveillance.⁷ We performed a scoping review of published literature to identify promising metrics, explored online resources, and conducted interviews with experts to explore the perceived salience of identified metrics and identify additional

promising data sources. Findings from the literature review, Internet scan, and interviews were synthesized and presented. We focused our scan on 3 categories:

- Physical environment (climate, ecology, land use, the built environment, air quality, etc.),
- Economic environment (economic stability, employment, financial credit, spending, etc.), and
- Social environment (community wellness, social cohesion or connectedness, overcrowding, daily patterns of mobility, housing, education, social media usage, population distributions, etc.).

The following 2 questions guided our review:

1. What measures of exposure to physical, economic, and social environments could potentially be incorporated into routine public health surveillance that are temporally and spatially granular? We defined temporally granular to mean measures available within 1 year of collection or capture and spatially granular as measures available at spatial levels smaller than county.
2. What are the most promising spatial methods and tools to access, analyze, and parse large or high-velocity data streams? Information on metrics was extracted using a standardized extraction form (see "Additional Methods," available as a supplement to the online version of this article at <https://ajph.org>, for additional methods, search terms employed, and consort flow diagram).

To complement the scoping review, we identified 7 senior experts from

academia, local and federal government, and industry to provide opinions on data sources and metrics as well as to give feedback on preliminary measures identified in the literature review. We used unstructured telephone interviews to explore what types of data on environmental conditions can and should be harnessed for public health surveillance, as well as any challenges experienced using new, high-velocity data sources or related metrics.

We identified many data sources that met 1 of our 2 core criteria—either temporal or spatial granularity. The number of data sources meeting both criteria was smaller. For a complete listing of data sources reviewed, see Table B (available as a supplement to the online version of this article at <https://ajph.org>).

GRANULAR MEASURES

We describe some of the sources of timely, local data for the physical, economic, and social environments, as well opportunities and actors involved in generating them.

Physical Environment

Perhaps the fastest-evolving area with respect to timely and spatially granular data is the physical environment, because, in part, of online access to urban planning administrative records and increasing availability of remote sensing technology (satellite imagery, aerial photography). The global coverage of satellite remote sensors and a stream of efforts to translate raw data into curated, publicly available data sources has wide-ranging potential for public health.^{8,9} Different satellite bands are being used to capture different measures of the environment.

For many years, air pollution data from satellites have been combined with data from monitoring stations to generate small-scale air pollution exposure assessment data.¹⁰⁻¹³ However, only in the past decade has the National Aeronautics and Space Administration (NASA) made major efforts, in partnership with academic institutions and other government agencies, to provide greater public access to near-real-time data on air quality and other satellite-derived measures relevant to health, most notably through the NASA Health and Air Quality Applied Sciences Team.¹⁴

Several NASA Web sites providing physical environment data offer a glimpse of a possible future state of public health surveillance. For example, NASA Giovanni allows users to download or interactively analyze gridded data online using flexible platforms.¹⁵

Options allow for time averaged or time-series data with user-defined dates of interest, as well as user-drawn geographical areas. However, much of these data are not yet optimized for health stakeholders. For example, ozone data are raw column satellite data, whereas health stakeholders require data combined with ground monitor and weather data to capture ozone measures associated with poor health outcomes. Google Earth Engine, another aggregation resource, provides 30 years of historical imagery on surface temperature, climate, land surface, weather, and more. Although designed as a resource for researchers, this Web site provides opportunities for development of public health surveillance-relevant tools and metrics.

Box 1 shows an extended list of potential physical environment surveillance

metrics obtainable from satellite data. These data are not yet used by many local health departments or community stakeholders, in part because of limited local technical capacity and because the data are not integrated with other health data. However, several compelling examples of academic-health department collaborations demonstrate their potential for timely, spatially granular surveillance metrics.²⁰ New York State health department scientists used the NASA-sponsored North American Land Data Assimilation System to examine granular temperature data and compare it with health outcomes across New York. Findings showed that adverse health effects occurred at less-extreme temperatures than initially thought, prompting officials to reduce the heat advisory threshold in 2018 from 100°F to 95°F. In a NASA-citizen scientist initiative, trained citizen

BOX 1— Potentially Granular Surveillance Metrics of Physical, Economic, and Social Environments Relevant to Health

Measure	Data Source	Temporal Availability	Spatial Availability
Physical environment			
Air pollution, blue space, water quality, and coastlines ^{16,17}	Moderate-resolution imaging spectroradiometer	Updated on an ongoing basis	250-m to 1-km spatial resolution
Ozone	Center for Spatial Science and Systems, George Mason University	Available from 2018 through 2021	12-km spatial resolution
Greenness ¹⁸	Advanced Very High Resolution Radiometer (AVHRR)	Available from 1979 through 2019	1.1-km multispectral data
Heat, urban heat islands ¹⁹	US Geological Survey EarthExplorer Landsat	Updated on an ongoing basis	30-m spatial resolution
Economic environment			
Unemployment	US Bureau of Labor Statistics, local area unemployment statistics	Monthly and annual employment, unemployment, and labor force data	Counties, metropolitan areas, cities with population > 25 000 Neighborhood or census tract information not available
Personal bankruptcy	US district courts Public Access to Court Electronic Records (PACER) database InfoUSA/Data Axle	Quarterly updates of past-12-mo period	County-level zip-code purchasable geographies (e.g., census tract or other)
Community credit insecurity index	Federal Reserve Bank of New York (combined American Community Survey and Equifax data)	2018 currently publicly available quarterly through 2021	County-level (available) city-level census tract (for cities with population > 50 000)
Social environment			
Foot traffic social distancing metrics	Safegraph	Weekly social distancing metrics (Jan 2019–Sep 2020)	Census block group, tract

scientists in Florida helped detect, forecast, and target responses to harmful algal blooms on the Florida coast using video and satellite data, producing 1 or 2 daily forecasts for beaches along the Florida Gulf Coast.

More recently, NYU Grossman School of Medicine partnered with researchers at George Mason University to generate fine-scale (12-kilometer grids) measures of ozone and particulate matter (PM)_{2.5}, leveraging a new high-resolution air pollution prediction system based on the Weather Research and Forecast model, the Community Multiscale Air Quality model, and ground-level monitors from the Environmental Protection Agency Air Quality System. Beginning in March 2022, these data updated through the end of 2021 will be featured and routinely updated on the City Health Dashboard, a publicly available data access Web site providing more than 35 measures of health and its drivers for more than 750 US cities with populations greater than 50 000. Figure 1 demonstrates spatial variability in annual maximum ozone values and the importance of temporal granularity attributable to seasonality.

Economic Environment

Economic conditions have a strong influence on the health of individuals and communities. The COVID-19 pandemic's economic fallouts have highlighted an urgent need for more timely economic measures at the neighborhood level. Many local public health agencies and community organizations routinely access county- and tract-level income and unemployment data from the US Census Bureau and American Community Survey (ACS). For census tracts, the ACS provides 5-year averaged estimates

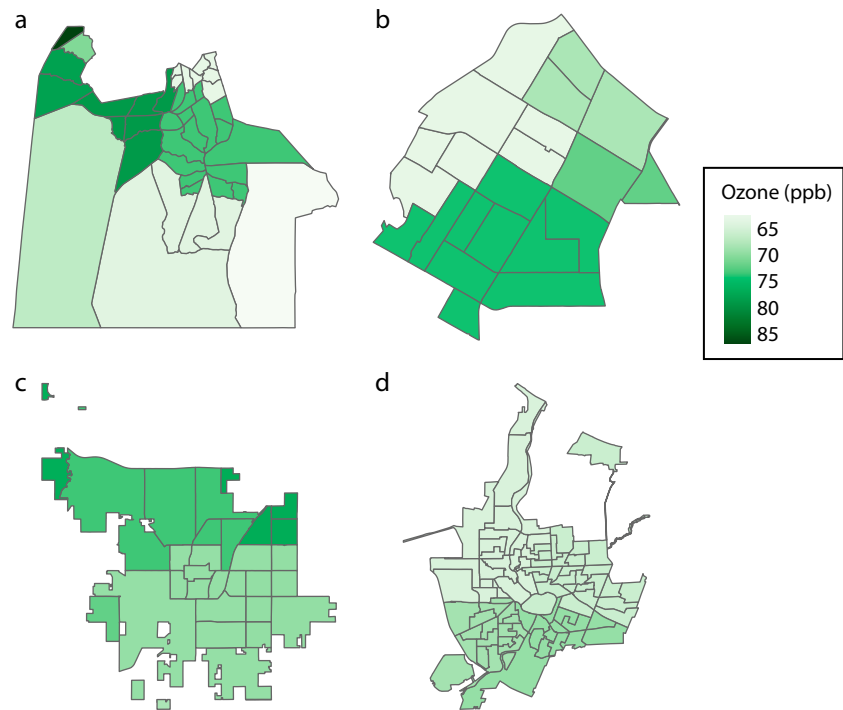


FIGURE 1— Example of Fine-Scale Ozone Measures Calculated to Be Appropriate for Health Surveillance at the Census Tract Level for All US Census Tracts in (a) Chesapeake, VA, (b) Downey, CA, (c) Olathe, KS, and (d) Rochester, NY: 2021

Note. ppb = parts per billion.

with a 2-year lag (e.g., in 2021, 5-year estimates from 2015 to 2019 were available). The Urban Institute provides a city-level Financial Health of Residents dashboard for 60 cities, but the Web site uses ACS and credit bureau data that are lagged by at least 2 years.

In May 2020, in response to the pandemic, Opportunity Insights researchers at Harvard University developed an online dashboard called Economic Tracker to monitor the economic impacts of COVID-19 on communities. The Web site offers near-real-time data (within 2–3 weeks) on consumer spending, small business revenue and openings, and unemployment claims for states, counties, and metro areas.²¹ Data are presented alongside COVID-19 case, death, and vaccination data. Weekly data summaries are compiled in partnership

with several private companies that sell subcounty data. The public-use Web site does not present subcounty data, but academic papers from this team include zip-code measures.²² Other publicly available data sources exist for timely and subcounty economic data, described in Box 1. Figure 2 displays a comparison of recent unemployment figures for select subcounty cities. In this example, Gary, Indiana, is compared with all other cities with a similar population range (75 000–90 000) and comparably low non-Hispanic White population (10%–20%) in the United States.

US Census Bureau and Internal Revenue Service data sources hold future promise for timely neighborhood metrics, although publicly they only provided data through 2018 at the time of

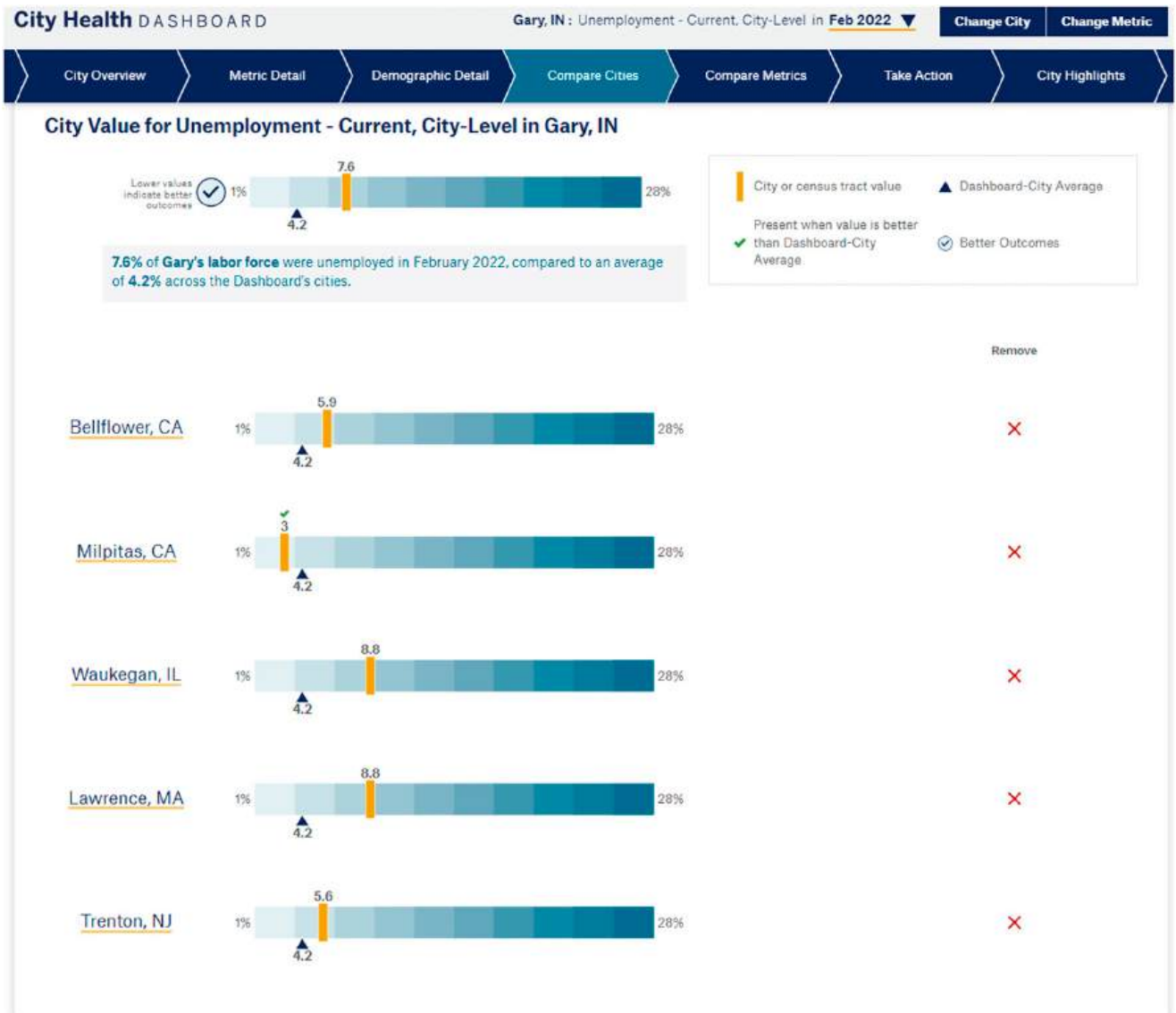


FIGURE 2— Example of Timely Surveillance of Unemployment for 6 US Cities (All Sub-County): February 2022

Source: City Health Dashboard.²³

writing this article. These include job totals by census block information on business establishments and employment at national and various subcounty levels and adjusted gross income and related tax information at the zip-code level. Several US Census Bureau initiatives were launched mid-2020 to provide more timely information on the US economy in response to the pandemic, including pulse surveys and weekly updated business formation

data, but unfortunately these lack local data.²⁴

The pandemic-associated economic crisis also catalyzed academic–health department collaborations to assess local economic impacts of the COVID-19 pandemic. For example, researchers at 5 universities partnered with the State of Illinois in a grant-funded initiative to use near-real-time data to examine weekly unemployment rates, replacement rates (ratio of unemployment insurance

benefits to average weekly wage in 2019), and consumer spending for 18 counties, spanning January to June 2020.²⁵ They published an in-depth analysis by August 2020 showing a massive drop in consumer spending and large spike in unemployment. Data sources were weekly, state-specific unemployment insurance claims and wage records, as well as spending data from the Opportunity Insights Economic Tracker.

Social Environment

The third environmental domain, “social environment,” is perhaps the most heterogeneous, generally referring to social conditions (e.g., overcrowding, racial residential segregation), as well as measures on education, housing (affordability, insecurity, eviction), broadband access, transportation behavior, neighborhood social cohesion, and community-level measures of social media usage. The ACS has been an important data source for many of these measures, and, as outlined earlier, subcounty (census tract) metrics are 5-year averaged estimates with a 2-year lag.

Beyond the ACS, several initiatives have yielded new data tools and resources on social conditions for audiences nationwide, yet most of these lack either temporal timeliness or spatial granularity. For example, online resources have been developed to track housing-related metrics such as evictions and subsidized housing. These data sources are lagged by more than 2 years. Urban planning advocacy organizations have played a leading role in improving data on transit connectivity and access. For example, Center for Neighborhood Technology has developed AllTransit, a database tracking numerous public transit metrics, including use, routes within one half mile of households, and jobs accessible within 30 minutes; data also lag more than 2 years. Awareness of access to broadband Internet as an SDOH has grown during the COVID-19 pandemic, as many workspaces and schools shifted to remote operation. Broadband providers file data with the Federal Communications Commission twice a year. Data are available at the census tract or block level, allowing for tracking of residential service connections per 1000 households. However,

the most recent public data available are from 2018.

Most recent innovations to produce timely, local social environment data fall into 2 arenas: (1) social media usage and content and (2) mobility data using geo-mobile device information. Data collected via Internet usage and social media sites have been used for public health surveillance for more than a decade. Early examples include the creation of Google Flu Trends.^{26,27} Many publicly available social media data tools provide limited geographic information, because of privacy restrictions or user-restricted geolocation data. Twitter is frequently used for digital public health surveillance, mainly because Twitter allows public access to a 1% random sample of Tweets. While Twitter provides its users with the option to “geo-tag” a tweet as it is posted, only a small number of Tweets are precisely geocoded (< 2%). These data are sometimes used with other data sources to monitor mobility patterns during outbreaks.²⁸

Nonprofit organizations such as Digital Epidemiology Lab have developed health trend-tracking tools, like Crowdbreaks, using tweets with keywords potentially related to specific health topics.²⁹ Google’s symptom search trend database includes aggregated, anonymized search trends for more than 400 symptoms and health conditions, and includes US county-level trends beginning in 2017. Facebook has also launched a “Data for Good” Web site, which provides a social connectedness index at the county level, measuring the frequency and density of social media ties.³⁰

The rapid development of communication technologies, combined with the data from Global Positioning System devices in mobile phones, has propelled the science of tracking human

mobility. Even before the COVID-19 pandemic, these data were being used to examine commuting patterns, commercial activity, and community connectedness.³¹ In response to the pandemic, several Internet technology companies, including Google and SafeGraph, rapidly developed online community mobility databases with measures updated weekly. Other communication technology companies make similar data sets available to researchers for purchase. These metrics have been used by local governments to assess resident mobility and recovery indicators, such as shelter-in-place behavior, foot traffic to points of interest, and more. Privacy policies often limit the availability of public data sets to county levels, yet more granular data are available upon request.

GENERATING AND REPRESENTING SMALL-AREA DATA

While the potential for “Big Data” to provide rapid information about communities is growing, few big data sources are currently free, are easily accessible, and require minimal additional manipulation. Additional analytic tools are needed to model data to smaller spatial boundaries. Translating and representing those data in ways that meet stakeholders’ needs requires flexible estimation and mapping tools. Here we briefly describe some important methods and innovations to characterize the physical, economic, and social environments.

Small-Area Estimate and Modeling Approaches

When large data sets are not sufficiently granular to provide precise data

specific to small geographic areas, statistical modeling innovations now enable researchers to generate increasingly precise small-area estimates.^{32,33} Small-area estimation methods can be broadly categorized as design-based, model-assisted, and model- or algorithm-based. In design-based methods, statistical properties of measures to be estimated are generated directly from the distribution of data.³⁴ Other auxiliary information can also be integrated when using a model-assisted approach. In a recent, compelling example of this method, researchers combined sparsely available survey data with satellite image data to estimate granular spatial distributions of poverty, which they used to enhance traditional census data measures.³⁵ Design-based methods can suffer when samples are small and cannot always address inconsistencies in data (e.g., if the data collection or satellite image features related to poverty differ by place).^{36,37}

Model-based methods assume that sample observations are realizations of random variables that satisfy some underlying model,³⁸ which requires more assumptions. This method has been applied by researchers at the World Bank to generate robust small-area measures of poverty and income inequality for several low-income countries, accomplished by combining both census and survey data via regression models to generate estimates for subpopulations one one-hundredth of the size that the original surveys would allow.³⁹ In general, model-assisted methods based on statistical learning techniques are being used to capture complex relationships including kernel methods, splines, neural networks, and others.

Recently, algorithm-based methods have also become popular. These

approaches build on model-based approaches by designing algorithms that map observed data to corresponding data to be predicted within a spatial area. Researchers then tune the algorithm underlying the model using a training data set so that it “learns” to successfully predict observed data, while other data are withheld for future validation and prediction. For example, Australian researchers generated small-area estimates of household poverty and financial stress by using probabilistic methods to borrow strength from reliable census data and then reweight samples from a national survey.⁴⁰

Mapping Conditions Using Natural Boundaries

Modern analytic methods now also allow for the creation of estimates that are dynamic in their “localization” (i.e., transcending traditionally defined areal unit boundaries). For example, machine learning empowers researchers to model data into flexible functional forms that can then be leveraged to cluster similar areas by location, geographic resolution, privacy, and properties of the disease condition being modeled using a type of artificial neural network called self-organized maps.⁴¹ This method can avoid statistical bias that occurs when aggregating point-based data into administrative units such as zip codes (known as the modifiable area unit problem).⁴² Other computing and user design technologies make it possible for areas of interest to be defined in real time by users. Design-based approaches can then be used to weight data and generate new estimates for the selected area.

Machine Learning

Granular surveillance metrics can be derived from data sources initially

produced for other purposes using machine-learning methods. For example, satellite images can be used to identify physical environment attributes such as green spaces, but only after key attributes are identified from images and assigned a label.^{43,44}

Machine learning methods such as Gaussian processes have also recently been applied to create representations, at a specific temporal frequency or by location, because of their flexibility and ability to deal with missing data, especially in health-related measures.^{45,46}

Methodological and Privacy Considerations

Other statistical challenges must be addressed when aggregating geolocated data from large-volume data streams. Data collected for commercial purposes, in particular requiring Internet or mobile app tools, represent self-selected population subgroups, making it difficult to know which groups are and are not well-represented by these data.⁴⁷ Results can thus be misleading and even damaging if surveillance under- or overdetects important problems. Advancing the science of bias adjustment to enable valid geographic estimation from large, nonrepresentative data sources is an important methodological area of research.^{48,49} Privacy concerns that limit the further disaggregation of social or economic data can be addressed by applying methods such as “injecting noise” into data sets, a method now widely used by the US Census Bureau and many private companies.⁵⁰ Access can also be expanded via protected enclaves or “data safe havens” for researchers to work with granular data and then release relevant metrics on public-use data aggregation

sites with limited or no risk of reidentifiability.⁵¹

SUMMARY

In this article, we focused on identifying measures available within the past year at the subcounty level as a general rubric that improves upon current standards for measuring SDOH. In general, we found more promising data sources for physical and economic environment measures than for social environment measures. We also identified emerging analytic methods to extend and improve opportunities for small-area estimation, but gaps currently exist between applications of new methods in academic research and private industry and the day-to-day data needs of public health practitioners. Federal and private foundation funding could support relevant applications of these methods to address current data gaps and privacy concerns.

For physical environment measures, global coverage of satellite remote sensors is a cornerstone asset. With multisector activity to curate publicly available data sources and developments in computer science and biostatistics for translating raw images into informative data, these tools and partnerships can have wide-ranging use for public health. The COVID-19 pandemic also stimulated extensive activity by federal agencies and researchers to link data sources for real-time tracking of economic activity, but additional efforts are needed to further disaggregate such data to subcounty levels. Social environment metrics were the most heterogeneous of the 3 categories examined and the realm most impacted by long data lags. Despite a proliferation of data sources, few measures met both criteria of timeliness and

spatial granularity except for social media and mobile geo-location data. Partnerships are needed between tech companies (and other data-focused private industries) and public health stakeholders to improve the spatial granularity of existing public-access data sources and generate new relevant measures.

In this work, our goal was to introduce a portfolio of important analytic tools more so than fully to review them. Findings nonetheless underscore that few local health departments or community stakeholders currently have the capacity to work with diverse arrays of raw data sources to generate timely, accurate environmental determinants of health. In this context, public health-oriented data aggregation Web sites that allow for download of relevant small-area data are valuable tools, especially when linked to health outcomes data. Several unique challenges also exist in generating small-area data for rural settings, including both statistical and privacy concerns for sparse populations, as well as the need for measures that are distinct from those widely used in urban areas.⁵²

Local governments and community leaders across the country require actionable surveillance data that include measures of the physical, economic, and social environment to identify local public health needs, drive change, and deliver results for local populations. Before the COVID-19 pandemic, the United States was already facing a stagnating trend in average life expectancy and tremendous geographic disparities in health and well-being. The COVID-19 pandemic has further exacerbated economic and social hardship while highlighting deep inequities. These intersecting crises underscore the urgent need for timely,

neighborhood-level data on health and environmental conditions to guide resource allocation and shape policies and programs for at-risk communities.

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CONTRIBUTORS

L. E. Thorpe conceptualized the study. N. Pantaleo, T. Roberts, C. Irvine, P. Y. Hsieh, and B. Spoer performed the scoping review. S. Conderino synthesized scoping review results and worked with R. Ofrane to assemble information from source Web sites. L. E. Thorpe and R. Chunara drafted the initial article. Y. Li prepared the data analysis. M. N. Gourevitch and S. Levine performed a detailed review and edit. All co-authors contributed to subsequent edits on the revised article.

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CONFLICTS OF INTEREST

The authors have no conflicts of interest to declare.

HUMAN PARTICIPANT PROTECTION

This work was not human participant research.

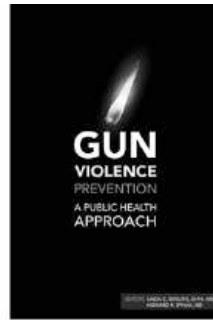
REFERENCES

1. Thacker SB, Qualters JR, Lee LM. Public health surveillance in the United States: evolution and challenges. *MMWR Suppl.* 2012;61(3):3-9.
2. US Department of Health and Human Services. Secretary's Advisory Committee on National Health Promotion and Disease Prevention objectives for 2020. 2010. Available at: <https://www.healthypeople.gov/2010/hp2020/advisory/SocietalDeterminantsHealth.htm>. Accessed April 5, 2021.
3. DeSalvo KB, O'Carroll PW, Koo D, Auerbach JM, Monroe JA. Public health 3.0: time for an upgrade. *Am J Public Health.* 2016;106(4):621-622. <https://doi.org/10.2105/AJPH.2016.303063>
4. DeSalvo KB, Wang YC, Harris A, Auerbach J, Koo D, O'Carroll P. Public health 3.0: a call to action for public health to meet the challenges of the 21st century. *Prev Chronic Dis.* 2017;14:E78. <https://doi.org/10.5888/pcd14.170017>
5. Office of Disease Prevention and Health Promotion, Office of the Secretary, US Department of Health and Human Services. Social Determinants of Health Workgroup. Available at: <https://health.gov/healthypeople/about/workgroups/social-determinants-health-workgroup>. Accessed April 5, 2021.
6. German RR, Lee LM, Horan JM, Milstein RL, Per-towski CA, Waller MN. Updated guidelines for evaluating public health surveillance systems: recommendations from the Guidelines Working Group. *MMWR Recomm Rep.* 2001;50(RR-13): 1-35; quiz CE31-37.
7. National Academies of Sciences, Engineering, and Medicine. *Safeguarding the Bioeconomy.* Washington, DC: National Academies Press; 2020.
8. De Sherbinin A, Levy MA, Zell E, Weber S, Jaiteh M. Using satellite data to develop environmental indicators. *Environ Res Lett.* 2014;9(8):084013. <https://doi.org/10.1088/1748-9326/9/8/084013>
9. Dietrich D, Dekova R, Davy S, Fahrni G, Geissbühler A. Applications of space technologies to global health: scoping review. *J Med Internet Res.* 2018; 20(6):e230. <https://doi.org/10.2196/jmir.9458>
10. Kleeman MJ, Kaufman JD, Ostro B, et al. Enhanced air pollution epidemiology using a source-oriented chemical transport model. Washington, DC: US Environmental Protection Agency; 2014.
11. Kloog I, Koutrakis P, Coull BA, Lee HJ, Schwartz J. Assessing temporally and spatially resolved PM_{2.5} exposures for epidemiological studies using satellite aerosol optical depth measurements. *Atmos*


- Environ.* 2011;45(35):6267-6275. <https://doi.org/10.1016/j.atmosenv.2011.08.066>
12. Lee HJ, Liu Y, Coull BA, Schwartz J, Koutrakis P. A novel calibration approach of MODIS AOD data to predict PM_{2.5} concentrations. *Atmos Chem Phys.* 2011;11(15):7991-8002. <https://doi.org/10.5194/acp-11-7991-2011>
13. Lindström J, Szpiro AA, Sampson PD, et al. A flexible spatio-temporal model for air pollution with spatial and spatio-temporal covariates. *Environ Ecol Stat.* 2014;21(3):411-433. <https://doi.org/10.1007/s10651-013-0261-4>
14. Holloway T, Miller D, Anenberg S, et al. Satellite monitoring for air quality and health. *Annu Rev Biomed Data Sci.* 2021;4(1):417-447. <https://doi.org/10.1146/annurev-biodatasci-110920-093120>
15. The National Aeronautics and Space Administration. Giovanni. Available at: <https://giovanni.gsfc.nasa.gov/giovanni>. Accessed April 10, 2021.
16. McCarthy MJ, Colna KE, El-Mezayen MM, et al. Satellite remote sensing for coastal management: a review of successful applications. *Environ Manage.* 2017;60(2):323-339. <https://doi.org/10.1007/s00267-017-0880-x>
17. Georgiou M, Morison G, Smith N, Tiegues Z, Chastin S. Mechanisms of impact of blue spaces on human health: a systematic literature review and meta-analysis. *Int J Environ Res Public Health.* 2021; 18(5):2486. <https://doi.org/10.3390/ijerph18052486>
18. Fong KC, Hart JE, James P. A review of epidemiologic studies on greenness and health: updated literature through 2017. *Curr Environ Health Rep.* 2018;5(1):77-87. <https://doi.org/10.1007/s40572-018-0179-y>
19. White-Newsome JL, Brines SJ, Brown DG, et al. Validating satellite-derived land surface temperature with in situ measurements: a public health perspective. *Environ Health Perspect.* 2013;121(8): 925-931. <https://doi.org/10.1289/ehp.1206176>
20. The National Aeronautics and Space Administration. NASA Earth's applied sciences program continues its commitment to public health on One Health Day 2018. 2018. Available at: <https://science.nasa.gov/earth-science/applied-sciences/making-space-for-earth/one-health-day>. Accessed April 10, 2021.
21. Chetty R, Friedman JN, Hendren N, Stepner M. The economic impacts of COVID-19: evidence from a new public database built using private sector data. NBER working paper no. 27431. Cambridge, MA: National Bureau for Economic Research; 2020.
22. Tulier ME, Reid C, Mujahid MS, Allen AM. "Clear action requires clear thinking": a systematic review of gentrification and health research in the United States. *Health Place.* 2019;59:102173. <https://doi.org/10.1016/j.healthplace.2019.102173>
23. Department of Population Health, NYU Langone Health. City Health Dashboard. Available at: <https://www.cityhealthdashboard.com>. Accessed May 27, 2022.
24. US Census Bureau. New census surveys provide near real-time info on households, businesses during COVID-19. 2020. Available at: <https://www.census.gov/library/stories/2020/04/new-census-surveys-provide-near-real-time-info-on-households-businesses-during-covid-19.html>. Accessed April 11, 2021.
25. Casado MG, Glennon B, Lane J, McQuown D, Rich D, Weinberg BA. *The Effect of Fiscal Stimulus: Evidence From COVID-19.* Working paper no.

27576. Cambridge, MA: National Bureau of Economic Research; 2020.
26. Althouse BM, Ng YY, Cummings DA. Prediction of dengue incidence using search query surveillance. *PLoS Negl Trop Dis.* 2011;5(8):e1258. <https://doi.org/10.1371/journal.pntd.0001258>
27. Aiello AE, Renson A, Zivich PN. Social media- and Internet-based disease surveillance for public health. *Annu Rev Public Health.* 2020;41(1):101-118. <https://doi.org/10.1146/annurev-publhealth-040119-094402>
28. Rocklöv J, Tozan Y, Ramadona A, et al. Using Big Data to monitor the introduction and spread of Chikungunya, Europe, 2017. *Emerg Infect Dis.* 2019;25(6):1041-1049. <https://doi.org/10.3201/eid2506.180138>
29. Müller MM, Salathé M. Crowdbreaks: tracking health trends using public social media data and crowdsourcing. *Front Public Health.* 2019;7:81. <https://doi.org/10.3389/fpubh.2019.00081>
30. Facebook Data for Good. Social Connectedness Index. Available at: <https://dataforgood.fb.com/tools/social-connectedness-index>. Accessed May 27, 2022.
31. Kang Y, Gao S, Liang Y, Li M, Rao J, Kruse J. Multi-scale dynamic human mobility flow dataset in the US during the COVID-19 epidemic. *Sci Data.* 2020;7(1):390. <https://doi.org/10.1038/s41597-020-00734-5>
32. Ghosh M, Rao J. Small area estimation: an appraisal. *Stat Sci.* 1994;9(1):55-76. <https://doi.org/10.1214/ss/1177010647>
33. Jia H, Muennig P, Borawski E. Comparison of small-area analysis techniques for estimating county-level outcomes. *Am J Prev Med.* 2004; 26(5):453-460. <https://doi.org/10.1016/j.amepre.2004.02.004>
34. Lavrakas PJ. *Encyclopedia of Survey Research Methods.* Thousand Oaks, CA: Sage Publications; 2008. <https://doi.org/10.4135/9781412963947>
35. Jean N, Burke M, Xie M, Davis WM, Lobell DB, Ermon S. Combining satellite imagery and machine learning to predict poverty. *Science.* 2016;353(6301):790-794. <https://doi.org/10.1126/science.aaf7894>
36. Buil-Gil D, Solymsos R, Moretti A. Nonparametric bootstrap and small area estimation to mitigate bias in crowdsourced data: simulation study and application to perceived safety. In: Hill CA, Biemer PP, Buskirk RD, eds. *Big Data Meets Survey Science: A Collection of Innovative Methods.* Hoboken, NJ: John Wiley and Sons; 2020:487-517.
37. Tatem AJ, Adamo S, Bharti N, et al. Mapping populations at risk: improving spatial demographic data for infectious disease modeling and metric derivation. *Popul Health Metr.* 2012;10(1):8. <https://doi.org/10.1186/1478-7954-10-8>
38. Pfeiffermann D. New important developments in small area estimation. *Stat Sci.* 2013;28(1):40-68. <https://doi.org/10.1214/12-STS395>
39. Elbers C, Lanjouw JO, Lanjouw P. Micro-level estimation of poverty and inequality. *Econometrica.* 2003;71(1):355-364. <https://doi.org/10.1111/1468-0262.00399>
40. Tanton R, Vidyattama Y, Nepal B, McNamara J. Small area estimation using a reweighting algorithm. *J R Stat Soc Ser A Stat Soc.* 2011;174(4):931-951. <https://doi.org/10.1111/j.1467-985X.2011.00690.x>
41. Relia K, Akbari M, Duncan D, Chunara R. Socio-spatial self-organizing maps: using social media to assess relevant geographies for exposure to

- social processes. *Proc ACM Hum Comput Interact*. 2018;2:145. <https://doi.org/10.1145/3274414>
42. Openshaw S. The modifiable areal unit problem. In: Wrigley N, Bennett RJ, eds. London, UK, and Boston, MA: *Quantitative Geography: A British View*. 1981:60–69.
 43. Guo Y, Liu Y, Georgiou T, Lew MS. A review of semantic segmentation using deep neural networks. *Int J Multimed Inf Retr*. 2018;7(2):87–93. <https://doi.org/10.1007/s13735-017-0141-z>
 44. Abdur Rehman N, Saif U, Chunara R. Deep landscape features for improving vector-borne disease prediction. *ArXiv*. 1904.01994v1. 2019.
 45. Flaxman S, Wilson A, Neill D, Nickisch H, Smola A. Fast Kronecker inference in Gaussian processes with non-Gaussian likelihoods. Paper presented at: 32nd International Conference on Machine Learning; July 6, 2015; Lille, France.
 46. Akbar M, Chunara R. Using contextual information to improve blood glucose prediction. *ArXiv*. 1909.01735. 2019.
 47. Chunara R, Wisk LE, Weitzman ER. Denominator issues for personally generated data in population health monitoring. *Am J Prev Med*. 2017; 52(4):549–553. <https://doi.org/10.1016/j.amepre.2016.10.038>
 48. Wang W, Rothschild D, Goel S, Gelman A. Forecasting elections with non-representative polls. *Int J Forecast*. 2015;31(3):980–991. <https://doi.org/10.1016/j.ijforecast.2014.06.001>
 49. Shirani-Mehr H, Rothschild D, Goel S, Gelman A. Disentangling bias and variance in election polls. *J Am Stat Assn*. 2018;113(522):7. <https://doi.org/10.1080/01621459.2018.144823>
 50. Abowd JM. Protecting the confidentiality of America's statistics: adopting modern disclosure avoidance methods at the Census Bureau. *Census Blogs: Research Matters*. Washington, DC: US Census Bureau; 2018.
 51. Burton PR, Murtagh MJ, Boyd A, et al. Data safe havens in health research and healthcare. *Bioinformatics*. 2015;31(20):3241–3248. <https://doi.org/10.1093/bioinformatics/btv279>
 52. Scally CP, Burnstein E, Gerken M. In search of “good” rural data. Urban Institute. 2020. Available at: https://www.census.gov/newsroom/blogs/research-matters/2018/08/protecting_the_conf.html. Accessed May 27, 2022.



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Gun Violence Prevention: A Public Health Approach

Edited By: Linda C. Degutis, DrPH, MSN,
and Howard R. Spivak, MD

Gun Violence Prevention: A Public Health Approach acknowledges that guns are a part of the environment and culture. This book focuses on how to make society safer, not how to eliminate guns. Using the conceptual model for injury prevention, the book explores the factors contributing to gun violence and considers risk and protective factors in developing strategies to prevent gun violence and decrease its toll. It guides you with science and policy that make communities safer.

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Surveying Hate and Its Effects During the COVID-19 Pandemic Among Asian Americans and Native Hawaiians and Pacific Islanders

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🔗 See also COVID-19 and Health Equity Data Gaps, pp. 1404–1453.

Objectives. To summarize data collection on anti-Asian American and Native Hawaiian/Pacific Islander (AANHPI) experiences during COVID-19 and measure the associations of anti-AANHPI hate incidents with mental health, health access, and public safety among AANHPI adults.

Methods. We cataloged COVID-19 surveys conducted in 2020 and 2021 on anti-AANHPI experiences. We then analyzed the 2020 California Health Interview Survey (CHIS) AANHPI COVID-19 module by constructing a variable of experiencing or witnessing a hate incident and estimating its associations with serious psychological distress, forgone care, and perceived neighborhood safety.

Results. Estimates of being a victim of a hate incident ranged from 6% to 30%. In the CHIS, 28% of respondents experienced or witnessed a hate incident. Experiencing or witnessing a hate incident was significantly associated with serious psychological distress (adjusted odds ratio [AOR] = 5.33), forgoing care (AOR = 2.27), and not feeling safe in one's neighborhood (AOR = 2.70).

Conclusions. Evidence from a multitude of data sources corroborates the toll of hate incidents suffered by AANHPIs. Findings regarding the negative effects of anti-AANHPI hate on mental health, health access, and public safety compel public and private investment to end victimization of AANHPI communities. (*Am J Public Health.* 2022;112(10):1446–1453. <https://doi.org/10.2105/AJPH.2022.306977>)

Asian Americans are the fastest growing racial/ethnic group in the United States, increasing by about 81% between 2000 and 2019, and Native Hawaiians and Pacific Islanders (NHPIs) are the third fastest growing group, increasing by 61% over the same period.¹ Hence, one would have expected data systems to be prepared to enumerate and publish the toll of COVID-19 on Asian American and Native Hawaiian and Pacific Islander (AANHPI) communities when the COVID-19 pandemic began.

However, early in the pandemic in 2020, researchers and advocates were left to rely on a hodgepodge of media stories, health worker memorials, and data collected by special interest groups to obtain information on the toll of COVID-19 in AANHPI communities. Although we now know NHPIs suffered disproportionately from COVID-19 cases and deaths,^{2,3} the lack of disaggregated case and mortality data in public health surveillance systems obstructed detection of the disproportionate burden of COVID-19 among

populations hidden in aggregated race categories.^{3,4}

Beyond the deficits of public health surveillance, the pandemic also quickly brought to light the lack of real-time data on hate targeted at AANHPI communities around the United States (i.e., anti-Asian or anti-AANHPI hate). Beginning in early 2020, AANHPIs in the United States experienced a rise in xenophobia and bigotry and called for action, out of which the Stop AAPI Hate initiative was born. The Asian Pacific Planning and Policy Council, Chinese

for Affirmative Action, and the Asian American Studies Department of San Francisco State University launched the Stop AAPI Hate reporting Web site in early March 2020. Stop AAPI Hate has grown to be a key source of hate incident reports, augmented by other data collection collaborative efforts that are community led or part of community-academic partnerships.⁵ These data collection efforts range from small convenience sample studies to large random sample population-based surveys.

The purpose of our study is twofold. First, we summarize data collection efforts on AANHPIs in 2020 and 2021 as a resource for understanding the various sources of insights on hate and the AANHPI experience during the COVID-19 pandemic. Second, we present findings on COVID-19-related effects on AANHPI adults from the California Health Interview Survey (CHIS) to render estimates related to the experience of AANHPIs within its population-based survey collection infrastructure. With data collection historically the backbone of community and political action for AANHPIs, we discuss where gaps remain and where investments in data collection may help move both science and advocacy forward.

METHODS

Using both Google Scholar and PubMed, we searched for data sources using the search terms “COVID-19,” “survey,” and “Asian American” or “Native Hawaiian, Pacific Islander.” We looked specifically for data sources that included any mention of variables related to “discrimination,” “racism,” “blame,” “attack,” “fear,” “hate,” “violence,” “anti-Asian,” “anti-AANHPI,” “crime,” “xenophobia,” “victim,” or “unfair treatment.” We also

used lists of data sources from the Asian and Pacific Islander American Health Forum and examined results from Web searches using the same search terms to find additional data sources that may not have been captured in the peer-reviewed literature searches. Surveys conducted between March 2020 and March 2022 were included in this search. We also conducted searches including subpopulations using “American” along with “Chinese,” “Filipino,” “Japanese,” “Korean,” “Vietnamese,” “South Asian,” “Cambodian,” “Southeast Asian,” “Native Hawaiian,” “Guamanian,” “Marshallese,” “Chamorro,” “Samoan,” and “Pacific Islander.”

Many of the data sources also included examinations of other outcomes such as mental health, financial hardship, access to services, and family effects. For all data sources, we collected information on dates of data collection, sample size, geography, topics and questions, languages, the organizations involved in the study, and main findings. This compilation of data sources was the foundation from which observations were made regarding the depth and breadth of available COVID-19 impact data on AANHPIs.

Nonsurvey data sources (e.g., online reporting data repositories or registries) on COVID-19 effects on AANHPIs were also compiled. These sources included community-based reporting platforms. Registries documenting hate incidents may undercount the toll on a community because some individuals who experienced a hate incident may not register the incident as a hate crime and may not capture a population-representative portrayal of the needs or hardships faced by segments of

populations. Thus, a combination of registry- or repository-based reporting and population-based survey data can provide a more complete picture of impact.

California Health Interview Survey Analysis

We used data from the CHIS, conducted by the Center for Health Policy Research at the University of California, Los Angeles (UCLA), to gain insights from a population-based perspective. The CHIS is the largest annual state-based population health survey in the United States and has facilitated the generation of population-based AANHPI subgroup estimates used in studies nationwide.⁶⁻⁸ The CHIS conducts interviews in Cantonese, Mandarin, Korean, Vietnamese, and Tagalog in addition to English and Spanish. The survey is limited to California, but California is home to the largest single-race NHPI and Asian population of any US state.⁹ In its annual continuous survey, CHIS randomly selects 1 adult to interview in a randomly sampled participating household. An address-based sample methodology is used to complete the random sampling, with multi-mode data collection done via Web or telephone. One of the primary goals of the sampling strategy is to produce statistics that reflect the state's racial/ethnic diversity.

We examined data from CHIS's AANHPI COVID-19 module (based on a survey administered to AANHPIs in July through September 2020) to estimate the impact of the pandemic on AANHPIs. The CHIS typically surveys more than 2500 Asian adults in a given year; however, because the AANHPI COVID-19 module was developed after the first

March 2020 stay-at-home orders in California and fielded beginning in July 2020, the module sample represented a subset of the CHIS annual AANHPI sample (700 Asian and 20 NHPI respondents). This AANHPI sample came from the CHIS annual survey of all households in California. The module was administered to CHIS adult respondents who reported “any mention” of “Asian” or “NHPI” for race, and thus both single-race and multiracial NHPIs were included. The AANHPI COVID-19 module was developed in collaboration with the UCLA Asian American Studies Center in response to the rise of hate, racism, xenophobia, and discrimination targeting AANHPI communities.¹⁰ Estimates were derived from restricted microdata files on the 2020 AANHPI COVID-19 module.

Measurement of Key Variables

In the AANHPI COVID-19 module, respondents were asked whether they had “directly experienced a hate incident due to coronavirus” in the past 12 months; those answering “yes” were asked to categorize the type of incident (physical, verbal, cyberbullying, other). Respondents were also asked whether they had “witnessed another Asian or Pacific Islander person being treated unfairly due to their race, ethnicity, or national origin.” The related questionnaires were published in a previous article.¹⁰ For the analyses presented here, we combined the questions on hate incidents to create a variable indicating whether respondents reported having had a direct experience of hate or witnessing a hate incident. Responses of “don’t know” and “not ascertained” were not included in our

analyses. The study analytic sample consisted of 668 respondents.

Multivariable logistic regression models examined associations between experienced or witnessed hate and 3 different outcomes: (1) serious psychological distress in the past year, (2) forgoing necessary care in the past year, and (3) current perception of safety in one’s neighborhood (i.e., reporting not feeling safe). Serious psychological distress in the past year was measured via a cutoff score of 13 to 24 on the Kessler 6, a validated measure designed to estimate the prevalence of diagnosable mental disorders within a population.¹¹ Forgoing necessary medical care was defined as delaying care and not obtaining the necessary care eventually. Finally, not feeling safe in one’s neighborhood was a combination of feeling safe only some of the time and feeling safe none of the time. All models controlled for psychosocial environmental variables representing stress vulnerabilities¹² that affect outcomes and may be associated with witnessing or experiencing hate (age, gender, limited English proficiency, immigrant, income below 100% of the federal poverty level as defined by the US Department of Health and Human Services, less than a high school education, unemployed, and interpersonal conflict in the household).

Analytic Approach

We present descriptive statistics and associations from multivariable models. By default, aggregated results for AANHPIs are presented, and, if statistically stable, they are presented as intermediate categories of NHPIs (Native Hawaiian, Samoan, Guamanian, Tongan, other NHPI), East Asian (Chinese, Japanese, Korean), Southeast Asian

(Filipino, Vietnamese, Cambodian, Thai, other Southeast Asian), South Asian (Indian, Pakistani, Bangladeshi, Nepali, Sri Lankan, other South Asian), and other Asian or multi-Asian. The “other Asian” category included single Asian groups that responded “yes” to Asian but “other” in the subgroup follow-up question. Multiracial Asians were assigned to the single-race Asian category they identified with unless they also reported NHPI race. In the latter case, we assigned respondents to the NHPI category, principally to increase the sample size for this group.

We used Stata version 16.1 (Stata-Corp LLC, College Station, TX) to analyze the AANHPI-specific COVID-19 module. We assessed statistical stability on the basis of a coefficient of variation below 30%,¹³ examined differences between groups using the χ^2 test, and assessed the statistical significance of associations at the $P < .05$ level. All estimates and multivariable regression models were weighted to California Department of Finance population estimates and adjusted for sampling design and nonresponse bias.¹⁴

RESULTS

The cataloging of data collection efforts on anti-AANHPI hate and the CHIS analysis of the AANHPI COVID-19 module are presented in the sections to follow.

Summary of Data Collection Efforts

We found 17 survey-based data sources and 4 nonsurvey-based repositories or reporting sites that collected data on COVID-19 hate targeted toward AANHPIs in 2020 or 2021 (Table A, available as a supplement to the online

version of this article at <https://www.ajph.org>). Some of the surveys came from small sample interviews of less than 100 respondents, whereas others were much larger, in the 2000 to 3000 sample range. Of the 17 surveys, 1 specifically included respondents younger than 18 years in the sample of parents and children. Only 2 surveys specifically reported NHPI disaggregated results.

There was wide variation in question wording on hate. In some cases, questions were framed as having witnessed or experienced an act of discrimination. Those that asked specifically about having experienced a hate incident in the past year, such as the Stop AAPI Hate Survey, further probed for the type of hate incident. There were 10 surveys that also included questions on mental health, fear, or stress. The AAPI Data Survey, for example, asked about worry regarding being a victim of hate crimes, experience of a hate crime in the past year, and comfort level in reporting the crime.

Questions regarding having experienced or been a victim of a hate incident differed slightly in wording across surveys. Of the 5 surveys estimating whether respondents had been direct victims of a hate incident (CHIS; AAPI Data Survey; AA & NHPI COVID-19 Needs Assessment Project; Asian Americans, Native Hawaiians, and Pacific Islanders COVID-19 Study; Stop AAPI Hate Survey), estimates ranged from 6% to 30%. About 30% of Asian Americans and NHPIs reported having seen or witnessed blame (Center for Public Integrity/Ipsos COVID-19 Poll; CHIS); similarly, approximately 30% reported fear or worry about being the victim of a hate incident (AAPI Data Survey; Pew Research Survey). About 75% of Asians believe that the United States has become more dangerous for their

racial/ethnic group (AA & NHPI COVID-19 Needs Assessment Project), 72% of AAPIs who experienced a hate incident believe that anti-Asian discrimination is the greatest source of stress (Stop AAPI Hate Follow-Up Survey), and 70% of AANHPIs believe that discrimination against Asians became more common during the pandemic (Asian Americans, Native Hawaiians, and Pacific Islanders COVID-19 Study).

The findings of the COVID-19 Effects on the Mental and Physical Health of Asian Americans and Pacific Islanders Survey Study (COMPASS) revealed that 59% of respondents believe that the country has become more dangerous for their ethnic group. Survey data from the Bureau of Justice Statistics National Crime Victimization Survey showed that there were no increases in violent crime involving any racial/ethnic group in 2020. (See Table A for a summary of key findings from each of the surveys described.)

Surveillance of and nonsurvey data on anti-Asian hate have quantified increases in both police-reported and self-reported incidents of hate (Table A). Comparisons of numbers of incidents between these surveillance sources are not possible because of the numerous differences in the way incidents are defined and reported; however, various data sources—from self-reported incidents of hate (via Stop AAPI Hate), media reports, and US law enforcement agency sources—all point to increases in hate incidents against AANHPIs.

California Health Interview Survey Analysis

Using data from CHIS's AANHPI COVID-19 module, we present estimates of COVID-19 hate incidents among AANHPI populations (Table 1). Table B

(available as a supplement to the online version of this article at <https://www.ajph.org>) provides estimates of hate incidents according to sociodemographic characteristics (gender, age, income, education, language proficiency, immigrant status, employment, and interpersonal conflict). We found that close to 7% of all AANHPIs (6% of East Asians and 9% of Southeast Asians) directly experienced a hate incident; 64% of these incidents involved verbal abuse or a verbal attack, and 22% took the form of cyberbullying (data not shown). About 26% of all AANHPIs witnessed another AANHPI person being treated unfairly (approximately 33% of Chinese respondents, 26% of Korean respondents, 25% of Filipino respondents, and 23% of Vietnamese respondents). There were no significant differences between any of the ethnic subgroups (χ^2 test).

About 28% of AANHPIs (1.5 million) experienced or witnessed a hate incident, with a higher rate among young adults 18 to 25 years of age (59%) than among other age groups ($P < .001$). Across all age groups, male and female respondents had similar reported levels of experiencing or witnessing a hate incident (24%–28%); however, among young adults, female AANHPIs were significantly more likely than male AANHPIs (67% vs 49%) to have experienced or witnessed a hate incident ($P < .001$).

Our multivariable models of associations between hate incidents with 3 different outcomes are presented in Table 2. Controlling for age, gender, language proficiency, immigration status, income, education, employment status, and interpersonal conflict in the household, we found that having experienced or witnessed a hate crime incident was associated with higher levels of serious psychological distress

TABLE 1— COVID-19 Hate Incidents Experienced or Witnessed by AANHPIs: California Health Interview Survey AANHPI COVID-19 Module, 2020

	Experienced a Hate Incident, No. (% of All Ages)	Witnessed a Hate Incident, No. (% of All Ages)	Experienced or Witnessed a Hate Incident			
			No.	All Ages, %	Age 18–25 Years, %	Female, %
AANHPI total	665 (6.8)	665 (26.0)	668	27.50	59.3	29.0
Race/ethnicity						
NHPI	19 (3.4 ^a)	19 (17.3 ^a)	19	20.7 ^a	48.1 ^a	38.4 ^a
East Asian	310 (6.5)	310 (29.9)	311	30.8	63.6	34.4
Chinese	172 (4.7 ^a)	171 (33.3)	172	33.0	60.4	42.4
Japanese	66 (3.2 ^a)	66 (19.1 ^a)	66	19.2 ^a	.. ^b	13.9 ^a
Korean	72 (16.0 ^a)	73 (26.0)	73	32.4	.. ^b	22.5 ^a
Southeast Asian	243 (9.5)	241 (25.0)	243	27.3	57.3	28.9
Filipino	143 (8.1 ^a)	142 (25.0)	143	25.8	46.8 ^a	29.4
Vietnamese	72 (10.9 ^a)	71 (22.6)	72	26.2	65.7	23.0 ^a
Other Southeast Asian	28 (14.3 ^a)	28 (52.2 ^a)	28	39.9	.. ^b	40.0 ^a
South Asian	60 (2.41 ^a)	62 (11.1 ^a)	62	12.0 ^a	40.3 ^a	12.7 ^a
Other Asian/ ≥ 2 Asian ^c	33 (3.6 ^a)	33 (52.2)	33	52.2	87.3	35.5 ^a

Note. AANHPI = Asian American and Native Hawaiian/Pacific Islander.

^aStatistically unstable (statistical stability is defined on the basis of a coefficient of variation < 30).

^bSample size too small to generate a result.

^cIncludes single-race groups that responded “yes” to Asian but “other” in the subgroup follow-up question and that indicated ≥ 2 Asian groups.

Multiracial Asians were assigned to the single-race Asian category unless they also reported NHPI race. In the latter case, respondents were coded as NHPI. The χ^2 test of significance between groups revealed no significant differences.

TABLE 2— Associations Between Hate Incidents and Mental Health, Forgone Care, and Neighborhood Safety: California Health Interview Survey AANHPI COVID-19 Module, 2020

	Serious Psychological Distress, OR (95% CI)	Had to Forgo Necessary Care, OR (95% CI)	Does Not Feel Safe in Neighborhood, OR (95% CI)
Experienced or witnessed a hate incident	5.33 (1.70, 16.67)	2.27 (1.15, 4.46)	2.70 (1.13, 6.43)
Age group, y (Ref = 40–64)			
18–25	12.65 (2.24, 71.34)	0.74 (0.27, 2.03)	0.60 (0.23, 1.52)
26–39	3.01 (0.81, 11.12)	0.30 (0.10, 0.88)	0.36 (0.15, 0.90)
≥ 65	0.62 (0.09, 4.05)	0.85 (0.34, 2.12)	0.32 (0.08, 1.31)
Female	0.99 (0.36, 2.75)	1.92 (0.92, 4.01)	0.88 (0.43, 1.81)
Limited English proficiency	2.77 (0.59, 13.09)	2.13 (0.75, 6.02)	2.99 (0.85, 10.53)
Immigrant	1.10 (0.37, 3.24)	0.72 (0.32, 1.62)	0.99 (0.41, 2.38)
Income < 100% of FPL	0.41 (0.06, 2.90)	0.69 (0.21, 2.25)	2.08 (0.64, 6.73)
< high school	1.40 (0.17, 11.6)	0.53 (0.07, 4.15)	1.59 (0.19, 13.7)
Unemployed	1.09 (0.28, 4.19)	1.01 (0.30, 3.37)	0.57 (0.10, 3.36)
Interpersonal conflict in household	0.72 (0.21, 2.42)	1.30 (0.47, 3.60)	1.94 (0.77, 4.92)
Constant	0.01 (0.002, 0.04)	0.09 (0.03, 0.25)	0.07 (0.03, 0.20)

Note. AANHPI = Asian American and Native Hawaiian/Pacific Islander; CI = confidence interval; FPL = federal poverty level (as defined by the US Department of Health and Human Services); OR = odds ratio. The sample size was 668.

(adjusted odds ratio [AOR] = 5.33; $P = .004$), having had to forgo necessary care (AOR = 2.27; $P = .018$), and not feeling safe in one's neighborhood (AOR = 2.70; $P = .025$). In line with our understanding of the challenges faced by the younger age group, we found that the 18- to 25-year-old group had higher odds of serious psychological distress than all older age groups. There was no age association in the other models focusing on forgoing necessary care and feeling safe in one's neighborhood. Female respondents had higher odds of forgoing care than male respondents, and in the model on neighborhood safety those with limited English proficiency had higher odds of not feeling safe in their neighborhood than those with English proficiency.

DISCUSSION

We found there have been numerous efforts to gauge the experience of hate during the COVID-19 pandemic among AANHPIs, many of which are ongoing data collection endeavors. These efforts range from incident reporting platforms and small studies to large population-based surveys. All sources point to an increase in hate, aggression, and discrimination experienced by AANHPI populations with the exception of the National Crime Victimization Survey. Note, however, that violent crime in that survey referred to rape or sexual assault, robbery, and assault; thus, incidents that do not rise to the level of these definitions (e.g., cyberbullying or verbal abuse) were not represented in the data. The COVID-19 Hate Crimes Act of May 2021 appropriately focuses on building a better data collection infrastructure for hate incidents. Early data gathering on hate incidents, public

outrage, and community action surely contributed to its passage.

The CHIS AANHPI module conducted in 2020 showed that 26% of Asian Americans and NHPs have witnessed another AANHPI individual being treated unfairly and 7% have directly experienced a hate incident. The CHIS estimates are slightly lower than those found in other surveys. The Stop AAPI Hate Survey, conducted in September and October 2021, revealed that about 20% of AANHPIs had directly experienced a hate incident in the past year. The AAPI Data Survey, conducted nationwide in March 2021, showed that 31% of Asian Americans and Pacific Islanders worry often about being the victim of a hate crime or incident and 12% report having been victimized. Because of the differences in timing of data collection, questionnaire wording, and population sampling methods, it is difficult to make additional comparisons between studies.

In California, home to more than 6 million AANHPIs, we found significant associations between having experienced or witnessed a hate incident and serious psychological distress, with young adults reporting more distress than older groups. Having experienced or witnessed a hate incident was also associated with having had to forgo necessary care and not feeling safe in one's neighborhood. These findings corroborate those of other surveys documenting heightened anxiety and worry about anti-AANHPI hate during the pandemic, particularly among women.¹⁵⁻¹⁹

In the AANHPI community, particularly the Asian community and subgroups under this aggregate tabulation, the continued rise in anti-AANHPI hate has been documented by various sources across the nation. Segments of the

AANHPI population, namely young adults and females, have experienced heightened COVID-19-related hate incidents and unfair treatment owing to their race/ethnicity, which may in turn be associated with negative effects in terms of mental health, health access, and perceived neighborhood safety. Young AANHPI women might benefit the most from investments in community-driven interventions and policy solutions to reduce psychological distress and provide protection from hate and unfair treatment. There has been a call by community members and advocates to find solutions to help curb hate incidents and address the mental health of community members. Positive examples of ways that might effect change include bystander training to educate people on how to stand up for others when they witness hate, support groups to improve mental health, and walking buddies or chaperones to address neighborhood safety.

PUBLIC HEALTH IMPLICATIONS

Incident reporting data repositories such as the Stop AAPI Hate platform have filled an important gap for people who have experienced an incident of hate (e.g., microaggression, verbal harassment, or discrimination) that is not reported to the police and not logged as a hate crime. However, these types of online registries may be prone to unique methodological challenges. For example, each submitted report has to be reviewed, which is done by a group of volunteer members. According to Stop AAPI Hate, there were more than 2800 reports in March 2021 alone. Reporting sites also rely on the assumption that people are aware, able, and willing to share their

experiences. The survey data drawn from registrants are valuable; without population-representative sampling, however, the experience of AANHPI populations will not be adequately represented, limiting the generalizability of results.

Historically, health data from large population-based surveys have shed light on AANHPI disparities in health behavior and health access variables between subgroups and provided insights on how health care providers and policymakers might better serve their patients.^{20–23} However, achieving robust samples to allow for reporting and more sophisticated analyses of data is the greatest challenge for population surveys.²⁴ The small number of Asian Americans within most survey samples may not produce robust statistical estimates, especially when the interest is in reporting on disaggregated populations.

Thus, population-based surveys not able to sample, collect, code, and report granular race/ethnicity data may tend to aggregate populations into rolled-up Asian or NHPI categories or an aggregated AANHPI category rather than tease out ethnic subgroups. Because probability sampling is used in these types of large surveys to reflect the population of interest, they are often costly and more slow to accommodate new questions or offer rapid assessments. Nonetheless, there are opportunities to launch rapid large-scale surveys (e.g., the CHIS and surveys conducted by Pew Research and AAPI Data).

The CHIS was in the unique position to react quickly to the COVID-19 pandemic because of its study design and resolute stakeholder engagement.¹⁰ However, one of our limitations in the AANHPI module data was our inability to produce disaggregated results for

the variables examined owing to a relative small sample. Through California Asian & Pacific Islander Legislative Caucus sponsorship and a partnership with the UCLA Asian American Studies Center, the CHIS continued to administer the COVID-19 module to the entire AANHPI sample in 2021, thus increasing the sample of this special module. By October 2022, a 2020–2021 data file of more than 2500 AANHPI respondents will be available, facilitating robust subgroup estimates. The AAPI legislative caucus continues to prioritize investments in better surveillance data systems for the AANHPI population.

Through the sponsorship of and a partnership with AAPI Data, the CHIS is conducting the AANHPI Community Needs Survey. Such efforts exemplify the importance of community groups advocating for legislators to exert political will to invest in surveillance systems detecting and monitoring the health needs of AANHPI populations that are “invisible” in public-facing data.

In this analysis, as with the other data sources, we were limited in our ability to produce causal estimates of the effects of experiences of hate on distress, feelings of neighborhood safety, and obtaining care. Thus, a call for AANHPI panel data—collecting data on the same group of individuals over time—could distinguish causal relationships and identify temporal contextual changes in the policy environment and public sentiments, which could allow better measurement of the magnitude of associations and help determine appropriate policy responses.

At a minimum, transforming public health data systems should require federal and state data systems to collect AANHPI data at more granular levels beyond the Office of Management and Budget’s 1997 race/ethnicity

categories. The Department of Health and Human Services 2011 guidance, which specified collection of data on 7 Asian subgroups (Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, other Asian) and 4 NHPI subgroups (Native Hawaiian, Guamanian or Chamorro, Samoan, other Pacific Islander), could be more widely adopted.²⁵

Despite current public health data limitations and possibilities for improvement, the COVID-19 period was a call for community, academic, philanthropy, and government partnerships to expand and sharpen surveillance tools, especially with respect to anti-AANHPI hate. Community-led stories that are then matched with Herculean efforts to collect data and produce quantitative research have historically been one of the key features of AANHPI data advocacy.^{8,24} Many of the studies we reviewed demonstrate this legacy, thus producing new knowledge and evidence. Our findings compel the establishment of public policies to care for people who are victimized and prevent further victimization of people because of their AANHPI identity. In tandem with interventions, public and private investments in surveillance systems are still much needed to more quickly and more precisely protect and monitor the health and well-being of AANHPI communities. **AJPH**

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CONFLICTS OF INTEREST

The authors have no conflicts of interest to report.

HUMAN PARTICIPANT PROTECTION

No protocol approval was needed for the survey of data collection efforts study because publicly available data were used. For the CHIS analysis, the UCLA Institutional Review Board approved the analyses of confidential CHIS data (UCLA IRB#17-000362).


REFERENCES

- Budiman A, Ruiz N. Asian Americans are the fastest-growing racial or ethnic group in the US. Available at: <https://www.pewresearch.org/fact-tank/2021/04/09/asian-americans-are-the-fastest-growing-racial-or-ethnic-group-in-the-u-s>. Accessed June 20, 2021.
- Kaholokula JK, Samoa RA, Miyamoto RES, Palafox N, Daniels SA. COVID-19 hits Native Hawaiian and Pacific Islander communities the hardest. *Hawaii J Health Soc Welf*. 2020;79(5):144–146.
- Ponce N, Shimkhada R, Tulua A. Disaggregating California's COVID-19 data for Native Hawaiians and Pacific Islanders and Asians. Available at: <https://healthpolicy.ucla.edu/publications/Documents/PDF/2021/COVID-19-Data-NHPI-Asians-factsheet-may2021.pdf>. Accessed June 20, 2021.
- Ponce NA, Huerto R, Manalo-Pedro E. Disaggregation for health equity: shedding light on COVID-19's impact on the Filipinx community. Available at: <https://www.kcet.org/shows/power-health/disaggregation-for-health-equity-shedding-light-on-covid-19s-impact-on-the-filipinx-community>. Accessed June 20, 2021.
- AA & NH/PI COVID-19 Needs Assessment Project. AA and NH/PI surveys. Available at: <https://www.aapicovidneeds.org/needsassessment>. Accessed June 20, 2021.
- Ponce N. *Health Issues in the Asian American Community*. Hoboken, NJ: Jossey-Bass Publishers; 2009.
- Ponce N. What a difference a data set and advocacy make for AAPI health. *AAPI Nexus*. 2011; 9(1–2):159–162. https://doi.org/10.36650/nexus9.1-2_159-162_Ponce
- Ponce NA. Centering health equity in population health surveys. *JAMA Health Forum*. 2020;1(12): e201429. <https://doi.org/10.1001/jamahealthforum.2020.1429>
- US Census Bureau. American Community Survey. Available at: <https://data.census.gov>. Accessed June 20, 2021.
- Ponce NA, Paycao D, Wells BM, Park R, Hughes T. COVID-19 Rapid response: how the California Health Interview Survey adapted during the global pandemic. *Am J Public Health*. 2021; 111(12):2122–2126. <https://doi.org/10.2105/AJPH.2021.306518>
- Kessler RC, Green JG, Gruber MJ, et al. Screening for serious mental illness in the general population with the K6 screening scale: results from the WHO World Mental Health (WMH) survey initiative. *Int J Methods Psychiatr Res*. 2010;19(suppl 1): 4–22. <https://doi.org/10.1002/mpr.310>
- Kinser PA, Lyon DE. A conceptual framework of stress vulnerability, depression, and health outcomes in women: potential uses in research on complementary therapies for depression. *Brain Behav*. 2014;4(5):665–674. <https://doi.org/10.1002/brb3.249>
- Klein RJ, Proctor SE, Boudreault MA, Turczyn KM. *Healthy People 2010 Criteria for Data Suppression*. Hyattsville, MD: National Center for Health Statistics; 2002.
- Center for Health Policy Research, University of California, Los Angeles. California Health Interview Survey 2019–2020 methodology report series 5: weighting and variance. Available at: [https://healthpolicy.ucla.edu/chis/design/Documents/CHIS%202019-2020%20Methodology%20Report%20Series/CHIS_2019_2020_MethodologyReport5_WeightingandVarianceEstimation_Final%20\(UCLA\)%2010SEP2021.pdf](https://healthpolicy.ucla.edu/chis/design/Documents/CHIS%202019-2020%20Methodology%20Report%20Series/CHIS_2019_2020_MethodologyReport5_WeightingandVarianceEstimation_Final%20(UCLA)%2010SEP2021.pdf). Accessed June 20, 2021.
- Stop AAPI Hate. Stop AAPI Hate mental health report. Available at: <https://stopaaphate.org/wp-content/uploads/2021/05/Stop-AAPI-Hate-Mental-Health-Report-210527.pdf>. Accessed June 20, 2021.
- Stop AAPI Hate. Stop AAPI Hate national report. Available at: <https://stopaaphate.org/wp-content/uploads/2021/11/Nov-2021-Stop-AAPI-Hate-National-Report-2021-11-11.docx.pdf>. Accessed June 20, 2021.
- AAPI Data. American experiences with discrimination. Available at: <https://www.surveymonkey.com/curiosity/aapi-data-2021-discrimination>. Accessed June 20, 2021.
- Artiga S, Hill L, Corallo B, Tolbert J. Asian immigrant experiences with racism, immigration-related fears, and the COVID-19 pandemic. Available at: <https://www.kff.org/coronavirus-covid-19/issue-brief/asian-immigrant-experiences-with-racism-immigration-related-fears-and-the-covid-19-pandemic>. Accessed June 20, 2021.
- Ruiz N, Edwards K, Lopez M. One-third of Asian Americans fear threats, physical attacks and most say violence against them is rising. Available at: <https://www.pewresearch.org/fact-tank/2021/04/21/one-third-of-asian-americans-fear-threats-physical-attacks-and-most-say-violence-against-them-is-rising>. Accessed June 20, 2021.
- Zhang Y, Misra R, Sambamoorthi U. Prevalence of multimorbidity among Asian Indian, Chinese, and non-Hispanic white adults in the United States. *Int J Environ Res Public Health*. 2020;17(9): 3336. <https://doi.org/10.3390/ijerph17093336>
- Mui P, Hill SE, Thorpe RJ Jr. Overweight and obesity differences across ethnically diverse subgroups of Asian American men. *Am J Mens Health*. 2018;12(6):1958–1965. <https://doi.org/10.1177/1557988318793259>
- Choi S. Sub-ethnic and geographic variations in out-of-pocket private health insurance premiums among mid-life Asians. *J Aging Health*. 2017;29(2): 222–246. <https://doi.org/10.1177/0898264316635563>
- Ye J, Mack D, Fry-Johnson Y, Parker K. Health care access and utilization among US-born and foreign-born Asian Americans. *J Immigr Minor Health*. 2012;14(5):731–737. <https://doi.org/10.1007/s10903-011-9543-9>
- Ponce NA, Bautista R, Sondik EJ, et al. Championing partnerships for data equity. *J Health Care Poor Underserved*. 2015;26(suppl 2):6–15. <https://doi.org/10.1353/hpu.2015.0058>
- National Committee for Quality Assurance. Improving data on race and ethnicity: a roadmap to measure and advance health equity. Available at: <https://www.gih.org/publication/improving-data-on-race-and-ethnicity-a-roadmap-to-measure-and-advance-health-equity>. Accessed June 20, 2021.

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Lost Lessons of the 1918 Influenza: The 1920s Working Hypothesis, the Public Health Paradigm, and the Prevention of Deadly Pandemics

C. Andrew Aligne, MD, MPH

 See also Torjussen and Mamelund, p. 1372.

In standard historical accounts, the hyperlethal 1918 flu pandemic was inevitable once a novel influenza virus appeared. However, in the years following the pandemic, it was obvious to distinguished flu experts from around the world that social and environmental conditions interacted with infectious agents and could enhance the virulence of flu germs. On the basis of the timing and geographic pattern of the pandemic, they hypothesized that an “essential cause” of the pandemic’s extraordinary lethality was the extreme, prolonged, and industrial-scale overcrowding of US soldiers in World War I, particularly on troopships. This literature synthesis considers research from history, public health, military medicine, veterinary science, molecular genetics, virology, immunology, and epidemiology. Arguments against the hypothesis do not provide disconfirming evidence. Overall, the findings are consistent with an immunologically similar virus varying in virulence in response to war-related conditions. The enhancement-of-virulence hypothesis deserves to be included in the history of the pandemic and the war. These lost lessons of 1918 point to possibilities for blocking the transformation of innocuous infections into deadly disasters and are relevant beyond influenza for diseases like COVID-19. (*Am J Public Health*. 2022;112(10):1454–1464. <https://doi.org/10.2105/AJPH.2022.306976>)

The 1918 flu pandemic killed more than 50 million people.^{1,2} (“Flu” here designates the illness, as distinguished from influenza virus, which was not isolated until the 1930s.) Current conventional wisdom maintains that it was an inevitable natural disaster, which occurred when the influenza virus mutated randomly into a novel strain (H1N1) against which people had no immunity.³

In the decade after 1918, scientists published thousands of studies investigating flu.³ This literature was reviewed in *Epidemic Influenza: A Survey* (published in 1927),⁴ regarded by preëminent flu historian Alfred Crosby as “the best single book on the 1918 pandemic.”^{3(p297)} Its

author, E. O. Jordan (Figure 1), concluded that war-related conditions caused the extraordinary mortality by increasing the virulence of the flu germ:

A more definite manner of accounting for the inception of the 1918 pandemic is to suppose that the unsettled conditions of the world’s population due to the Great War, with its numerous close contacts and generally crowded and unhygienic ways of living, led to enhancement of microbic virulence. . . . We are forced to accept the hypothesis of a change in the virulence of the infecting microbe as the essential cause of the rise and fall of pandemic influenza.^{4(pp506,511)}

Similarly, the official 1929 US Army report stated:

The pandemic occurred at about the peak of the greatest mobilization in history of men into military units. . . . It is difficult to imagine a greater opportunity for enhancement of virulence by rapid passage from man to man of the organisms causing influenza, and of those producing secondary infections. Increase in virulence by this means must be considered as a factor of great importance in the production of the high morbidity and mortality.^{5(p8)}

The 1920 British Ministry of Health (MOH) report added that conditions in

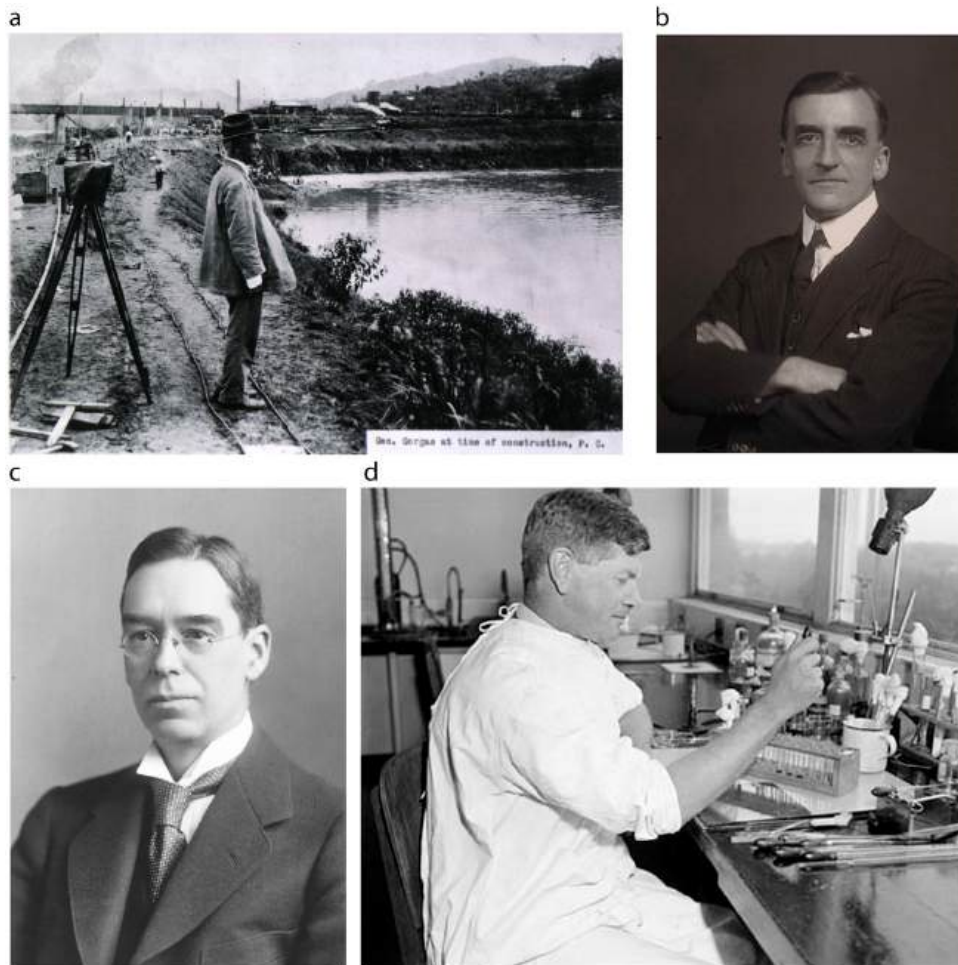


FIGURE 1— Notable Influenza Experts (a) William Gorgas, (b) Major Greenwood, (c) Edwin Oakes Jordan, and (d) Frank Macfarlane Burnet

Note. William Gorgas (1854–1920) was an international celebrity for his leadership of the Panama Canal Zone Sanitation Commission, and during World War I was US Army surgeon general. Major Greenwood (1880–1949) was a leading medical statistician of the first half of the 20th century and coauthored the 1920 British Ministry of Health’s report on the epidemiology of the pandemic. Edwin Oakes Jordan (1866–1936) was founding editor of the *Journal of Infectious Diseases* as well as the *Journal of Preventive Medicine* and received the Sedgwick Memorial Medal from the American Public Health Association. Frank Macfarlane Burnet (1899–1985) was an Australian virologist who won the Nobel Prize for his research in immunology. His work with influenza virus led to the methods used for many decades to manufacture influenza vaccines, and his team was the first to describe how reassortments of influenza genes could lead to the antigenic shifts that produce novel pandemic viruses.

Sources. William C. Gorgas at time of Panama Canal construction: courtesy of National Library of Medicine, (NLM#101416944, Image B013225). Portrait of Major Greenwood: photograph by Walter Stoneman, UK National Portrait Gallery (NPG #67957). Portrait of E. O. Jordan: photograph by Walinger, US National Library of Medicine (#101419931, Image B015878). Portrait of Sir Frank Macfarlane Burnet: photograph by N. Murray, Wikimedia Commons (#4746503).

“garrisons, war-time factories, or abnormally over-crowded and ill-ventilated means of transport” constituted “involuntary experimentation in intensive cultivation” and “selection” of a “destructive” microbe, and that this was “essential” in “the chain of causality,” and emphasized that “it is false science to neglect the teaching of a working hypothesis, the practical inferences deducible from it,

because it may ultimately have to be rejected”^{6(ppviii,190–191)} (Figures 1 and 2).

On the basis of the evidence available today, did the 1920s hypothesis have to be rejected?

METHODS

This realist best-evidence synthesis employs a broad paradigm of disease

causation that ranges from the infectious agent to the sociopolitical context.⁷ Initial scoping of the literature began with thorough reading of two books: Jordan’s *Epidemic Influenza* and Crosby’s canonical *America’s Forgotten Pandemic*, which appear to be the key documents establishing and rejecting the enhancement-of-virulence hypothesis, respectively.^{8,9} Jordan’s book and



FIGURE 2— Industrial-Scale, Prolonged Extreme Overcrowding on US Troopships

Note. The USS *Leviathan* was the largest ship in the world, transporting as many as 14 000 soldiers to France at a time, versus the 4000 passengers it was designed to carry as a German ocean liner. Men slept in berths stacked four high, sometimes sharing beds in shifts. Portholes were kept closed and covered to evade submarine attacks. The voyage typically took 10 days. The return trips for demobilized troops were somewhat better, with only 8000 troops.

Source. Troops seek fresh air aboard the troopship USS *Leviathan*: photographed by Zimmer, US Naval History and Heritage Command (Image NH 41881).

Greenwood and Carnwath's MOH report, for example, are scientific reviews, but they are also primary historical sources, since they have served as the relevant references cited for decades by historians. I examined newspaper stories, photographs, and government documents about conditions in the US military. I performed broad literature searches for studies of "influenza" and "crowding," "pandemic," "virulence," and "1918," as well as targeted searches (e.g., on the original capacity of the USS *Leviathan*). This yielded hundreds of publications from fields like medical history, epidemiology, infectious diseases, public health, and virology. Articles were found principally through citation searches on Web of Science, PubMed, and JSTOR, starting from Crosby, Jordan, Barry, Ewald, and Taubenberger, repeating the process for new relevant articles (e.g., by Mamelund), and examining their citations. I gave more weight to sources employing

relevant objective measures of both outcomes and exposures.

RESULTS

What follows is a very brief history of the flu pandemic, with evidence for a role of industrial-scale, prolonged, extreme overcrowding in the development of highly virulent influenza.

Prelude to Pandemic and the First Wave

The United States declared war on Germany in April 1917. Over the following year, America ramped up from 100 000 men in uniform to nearly five million, in a nation of 99 million. In the hastily built camps, many soldiers spent the exceptionally cold winter sleeping in tents, often huddling together to avoid freezing to death.¹⁰ During the 1917–1918 winter, an epidemic of measles pneumonia killed 6000 soldiers. Public

health leader Victor Vaughan stated: "Insufficient clothing, overcrowding in tents, barracks and hospitals, and lack of heat in the houses have been potent in the development of the pneumonia."^{11(p55)} Even to the general public, it was obvious that extreme overcrowding contributed to these deaths.^{11(p60)}

In January 1918, Army Surgeon General William Gorgas testified before the US Senate, pleading for a reduction in overcrowding¹² (Figure 1). *The New York Times* opined:

It seems astonishing, in fact inexplicable, that the advice of the surgeon who combated and by scientific discoveries triumphed over yellow fever at Havana, and who made the Panama Zone a sanatorium for canal builders . . . should have been disregarded. . . . But the waste of life, which was so unnecessary and is such a reproach to the War Department, had another salient cause than the lack of adequate hospital facilities, and that was overcrowding in the camps. General Gorgas urged as the minimum of floor space forty-five square feet—his preference was sixty feet as a sanitary precaution¹³ (1 sq ft ≈ 0.1 m²).

The flu pandemic occurred in waves. The first, "herald" wave was mild—often going unnoticed.^{3,4,14} In January 1918 it appeared in Philadelphia, Pennsylvania. It spread gradually and irregularly across the United States, producing rare cases of severe flu, with large outbreaks in army training camps between March and May; by April it had traveled to Europe on American troopships, and it then reached various parts of the world.¹⁵

By contrast, the second wave resulted in many millions of deaths. Therefore, a crucial question is: what could explain

the remarkable transformation of flu from mild to severe between the first and second waves?

The Deadly Second Wave

The American Expeditionary Forces (AEF) comprised 437 000 men in April. By August, this number would soar to 1 300 000, eventually reaching over two million in November. From the overcrowded camps, soldiers were squeezed into trains for long trips to ports.^{10(p216)} Several hundred thousand men per month then crossed the Atlantic. As bad as the overcrowding was in the camps, it was even worse on the ships (Figure 2).^{16(p88),17}

The second wave exploded in mid-August 1918 in the port town of Brest, France, which is where many men of the AEF disembarked.^{1(p53),10(pp170,182)}

From Brest, the hyperlethal second wave spread around the world, following a consistent pattern. From troop ships, deadly flu followed the soldiers to army installations, but also spread to civilians in ports and then out from there. From Britain to Brazil, there was generally higher mortality in coastal areas, large cities, and along rail networks than in inland or rural areas.^{1(p59),18,19} The role of the military in introducing severe flu has been noted globally from Spain to the South Pacific.^{3(p56),20(p35),21(p118),22,23(pp125–126),24} The war directly connected people around the world—for example, Senegalese, Tunisians, and Vietnamese fought with the French (Figure 3). India, which was the country to suffer the most deaths in the pandemic, contributed to Britain's war effort with 1.4 million soldiers and a major part of its wheat output; a related

1918 famine further increased vulnerability to flu.²⁵

In the United States, the second wave erupted on August 27 in Boston, Massachusetts, with the arrival of a troopship returning from Brest.^{10(pp170,184)} The deadly contagion spread west and south from Boston across the United States in just a few weeks. Especially hard hit were army camps connected to railroads. Epidemiological research reveals that within the US training camps, overcrowding was the factor most clearly associated with severe flu, even after considering length of service, race, cleanliness, food, weather, and other factors.^{26,27(p111),28} As public criticism about the situation in camps mounted, army physicians passed their concerns up the chain of command.^{11(pp104–107)} On September 28, Acting US Army Surgeon General



FIGURE 3— Spread of the Severe Flu Beyond the US Army, and After 1918

Note. The war put people from around the world in contact with each other, creating opportunities for widespread transmission of infections. These contacts continued even after the Armistice, for example in prisoner of war (POW) camps, where severe flu was observed in 1919. The “Third Wave” of the pandemic corresponds with the return home of POWs, demobilized troops, and wartime guest-workers.

Source. “A group of captured soldiers representing 8 nationalities: Anamite [Vietnamese], Tunese [Tunisian], Senegalese, Sudanese, Russian, American, Portugese [sic] and English.” Official German photograph from Western Front, US National Archives (Image #17391518).

Charles Richard submitted a report to the chief of staff with the following recommendation:

Overcrowding in camps and hospitals increases the percentage of pneumonia cases during epidemics of influenza. The danger of overcrowding troop ships is even greater. . . . It is believed that the present authorized capacity of troopships should be reduced at least one-half.^{29(pp350-359)}

The Wilson administration continued the mobilization, and in autumn 1918 pushed outspoken General Gorgas into retirement.¹¹ The conditions of “acute demographic congestion, in camps, factories, . . . intensified as the war approached its crisis,” coincident with the height of the pandemic.⁶

As the MOH report explained:

for the realisation of a pandemic it is not essential that the conditions initially needed to produce the modification shall be present. . . . This

hypothesis will account for the almost incredible fatality of the second [wave] influenza, not only in transports but also in some civilian communities, such as New Zealand, into which it was directly introduced from crowded ships⁶⁽¹⁸⁶⁻¹⁸⁸⁾ (Figure 4).

According to the 1920s hypothesis, populations directly exposed to the high-virulence germ experienced more severe flu, and virulence remained high if transmission continued through a chain of unsanitary conditions, but virulence declined with more separation from the overcrowding. Evolutionary biology provides models for understanding how social and environmental conditions can alter microbial virulence.³⁰ Normally, transmission of respiratory germs happens when infected people walk about coughing and sneezing; transmission is dependent on the mobility of the host, and mild variants will replicate more successfully than those that render people

bedridden. In contrast, prolonged overcrowding facilitates transmission from moribund hosts to the uninfected, removing the normal selective pressure against virulence.

Current research supports this effect of overcrowding on virulence. Studies around the world reveal that highly virulent avian influenza variants can “evolve directly from low-pathogenic virus precursors” in industrial poultry farms.^{31-33(p4375)} In other words, humans can manufacture virulence in (avian) influenza virus by creating conditions of industrial-scale prolonged extreme overcrowding. Furthermore, it is well-established that human activity can select for dangerous traits, such as antiviral resistance, in human influenza virus.³⁴

Variations within a given antigenic strain, such as H1N1, are possible because “the influenza virus” is not a single entity: it consists of many mutating cocirculating variants. These variants

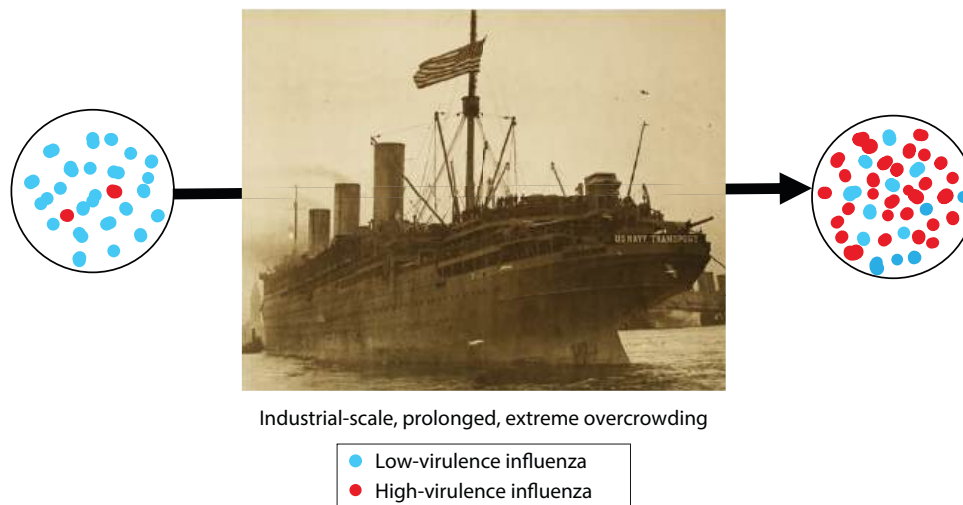


FIGURE 4— The 1920s Working Hypothesis: Enhancement of Virulence

Note. War-related conditions, particularly the transoceanic transport of millions of troops on extremely overcrowded ships, constituted “experimentation” in “enhancement of virulence” of a respiratory virus. Once severe influenza appeared, it would have been dangerous for those directly exposed. A similar phenomenon is observed today with avian influenza, which can become highly virulent inside industrial poultry farms. One hypothesis for the genesis of the recent COVID-19 pandemic is that industrial wildlife-farming enhanced virulence of SARS-CoV-2. (The diagram is a conceptual description of a model and is not meant to be a precise representation of the proportion of virulent viral variants.)

Source. Photograph of USS *Leviathan* by Kadel and Herbert, US National Archives (ID #26433439, Image #165-WW-138A-33).

exhibit abundant genetic diversity, which does not arise from immune selection.³⁵ Genetic testing of 1918 autopsy samples indicates that influenza viruses were almost identical in the first and second waves.³⁶ Given that the first wave was mild and the second wave severe, this argues against the sudden appearance of an inherently lethal virus, and so “the data cannot . . . rule out effects of . . . host or environmental cofactors” on the high mortality.^{36(p16420)} Furthermore, immunological research indicates that antigenically similar influenza virus circulated throughout the 1918–1930 period.³⁷ Meanwhile, epidemiological research finds rare instances of fatal flu in the first wave, implying that a lethal virus was already present but relatively underrepresented in early 1918, and then became more predominant by autumn.³⁸ It has been found that people infected during the mild first wave often proved immune to the severe second wave, again implying an immunologically similar virus that varied in virulence depending on conditions.^{1(pp107,111),4(pp293–295),39}

World War I altered the daily lives of entire populations with shortages of essentials, even in the United States. For example, the rush to build ships in Philadelphia exacerbated crowding in squalid tenements with several families to each apartment.^{10(pp197,198)} In cities across the United States, people living in slums had the highest flu mortality.^{3(p87),4(p476),10(p361)} In or out of cities, mortality was highest for those, like coal miners and factory workers, who lived in overcrowded conditions even though these occupations enjoyed relatively high incomes during the war. From Iran to Iceland, the common markers for flu mortality were environments associated with crowding or poverty.^{40–43}

Recent studies from around the world confirm that individual-level crowding (number of people per square meter) as opposed to population density (number of people per square kilometer) was a predictor of flu mortality. For example, in Paris, France, deaths from flu disproportionately affected housemaids, who lived in cramped attics even in rich neighborhoods.⁴⁴ Perhaps the most rigorous study of this relationship contrasts neighborhoods in Oslo; Norway was a neutral nation, but “because of increasing shortage of housing during the 1914–18 war . . . an increasing number of families . . . were forced to live in cold and damp basements, draughty attic stories, garden pavilions and hen houses, in conditions not normally permitted for human habitation.”^{45(p936)}

After the Second Wave

Flu mortality in the United States declined precipitously with the end of the war (November 11, 1918). After the second wave, there was a seasonal bump of flu in winter 1918–1919 with higher than usual pneumonia mortality, and sporadic outbreaks dispersed throughout the world in 1919 and even 1920. These outbreaks are collectively considered the “third wave” and often coincided with the return of demobilized troops and war-industry workers to their homes.^{1(p191),46} A variation on this is the small but severe 1919 outbreak in nonbelligerent Denmark, following the billeting there of French and Belgian prisoners of war.^{47(p215)} Overall, though, flu returned to lower virulence. A dramatic example of this is the experience around the Pacific, where there was tremendous variation in mortality. For example, New Caledonia and American Samoa enjoyed near-zero

flu mortality, whereas in Western Samoa, 22% of the people died.²⁴ The places with low mortality practiced strict maritime quarantine to avoid the severe ship-borne second wave flu; then they experienced *mild* flu afterward.

Arguments Against the 1920s Hypothesis

“The rich died as readily as the poor.”^{3(p227)} This quote comes from Crosby, whose original source is a passage in Jordan’s book. However, the paragraph in question specifically deals with “attack rate” and “spread of influenza,” so it is not about who “died.”⁴ Jordan emphasized that infection is not the same thing as death.⁴ Nevertheless, 80 years later, a researcher commented:

A possible explanation for this view . . . having prevailed in the literature may be that too little distinction has been made between the risk of being *infected* by influenza on the one hand (“everybody gets it”), and the risk of actually *dying* from influenza or pneumonia.^{45(p924)}

A similar quote comes from the British Registrar-General: “The mortality of the late epidemic fell almost alike upon the sanitariously just and on the unjust.”^{48(p29)} This conclusion comes from uninterpretable unadjusted crude data.⁴⁹ The MOH report explicitly stated that the “inability to assign moderately accurate population totals or criteria of housing density would render such comparison misleading, and it has not been attempted.”^{6(p172)} In other words, one must avoid inferring anything from low-quality crowding data, and therefore “these results do *not* lead to the conclusion that overcrowding is a matter of indifference. . . . the very serious

mortality experienced on several of the United States Transports hurrying men to this country at the crisis of the war is *prima facie* evidence of the importance of this factor when mortality is to be assessed.^{6(p172)} That is, the role of extreme war-related overcrowding was obvious. Nevertheless, the MOH report has long been cited as evidence that overcrowding did not play a part in pandemic mortality.^{50,51}

The pandemic affected women and civilians—not just soldiers.^{52,53} This is true, but these groups were neither isolated from soldiers nor unaffected by the war. They were often exposed to the severe flu, either directly from soldiers or along a transmission chain of unsanitary conditions. They still typically suffered less than soldiers in neighboring army camps.^{4(pp450,451)} Sweden was neutral in World War I but had a standing army, and the “soldiers in their crowded barracks were severely affected by the pandemic of 1918, and the outbreaks often started in the garrisons before spreading to the surrounding communities.”^{54(p144)}

The pandemic affected nonbelligerent nations.⁵⁵ This is true, but the World War altered conditions and displaced people in many neutral countries. In Spain, for example, Portuguese soldiers passing through and returning Spanish guest-workers introduced severe flu.^{56,57(p177)} Guest-workers came to Western Europe from as far away as East Asia. Even in remote populations, flu mortality can be timed precisely to (ship-borne) introduction of second-wave influenza along a chain of overcrowding. Theoretically, some other factor could be more important, but there is no clear pattern of nutrition, demographics, exposures, geographic

distance, connectedness, or genetics to explain the variations in flu mortality across these populations.^{24,58,59}

The pandemic disproportionately killed soldiers because they were young adults whose healthy immune systems overreacted to the pandemic influenza virus (e.g., with cytokine storms).^{3(p222)} The following facts call this concept into question. Generally, young adults infected in the first influenza wave had few symptoms and were immune against the severe second wave. The US demographic group with the biggest jump in pandemic mortality was infants and young children, who are vulnerable because of *immature* immune systems.⁴ The elderly had *negative* excess mortality, and this suggests not weakness but rather strong immunity acquired following a previous H1N1 pandemic.^{4(pp237,275),60,61} Globally, there was not a uniform pattern of W-shaped mortality curves with excess deaths in those aged 20 to 40 years.⁵⁸ Soldiers were not particularly healthy: army rations were nutritionally deficient; soldiers were pushed to smoke cigarettes; war is traumatic. Measles ravaged the US Army before the flu pandemic, and measles can impair subsequent immunological response to influenza.⁶² American and European young-adult tuberculosis mortality, which increases with unsanitary living conditions, had been declining before World War I but increased beginning in 1914 and then resumed its decline after the war.⁶³ Young men had higher mortality than young women.⁵²

The pandemic disproportionately killed soldiers because of conditions at the front unrelated to overcrowding.⁶⁴ Jordan investigated this, and found that flu victims’ “death rate from disease was

about five times as high . . . among the troops in the United States as among the troops in France.” The exception in France was the “Service of Supply where men were housed in barracks with a large number of men to a single room; [there] the epidemic ran much the same course with high mortality as it did in cantonments in the United States.”^{4(p455)} Similarly, a recent study of soldiers from New Zealand found that influenza mortality was higher among those who stayed home in crowded camps than in those at the front.⁶⁵

“Once an entirely novel influenza virus had emerged, a pandemic was inevitable; thus, the war did not per se cause the pandemic.”^{1(p186)} This idea was rejected by Jordan because it fails to explain the waxing and waning of the flu’s lethality.^{4(pp503–512)} Nobel prize-winning virologist and immunologist Frank Macfarlane Burnet (Figure 1) concurred that “from the human angle” influenza virulence and immunological type were separate characteristics.^{66(pp179,121)} He also noted that looking at the best information available on the early phases of the pandemic in Europe “leads inevitably to the impression that its origin is intimately related to war conditions and especially the arrival of American troops in France.”^{67(p69)} If immunological shifting to novel H1N1 were the sufficient cause of pandemic lethality, then there should have been 1918-type mortality in 1976 and 2009; there wasn’t.^{68–70}

Overcrowding didn’t matter because there was not a pandemic in World War II despite tremendous war-related crowding during the London Blitz.^{3(p217)} Only 4% of Londoners used Tube shelters; millions of families used table-like

“Morrison shelters,” backyard-dugout “Anderson shelters,” or their basements.^{71(pp57–61,48,109,114,121,122)} Londoners in shelters were not stacked on top of each other for 10 days like soldiers on World War I troopships. Meanwhile, in US Army camps, standard World War II barracks had about 75 sq ft per man (i.e., 166% of the 45 sq ft requested by Gorgas, and 357% of the 21 sq ft experienced in some World War I camps).^{72(pp10,47,55),73(pp169–175)} The type of industrial-scale overcrowding relevant to the 1920s hypothesis was deliberately avoided in World War II.

Overcrowding mattered, but only because it increased transmission—not virulence. Historians like Crosby describe horrendous overcrowding as something that “promoted the spread of the virus.”^{3(p135)} Jordan explicitly addressed this distinction: “Most observers of conditions in the army camps believed that crowding, whatever its effect on the incidence of disease, undoubtedly increased the severity of the infection and its complications.”^{4(p475)} Overcrowding could have increased both transmission and virulence. Crowding also could have promoted severe flu by increasing the infectious dose.⁷⁴ This isn’t either/or.

It’s all about the virus. According to Crosby, the “infinitely tiny virus” is “the focus of all the mysteries,” and it is a “rule of thumb of modern disease theory” that “each distinct infective disease is caused by a distinct kind of microbe in almost all cases.”^{3(pp290,218)} This is the “doctrine of specific etiology.”⁷⁵ It has been valuable for understanding many diseases, including flu. Nevertheless, disasters are often multifactorial cascades.⁷⁶ Fatal flu cases in 1918 often involved bacterial pneumonias,

so even within the realm of infectious diseases, focusing on one agent is a narrow frame.^{4(pp337–356),34} The epidemiological triad of agent, host, and environment provides a broader public health paradigm. As the US Centers for Disease Control and Prevention states, “Development of appropriate, practical, and effective public health measures to control or prevent disease usually requires assessment of all three components and their interactions.”^{77(p1/52)} The influenza virus is a piece of the puzzle, but not the whole story.

DISCUSSION

Taken together, the findings presented here from history, public health, military medicine, veterinary science, molecular genetics, virology, immunology, and epidemiology are consistent with a virus that was immunologically similar throughout the World War I pandemic, but varied intensely in virulence in response to war-related environmental factors such as industrial-scale, prolonged, extreme overcrowding. The 1920s enhanced-virulence hypothesis offers a parsimonious explanation for numerous observations, including the extraordinary total lethality, the increase and decrease in virulence, the timing, the geographic spread, and the demographic pattern of the 1918 pandemic. In contrast, why the pandemic was hyperlethal, why it targeted young adults, and what can be done to prevent it from happening again all remain unexplained in the virus-focused conventional wisdom.⁷⁸

In a public health paradigm, a novel virus along with modifiable conditions can cause a catastrophic pandemic.^{1,3,58,79} Therefore, modifying conditions could decrease pandemic-related deaths. The 2003 SARS experience, and the COVID-19 pandemic, have revived interest in the

lessons of 1918 and increased recognition that nonpharmaceutical public health interventions like social distancing and hygiene might mitigate the impact of respiratory epidemics, even in the absence of germ-specific treatments.^{3,4,6,80,81} During the COVID-19 coronavirus pandemic, poor housing conditions, including overcrowding, have been associated with elevated mortality even after adjusting for population density, poverty, age, and underlying medical problems.^{82,83} A different coronavirus was involved in the 2003 SARS epidemic. In that instance, evidence indicates that industrial-scale overcrowding of “wildlife-farm” animals selected for a virulent form of coronavirus, which then caused human deaths.⁸⁴ The National Academy of Medicine connects this to the importance of a “One Health” approach to improving conditions for both humans and animals. Nevertheless, more than a decade after SARS there are still 14 million people employed in “wildlife-farming” in China alone, and “the wealth of knowledge for mitigating epidemic and pandemic threats remains largely untapped.”^{85(pp23–27)} In 2022, it’s still unclear whether deadly COVID-19 arose from industrial animal-trading or something else.^{86,87} Future research on epidemics could promptly expand beyond a focus on one infectious agent to include host factors and environmental conditions. The role of agricultural crowding in producing highly pathogenic agents could be further elucidated. From a history and policy perspective, it would be interesting to explore how the 1920s hypothesis was lost.

In the aftermath of the 1918 pandemic, it was clear to experts from many fields that the industrial-scale extreme overcrowding of US troops played a role in the pandemic’s

extraordinary mortality. In the decades following 1918, policy leaders and medical scientists continued to think that a major lesson was to avoid such unsanitary conditions.^{72,73} The 1918 pandemic was never forgotten; it remained prominent in public discourse.^{3(p323),88} What did get lost over time was the commonly held understanding of its preventable causes. Some of the historical arguments against the 1920s hypothesis are objectively false; others are debatable. Given the overall weight of the best available current evidence, it remains conceivable that industrial-scale prolonged extreme overcrowding of American soldiers constituted a successful “experimentation” in selecting for highly virulent influenza. Therefore, the 1920s “working hypothesis” does not yet “have to be rejected.”^{6(ppviii,190–191)} It deserves to be included in histories of the war and the pandemic. More importantly, it suggests a possible path forward to stop the transformation of innocuous infections into deadly disasters. **AJPH**

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REFERENCES

- Johnson NP. *Britain and the 1918–19 Influenza Pandemic: A Dark Epilogue*. New York, NY: Routledge; 2006.
- Johnson NP, Mueller J. Updating the accounts: global mortality of the 1918–1920 “Spanish” influenza pandemic. *Bull Hist Med*. 2002;76(1):105–115. <https://doi.org/10.1353/bhm.2002.0022>
- Crosby AW. *America's Forgotten Pandemic: The Influenza of 1918*. New York, NY: Cambridge University Press; 2003. <https://doi.org/10.1017/CBO9780511586576>
- Jordan EO. *Epidemic Influenza. A Survey*. Chicago, IL: American Medical Association; 1927.
- Callender GR, Coupal JF. Pathology of the acute respiratory diseases and of gas gangrene following war wounds. In: Lynch C, ed. *The Medical Department of the United States Army in the World War*, vol. 12. Washington, DC: US Government Printing Office; 1929.
- Greenwood M, Carnwath T. A general discussion of the epidemiology of influenza. In: *Reports on Public Health and Medical Subjects, no. 4. Report on the Pandemic of Influenza, 1918–19*. London, UK: Great Britain Ministry of Health; His Majesty's Stationery Office; 1920.
- Wong G, Greenhalgh T, Westhorp G, Buckingham J, Pawson R. RAMESES publication standards: realist syntheses. *BMC Med*. 2013;11(1):21. <https://doi.org/10.1186/1741-7015-11-21>
- Rogers N. America's forgotten pandemic: the influenza of 1918 [book review]. *Med Anthropol Q*. 1991;5(3):292–293.
- Neumann CE. Review: America's forgotten pandemic: the influenza of 1918. *Soc Hist Med*. 2004;17(3):523–524. <https://doi.org/10.1093/shm/17.3.523>
- Barry JM. *The Great Influenza: The Epic Story of the Deadliest Plague in History*. New York, NY: Viking Adult; 2004.
- Byerly CR. *Fever of War: The Influenza Epidemic in the US Army During World War I*. New York, NY: NYU Press; 2005.
- General Gorgas ascribes deaths to haste. *New York Times*. January 26, 1918:1. Available at: <https://timesmachine.nytimes.com/timesmachine/1918/01/26/issue.html>. Accessed December 30, 2021.

- General Gorgas unheeded. *New York Times* [editorial]. January 27, 1918:22. Available at: <https://timesmachine.nytimes.com/timesmachine/1918/01/27/issue.html>. Accessed April 13, 2020.
- McLaughlin AJ. The Shattuck lecture—epidemiology and etiology of influenza. *Boston Med Surg J*. 1920;183:1–23. Available at: <https://quod.lib.umich.edu/cgi/t/text/idx/f/flu/9580flu.0016.859/8/-shattuck-lectureepidemiology-and-etiology-of-influenza?page=root;size=50;view=pdf;q1=Boston+Medical+and+Surgical+Journal>. Accessed April 13, 2020.
- Simonsen L, Chowell G, Andreasen V, et al. A review of the 1918 herald pandemic wave: importance for contemporary pandemic response strategies. *Ann Epidemiol*. 2018;28(5):281–288. <https://doi.org/10.1016/j.annepidem.2018.02.013>
- Jackson OP, Evans FE. *The Marvel Book of American Ships*. New York, NY: Frederick A. Stokes Company; 1917.
- Demobilization—Miscellaneous—Leviathan largest transport in American service arrives with 8,000 US troops. The huge transport as she pulled into her dock at New York City. Photograph by Kadel and Herbert. US National Archives ID# 26433439, Image# 165-WW-138A-33.
- Massad E, Burattini MN, Coutinho FA, Lopez LF. The 1918 influenza A epidemic in the city of São Paulo, Brazil. *Med Hypotheses*. 2007;68(2):442–445. <https://doi.org/10.1016/j.mehy.2006.07.041>
- Chowell G, Bettencourt LM, Johnson N, Alonso WJ, Viboud C. The 1918–1919 influenza pandemic in England and Wales: spatial patterns in transmissibility and mortality impact. *Proc Biol Sci*. 2008;275(1634):501–509. <https://doi.org/10.1098/rspb.2007.1477>
- Honigsbaum M. *Living With Enza: The Forgotten Story of Britain and the Great Flu Pandemic of 1918*. New York, NY: Macmillan; 2009. https://doi.org/10.1007/978-0-230-23921-0_3
- Torres-Silveira AJ. The reign of the Spanish flu: impact and responses to the 1918 influenza pandemic in Minas Gerais, Brazil. In: Porras-Gallo MI, Davis RA, eds. *The Spanish Influenza Pandemic of 1918–1919: Perspectives From the Iberian Peninsula and the Americas*. Rochester, NY: University of Rochester Press; 2014:61–169.
- Kawana A, Naka G, Fujikura Y, et al. Spanish influenza in Japanese armed forces, 1918–1920. *Emerg Infect Dis*. 2007;13(4):590–593. <https://doi.org/10.3201/eid1304.060615>
- McCracken K, Curson P. Flu down under: a demographic and geographic analysis of the 1919 epidemic in Sydney, Australia. In: *The Spanish influenza pandemic of 1918–1919: New perspectives*. New York, NY: Routledge; 2003:125–126.
- Shanks GD, Wilson N, Kippen R, Brundage JF. The unusually diverse mortality patterns in the Pacific region during the 1918–21 influenza pandemic: reflections at the pandemic's centenary. *Lancet Infect Dis*. 2018;18(10):e323–e332. [https://doi.org/10.1016/S1473-3099\(18\)30178-6](https://doi.org/10.1016/S1473-3099(18)30178-6)
- Bagchi AK. Indian economy and society during World War One. *Soc Sci*. 2014;42(7/8):5–27.
- Brewer IW. Report of epidemic of “Spanish Influenza,” which occurred at Camp AA Humphreys, VA, During September and October, 1918. *J Lab Clin Med*. 1918;(Dec):87–111.

27. Hall MW. Inflammatory diseases of the respiratory tract (bronchitis, influenza, bronchopneumonia, lobar pneumonia). In: Lynch C, ed. *The Medical Department of the United States Army in the World War; Siler JF, ed. Vol. IX: Communicable And Other Diseases*. Washington DC, US Army Surgeon General's Office; 1928: 111–116.
28. Aligne CA. Overcrowding and mortality during the influenza pandemic of 1918. *Am J Public Health*. 2016;106(4):642–644. <https://doi.org/10.2105/AJPH.2015.303018>
29. Haven DC, Chamberlain WP, Love AG. The influenza epidemic of 1918. Administrative correspondence dealing with the control of the epidemic. In: Lynch C, ed. *Sanitation in the American Expeditionary Forces. Chamberlain MC, Weed FW, eds.; The Medical Department of the United States Army in the World War: Sanitation in the United States*; vol. 6. Washington, DC: US Government Printing Office; 1926:350–359.
30. Ewald PW. The evolution of virulence. *Sci Am*. 1993;268(4):86–93. <https://doi.org/10.1038/scientificamerican049386>
31. Leibler JH, Otte J, Roland-Holst D, et al. Industrial food animal production and global health risks: exploring the ecosystems and economics of avian influenza. *EcoHealth*. 2009;6(1):58–70. <https://doi.org/10.1007/s10393-009-0226-0>
32. Graham JP, Leibler JH, Price LB, et al. The animal–human interface and infectious disease in industrial food animal production: rethinking biosecurity and biocontainment. *Public Health Rep*. 2008;123(3):282–299. <https://doi.org/10.1177/003335490812300309>
33. Monne I, Fusaro A, Nelson MI, et al. Emergence of a highly pathogenic avian influenza virus from a low-pathogenic progenitor. *J Virol*. 2014; 88(8):4375–4388. <https://doi.org/10.1128/JVI.03181-13>
34. Dong G, Peng C, Luo J, et al. Adamantane-resistant influenza A viruses in the world (1902–2013): frequency and distribution of M2 gene mutations. *PLoS One*. 2015;10(3):e0119115. <https://doi.org/10.1371/journal.pone.0119115>
35. Nelson MI, Simonsen L, Viboud C, et al. Stochastic processes are key determinants of short-term evolution in influenza A virus [published correction in *PLoS Pathog*. 2006;2(12):e138]. *PLoS Pathog*. 2006;2(12):e125. <https://doi.org/10.1371/journal.ppat.0020125>
36. Sheng ZM, Chertow DS, Ambroggio X, et al. Autopsy series of 68 cases dying before and during the 1918 influenza pandemic peak. *Proc Natl Acad Sci U S A*. 2011;108(39):16416–16421. <https://doi.org/10.1073/pnas.111179108>
37. Yu X, Tsibane T, McGraw PA, et al. Neutralizing antibodies derived from the B cells of 1918 influenza pandemic survivors [published correction in *Nature*. 2012;490(7421):570]. *Nature*. 2008; 455(7212):532–536. <https://doi.org/10.1038/nature07231>
38. Chertow DS, Cai R, Sun J, Grantham J, Taubenberger JK, Morens DM. Influenza circulation in United States Army training camps before and during the 1918 influenza pandemic: clues to early detection of pandemic viral emergence. *Open Forum Infect Dis*. 2015;2(2):ofv021. <https://doi.org/10.1093/ofid/ofv021>
39. Barry JM, Viboud C, Simonsen L. Cross-protection between successive waves of the 1918–1919 influenza pandemic: epidemiological evidence from US Army camps and from Britain. *J Infect Dis*. 2008;198(10):1427–1434. <https://doi.org/10.1086/592454>
40. Afkhami A. Compromised constitutions: the Iranian experience with the 1918 influenza pandemic. *Bull Hist Med*. 2003;77(2):367–392. <https://doi.org/10.1353/bhm.2003.0049>
41. Dib J Jr. Nonpharmaceutical interventions implemented during the 1918–1919 influenza pandemic. *JAMA*. 2007;298(19):2260–2261. <https://doi.org/10.1001/jama.298.19.2260-a>
42. Ranger T. A historian's foreword. In: Phillips H, Killingray D, eds. *The Spanish Influenza Pandemic of 1918–19: New Perspectives*. New York, NY: Routledge; 2003.
43. Gottfredsson M, Halldórsson BV, Jónsson S, et al. Lessons from the past: familial aggregation analysis of fatal pandemic influenza (Spanish flu) in Iceland in 1918. *Proc Natl Acad Sci U S A*. 2008;105(4):1303–1308. <https://doi.org/10.1073/pnas.0707659105>
44. Zylberman P. A holocaust in a holocaust. The Great War and the 1918 Spanish influenza epidemic in France. In: Phillips H, Killingray D, eds. *The Spanish Influenza Pandemic of 1918–19: New Perspectives*. New York, NY: Routledge; 2003:191–201.
45. Mamelund SE. A socially neutral disease? Individual social class, household wealth and mortality from Spanish influenza in two socially contrasting parishes in Kristiania 1918–19. *Soc Sci Med*. 2006; 62(4):923–940. <https://doi.org/10.1016/j.socscimed.2005.06.051>
46. Chandra S, Christensen J, Chandra M, Paneth N. Pandemic reemergence and four waves of excess mortality coinciding with the 1918 influenza pandemic in Michigan: insights for COVID-19. *Am J Public Health*. 2021;111(3):430–437. <https://doi.org/10.2105/AJPH.2020.305969>
47. Low RB. *The Incidence of Epidemic Influenza During 1918–19 in Europe and in the Western Hemisphere. Reports on Public Health and Medical Subjects, no. 4. Report on the Pandemic of Influenza, 1918–19. Part III: Influenza in Foreign Countries. Great Britain Ministry of Health*. London, UK: His Majesty's Stationery Office; 1920.
48. Great Britain Ministry of Health. *Supplement to the Eighty-first Annual Report of the Registrar General of Births, Deaths and Marriages. Report on the Mortality From Influenza in England and Wales During the Epidemic of 1918–1919*. London, UK: His Majesty's Stationery Office; 1920.
49. Kopf EW. Report on the pandemic of influenza, 1918–1919 [book review]. *Q Publ Am Stat Assoc*. 1921;17(136):801–802. <https://doi.org/10.2307/2965230>
50. Sydenstricker E. The incidence of influenza among persons of different economic status during the epidemic of 1918. 1931. *Public Health Rep*. 2006;121(suppl 1):191–204.
51. Morabia A. Why does influenza hit the poor more than the rich? A 1931 social epidemiology article that broke new ground in the history of confounding, mediation, and interaction. *Am J Epidemiol*. 2021;190(11):2235–2241. <https://doi.org/10.1093/aje/kwab198>
52. Viboud C, Eisenstein J, Reid AH, Janczewski TA, Morens DM, Taubenberger JK. Age- and sex-specific mortality associated with the 1918–1919 influenza pandemic in Kentucky. *J Infect Dis*. 2013;207(5): 721–729. <https://doi.org/10.1093/infdis/jis745>
53. Noymer A, Garenne M. The 1918 influenza epidemic's effects on sex differentials in mortality in the United States. *Popul Dev Rev*. 2000;26(3): 565–581. <https://doi.org/10.1111/j.1728-4457.2000.00565.x>
54. Holmberg M. The ghost of pandemics past: revisiting two centuries of influenza in Sweden. *Med Humanit*. 2017;43(3):141–147. <https://doi.org/10.1136/medhum-2016-011023>
55. Ansart S, Pelat C, Boelle PY, Carrat F, Flahault A, Valleron AJ. Mortality burden of the 1918–1919 influenza pandemic in Europe. *Influenza Other Respir Viruses*. 2009;3(3):99–106. <https://doi.org/10.1111/j.1750-2659.2009.00080.x>
56. Porras Gallo MI. Between the pandemic and World War I: the 1918–19 influenza pandemic in the Spanish Army, through the eyes of the press. In: Phillips H, Killingray D, eds. *The Spanish Influenza Pandemic of 1918–19: New Perspectives*. New York, NY: Routledge; 2003:93–109.
57. Echeverri B. Spanish Influenza Seen From Spain. In: Phillips H, Killingray D, eds. *The Spanish Influenza Pandemic of 1918–19: New Perspectives*. New York, NY: Routledge; 2003:173–190.
58. Mamelund SE. Geography may explain adult mortality from the 1918–20 influenza pandemic. *Epidemics*. 2011;3(1):46–60. <https://doi.org/10.1016/j.epidem.2011.02.001>
59. McLeod MA, Baker M, Wilson N, Kelly H, Kiedrzyński T, Kool JL. Protective effect of maritime quarantine in South Pacific jurisdictions, 1918–19 influenza pandemic. *Emerg Infect Dis*. 2008;14(3):468–470. <https://doi.org/10.3201/eid1403.070927>
60. Luk J, Gross P, Thompson WW. Observations on mortality during the 1918 influenza pandemic. *Clin Infect Dis*. 2001;33(8):1375–1378. <https://doi.org/10.1086/322662>
61. Langford C. The age pattern of mortality in the 1918–19 influenza pandemic: an attempted explanation based on data for England and Wales. *Med Hist*. 2002;46(1):1–20. <https://doi.org/10.1017/S002572730006871X>
62. Mina MJ, Kula T, Leng Y, et al. Measles virus infection diminishes preexisting antibodies that offer protection from other pathogens. *Science*. 2019;366(6465):599–606. <https://doi.org/10.1126/science.aay6485>
63. Drolet GJ. World War I and tuberculosis: a statistical summary and review. *Am J Public Health Nations Health*. 1945;35(7):689–697. <https://doi.org/10.2105/AJPH.35.7.689>
64. Oxford JS, Lambkin R, Sefton A, et al. A hypothesis: the conjunction of soldiers, gas, pigs, ducks, geese and horses in northern France during the Great War provided the conditions for the emergence of the “Spanish” influenza pandemic of 1918–1919. *Vaccine*. 2005;23(7): 940–945. <https://doi.org/10.1016/j.vaccine.2004.06.035>
65. Summers JA, Stanley J, Baker MG, Wilson N. Risk factors for death from pandemic influenza in 1918–1919: a case-control study. *Influenza Other Respir Viruses*. 2014;8(3):329–338. <https://doi.org/10.1111/irv.12228>
66. Burnet FMF. *Changing Patterns: An Atypical Autobiography*. London, UK: Heinemann; 1968.
67. Burnet FMF, Clark E. *Influenza. A Survey of the Last 50 Years in the Light of Modern Work on the Virus of Epidemic Influenza*. Melbourne, Australia: MacMillan; 1942.
68. Dutton DB, Preston TA, Pfund NE. *Worse Than the Disease: Pitfalls of Medical Progress*. Cambridge, UK: Cambridge University Press; 1988. <https://doi.org/10.1017/CBO9780511572951>

69. Neustadt RE, Fineberg HV. *The Epidemic That Never Was: Policy-Making and the Swine Flu Scare*. New York, NY: Vintage; 1983.
70. Doshi P. The elusive definition of pandemic influenza. *Bull World Health Organ*. 2011;89(7):532–538. <https://doi.org/10.2471/BLT.11.086173>
71. Bell AH. *London Was Ours: Diaries and Memoirs of the London Blitz*. London, UK: I. B. Tauris; 2008. <https://doi.org/10.5040/9780755624942>
72. Wasch DS, Bush P. Part I: The historical context of WWII mobilization construction. In: Kriv AR, ed. *World War II and the US Army Mobilization Program: A History of 700 and 800 Series Cantonment Construction*. Washington, DC: Department of the Interior; 1991:3–78.
73. Landreth K, Hayes R, Lapp DR, et al. Part II: Camp Edwards: a 700 series cantonment. In: Kriv AR, ed. *World War II and the US Army Mobilization Program: A History of 700 and 800 Series Cantonment Construction*. Washington, DC: Department of the Interior; 1992:79–204.
74. Paulo AC, Correia-Neves M, Domingos T, Murta AG, Pedrosa J. Influenza infectious dose may explain the high mortality of the second and third wave of 1918–1919 influenza pandemic. *PLoS One*. 2010;5(7):e11655. <https://doi.org/10.1371/journal.pone.0011655>
75. Dubos R. *Mirage of Health: Utopias, Progress and Biological Change*. New York, NY: Perennial Library; 1959.
76. Perrow C. *Normal Accidents: Living With High-Risk Technologies*. Princeton, NJ: Princeton University Press; 1999.
77. Dicker RC, Coronado F, Koo D, Parrish RG. *Principles of Epidemiology in Public Health Practice, Third Edition: An Introduction to Applied Epidemiology and Biostatistics*. US Department of Health and Human Services; Centers for Disease Control and Prevention (CDC) Office of Workforce and Career Development. 2012. Available at: <https://www.cdc.gov/csels/dsepd/ss1978/lesson1/section8.html>. Accessed August 24, 2020.
78. Morens DM, Taubenberger JK, Fauci AS. A century tale of two pandemics: the 1918 influenza pandemic and COVID-19, part I. *Am J Public Health*. 2021;111(6):1086–1094. <https://doi.org/10.2105/AJPH.2021.306310>
79. Morens DM, Folkers GK, Fauci AS. Emerging infections: a perpetual challenge. *Lancet Infect Dis*. 2008 Nov;8(11):710–9. [https://doi.org/10.1016/S1473-3099\(08\)70256-1](https://doi.org/10.1016/S1473-3099(08)70256-1)
80. Naylor CD, Chantler C, Griffiths S. Learning from SARS in Hong Kong and Toronto. *JAMA*. 2004; 291(20):2483–2487. <https://doi.org/10.1001/jama.291.20.2483>
81. Jefferson T, Del Mar CB, Dooley L, et al. Physical interventions to interrupt or reduce the spread of respiratory viruses. *Cochrane Database Syst Rev*. 2020;11(11):CD006207. <https://doi.org/10.1002/14651858.CD006207.pub5>
82. Ahmad K, Erqou S, Shah N, et al. Association of poor housing conditions with COVID-19 incidence and mortality across US counties. *PLoS One*. 2020;15(11):e0241327. <https://doi.org/10.1371/journal.pone.0241327>
83. Kamis C, Stolte A, West JS, et al. Overcrowding and COVID-19 mortality across US counties: are disparities growing over time? *SSM Popul Health*. 2021;15:100845. <https://doi.org/10.1016/j.ssmph.2021.100845>
84. Weiss RA, McLean AR. What have we learnt from SARS? *Philos Trans R Soc Lond B Biol Sci*. 2004; 359(1447):1137–1140. <https://doi.org/10.1098/rstb.2004.1487>
85. National Academy of Medicine. *Public Health Lessons for Non-Vaccine Influenza Interventions: Looking Past COVID-19*. Capron A, Garcia P, Schenk E, eds. Washington, DC: National Academies Press. 2021. <https://doi.org/10.17226/26283>
86. Bloom JD, Chan YA, Baric RS, et al. Investigate the origins of COVID-19. *Science*. 2021;372(6543):694. <https://doi.org/10.1126/science.abj0016>
87. Frutos R, Gavotte L, Devaux CA. Understanding the origin of COVID-19 requires to change the paradigm on zoonotic emergence from the spill-over to the circulation model. *Infect Genet Evol*. 2021;95:104812. <https://doi.org/10.1016/j.meegid.2021.104812>
88. Blakely DE. *Mass Mediated Disease: A Case Study Analysis of Three Flu Pandemics and Public Health Policy*. Lanham, MD: Lexington Books; 2006.

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Immunities of the Herd in Peace, War, and COVID-19

Warwick Anderson, MD, PhD

Intermittently, the concept of herd immunity has been a potent, if sometimes ambiguous and controversial, means of framing the global response to the COVID-19 pandemic and envisaging its end. Realizing the full meaning of human herd immunity requires further attention to its connections after World War I with British social theory. Distracted by “obvious” yet unsubstantiated correspondences with veterinary research, historians of the concept have not engaged with the more proximate influence of discussions of social psychology and group dynamics on postwar epidemiology. Understanding the openness of early 20th century epidemiology to social thought deepens our appreciation of the significance of herd or population immunity, as well as suggests new avenues for exchange between public health and contemporary social sciences. (*Am J Public Health*. 2022;112(10):1465–1470. <https://doi.org/10.2105/AJPH.2022.306931>)

One hundred years ago, there was no formal concept of human “herd immunity.” When influenza swept across the world in 1918–1919, the rise and fall of the pandemic were not explained in relation to the absence or presence of herd or population immunity. The notion of specific personal immunity had caught on only 30 or so years earlier, displacing older and looser impressions of an individual’s constitutional resistance or susceptibility to disease.¹ Accordingly, immunity immediately after World War I still referred to a person’s reaction to infection, the singular response of the body’s defense mechanisms to contact with the foreign and unfamiliar.

Until British epidemiologists W. W. C. Topley and G. S. Wilson coined the term “herd immunity” in 1923, public health officers struggled to describe and to frame how human collectives might eventually become invulnerable to epidemic disease.² It was not until the 1920s, particularly through

Sheldon F. Dudley’s epidemiological studies, that herd immunity gained currency as a conceptual tool tracing the human population’s shifting immunological terrain. But herd immunity then signaled social gregariousness and altruism, generative mutualism, and a spectrum of collective protections—not a simple threshold of past infection and vaccination as it so often does now.

At the beginning of 2020, with the global spread of the novel severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), herd immunity became a common, if often ambiguous, simplistic, and controversial, locution. Before much was known about the virus’s infectivity and virulence, some public health leaders and politicians hoped that mitigated transmission might quickly result in natural herd immunity, when enough of the population had been infected and recovered. Once it was clear that such a policy would lead to excessive deaths and collapse of health care systems, herd immunity

often became a term of reproach, signifying state indifference to the survival of its citizens. Instead, most governments articulated a commitment to suppression or even elimination of the virus until artificial herd immunity, through immunization, could be achieved. Unaware of actual historical usage of the term, many experts felt uncomfortable with the simple veterinary analogies they presumed it implied. Epidemiologists and politicians frequently disavowed any hankering for natural herd immunity; various activists demanded to be “unherded.” There was a misapprehension that a herd could only refer to collectives of nonhuman animals, and that it must, therefore, be demeaning.

My intention here is to reveal more clearly a little of the changing conceptual landscape of collective immunity, thereby contributing to making our understanding of epidemic sociality and solidarity more robust and usable. What did it mean in the 1920s to

imagine the immunity of a human herd? What lessons for contemporary public health can be gleaned from these earlier conceptual frameworks? Recent historical accounts have gestured toward veterinary similes of herd immunity, emphasizing the power of animal symbolism³ or multispecies crossovers and ecological mindsets.⁴ Of course, it would be silly to deny that alluding to a herd signifies some connection with animal husbandry.

But I want to explore the more proximate link to popularity of the herd—not just as a convenient veterinary analogy—in nascent social psychology, particularly in the study by surgeon and social theorist Wilfred Trotter, *Instincts of the Herd in Peace and War* (1916).⁵ Trotter's investigation of human gregariousness, altruism, corporate morale, and suggestibility exerted profound influence in the 1920s on psychoanalysis, sociology, and British epidemiology—even if the work is largely forgotten now. It made the herd a supple and powerful metaphor for the social dynamics and connectedness of human populations, a functional means to describe altruism and self-sacrifice. In view of the many uses and abuses of herd immunity in recent years, there is clearly much at stake in getting this history right.

“ANOTHER WORD FOR MASS MURDER”

The debate over herd immunity against COVID-19 was especially fierce during 2020 in Britain, where the concept had originated. Sir Jeremy Farrar, director of the Wellcome Trust (now simply Wellcome), remembered that at the start of the year “herd immunity stampeded on to the scene. It caused a public outcry.” An infectious diseases physician, Farrar

served in the government's Scientific Advisory Group for Emergencies (Sage). In March 2020, he was incredulous on hearing Sir Patrick Vallance, the chief scientific advisor, casually mention that Britain was pursuing a strategy to attain herd immunity through natural infection. Farrar believed that seriously considering “such an idea three months into a new disease beggared belief.”⁶ As British journalists Jonathan Calvert and George Arbutnot later put it, “herd immunity was a view that appears to have infected the government.”⁷

And yet, before long, when the scale of the threat was obvious, everyone denied having ever contemplated nonintervention, letting the virus rip through the community. Rather, Sage came to suggest a series of intermittent lockdowns and other social and behavioral changes to reduce transmission and lower mortality rates in advance of effective vaccination. “It was still, technically,” Farrar admitted, “a managed herd immunity strategy but over a longer period of time that would leave fewer deaths in its wake.”⁸ Containment or elimination was out of the question, leaving eventual population immunity through natural and artificial means as the clearest route to ending the pandemic. But, for most British scientific advisors and politicians, “herd” had become a dirty word, rarely to be uttered in public.

All the same, blatant aspirations for herd immunity were not entirely abandoned during the first year of the pandemic. The desire to attain natural herd immunity, before widespread vaccination was possible, became a particular enthusiasm of libertarian, free-market groups and some fringe or ostentatiously heterodox biomedical researchers. Thus, in October 2020, an assembly of scientists drafted a statement

proposing “focused protection” of those most at risk from COVID-19 while others resumed normal lives and exposed themselves to infection to build herd immunity.⁹ Originated at the American Institute for Economic Research, a right-wing thinktank in Great Barrington, Massachusetts, the declaration considered neither the resultant stresses on health care systems, nor the difficulties of long-term segregation of the aged and infirm, nor the possibly limited duration of any postinfection immunity. It signaled to some readers that the idea of herd immunity had been captured by reactionaries indifferent to human suffering, perhaps bent on culling the “unfit” from the population.

Several conventional public health experts perceived the taint of eugenics, or doctrines promoting survival of the fittest, in these herd immunity strategies. Tedros Adhanom Ghebreyesus, director-general of the World Health Organization, warned that “never in the history of public health has herd immunity been used as a strategy for responding to an outbreak, let alone a pandemic.” He was convinced that true population immunity could be reached safely only through future vaccination: thus, “herd immunity is achieved by protecting people from a virus, not by exposing them to it.”¹⁰ In a further riposte to the Great Barrington Declaration, William A. Haseltine, virologist and biotech entrepreneur, asserted that “herd immunity is another word for mass murder.”¹¹ Other researchers denounced the natural herd immunity game plan in the John Snow Memorandum, published in *The Lancet*, stating it was “a dangerous fallacy unsupported by the scientific evidence.”¹² Herd immunity had come to imply a sort of microbiological dystopia, nature red in tooth and claw.

During 2021, the advent of a more readily transmitted but supposedly less virulent strain of SARS-CoV-2, along with augmented vaccine coverage in wealthy countries, raised hopes that higher rates of population immunity would allow greater control of the pandemic. This optimism was predicated on a process of herd immunity, yet few experts were prepared any longer to acknowledge it publicly. Journalists sometimes speculated on what levels of Omicron variant spread and vaccine uptake were required to end COVID-19 in their nations, but as the pandemic persisted, most avoided explicit debate about the virtues and harms of herd immunity.¹³ Instead, “opening up,” “lifting restrictions,” “living with COVID,” and “vaccine rollout” became acceptable euphemisms. Yet such herd immunities, ever less spoken, of the COVID-19 pandemic were quite distinct from the concept of herd immunity that had circulated some 100 years earlier.

OF MICE AND MEN

Writing in 1919, toward the end of the influenza pandemic, William W. C. Topley lamented that “circumstances of the past year have rendered research work of any kind far from easy.” At Charing Cross Hospital, London, the local response to the scourge—the agent of which was still undetected—had impressed upon the young epidemiologist that most microbiologists were “more concerned with the minute investigation of comparatively small samples of cases than with the broad view of an epidemic of disease as a biological process.”¹⁴ How, he asked, might one explain the characteristic wave form of the epidemic—its rise, cresting, and subsidence? Intrigued, like so many of his colleagues, by variety and

diversity within bacterial species,¹⁵ Topley wondered if increased pathogenicity or virulence of the microorganism or parasite could disturb the equilibrium with its host, thus inciting an epidemic. Moreover, he suspected that “the outstanding feature in the subsidence of an epidemic is the loss of infectivity by the bacterial virus.”¹⁶ At the time, he preferred this interpretation to speculations about changes in host resistance and alterations in the surrounding environment. Nonetheless, the correct answer to such a puzzle in population immunity would await the results of laboratory experiments in epidemiology, which he was proposing to conduct.¹⁷

Observation of his mouse colonies soon caused Topley to reassess what gives rise to epidemics. In 1923, he reported from his new post at the University of Manchester that when he added “susceptible individuals” to a mouse population previously in equilibrium with the bacterial parasite, a wave of new cases quickly broke out. As the susceptible mice died or recovered, the epidemic declined.¹⁸ His attention turned to the immune pattern of the host population. The same year, with junior colleague Graham S. Wilson, he began to ponder “the question of immunity as an attribute of the herd.” They noted that as the proportion of immune individuals—resistant after vaccination or surviving infection—rises in a population, a limited number of susceptible individuals also might be protected from disease.¹⁹

After moving to the London School of Hygiene and Tropical Medicine in 1927, Topley joined his old friend Major Greenwood, Britain’s premier epidemiologist, in a series of experiments to determine the distribution of immunity across mouse populations. They tended to discount the logistics of

germ transmission, focusing instead on the rapidly evolving character and quality of the herd, examining how resistance and susceptibility were figured dynamically across the host population. Distinguishing their approach from common interwar obsessions with breeding and eugenics, they highlighted a range of social and “educational” factors influencing herd immunity, rejecting hereditary or genetic contributions.²⁰ “Nothing has emerged from our researches,” Topley et al. wrote in 1930, “to suggest that under any conditions of selection or immunization, environmental factors, in the sense of quality and quantity of infection, would become negligible.”²¹ Topley was principally interested in how broad histories of exposure and contact, sometimes along with vaccination, might reshape or re-educate the immunological profile of his experimental herds. Thus, the herd had become a socio-biological formulation, shorthand for community, or possible co-immunity—not signifying bare life to be culled by infection.

At the Royal Naval Hospital, Chatham, England, pathologist Sheldon F. Dudley began to investigate communal aspects of immunity among schoolboys in the 1920s, thereby transferring the notion to practical studies of human populations. Friendly with Topley and Greenwood, Dudley was eager to explore herd immunity in human groups, tracing the parallels of mice and men. In 1924, he observed that when diphtheria broke out among boys in a dormitory of the Royal Hospital School in Greenwich, England, known as the cradle of the British navy, the extent of population immunity from past infection and vaccination set the level of spread of the bacillus to both the protected and the unprotected. Thus, he

wrote, “the degree of herd immunity determines ultimately the disease-producing power of the biological agents of illness.”²²

Having trained in tropical and naval medicine, Dudley was acutely aware of the importance of ecological and sociological reasoning in accounting for patterns of infectious disease. The notion of the herd seemed an especially effective way to imprint an ecological attitude on epidemiology. He believed it was

only by approaching human infection from the ecological point of view, and looking at epidemics as manifestations of a loss of balance between the mutual adjustment of host and parasite, that the natural laws controlling periodicity, extent and malignancy of diseases of herd and individual will finally be defined.

British psychologists and social theorists had taught him—and Topley and Greenwood, too, he was sure—that the herd was a suitable model for gregariousness and cooperative action within human populations. “The prevention of disease in herds and individuals,” Dudley concluded, “necessitates a proper understanding of their evolutionary biology and psychology.”²³

IMMUNOGENIC HERDS

Topley had learned from Wilfred Trotter’s *Instincts of the Herd in Peace and War* about the emotional force exerted in collective interaction, the need to respect humans as social animals, as gregarious as other herding animals. He read his surgical colleague’s “admirable essay” soon after its publication and kept it close the rest of his life.²⁴ *Instincts of the Herd*, wrote Topley, “illuminated and reoriented our mind in such a way that it has thereafter a value

peculiar to itself.” He felt “it will remain our bed-rock”²⁵—a book that “seems fundamental to us.”²⁶

Dudley, too, recalled that it was Trotter who had shown his generation of epidemiologists that the herd is “an apt symbol to use in describing the attributes of human groups, because it emphasizes the biological truth that there is so much that is strangely similar and familiar in the behaviour of all gregarious animals.”²⁷ While social anthropologist Bronislaw Malinowski may take those referring to herds to task for assuming human society correlates with a biological collective,²⁸ Dudley and other medical scientists in London dismissed such reservations. It was Trotter’s invocation of the herd instinct during the war that made them realize “the truly overriding and irresistible influence of the community and group on the character of the individuals who compose the community and group.” For Dudley, the herd instinct, as he put it, “fulfils a most essential function in preserving the stability and status quo of society and inhibiting any impulse which members of the herd may acquire or possess to run ‘after false Gods,’ cranks, and new ideas.”²⁹ The herd instinct, he suggested, gives us altruistic social measures and mass vaccination, from which derives herd immunity. Thus, the operation of the herd produces assent and submission, or common resistance, rather than inscribing an index or threshold of protection to be achieved.

An accomplished head-and-neck surgeon who dabbled in social theory, Trotter was a star in the elite London medical firmament. An aloof figure at University College Hospital, London, he rarely left the vicinity of Gower Street, though for a time he became the King’s surgeon (and Sigmund Freud’s last

surgeon). Married to the sister of psychoanalyst Ernest Jones, Trotter engaged critically with Freud’s early work, stimulating the Viennese psychiatrist to apply his insight to collective behavior. In 1908, on his return from the first international psychoanalytic congress in Salzburg, Austria, Trotter had begun writing on herd instinct for the new *Sociological Review*, arguing for “gregariousness as a phenomenon of profound biological significance.”³⁰ Unlike sociologist Gustave Le Bon, who had recently described the morbid nervous excitement of the crowd,³¹ Trotter chose to extol the herd’s homogeneity, camaraderie, suggestibility, and fear of alienation, which he claimed brought about modern civilization, national ideals, and self-sacrifice. According to Trotter, “the only medium in which man’s mind can function satisfactorily is the herd, which therefore is not only the source of his opinions, his credulities, his disbeliefs, and his weaknesses, but also of his altruism, his charity, his enthusiasms, and his power.”³² Our instinctive herding, he believed, is the conduit for all intercommunication and connectivity, the condition of associated life and flourishing.³³

The chauvinism of nations in World War I sharpened Trotter’s perceptions of the human herd instinct. In new essays published in the popular *Instincts of the Herd in Peace and War* in 1916, he expatiated on biological mass psychology, or “anthropocentric biology” as he called it. The herd instinct—“the stamp of being regulated by the existence and influence of his fellows”—means the target of natural selection shifts from the individual to the collective, with the herd constituting a sheltering organism, conferring a kind of immunity. Ease of intercommunication and the prevailing sense of

altruism, Trotter believed, enable “the herd to act as a single creature whose power is greatly in excess of the sum of the powers of its individual members.”³⁴ It was this concept of the human herd as a superorganism with distinctive and widely encompassing immunological or protective capabilities that most impressed postwar epidemiologists.

Others seized on Trotter’s argument for the homogeneity and suggestibility of human herds and their need for aggressive leadership. The herd instinct is responsible for social morale, which “gives smoothness of working, energy and enterprise to the whole national machine, while from the individual it ensures the maximal outflow of effort with a minimal interference from such egoistic passions as anxiety, impatience, and discomfort.”³⁵ No wonder that Edward Bernays, Freud’s nephew and founder of public relations; Joseph Goebbels; and Benito Mussolini expressed admiration for Trotter’s theories.³⁶ His influence thus extended well beyond epidemiology. Trotter also inspired one of his medical students, Wilfred Bion, to take up psychoanalysis and develop programs in “group dynamics.” Reading Trotter’s speculations on the herd in peace and war later stirred Elias Canetti to write his magnum opus *Crowds and Power* (1960).³⁷

CONCLUSION

The concept of herd immunity emerged after World War I congruent with a new theory of human bio-sociality. It was the product of passage from animal biology to human social thought, then across to the equally permeable working knowledges of immunology and epidemiology. This is not the place to trace the fortunes of herd immunity over the

past hundred years, leading up to its various consummations in the current pandemic. Evidently, the bonds of herd immunity with an old, forgotten social theory have become attenuated. But perhaps not completely sundered.

The most telling example is surely the celebrated 1985 article by Roy M. Anderson and Robert M. May modeling attainment of herd immunity. Although it concentrated on figuring out the necessary level of vaccination coverage, building on recent successes of smallpox eradication and childhood immunization programs, the bio-social configuration of the herd was deemed equally valuable. Reaching a threshold vaccinated proportion of the group is not all that matters. Herd immunity depends also on the “degree and intimacy of contacts among people and the prevailing levels of genetic, spatial and behavioural heterogeneity in susceptibility/resistance to infection.”³⁸ In Anderson and May’s framing, the herd’s social and motivational qualities—its gregariousness and communicability—remain crucial in getting to population immunity. Thus, Trotter’s ghost continued to haunt epidemiology, albeit intermittently.

It seems we have a choice. Rather than be content with resorting casually to worn and facile veterinary metaphors and folk social theories, or searching for simple levels and thresholds, we might properly return sociological complexity and ethical nuance to our apprehension of herd immunity, drawing more deeply, as did Topley and Dudley and their colleagues, from Trotter’s social psychology and moral imagination. If we must carry the burden of epidemiologies past, let us be sure it is decent conceptual baggage, not just a basket of empty metaphors. Or, more radically, we could simply consign the herd, whether instinctual or immunological, to history.

In the past hundred years, the social sciences have moved on, offering even more compelling perceptions and insights that can be harnessed to explain what population immunity—indeed, what “population”—means today.³⁹ Maybe it is time, sociologically, to unherd. **AJPH**

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CONFLICTS OF INTEREST

The author reports no conflicts of interest.

ENDNOTES

1. Warwick Anderson, “Immunities of Empire: Race, Disease and the New Tropical Medicine,” *Bulletin of the History of Medicine* 70, no. 1 (1996): 94–118. <https://doi.org/10.1353/bhm.1996.0002>
2. W.W.C. Topley and G.S. Wilson, “The Spread of Bacterial Infection: The Problem of Herd Immunity,” *Journal of Hygiene* 21, no. 3 (1923): 243–249. <https://doi.org/10.1017/S0022172400031478>
3. David S. Jones and Stefan Helmreich, “A History of Herd Immunity,” *The Lancet* 396, no. 10254 (2020): 810–811. [https://doi.org/10.1016/S0140-6736\(20\)31924-3](https://doi.org/10.1016/S0140-6736(20)31924-3)
4. David S. Robertson, “Of Mice and Schoolchildren: A Conceptual History of Herd Immunity,” *American Journal of Public Health* 111, no. 8 (2021): 1473–1480. <https://doi.org/10.2105/AJPH.2021.306264>

5. Wilfred Trotter, *Instincts of the Herd in Peace and War*, 2nd ed. (London, UK: T. Fisher Unwin, 1919 [1916]).
6. Jeremy Farrar with Anjana Ahuja, *Spike: The Virus and the People, the Inside Story* (London, UK: Profile Books, 2021), 103, 106.
7. Jonathan Calvert and George Arbutnot, *Failures of State: The Inside Story of Britain's Battle With Coronavirus* (London, UK: Mudlark, 2021), 106.
8. Farrar with Ahuja, *Spike*, 112.
9. Martin Kulldorff, Sunetra Gupta, Jay Bhattacharya, "Great Barrington Declaration," <https://gbdeclaration.org> (accessed March 12, 2022).
10. Tedros Adhanom Ghebreyesus, "WHO Director-General's Opening Remarks at the Media Briefing on COVID-19, 12 October 2020," World Health Organization, <https://www.who.int/director-general/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing-on-covid-19-12-october-2020> (accessed March 12, 2022).
11. Martin Finucane, "Boston Researchers Join Letter in *The Lancet* Rejecting Herd Immunity Strategy," *Boston Globe*, October 14, 2020, <https://www.bostonglobe.com/2020/10/14/nation/boston-researchers-join-letter-lancet-rejecting-herd-immunity-strategy> (accessed March 12, 2022).
12. Nisreen A. Alwan et al., "Scientific Consensus on the COVID-19 Pandemic: We Need to Act Now," *The Lancet* 396, no. 10260 (2020): e71–e72. [https://doi.org/10.1016/S0140-6736\(20\)32153-X](https://doi.org/10.1016/S0140-6736(20)32153-X)
13. For example, Donald G. McNeill Jr, "Covid-19: How Much Herd Immunity Is Enough?" *New York Times*, December 24, 2020, <https://www.nytimes.com/2020/12/24/health/herd-immunity-covid-coronavirus.html> (accessed March 12, 2022).
14. W. W. C. Topley, "The Goulstonian Lectures: The Spread of Bacterial Infection," *The Lancet* 194, no. 5002 (1919): 1–5, 45–49, 91–96. 1, [https://doi.org/10.1016/S0140-6736\(01\)48373-5](https://doi.org/10.1016/S0140-6736(01)48373-5)
15. Olga Amsterdamska, "Achieving Disbelief: Thought Styles, Microbial Variation, and American and British Epidemiology, 1900–1940," *Studies in History and Philosophy of Biological and Biomedical Sciences* 35, no. 3 (2004): 483–507. <https://doi.org/10.1016/j.shpsc.2004.06.001>
16. Topley, "The Goulstonian Lectures," 94.
17. Olga Amsterdamska, "Standardizing Epidemics: Infection, Inheritance and Environment in Prewar Experimental Epidemiology," in *Heredity and Infection: The History of Disease Transmission*, eds. Jean-Paul Gaudillière and Ilana Löwy (London, UK: Routledge, 2001). See also Paul E. M. Fine, "Herd Immunity: History, Theory, Practice," *Epidemiological Reviews* 15, no. 2 (1993): 265–302. <https://doi.org/10.1093/oxfordjournals.epirev.a036121>
18. W. W. C. Topley, "The Spread of Bacterial Infection: Some General Considerations," *Journal of Hygiene* 21, no. 3 (1923): 226–236. <https://doi.org/10.1017/S0022172400031454>
19. Topley and Wilson, "The Spread of Bacterial Infection," 243.
20. M. Greenwood et al., "On the Mechanisms by Which Protection Against Infectious Disease Is Acquired in 'Natural' Epidemics," *Journal of Hygiene* 25, no. 3 (1926): 336–353. <https://doi.org/10.1017/S0022172400017459>
21. M. Greenwood et al., "A Further Study of Herd Mortality Under Epidemic Conditions," *Journal of Hygiene* 30 (1930): 240–265, 264. <https://doi.org/10.1017/S0022172400010421>
22. Sheldon F. Dudley, "Some Fundamental Factors Concerned in the Spread of Infectious Disease," *The Lancet* 203, no. 5258 (1924): 1141–1146, 1146. [https://doi.org/10.1016/S0140-6736\(01\)6362-2](https://doi.org/10.1016/S0140-6736(01)6362-2)
23. Sheldon F. Dudley, "Herds and Individuals," *Public Health (London)* 42 (1929): 219–229, 221, 229. See also Warwick Anderson, "Natural Histories of Infectious Disease: Ecological Vision in Twentieth-Century Biomedical Science," *Osiris* 19 (2004): 39–61. <https://doi.org/10.1086/649393>
24. W. W. C. Topley, "Preventive Medicine and Biology. Address to the Manchester University Science Foundation," January 24, 1924 [typescript], Topley papers, PP/TOP, Accession 937, Wellcome Collection, London, box 1 [uncatalogued]. Trotter's well-thumbed book is one of three held in Topley's private papers.
25. W. W. C. Topley, "Experimentalism," 3rd draft c. 1942 [typescript], Topley papers, box 1. An accompanying note from Topley's widow states that Trotter had read and commented on earlier versions of this draft book before his death in 1939.
26. W. W. C. Topley, "Experimentalism," 2nd draft c. 1940 [typescript], Topley papers, box 1.
27. Sir Sheldon F. Dudley, *The Four Pillars of Wisdom: A Rational Approach to a Healthy Education* (London, UK: Watts and Co, 1950), xiii.
28. Bronislaw Malinowski, "Biology and Sociology," *Nature* 114 (1924): 274–275. <https://doi.org/10.1038/114274a0>
29. Dudley, *Four Pillars of Wisdom*, 86, 87.
30. Wilfred Trotter, "Herd Instinct and Its Bearing on the Psychology of Civilised Man," *The Sociological Review* 1, no. 3 (1908): 227–248, 233. <https://doi.org/10.1111/j.1467-954X.1908.tb02713.x>
31. Gustave Le Bon, *Psychologie des foules* (Paris, France: Félix Alcan, 1895).
32. Wilfred Trotter, "Sociological Application of the Psychology of Herd Instinct," *The Sociological Review* 2, no. 1 (1909): 36–54, 36. <https://doi.org/10.1111/j.1467-954X.1909.tb02535.x>
33. Gillian Swanson, "Collectivity, Human Fulfilment and the 'Force of Life': Wilfred Trotter's Concept of the Herd Instinct in Early Twentieth Century Britain," *History of the Human Sciences* 27, no. 1 (2014): 21–50. <https://doi.org/10.1177/0952695113514594>. And Harvey C. Greisman, "Herd Instinct and the Foundations of Biosociology," *Journal of the History of the Behavioral Sciences* 15, no. 4 (1979): 357–369. [https://doi.org/10.1002/1520-6696\(197910\)15:4<357::AID-JHBS2300150409>3.0.CO;2-S](https://doi.org/10.1002/1520-6696(197910)15:4<357::AID-JHBS2300150409>3.0.CO;2-S)
34. Trotter, *Instincts of the Herd in Peace and War*, 67, 99, 159. Trotter added a postscript to the second edition regretting the wartime jingoism of the 1916 first edition.
35. Trotter, *Instincts of the Herd*, 7.
36. Swanson, "Collectivity, Human Fulfilment and the 'Force of Life.'"
37. Elias Canetti, *Crowds and Power* (New York, NY: Farrar, Straus, and Giroux, 1984 [1960]).
38. Roy M. Anderson and Robert M. May, "Vaccination and Herd Immunity to Infectious Diseases," *Nature* 318, no. 6044 (1985): 323–329, 323. <https://doi.org/10.1038/318323a0>
39. A. David Napier, "I Heard It Through the Grapevine: On Herd Immunity and Why It Is Important," *Anthropology Today* 36, no. 3 (2020): 3–7. <https://doi.org/10.1111/1467-8322.12572>

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Partisan Polarization of Childhood Vaccination Policies, 1995–2020

Kevin Estep, PhD, Annika Muse, BS, Shannon Sweeney, BS, and Neal D. Goldstein, PhD, MBI

Objectives. To examine trends in partisan polarization of childhood vaccine bills and the impact of polarization on bill passage in the United States.

Methods. We performed content analysis on 1497 US state bills (1995–2020) and obtained voting returns for 228 legislative votes (2011–2020). We performed descriptive and statistical analyses using 2 measures of polarization.

Results. Vote polarization rose more rapidly for immunization than abortion or veterans' affairs bills. Bills in 2019–2020 were more than 7 times more likely to be polarized than in 1995–1996 (odds ratio [OR] = 7.04; 95% confidence interval [CI] = 3.54, 13.99). Bills related to public health emergencies were more polarized (OR = 1.76; 95% CI = 1.13, 2.75). Sponsor polarization was associated with 34% lower odds of passage (OR = 0.66; 95% CI = 0.42, 1.03).

Conclusions. State lawmakers were more divided on vaccine policy, but partisan bills were less likely to pass. Bill characteristics associated with lower polarization could signal opportunities for future bipartisanship.

Public Health Implications. Increasing partisan polarization could alter state-level vaccine policies in ways that jeopardize childhood immunization rates or weaken responsiveness during public health emergencies. Authorities should look for areas of bipartisan agreement on how to maintain vaccination rates. (*Am J Public Health.* 2022;112(10):1471–1479. <https://doi.org/10.2105/AJPH.2022.306964>)

Responses to the availability and promotion of COVID-19 vaccines have been influenced by political party. Partisanship is a significant predictor of intent to be vaccinated against COVID-19,¹ actual rates of vaccination,² and lawmakers' support for vaccine mandates.³ Did the unique circumstances of the pandemic give rise to these partisan outcomes, or was immunization already a polarized issue?

We define “polarization” as an alignment of partisan identity with particular policy positions. Scholars have given attention to such partisan alignments on public health policy,^{4,5} often with warnings that health policymaking is most likely to advance population

health when it remains free of partisan politics.^{6,7} Difficulties related to managing the COVID-19 pandemic support those claims.^{1,8,9} When it comes to childhood immunizations, evidence suggests state policies have a strong effect on rates of vaccination and disease.^{6,10,11} Therefore, it is especially important to examine polarization among those making these important policy decisions.

Goldstein et al.¹² examined immunization bills proposed in state legislatures from 2011 to 2017 and found that Republicans were more likely to sponsor “antivaccination” bills. Their analysis was limited to exemption bills and does not account for important

political and epidemiological occurrences since 2017 (e.g., the majority of Trump's presidency, measles outbreaks in 2019). We build on their work by examining a broader spectrum of childhood vaccine bills over a much longer period (1995–2020). This allows us to address 3 specific questions: (1) Have childhood vaccination policies become more polarized over time? (2) Are some types of vaccination bills more polarized? (3) What is the relationship between polarization and the likelihood of a bill passing into law?

Our study period encompasses significant episodes in the history of US immunization policy, including the

autism–mercury controversy, the politicized rollout of the human papillomavirus (HPV) vaccine, and the resurgence of measles.^{6,13,14} Although childhood immunization laws have historically enjoyed widespread support across party lines,¹⁵ organized campaigns to “green our vaccines” or to oppose HPV mandates on the basis of concerns about sexual promiscuity¹⁴ could resonate more with the ideological commitments of the political left or right. Thus, the emergence and decline of these conflicts could produce changes in polarization over time.

Recent public opinion¹⁶ as well as academic research on policymakers,¹² health communication,¹⁷ and vaccine exemptions¹⁸ indicate a correlation between vaccine opposition and political conservatism. Importantly, vaccine opposition is increasingly framed as an issue of civil liberties.¹⁷ Thus, lawmakers may take positions based on partisan ideologies concerning state authority and parental rights^{14,19} rather than on scientific recommendations or safety concerns. Certain bills could be more likely to trigger these ideological differences, such as those that target parents, modify vaccine mandates, or adjust public health authority during outbreaks.

To address these questions, we used sponsorship data on 1497 bills and voting returns for 228 legislative votes to create 2 separate measures of polarization: sponsor polarization and vote polarization. The first allowed us to view changes in polarization over a longer period; the second allowed us to compare polarization levels on immunization with 2 issues commonly considered more and less polarized (abortion and veterans’ affairs).

METHODS

We searched NexisUni’s (LexisNexis) comprehensive “bill text” database to identify childhood vaccination bills introduced into state legislatures between 1995 and 2020. Because of our focus on childhood immunizations, we excluded bills concerning adults, college students, insurance coverage, funding appropriations, provider education, and professional criteria for administering vaccines. To obtain search results that best matched our inclusion criteria, we used the following Boolean search: “(Vaccin* OR Immuniz*) AND NOT (military OR dog OR veterinarian* OR pet OR animal OR rabies OR flu OR influenza OR appropriations OR ‘higher education’ OR college).” We identified 1044 unique bills from 7093 results.

We located an additional 432 bills in a data set of vaccine bills (1995–2012) provided by the authors of a previous study¹³ and 127 bills in a list compiled by the Association of State and Territorial Health Officials (2011–2016).²⁰ This yielded 1603 bills. We eliminated 106 cases for missing data on key variables (as noted subsequently), resulting in 1497 bills in our primary data set. Two of these sources cover only a subset of years in our study: the period for the Lillis et al. study ended in 2012,¹³ and the Association of State and Territorial Health Officials only tracked immunization bills for 5 years.²⁰ To ensure this did not bias our results, we conducted a sensitivity analysis using only bills from the NexisUni search.

We used yearly partisan composition data from the National Conference of State Legislatures to identify the majority party in the chamber in which each bill was introduced.²¹ We were also

interested in whether polarization is related to how strict or lenient a state’s policy is regarding exemptions. We used National Conference of State Legislatures’ data on current exemption policies²² and Conis’s²³ historical analysis of changes to state exemption policies to generate a yearly variable with categories: medical exemptions only, medical and religious exemptions, or medical, religious, and philosophical exemptions.

We created a second data set that captures information on how Republican and Democratic legislators voted on the bills in our primary data set. We obtained voting records from LegiScan (LegiScan LLC, Elkview, WV), which pulls data from state legislature Web sites. We looked up each bill introduced between 2011 (the beginning of the earliest complete legislative session in the LegiScan database) and 2020 and recorded available data for votes that occurred in committees or on the House or Senate floor. Votes on amendments and administrative procedures were not included. When multiple votes occurred in a single committee or chamber, we recorded the final vote. A bill that progressed through 1 committee in each chamber and ultimately passed into law would yield 4 observations: 1 committee vote and 1 floor vote in both the House and Senate. We were able to obtain data for 228 votes.

To benchmark levels of vaccine polarization, we calculated vote polarization for 2 comparison issues to represent the high and low ends of the issue-polarization spectrum. Abortion is considered highly partisan, whereas bipartisanship on veterans’ affairs is common even during times of intense conflict between the major parties.²⁴ Details on the creation of these benchmarks are included in “Methodology for Abortion

and Veterans' Affairs Benchmarks" in the appendix (available as a supplement to the online version of this article at <https://ajph.org>).

Variables

The first author (K. E.) read the text of each bill and performed content analysis. To check for subjectivity in coding, the second author (A. M.) coded 50 randomly selected bills and obtained 95% observed agreement for variables used in this analysis, with a pooled κ of 0.83.²⁵

We defined our primary outcome of interest, partisan polarization, as alignment of vaccine positions with party identity. To operationalize this, we first classified bills as "pro" or "anti." Consistent with Goldstein et al.,¹² we coded a bill as pro if it was interpreted as an effort to sustain or increase vaccinations among the target population, and anti if interpreted as having the potential to decrease vaccination rates. Twenty-five bills were dropped because of insufficient publicly available information to determine pro-anti valence. We also located the primary sponsor's party affiliation on state legislature Web sites. We eliminated 81 cases for missing data on this variable (51 sponsored by committees, 21 sponsored by Independent or other party, 9 for which sponsor party could not be found). Anti bills sponsored by Republicans and pro bills sponsored by Democrats were coded 1 for sponsor polarization; anti bills sponsored by Democrats and pro bills sponsored by Republicans were coded 0.

In our content analysis, we also generated the following non-mutually exclusive dichotomous variables to indicate the goals of each bill: exemption (medical or nonmedical

exemptions from school-based requirements); mandate change (adding or removing required immunization or changes to how requirements are established); vaccine contents (materials used in vaccines [e.g., mercury, fetal tissue]); education (provide or require education about risks, benefits, schedules, or exemptions); registry (establishes or modifies immunization tracking systems; guidelines for sharing immunization data); consent (rules for obtaining consent before immunization); and HPV; meningitis; measles, mumps, and rubella; and varicella (related to those specific vaccines).

We created a categorical variable indicating the bill's primary target (i.e., the constituency whose interests, activities, responsibilities, or authority are most affected). Categories were health care providers, local or state health department, schools, parents or patients, pharmaceutical companies, and other.

Using data from state legislature Web sites, we created a variable to indicate if the bill ultimately passed into law. This variable was used to evaluate the effect of sponsor polarization on a bill's likelihood of becoming law.

We used our secondary data set consisting of 228 votes on vaccine bills to create a second measure of polarization: vote polarization. We calculated an index of dissimilarity equal to half the sum of the absolute difference between the proportions of Democrats or Republicans voting yes or no. We used the following equation:

$$(1) \quad P = \frac{1}{2} \sum_i^n \left| \frac{d_i}{D_T} - \frac{r_i}{R_T} \right|$$

where n = number of vote categories (i.e., 2: yes or no); d_i = number of Democratic votes in vote category i ;

D_T = total number Democratic votes in the floor or committee roll call; r_i = number of Republican votes in vote category i ; and R_T = total number Republican votes in the floor or committee roll call. Vote polarization (P) represents the proportion of Republicans (or Democrats) that would need to change their votes for the bill to be perfectly bipartisan. The index ranges from 0 (bipartisan; equal proportions of Democrats and Republicans voted yes or no) to 1 (completely partisan; Republicans and Democrats segregated into yes-no vote categories). A unanimous vote would have a value of 0. If all Republicans voted for and all Democrats against a bill (or vice versa), the value would be 1. We multiplied the index by 100 to improve interpretation. We also calculated vote polarization for abortion and veterans' affairs bills.

Finally, legislative session indicates when the bill was originally introduced. We used 2-year increments because sessions in many states span 2 years.

Statistical Analyses

In our analysis, we used both descriptive and inferential statistical techniques. To examine changes in polarization over time, we first conducted a linear time-trend test using an ordinary least squares regression model predicting sponsor polarization with a continuous measure of legislative session as the only predictor. Next, we plotted the proportion of bills in each session (1995–2020) coded 1 for sponsor polarization. Finally, we plotted the mean for vote polarization in each session (2011–2020), compared with abortion and veterans' affairs bills, and conducted similar time-trend tests as described previously for each of the 3 issues by regressing

vote polarization on our continuous legislative session variable.

To identify characteristics of bills that tend to be more polarized, we estimated a Bayesian generalized linear mixed-effects regression model with sponsor polarization as the dependent variable and various bill characteristics (goals, targets, specific vaccines, political context, legislative session) as independent variables. Finally, using passed as the dependent variable and sponsor polarization as a key independent variable, we estimated a second regression model to assess whether polarized bills are more or less likely to pass into law, while controlling for bill characteristics, political context, and session. Both regression models specified state as a random intercept to account for nonindependence of multiple bills being proposed in the states. The use of a Bayesian framework improved model convergence by allowing us to specify a Gaussian prior on the fixed effects with a mean of 0 and standard deviation of 10 (intercepts) and 2.5 (slopes).

We used Excel Version 16.37 (Microsoft Corp, Redmond, WA) to perform content coding. We used R version 3.6.3 (R Foundation for Statistical Computing, Vienna, Austria) to perform statistical analyses.

RESULTS

Results of our time-trend test indicated a statistically significant increase in sponsor polarization between 1995 and 2020 ($b = 0.096$; $P < .01$). Figure 1 displays the level of sponsor polarization in each legislative session. Between 1995 and 2014, the alignment of pro or anti with political party was somewhat inconsistent, ranging from a low of 50% in 2005–2006 (i.e., Republicans and

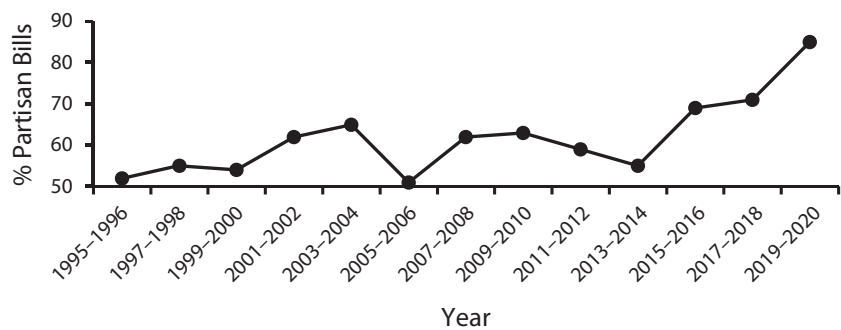


FIGURE 1— Proportion of Polarized Childhood Immunization Bills Proposed in State Legislatures, Based on Party Affiliation of Bill Sponsors: United States, 1995–2020

Note. The total number of bills was 1497. The number of bills ranges from a low of 60 in 1995–1996 to a high of 224 in 2007–2008. Time-trend test: $b = 0.096$; $P < .001$.

Democrats were equally likely to sponsor pro and anti bills) to a high of 65% in 2003–2004. Overall, the degree of sponsor polarization during this period was relatively low—5 of 10 legislative sessions at or below 55%. However, beginning in 2015, sponsor polarization increased rapidly. In 2013–2014, just over half of childhood vaccine bills (55%) were either Republican–anti or Democrat–pro bills, but this increased to 85% in 2019–2020.

Figure 2 shows vote polarization for immunization, abortion, and veterans' bills for 2011–2020. As expected, abortion was the most polarized during this period, while votes related to veterans were far less partisan. Time-trend tests showed vote polarization for immunization bills increased at twice the rate of abortion bills ($b = 0.092$ and 0.044 , respectively), with no statistically significant change for veterans' bills. In 2011–2012, polarization for immunization bills was somewhat higher than for veterans' affairs bills (24% Republicans or Democrats required to change vote to achieve bipartisanship, compared with 9%). In 2019–2020, polarization for veterans' bills was still very low (13%),

but polarization for vaccine bills rose to 58%. Abortion remained the most polarized issue, but the gap between abortion and immunization closed substantially.

Figure 3 displays odds ratios (ORs) for the regression model predicting sponsor polarization. Bills proposed in 2015–2016 or 2017–2018 were more than twice as likely to be polarized compared with 1995–1996; bills introduced in 2019–2020 were more than 7 times as likely to be polarized. Because the model adjusts for bill characteristics, this indicates that the trend in Figure 1 is not simply an artifact of different kinds of bills being proposed in this later period.

Figure 3 also reveals several important insights about which kinds of bills were more (or less) likely to follow the polarized Republican–anti and Democrat–pro pattern. When we looked at goals of the bill, policies concerning immunizations during public health emergencies had 76% greater odds of being polarized (OR = 1.76; 95% confidence interval [CI] = 1.13, 2.75). Bills related to exemptions (OR = 0.58; 95% CI = 0.40, 0.84) were polarized in the

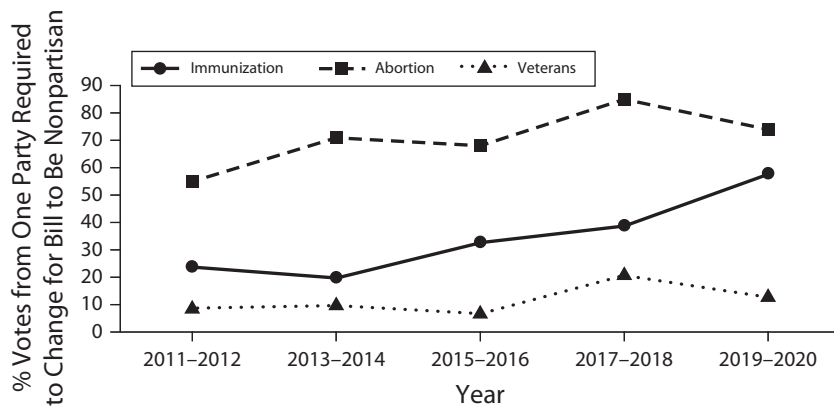


FIGURE 2— Partisan Polarization on US State Legislature Votes Related to Immunization, Abortion, and Veterans' Affairs Bills: 2011–2020

Note. The number of votes was 228 on immunization, 221 on abortion, and 224 on veterans. The number of votes ranges from a low of 22 votes on veterans' affairs bills in 2011–2012 to a high of 65 votes on immunization bills in 2019–2020. Immunization trend: $b = 0.092$; $P < .001$. Abortion trend: $b = 0.044$; $P = .006$. Veterans trend: $b = 0.022$; $P = .16$.

reverse direction, with Democrats more likely to sponsor anti bills. For bills that mentioned specific vaccines, odds of polarization increased 2-fold for HPV bills (OR = 2.1; 95% CI = 1.29, 3.43), whereas meningitis was associated with reverse polarization (OR = 0.49; 95% CI = 0.29, 0.85). Results also suggest that Republican-sponsored bills were less polarized (OR = 0.64; 95% CI = 0.49, 0.83).

Figure 4 addresses our final research question about the effect of polarization on the likelihood of a bill becoming law. Adjusting for bill characteristics, sponsor polarization was associated with a 34% decrease in the odds of passage (OR = 0.66; 95% CI = 0.42, 1.03). Also notable, bills that would increase or decrease access to exemptions had 66% decreased odds of passage (OR = 0.34; 95% CI = 0.18, 0.64).

Our sensitivity analyses restricted to bills obtained only from NexisUni did not meaningfully alter our overall conclusions (Tables A and B, available as supplements to the online version of this article at <https://ajph.org>).

DISCUSSION

Some have described the nature of political polarization in the United States as an “oil spill” that gradually taints previously “apolitical” issues.²⁶ Our analysis indicates that political polarization has, in fact, spread to vaccine policy. Among state legislators, positions on childhood immunization policy became substantially more aligned with political party between 2015 and 2020. This was true for 2 separate measures of partisan polarization—sponsorship and voting. Although increases in polarization across the political arena likely contributed to this shift,²⁷ our comparative analysis of voting on immunization, abortion, and veterans' affairs bills revealed an especially rapid increase in polarization for vaccine bills in recent years. By 2019–2020, nearly 60% of one party would need to “defect” to obtain bipartisanship on immunization bills. To put this in perspective, legislators were more likely to vote along party lines for vaccine bills in 2019–2020 than for

abortion bills in 2011–2012, which was the height of polarized conflict between the Tea Party and the Obama administration (Figure 2).

The trends we have identified can be explained, in part, by the rise and fall of controversies during this time-frame. Beginning in 1998, Democratic and Republican lawmakers alike were focused on the possibility that the mercury-containing vaccine preservative thimerosal could be linked to autism. The high frequency of bills to prohibit mercury in vaccines and to expand access to exemptions in the early 2000s were almost certainly motivated by these safety concerns.¹³ However, a 2004 Institute of Medicine report established the scientific consensus against the autism–mercury hypotheses, the *Lancet* retracted the study that first proposed a vaccine–autism link because of ethical and scientific concerns, and the study's lead author, Andrew Wakefield, was removed from the United Kingdom's registry of physicians in 2010.^{13,14,28}

Faced with the loss of legitimate scientific arguments, leaders of vaccine-critical organizations were compelled to innovate new narratives that might resonate with blocks of potential supporters.²⁸ In their analysis of antivaccine Facebook pages from 2009 to 2019, Broniatowski et al.¹⁷ found a decreasing prevalence of safety or efficacy concerns and an increasing emphasis on protecting individual liberty from government intrusion. This shift in emphasis from safety to parental freedom would certainly have been felt by policymakers. Legislators might strongly disagree about whether certain vaccines are safe for children, but such disagreements are not inherently partisan. By contrast,

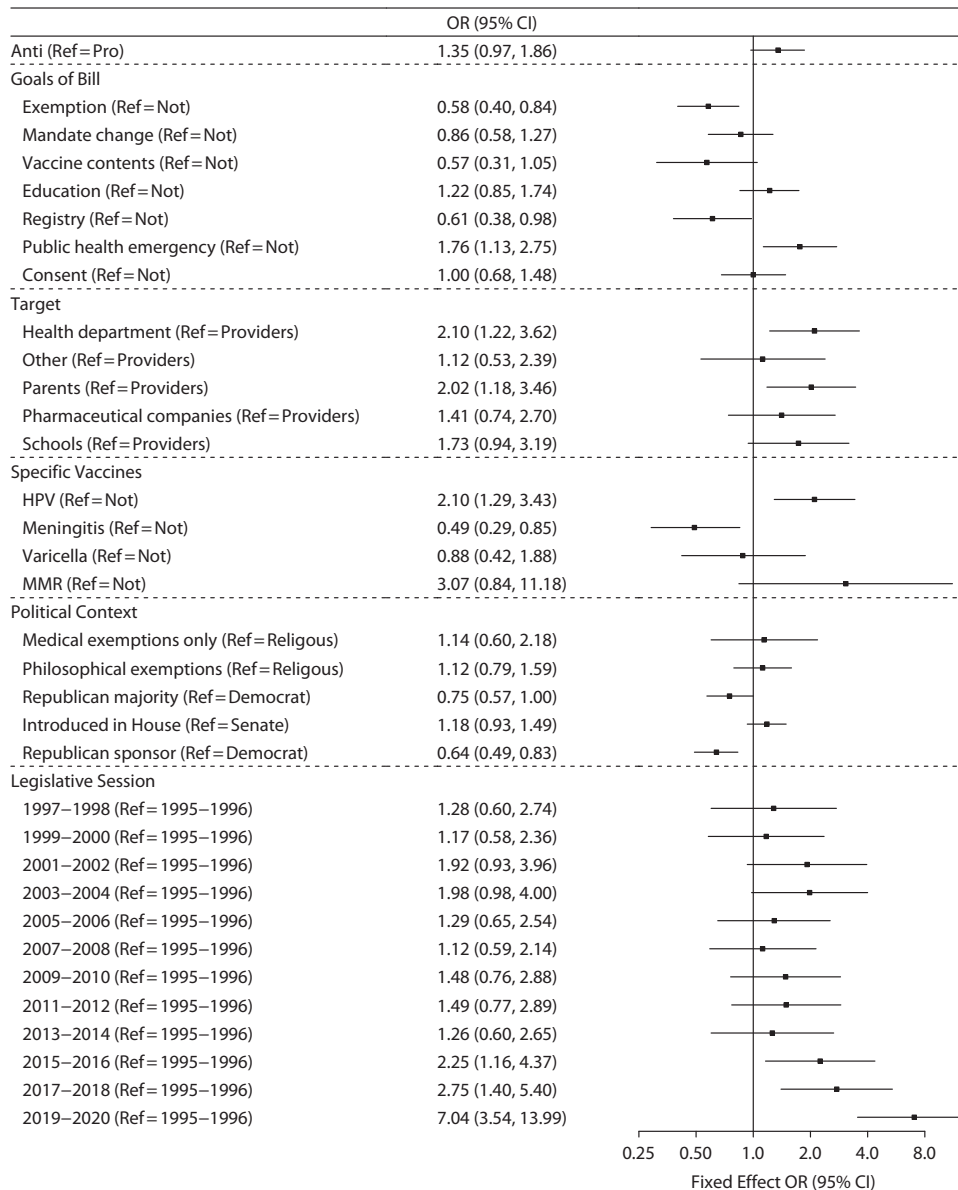


FIGURE 3— Bill Characteristics Associated With Sponsor Polarization of Childhood Immunization Bills: United States, 1995–2020

Note. CI = confidence interval; OR = odds ratio. ORs are from a Bayesian generalized linear mixed effects regression model to account for clustering by state; n = 1497. Statistically significant values greater than 1 (95% CI to the right of the 1 line) indicate partisan alignment in the expected direction. Significant values less than 1 (95% CI to the left of the 1 line) indicate reverse partisan alignment: anti bills associated with Democratic sponsorship and pro bills with Republican sponsorship. A CI that includes 1 means that bill characteristic is not significantly associated with sponsor polarization.

as vaccine policies became increasingly framed in terms of individual liberty versus the state, legislators might have faced mounting pressure to choose their side based on adherence to conservative or progressive views on the appropriate role of government.

In addition, the 2015 measles outbreak in California, the publicity generated by the outbreak’s association with Disneyland, and the legislature’s subsequent decision to eliminate nonmedical exemptions brought intense public attention to this issue.¹⁷ Sociologists have shown that such “takeoff”

conditions bring previously unrecognized disagreements to the surface.²⁹ This, in turn, increases partisan polarization,³⁰ as people interpret the newly contentious issue through the lens of existing partisan identities.³¹ In this case, California’s identity as a liberal state led by a well-known Democratic

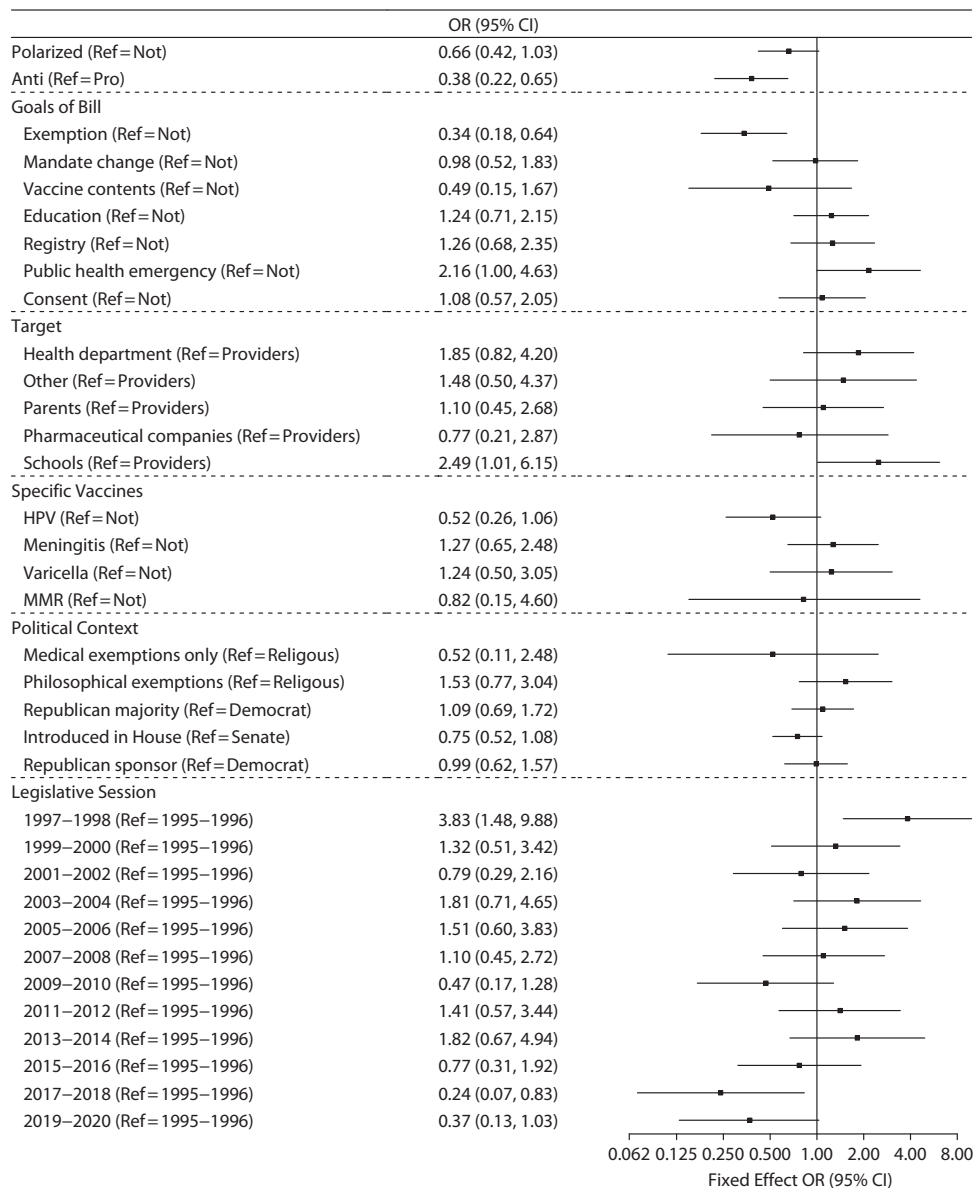


FIGURE 4— Bill Characteristics Associated With Childhood Immunization Bills Being Passed: United States, 1995–2020

Note. CI = confidence interval; OR = odds ratio. ORs are from a Bayesian generalized linear mixed effects regression model to account for clustering by state; n = 1490.

governor clearly signaled the Democratic position on vaccine exemptions to legislators in other states who were forming their own policy positions. The measles epidemic of 2019 put vaccines in the spotlight once again,¹⁷ forcing state legislatures to weigh calls from public health officials to restrict exemptions against the demands of those who saw this as an infringement on

parental rights. Our findings suggest this second round of “takeoff” conditions further solidified party lines.

Not All Bills Equally Polarized

The partisan divide is narrower for some proposed vaccine policy changes than others. For instance, HPV tended

to be more partisan, as others have shown,³² but not bills concerning varicella or measles, mumps, and rubella. Pro–anti stances on bills related to immunization registries, education, consent, and even proposed changes to vaccine mandates were not associated with political party. Such findings could help lawmakers identify areas of potential bipartisanship.

Importantly, Republicans and Democrats did not see eye-to-eye on how to respond during public health emergencies—such as whether to exclude children with exemptions from school (102 bills) or to allow mercury-containing vaccines (52 bills) during outbreaks. The frequency of these bills peaked in 2005–2006, declined sharply even as cases of pertussis surged in 2012–2014,³³ and remained very low during the measles outbreaks of 2015–2020, suggesting epidemiological threat might not have been legislators' central concern. Here again, partisan convictions about the role of the state could be relevant. Exclusion of nonvaccinated students during an outbreak seems like a reasonable precaution, but such proposals could appear threatening to conservative legislators who are eager to protect parental control over school attendance. This sense of threat could explain why, in response to the actual crisis of a global pandemic, Republican lawmakers in at least 26 states have pushed to limit emergency powers of public health officials.³⁴

Republican-sponsored bills were less likely to be polarized and, though falling just short of statistical significance, anti bills appear to be more polarized than pro bills. In other words, bills that might decrease vaccination coverage were usually sponsored by Republicans, but Republicans were also more willing than Democrats to cross the party line.

Polarized Bills Less Likely to Pass

Experts suggest partisan polarization hinders effective public health policy.^{6,7} From this perspective, our findings are mostly disheartening. However, we find some encouragement in the fact that polarization decreased likelihood of a bill becoming law. Put differently, the

policy proposals that are most likely to be passed and implemented are those that bridge the partisan divide. By its very design, lawmaking in the United States requires compromise and coalition building,³⁵ which might protect population health from the worst effects of polarization.

Limitations

We analyzed bills before the COVID-19 pandemic. Our findings shed light on current vaccination policy conflicts, but our data did not include COVID-19-specific bills. Our analysis focused on childhood immunization, so some caution is warranted when applying these findings to adult vaccination policies. In addition, although we relied on multiple sources to identify bills that met our inclusion criteria, it is possible that some bills were unintentionally omitted. Finally, we relied on publicly available records, which could be incomplete.

Public Health Implications

This analysis demonstrated a clear increase in partisan polarization of childhood immunization bills in state legislatures between 1995 and 2020, which contradicts popular notions that vaccine polarization began with the COVID-19 vaccines. Fortunately, state-level legislative processes appear to have a protective effect, as polarized bills were less likely to pass into law, thereby lowering the potential for partisan agendas to translate into policies that could jeopardize childhood vaccination rates. Nevertheless, given the current consideration being paid to mandating COVID-19 vaccination among children in schools and previous legislative and legal controversies

over mandating COVID-19 vaccination for adults, our analysis might suggest characteristics of bills less likely to engender polarization. **AJPH**

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K. Estep designed the study, performed content analysis, conducted descriptive analyses, and drafted the article. A. Muse and S. Sweeney collected data, assisted with content analysis, and revised drafts. N. D. Goldstein assisted with study design and interpretation of results, performed statistical analyses, and critically revised drafts.

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CONFLICTS OF INTEREST

The authors have no known conflicts of interest.

HUMAN PARTICIPANT PROTECTION

Institutional review board approval was not required because all data are publicly available, and the study was not human participant research.

REFERENCES

- Gadarian SK, Goodman SW, Pepinsky TB. Partisanship, health behavior, and policy attitudes in the early stages of the COVID-19 pandemic. *PLoS One*. 2021;16(4):e0249596. <https://doi.org/10.1371/journal.pone.0249596>
- Ye X. Exploring the relationship between political partisanship and COVID-19 vaccination rate. *J Public Health (Oxf)*. 2021: Epub ahead of print. <https://doi.org/10.1093/pubmed/fdab364>
- Censky A, Sostarik K. Republicans are changing state laws to try to get out of federal vaccine mandates. *NPR*. November 22, 2021. Available at: <https://www.npr.org/2021/11/22/1057427047/republicans-are-changing-state-laws-to-try-and-get-out-of-federal-vaccine-mandat>. Accessed April 25, 2022.
- Gollust SE, Lantz PM, Ubel PA. The polarizing effect of news media messages about the social determinants of health. *Am J Public Health*. 2009;99(12):2160–2167. <https://doi.org/10.2105/AJPH.2009.161414>
- Purtle J, Goldstein ND, Edson E, Hand A. Who votes for public health? US senator characteristics associated with voting in concordance with public health policy recommendations (1998–2013). *SSM Popul Health*. 2016;3:136–140. <https://doi.org/10.1016/j.ssmph.2016.12.011>
- Fowler EF, Gollust SE. The content and effect of politicized health controversies. *Ann Am Acad Pol Soc Sci*. 2015;658(1):155–171. <https://doi.org/10.1177/0002716214555505>
- Kindig DA. Can there be political common ground for improving population health? *Milbank Q*. 2015;93(1):24–27. <https://doi.org/10.1111/1468-0009.12101>
- Adolph C, Amano K, Bang-Jensen B, Fullman N, Wilkerson J. Pandemic politics: timing state-level social distancing responses to COVID-19. *J Health Polit Policy Law*. 2021;46(2):211–233. <https://doi.org/10.1215/03616878-8802162>
- Allcott H, Boxell L, Conway J, Gentzkow M, Thaler M, Yang D. Polarization and public health: partisan differences in social distancing during the coronavirus pandemic. *J Public Econ*. 2020;191:104254. <https://doi.org/10.1016/j.jpubeco.2020.104254>
- Bradford WD, Mandich A. Some state vaccination laws contribute to greater exemption rates and disease outbreaks in the United States. *Health Aff (Millwood)*. 2015;34(8):1383–1390. <https://doi.org/10.1377/hlthaff.2014.1428>
- Omer SB, Porter RM, Allen K, Salmon DA, Bednarczyk RA. Trends in kindergarten rates of vaccine exemption and state-level policy, 2011–2016. *Open Forum Infect Dis*. 2017;5(2):ofx244. <https://doi.org/10.1093/ofid/ofx244>
- Goldstein ND, Suder JS, Purtle J. Trends and characteristics of proposed and enacted state legislation on childhood vaccination exemption, 2011–2017. *Am J Public Health*. 2019;109(1):102–107. <https://doi.org/10.2105/AJPH.2018.304765>
- Lillvis DF, Kirkland A, Frick A. Power and persuasion in the vaccine debates: an analysis of political efforts and outcomes in the United States, 1998–2012. *Milbank Q*. 2014;92(3):475–508. <https://doi.org/10.1111/1468-0009.12075>
- Reich JA. *Calling the Shots: Why Parents Reject Vaccines*. New York, NY: New York University Press; 2018.
- Colgrove J. *State of Immunity: The Politics of Vaccination in Twentieth-Century America*. Berkeley, CA: University of California Press; 2006.
- Pew Research Center. Vast majority of Americans say benefits of childhood vaccines outweigh risks. Pew Research Center. February 2, 2017. Available at: <https://www.pewresearch.org/science/2017/02/02/vast-majority-of-americans-say-benefits-of-childhood-vaccines-outweigh-risks>. Accessed February 9, 2022.
- Broniatowski DA, Jamison AM, Johnson NF, et al. Facebook pages, the “Disneyland” measles outbreak, and promotion of vaccine refusal as a civil right, 2009–2019. *Am J Public Health*. 2020;110(suppl 3):S312–S318. <https://doi.org/10.2105/AJPH.2020.305869>
- Estep KA. Neighborhood political composition and personal belief exemptions from immunization requirements in California kindergartens, 2000–2015. *Vaccine*. 2018;36(29):4298–4303. <https://doi.org/10.1016/j.vaccine.2018.05.108>
- Estep K, Greenberg P. Opting out: individualism and vaccine refusal in pockets of socioeconomic homogeneity. *Am Sociol Rev*. 2020;85(6):957–991. <https://doi.org/10.1177/0003122420960691>
- Association of State and Territorial Health Officials. Immunization legislation tracking. State public health. Available at: <https://www.astho.org/Programs/Immunization/Legislative-Tracking>. Accessed February 9, 2022.
- National Conference of State Legislatures. State partisan composition. Available at: <https://www.ncsl.org/research/about-state-legislatures/partisan-composition.aspx>. Accessed February 9, 2022.
- National Conference of State Legislatures. States with religious and philosophical exemptions from school immunization requirements. Available at: <https://www.ncsl.org/research/health/school-immunization-exemption-state-laws.aspx>. Accessed February 9, 2022.
- Conis E. The history of the personal belief exemption. *Pediatrics*. 2020;145(4):e20192551. <https://doi.org/10.1542/peds.2019-2551>
- Fandos N. A bipartisan congress that works? Veterans committees show how it's done. *New York Times*. July 10, 2017. Available at: <https://www.nytimes.com/2017/07/10/us/politics/house-senate-veteran-affairs-committees.html>. Accessed May 27, 2022.
- De Vries H, Elliott MN, Kanouse DE, Teleki SS. Using pooled kappa to summarize interrater agreement across many items. *Field Methods*. 2008;20(3):272–282. <https://doi.org/10.1177/1525822X08317166>
- DellaPosta D. Pluralistic collapse: the “oil spill” model of mass opinion polarization. *Am Sociol Rev*. 2020;85(3):507–536. <https://doi.org/10.1177/0003122420922989>
- Fiorina MP. *Unstable Majorities: Polarization, Party Sorting, and Political Stalemate*. Redwood City, CA: Hoover Institution Press, Stanford University; 2017.
- Kirkland A. The legitimacy of vaccine critics: what is left after the autism hypothesis? *J Health Polit Policy Law*. 2012;37(1):69–97. <https://doi.org/10.1215/03616878-1496020>
- Baldassarri D, Bearman P. Dynamics of political polarization. *Am Sociol Rev*. 2007;72(5):784–811. <https://doi.org/10.1177/00031224070200507>
- McVeigh R, Cunningham D, Farrell J. Political polarization as a social movement outcome: 1960s Klan activism and its enduring impact on political realignment in southern counties, 1960 to 2000. *Am Sociol Rev*. 2014;79(6):1144–1171. <https://doi.org/10.1177/0003122414555885>
- Kahan DM. Ideology, motivated reasoning, and cognitive reflection. *Judgm Decis Mak*. 2013;8(4):407–424. <https://dx.doi.org/10.2139/ssrn.2182588>
- Abiola SE, Colgrove J, Mello MM. The politics of HPV vaccination policy formation in the United States. *J Health Polit Policy Law*. 2013;38(4):645–681. <https://doi.org/10.1215/03616878-2208567>
- Centers for Disease Control and Prevention. Pertussis surveillance. Cases by year. May 25, 2021. Available at: <https://www.cdc.gov/pertussis/surveillance/cases-by-year.html>. Accessed April 25, 2022.
- Weber L, Barry-Jester AM. Over half of states have rolled back public health powers in pandemic. *Kaiser Health News*. Available at: <https://khn.org/news/article/over-half-of-states-have-rolled-back-public-health-powers-in-pandemic>. Accessed February 9, 2022.
- Hamilton A, Madison J, Jay J, Hamilton A. *The Federalist Papers*. New York, NY: Signet Classic; 2003.

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Hourly Wages and Turnover of Community Health Workers According to US State Certification Policy and Medicaid Reimbursement, 2010–2021

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 See also Covert, p. 1368.

Objectives. To evaluate the effects of state community health worker (CHW) certification programs and Medicaid reimbursement for CHW services on wages and turnover.

Methods. A staggered difference-in-differences design was used to compare CHWs in states with and without CHW certification or CHW Medicaid reimbursement policies. Data were derived from the 2010 to 2021 Current Population Survey in the United States.

Results. CHW wages increased by \$2.42 more per hour in states with certification programs than in states without programs ($P = .04$). Also, hourly wages increased more among White workers, men, and part-time workers ($P = .04$). Wages increased by \$14.46 in the state with the earliest CHW certification program adoption ($P < .01$). Neither of the policies assessed had an effect on occupational turnover.

Conclusions. CHW wages are higher in states with certification programs. However, wage gaps exist between Whites and non-Whites and between men and women.

Public Health Implications. Federal, state, and employer-based strategies are needed to establish and sustain effective CHW programs to meet the needs of communities experiencing health and access disparities. (*Am J Public Health.* 2022;112(10):1480–1488. <https://doi.org/10.2105/AJPH.2022.306965>)

Community health workers (CHWs) are recognized as part of the multidisciplinary health and social services workforce in the United States. As trusted members of the community with local knowledge and shared life experiences, CHWs are generally recognized as uniquely able to identify problems contributing to health disparities, improve access to health services, and connect people to needed social services.^{1,2} Public health departments and community-based organizations have traditionally been the largest employers

of CHWs. In recent years, health systems and insurers have increased employment of CHWs, in part to enhance their ability to address social determinants of health, support access to primary and preventive health programs, and reduce unnecessary use of services for conditions that can be managed by primary care among difficult-to-serve populations.^{3–5}

Increased job growth and employment reflects the increasing demand for services delivered by CHWs. In 2020, an estimated 64 100 CHWs were employed in the United States.⁶ The majority of CHWs

are Hispanic (35%), non-Hispanic White (39%), Black (15.5%), and female (82%).⁷ The US Bureau of Labor Statistics has projected a 21% increase in CHW jobs (approximately 13 500) by 2030, a rate of growth much faster than the average for all US occupations (7.7%).⁸ However, current employment estimates and projections may be substantially underestimated because of recent calls to rapidly scale the CHW workforce in response to the COVID-19 pandemic and because employment estimates are not consistent with results from a national survey

that estimated the workforce at approximately 86 000.^{2,7}

High employment turnover is also relevant in this occupation as it is evolving in terms of its recognition and credentialing as well as education of CHWs. This, coupled with an increased demand for CHWs in health systems, has left employers from health and social assistance sectors (e.g., public health, health care, social services) with significant challenges in recruiting, hiring, and retaining experienced CHWs.^{9,10} Employment turnover occurs when either employers lay off workers or employees voluntarily resign. According to a 2021 estimate, 2470 workers left CHW jobs and another 5073 transferred from one job to another, accounting for almost 12% of the estimated employed CHWs in that year.¹¹ This was considerably higher than the approximately 9.3% turnover reported for all other occupations in the United States.¹²

Turnover in the CHW workforce has been attributed to short-term funding for CHW programs, low wages, and lack of professional and organizational recognition for work contributions. Initiatives targeting the development of CHW programs and employment of CHWs have historically been funded through short-term grants. As grant funding has decreased, CHW programs and employment of CHWs have not been sustained.

In addition, the median annual wage for CHWs is estimated at \$42 000 (approximately \$20.19 per hour), almost \$10 000 less than the median wage for all other occupations.¹³ Low wages are the leading predictor of premature employee resignations among front-line health workers.^{14,15} Evidence suggests that even moderately higher wages improve satisfaction and retention, whereas dissatisfaction with low pay leads to higher turnover.¹⁶⁻¹⁸ The

short-term nature of grant funding arrangements for CHW programs, coupled with relatively low wages and wage disparities linked to race, ethnicity, and sex, makes it difficult to build CHW programs that have a high level of continuity in providing services to populations with health disparities and a disproportionate share of barriers to accessing health and community services.¹⁹⁻²¹

CHW advocates, researchers, and policymakers have suggested efforts to recognize the role of CHWs through occupational certification. Voluntary occupational certification of knowledge and skill is expected to standardize the practice of CHWs without creating unnecessary barriers to employment and career entry. This form of external recognition may promote respect for CHWs, reinforce the value of the services they provide, and motivate employment practices that retain CHWs.^{3,22-24} Increased retention of CHWs is expected to contribute to service delivery improvements and signal a long-term commitment to these workers as part of the labor force. Stable employment opportunities for CHWs will lead to a steadier supply of workers to meet the growing demand for their services.²⁰

As of 2021, fewer than half of US states had CHW certifications.²⁵ CHW certification is voluntary in most states, although some health insurers (e.g., state Medicaid programs) require certification as a condition of reimbursement for services provided by CHWs. States with CHW certification programs may expect to see an increase in wages and a reduction in occupational turnover if the response to certification is similar to that of other low-wage and direct care workers.^{14,15,22}

Medicaid reimbursement is a more sustainable source of funding for CHW services than short-term grant funding.

States have several funding mechanisms by which CHW services can be covered through Medicaid programs: fee-for-service reimbursement of covered benefits, Section 1115 Demonstration Waivers, value-added services provided through managed care contracts, shared savings via accountable care organizations contracting with providers, dual eligibility programs, and negotiated reimbursement for services (e.g., reimbursement provided by Federally Qualified Health Centers).^{26,27} In recent years, anecdotal literature identified innovation grants and other temporary funding sources as instrumental in motivating CHW employment growth and changes implemented by health care and community organizations to improve care and services for underserved populations.

Employers are key in developing and maintaining a stable CHW workforce and in generating job growth that attracts new entrants to the CHW role.^{25,28} Currently, there is a paucity of evidence related to changes in CHW wages, labor turnover, and funding policies (e.g., personnel or otherwise) that might influence wages or turnover. The current CHW workforce literature is focused on CHWs' impact on addressing chronic and preventable health conditions, understanding the competencies and skills needed by CHWs, and advancing integration of CHWs into health care organizations. In response to the need for understanding how policies affect CHW employment, we investigated state policies related to certification of CHWs and funding models that pay for services provided by CHWs. Specifically, we studied the effects of state CHW certification policies and Medicaid reimbursement policies for CHW services adopted between 2010 and 2021 on changes

in CHW hourly wages and occupation turnover.

METHODS

We used a staggered difference-in-differences design to compare CHWs in states with and without CHW certification (model 1) or CHW Medicaid reimbursement policies (model 2).²⁹ Because policies started in different states at different times, this afforded the opportunity to use the following difference-in-differences model estimate:

$$y_{ist} = \alpha + \gamma_s + \delta_t + \phi D_s \times T_t + \rho X_{ist} + \varepsilon_{ist} \quad (1)$$

where i indexes individual, s indexes state, and t indexes time; y_{ist} is an outcome variable, γ_s are state-fixed effects that control for time invariant state-specific heterogeneity; δ_t are year-month fixed effects that control for contemporaneous shock across states (e.g., the COVID-19 pandemic after the first quarter of 2020); D_s is an indicator variable for states with a specific policy (i.e., CHW certification or Medicaid reimbursement for CHW services); T_t is an indicator variable for the postimplementation phase of a specific policy in a state; ϕ captures the effects of policies (certification programs or Medicaid reimbursement) on outcomes; X_{ist} is a vector of control variables; and ε_{ist} are standard errors clustered at the state level. We used Stata version 14.2 in conducting all of our analyses.³⁰

The empirical model for this study relied on the assumption that, in the absence of treatment, states with and without a specific policy (CHW certification or Medicaid reimbursement for CHW services) would exhibit common trends in the outcomes. We examined differences in outcomes between treatment and control states across years

relative to the base year to validate the common trend assumption. The common trend assumption held for our analysis. The Appendix (available as a supplement to the online version of this article at <http://www.ajph.org>) provides a detailed discussion of the common trend assumption, robustness checks, and placebo tests we conducted to confirm the validity of the models tested and their results.

Study Sample and Data

The primary source of our data was the Current Population Survey (CPS). The CPS is a monthly labor force survey conducted by the US Census Bureau; the survey involves a nationally representative civilian, noninstitutionalized adult sample and provides the most widely used data for labor force studies in the United States. We retrieved January 2010 through April 2021 data from the Integrated Public Use Microdata Series-CPS, which provides identically coded variables over multiple years to facilitate longitudinal analyses.³¹ We restricted our sample to survey participants aged 16 years or older who were employed as CHWs. CHWs are defined by census occupation code 2020 or 2025; these codes are equivalent to the Bureau of Labor Statistics Standard Occupational Classification code for CHWs (21-1094).³² Also, we included only observations including responses to the survey question on wages and observations for which we were able to calculate turnover. The final sample for model 1 included 844 wage observations and 5694 turnover observations. The final sample for model 2 included 766 wage observations and 5289 turnover observations.

Model 1: CHW certification programs. The first model evaluated the effects of state

CHW certification programs on hourly wages and turnover. The treatment group comprised 18 states that launched CHW certification programs between 2010 and 2021; these states (with year of CHW certification program implementation in parentheses) are as follows: South Carolina (2012); Indiana, New Mexico, and Oregon (2014); Florida and Hawaii (2015); Illinois, Kentucky, and Rhode Island (2016); Massachusetts and Michigan (2017); Arizona and Virginia (2018); Maryland, Missouri, Nevada, and Pennsylvania (2019); and Connecticut (2020). Alaska, Texas, and Ohio have certification programs but were not included in the treatment group because their programs commenced before the study period.

The control group, which did not have CHW certification programs at the time of the study, comprised 30 states and jurisdictions: Alabama, Arkansas, California, Colorado, Delaware, District of Columbia, Georgia, Idaho, Iowa, Kansas, Louisiana, Maine, Minnesota, Mississippi, Montana, Nebraska, New Hampshire, New Jersey, New York, North Carolina, North Dakota, Oklahoma, South Dakota, Tennessee, Utah, Vermont, Washington, West Virginia, Wisconsin, and Wyoming.

Model 2: Medicaid reimbursement for CHW services. In the second model, we evaluated the effects of state CHW service Medicaid payment policies on hourly wages and turnover. The treatment group comprised 20 states and jurisdictions that implemented Medicaid reimbursement for CHW services between 2010 and 2021; these states (with year of policy implementation in parentheses) are as follows: Texas (2011); North Dakota and Oregon (2012); South Carolina (2013); Connecticut and West Virginia (2014); Colorado,

Missouri, and New Hampshire (2015); Maine, Michigan, Montana, and New York (2016); Alaska, District of Columbia, and Wisconsin (2017); California and Indiana (2018); South Dakota (2019); and Washington (2020). Arkansas, New Mexico, Massachusetts, Minnesota, Pennsylvania, Vermont, and Rhode Island allow Medicaid reimbursement for CHW services but were not included in the study because their Medicaid reimbursement policies commenced before the study period.

The control group comprised the 24 states that did not permit Medicaid reimbursement during the study period: Alabama, Arizona, Delaware, Florida, Georgia, Hawaii, Idaho, Illinois, Iowa, Kansas, Kentucky, Louisiana, Maryland, Mississippi, Nebraska, Nevada, New Jersey, North Carolina, Ohio, Oklahoma, Tennessee, Utah, Virginia, and Wyoming.

Dependent Variables

The dependent variables in both models were hourly wage and occupational turnover. Hourly wages were self-reported and pretax. To adjust for inflation over the study period, we converted wages to 2015 dollars using the Consumer Price Index.³³ We evaluated occupational turnover by tracing respondents' reported occupation codes over the 16-month CPS interview period (the CPS methodology entails contacting participant panels for 8 interviews over a 16-month period). We grouped participants into the turnover category if they reported their occupation as a CHW at the beginning of the interview period and later reported another occupation.

Treatment Variables

Treatment variables were state CHW certification program in model 1 and

Medicaid reimbursement policy in model 2. In both models, treatment was a binary indicator variable identified as 0 (in years) when the certification program did not exist and 1 after the policy was implemented.

Control Variables

Control variables included age in years (16–24, 25–44, 45–64, or ≥ 65), sex (male or female), marital status (currently married or not currently married), race/ethnicity (Hispanic, White, Black, Asian, other), level of education (less than high school, high school, some college, college, more than college), area of residence (metropolitan or nonmetropolitan), and working status (full time or part time).

RESULTS

Table 1 presents sample characteristics of CHWs in states with CHW certification policies (model 1) and Medicaid reimbursement policies (model 2). Approximately 36% of CHWs were employed in states with a CHW certification policy, and 55.8% were employed in states where Medicaid programs reimburse services provided by CHWs. The demographic characteristics of the treatment and control groups were not significantly different. However, the percentage of Hispanic CHWs was higher in states without CHW certification policies, and Hispanic workers were almost 3 times more likely to be employed in states where Medicaid covers services provided by CHWs.

Community Health Worker Certification

Estimates of the effects of CHW certification on hourly wages and occupational turnover are shown in Table 2. States that adopted CHW certification

policies between 2010 and 2021 had significantly higher hourly wages after policy implementation than states without certification policies. Hourly wages were \$2.42 higher in these states ($P = .04$), which translates to a 13.2% increase relative to the baseline hourly wage of \$18.30 (i.e., the hourly wage in treated states before the implementation of certification programs). We did not find a statistically significant effect on occupational turnover. We further examined heterogeneous effects on hourly wages among states that adopted CHW certification policies. In 6 states (South Carolina, Missouri, Michigan, Indiana, Illinois, and New Mexico), there were statistically significant changes in hourly wages after adoption of CHW certification policies. South Carolina, Missouri, Michigan, Indiana, and Illinois had significant increases in hourly wages. New Mexico had a decrease. South Carolina had the highest increase in hourly wages (\$14.46; $P < .01$). Figure 1 shows the results of the state-level analysis.

We also conducted subgroup analyses based on differences according to employee race/ethnicity, sex, and work status (i.e., full time vs part time). We found that hourly wages were significantly higher among Whites (\$2.72; $P = .04$) in treated states; however, there was no significant difference in wages among non-Whites (\$1.74; $P = .35$). Also, hourly wages were significantly higher among men (\$5.16; $P = .03$) but not women (\$1.32; $P = .33$). We further examined possible effects based on race/ethnicity and sex. Non-White male CHWs had a slightly higher increase in wages (\$5.10; $P = .05$) than their White counterparts. We found a significantly higher increase in hourly wages among part-time CHWs (\$4.02; $P = .04$) but no significant difference among full-time CHWs (\$1.56; $P = .23$).

TABLE 1— Sample Characteristics: Current Population Survey Respondents, United States, January 2010–April 2021

	Model 1 ^a : State Certification Policy, % or Mean (No. of Observations)			Model 2 ^b : Medicaid CHW Reimbursement, % or Mean (No. of Observations)		
	Full (6958)	Treated (2426)	Control (4532)	Full (6471)	Treated (3610)	Control (2861)
Female	72.3	71.7	72.7	72.1	70.1	74.2
Married	47.4	46.2	48.3	48.7	46.7	50.8
Age, y						
< 25	9.7	8.8	10.5	9.5	10.8	8.2
25–44	44.4	43.3	45.2	44.6	46.2	43.0
45–64	40.9	42.2	39.9	40.6	39.2	42.0
≥ 65	5.0	5.7	4.4	5.3	3.8	6.8
Race/ethnicity						
Hispanic	13.5	10.5	15.9	15.3	22.0	8.3
White	60.1	62.2	58.5	57.4	55.5	59.3
Black	20.1	21.5	19.1	21.1	16.2	26.2
Asian	2.4	2.3	2.6	2.5	3.2	1.7
Other	3.8	3.6	4.0	3.8	3.1	4.5
Level of education						
< high school	2.9	2.7	3.1	2.9	3.1	2.8
High school	14.9	15.9	14.1	15.1	15.9	14.2
Some college	29.9	28.8	30.7	29.0	28.9	29.1
College	32.1	29.1	34.4	33.3	33.8	32.8
> college	20.3	23.6	17.7	19.6	18.2	21.1
Working full time	66.3	68.0	64.9	66.1	64.6	67.6
Outcome						
Hourly wage, \$ ^c	19.3 (n = 844)	18.3 (n = 304)	19.3 (n = 540)	19.3 (n = 766)	19.2 (n = 433)	19.3 (n = 333)
Turnover	24.7 (n = 5694)	24.3 (n = 1975)	25.0 (n = 3719)	24.4 (n = 5289)	24.9 (n = 2950)	24.0 (n = 2339)

Note. The sample was restricted to workers whose occupation code was 2020 or 2025 (equivalent to 21-1094 in the Standard Occupational Classification Code System). All estimates were weighted via Current Population Survey weights.

^aThe treatment group includes SC, IN, NM, OR, FL, HI, IL, KY, RI, MA, MI, AZ, VA, MD, MO, NY, PA, and CT. Control states and jurisdictions are AL, AR, CA, CO, DC, DE, GA, IA, ID, KS, LA, ME, MN, MS, MT, NC, ND, NE, NH, NJ, NY, OK, SD, TN, UT, VT, WA, WI, WV, and WY.

^bThe treatment group includes TX, ND, OR, SC, CT, WV, CO, MO, NH, ME, MI, MT, NY, AK, DC, WI, CA, IN, SD, and WA. Control states are AL, AZ, DE, FL, GA, HI, ID, IL, IA, KS, KY, LA, MD, MS, NE, NV, NJ, NC, OH, OK, TN, UT, VA, and WY.

^cIn 2015 dollars.

State CHW certification was not found to have a significant effect on occupational turnover in the full sample. However, it did account for a 14.1% decrease in employment turnover among non-White male CHWs in states with certification programs ($P < .01$).

Medicaid Reimbursement

The results of the analyses of the effects of Medicaid reimbursement on

hourly wages and occupation turnover are presented in Table 2. Medicaid reimbursement was not found to have a significant effect on changes in either wages or occupational turnover among CHWs during the study period.

DISCUSSION

In this study, we explored the effects of state CHW certification policies and

Medicaid reimbursement for CHW services on hourly wages and occupational turnover. We found significant causal effects of state CHW certification on hourly wages in the full sample of CHWs. However, Medicaid reimbursement was not found to have a significant effect on wages over the period of the study. State certification was found to reduce turnover among non-White male CHWs. Otherwise, neither CHW certification nor state Medicaid

TABLE 2— Average Treatment Effects of Policies on Wages and Turnover: Current Population Survey, United States, January 2010–April 2021

Model	Hourly Wage, <i>b</i> (95% CI) or No.	Turnover, <i>b</i> (95% CI) or No.
Model 1: effects of state certification policies		
$D_s \times T_t$	2.42 (0.16, 4.68)	-0.02 (-0.07, 0.03)
Model 1-1: heterogeneous effects by race (White vs non-White)		
$D_s \times T_t \times \text{White}$	2.72 (0.12, 5.33)	-0.02 (-0.08, 0.04)
$D_s \times T_t \times \text{non-White}$	1.74 (-1.96, 5.43)	-0.01 (-0.08, 0.05)
Model 1-2: heterogeneous effects by sex (male vs female)		
$D_s \times T_t \times \text{male}$	5.16 (0.52, 9.80)	-0.02 (-0.12, 0.08)
$D_s \times T_t \times \text{female}$	1.32 (-1.38, 4.02)	-0.02 (-0.07, 0.03)
Model 1-3: heterogeneous effects by race among male CHWs		
$D_s \times T_t \times \text{male} \times \text{White}$	5.06 (-2.41, 12.53)	0.03 (-0.11, 0.17)
$D_s \times T_t \times \text{male} \times \text{non-White}$	5.09 (0.04, 10.14)	-0.14 (-0.21, -0.07)
Model 1-4: Heterogeneous effects by working status (full vs part time)		
$D_s \times T_t \times \text{full time}$	1.55 (-1.04, 4.14)	-0.02 (-0.07, 0.04)
$D_s \times T_t \times \text{part time}$	4.02 (0.12, 7.91)	-0.02 (-0.09, 0.05)
Observations	834	5694
Model 2: effects of Medicaid CHW reimbursement		
$D_s \times T_t$	-1.11 (-3.81, 1.60)	0.02 (-0.03, 0.06)
Observations	754	5289

Note. CHW = community health worker; CI = confidence interval. The sample was restricted to workers whose occupation code was 2020 or 2025 (equivalent to 21-1094 in the Standard Occupational Classification Code System). All models were weighted via Current Population Survey weights. Hourly wages were reported in 2015 dollars. Individual controls included age, sex, race/ethnicity, level of education, area of residence (metropolitan or nonmetropolitan), and working status (full time or part time). Standard errors were clustered at the state level. Models included individual controls, state fixed effects, and year-month fixed effects.

reimbursement for CHW services was associated with reductions in CHW turnover.

It is widely believed that the greatest value of CHWs is that they are representative of the underserved populations they are hired to work with. This assumption about the demographics of the CHW workforce led us to consider whether state certification and Medicaid reimbursement policies had equitable effects on subgroups in our sample. In the subgroup analyses, we found that White, male, and part-time CHWs had higher wage increases than CHWs who were non-White, were female, and worked full time. The finding related to men having significantly higher wage increases than women is a concern given the predominance of women in

the CHW workforce.⁷ Our results are consistent with findings from other studies estimating gender pay gaps of 26% in high-income countries, with the health care and social sectors having the widest gaps among low-income occupations.³⁴ The wage gap in this occupation may contribute to a persistent shortage of workers and may hinder employers attempting to hire and recruit CHWs.

Only 66% of CHWs in the sample reported working full time. This finding led us to question whether there is higher turnover among CHWs because a high proportion of these workers are employed part time. This may lead employers to offer higher wages to recruit and retain part-time workers.

Our findings are relevant to inform several recommendations for future

research on CHWs. First, we recommend that researchers consider the relationship between payment policies and the number of CHWs employed. Second, previous literature indicates that wages are the leading indicator of workers' intent to leave their current employment. We recommend that future research evaluate the effects of wages on intent to leave and turnover among CHWs.

Third, our results suggest that voluntary state certification of CHWs may have different effects on employment practices, wages, and turnover than required certification. Finally, in our previous research on CHW certification, we found variations in adoption of nationally defined occupational roles, skills, and qualities by type of employer

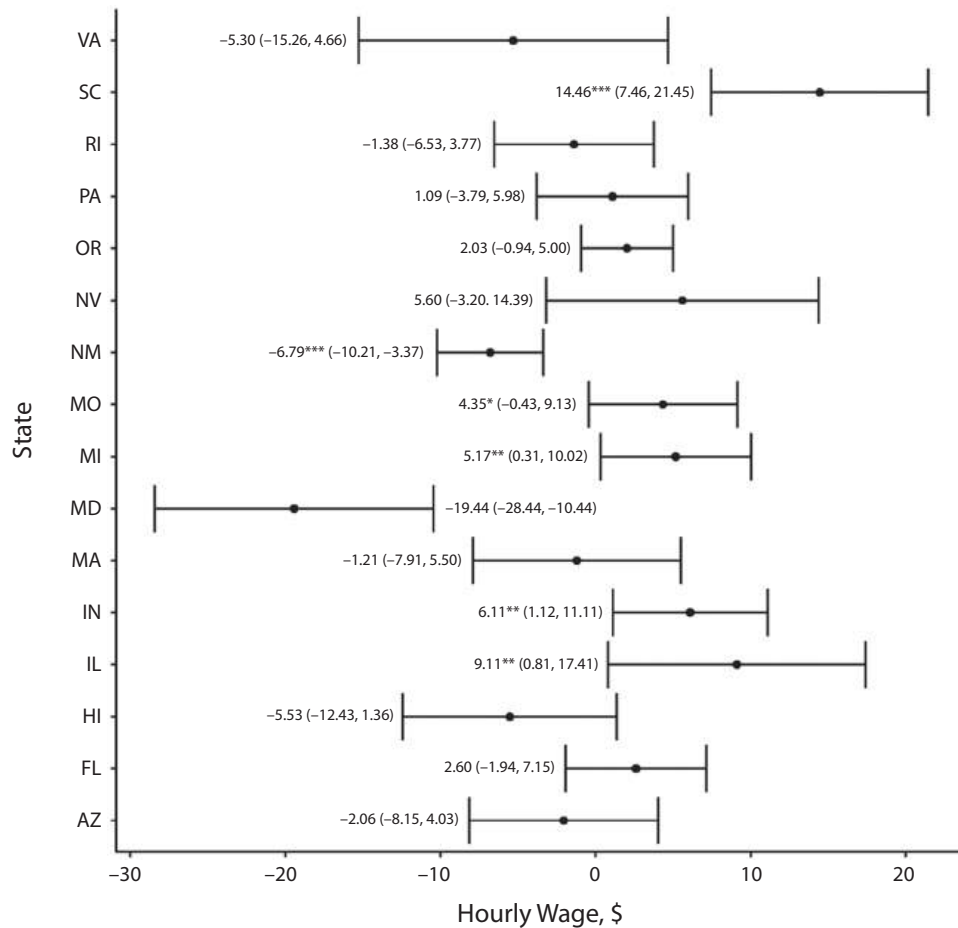


FIGURE 1— Effects of Certification Policies on Hourly Wages Within Treated States: Current Population Survey, United States, January 2010–April 2021

Note. The sample was restricted to workers whose occupation code was 2020 or 2025. Each point shows mean differences in hourly wages relative to control states. Error bars show 95% confidence intervals.

(e.g., insurers, health systems, community-based organizations).²⁴

There was less evidence of standardization in roles, skills, and qualities in job ads posted by organizations that employed CHWs in a greater variety of roles. That finding, coupled with those of this study, led us to consider what effects role standardization (i.e., unambiguous responsibilities and expectations) and employer type may have on reducing role confusion, improving employee satisfaction, increasing intent to remain in one's current position, and decreasing turnover (i.e., resignations).

Limitations

We acknowledge several limitations of this study. First, the number of CHWs directly affected by state certification policies may be limited because most states do not require CHWs to be certified to practice. States that require certification may have higher uptake of certification.²⁵ Second, the number of CHW programs and CHWs affected by state Medicaid payment policies may also be limited given that reimbursement or shared savings realized through the benefits of CHW services are limited to a discrete population.

Third, this study included an analysis of the direct effects of state policies on turnover. There is possibly an indirect effect of wages on turnover that was not explored in our study. Finally, the sample of CHWs that participated in the CPS may not be nationally representative of CHWs. Estimates from the Bureau of Labor Statistics are likely understated, and the most current national survey of CHWs is 15 years old.

Public Health Implications

Payment policies have historically influenced the behavior of health system

employers. However, in this study, Medicaid reimbursement was not found to have an effect on wages or turnover (i.e., measures of employer behavior). The current level of reimbursement from Medicaid for CHW services may not be sufficient to change employer practices related to employment and retention of CHWs.

We considered all types of Medicaid payment policies in this study. As an example, specific payment models such as the alternative payment methodologies available to states under Medicare, Medicaid, and the State Child Health Insurance Program Benefits Improvement and Protection Act of 2000 may provide sustainable and more favorable funding for organizations to offer CHW programs and increase their employment of CHWs. The services reimbursed under such funding strategies (e.g., patient and family support, referral to community and social support services) are well aligned with services typically provided by CHWs and may be more effective in influencing employer behavior (e.g., creating CHW jobs and setting wages sufficient to retain workers).

States that adopted CHW certification programs saw an increase in wages for CHWs. This is an important finding considering that increases in wages in response to certification have been found to reduce turnover among low-wage workers in previous studies. In addition to federal and state policies related to CHW payment and occupational certification, employer behavior regarding job creation and human resource management practices are known to influence occupational turnover and employee retention. Federal, state, and employer-based strategies employed collectively could have an immediate and lasting effect on

developing and maintaining a CHW workforce that is able to meet the needs of populations with health disparities and disproportionate barriers to accessing care and services. *AJPH*

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CONTRIBUTORS

T. M. Jones co-developed the concept and design for the research, conducted the literature review, and was the lead author. C. Jeung co-developed the concept and design for the research, conducted the econometric analysis, and was a major contributor in writing the article. A. Schulte conducted background research and was a major contributor in writing the article. C. M. Lewis provided public health expertise and was a major contributor in writing the article. P. J. Maddox supervised the research project team, provided health workforce data and policy expertise that contributed to the development and design of the research, and was a contributor in writing the article.

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CONFLICTS OF INTEREST

The authors have no potential or actual conflicts of interest from funding or affiliation-related activities to disclose.

HUMAN PARTICIPANT PROTECTION

No protocol approval was needed for this study because no human participants were involved.

REFERENCES

1. Corder-Mabe J, Johnson S, Mazmanian PE, Smith WR. Development of a framework to describe functions and practice of community health workers. *J Contin Educ Health Prof*. 2019;39(4):274–278. <https://doi.org/10.1097/CEH.000000000000274>
2. Goldfield NI, Crittenden R, Fox D, McDonough J, Nichols L, Lee Rosenthal E. COVID-19 crisis creates opportunities for community-centered population health: community health workers at the center. *J Ambul Care Manage*. 2020;43(3):184–190. <https://doi.org/10.1097/JAC.0000000000000337>
3. Malcarney MB, Pittman P, Quigley L, Horton K, Seiler N. The changing roles of community health workers. *Health Serv Res*. 2017;52(suppl 1):360–382. <https://doi.org/10.1111/1475-6773.12657>
4. Park J, Regenstein M, Chong N, Onyilofor CL. The use of community health workers in community health centers. *Med Care*. 2021;59(suppl 5):S457–S462. <https://doi.org/10.1097/MLR.0000000000001607>
5. Kim K, Choi JS, Choi E, et al. Effects of community-based health worker interventions to improve chronic disease management and care among vulnerable populations: a systematic review. *Am J Public Health*. 2016;106(4):E3–E28. <https://doi.org/10.2105/AJPH.2015.302987>
6. Bureau of Labor Statistics. Health education specialists and community health workers: occupational outlook handbook. Available at: <https://www.bls.gov/oooh/community-and-social-service/health-educators.htm#tab-6>. Accessed March 15, 2022.
7. Health Resources and Services Administration. Community Health Worker National Workforce Study. Available at: <https://bhw.hrsa.gov/sites/default/files/bureau-health-workforce/data-research/community-health-workforce.pdf>. Accessed March 24, 2021.
8. Bureau of Labor Statistics. Occupational projections, 2020–30, and worker characteristics. Available at: <https://www.bls.gov/emp/tables/occupational-projections-and-characteristics.htm>. Accessed November 10, 2021.
9. Anabui O, Carter T, Phillippi M, Ruggieri DG, Kangovi S. Developing sustainable community health worker career paths. Available at: <https://www.milbank.org/publications/developing-sustainable-community-health-worker-career-paths>. Accessed November 10, 2021.
10. Nkonki L, Cliff J, Sanders D. Lay health worker attrition: important but often ignored. *Bull World Health Organ*. 2011;89(12):919–923. <https://doi.org/10.2471/BLT.11.087825>
11. Chmura. JobsEQ. Available at: <http://www.chmuraecon.com/jobseq>. Accessed January 3, 2022.
12. Bureau of Labor Statistics. Job openings and labor turnover summary. Available at: <https://www.bls.gov/news.release/jolts.nr01.htm>. Accessed March 23, 2022.
13. Bureau of Labor Statistics. Occupational employment and wage statistics: community health workers. Available at: <https://www.bls.gov/oes/current/oes211094.htm>. Accessed May 26, 2021.

14. Ben-Dror R. Employee turnover in community mental health organization: a developmental stages study. *Community Ment Health J*. 1994;30(3):243–257. <https://doi.org/10.1007/BF02188885>
15. Morgan JC, Dill J, Kalleberg AL. The quality of healthcare jobs: can intrinsic rewards compensate for low extrinsic rewards? *Work Employ Soc*. 2013;27(5):802–822. <https://doi.org/10.1177/0950017012474707>
16. De Beaumont Foundation. Public Health Workforce Interests and Needs Survey. Available at: <https://debeaumont.org/wp-content/uploads/2019/04/PH-WINS-2017.pdf>. Accessed October 15, 2021.
17. Morris L. Quits and job changes among home care workers in Maine: the role of wages, hours, and benefits. *Gerontologist*. 2009;49(5):635–650. <https://doi.org/10.1093/geront/gnp071>
18. Bukach AM, Ejaz FK, Dawson N, Gitter RJ. Turnover among community mental health workers in Ohio. *Adm Policy Ment Health*. 2017;44(1):115–122. <https://doi.org/10.1007/s10488-015-0706-1>
19. Frogner BK, Schwartz M. Examining wage disparities by race and ethnicity of health care workers. *Med Care*. 2021;59(suppl 5):S471–S478. <https://doi.org/10.1097/MLR.0000000000001613>
20. Chapman S, Okwandu O, Schindel J, Miller J. Utilization of community health workers in emerging care coordination models in California. Available at: <https://healthforce.ucsf.edu/sites/healthforce.ucsf.edu/files/publication-pdf/BSCF%20CHW%20Policy%20Brief%20Final%201.4.17%5B1%5D.pdf>. Accessed October 18, 2021.
21. Felix C, Gibson C, Alvisurez J, et al. Funding community health workers: best practices and the way forward. Available at: https://elischolar.library.yale.edu/ysph_pbchrr/50. Accessed October 18, 2021.
22. Albert K. The certification earnings premium: an examination of young workers. *Soc Sci Res*. 2017; 63:138–149. <https://doi.org/10.1016/j.ssresearch.2016.09.022>
23. Ingram M, Sabo S, Redondo F, et al. Establishing voluntary certification of community health workers in Arizona: a policy case study of building a unified workforce. *Hum Resour Health*. 2020; 18(1):46. <https://doi.org/10.1186/s12960-020-00487-7>
24. Jones T, Schulte A, Ramanathan S, Assefa M, Rebala S, Maddox PJ. Evaluating the association of state regulation of community health workers on adoption of standard roles, skills, and qualities by employers in select states: a mixed methods study. Available at: <https://human-resources-health.biomedcentral.com/articles/10.1186/s12960-021-00684-y>. Accessed October 18, 2021.
25. National Academy for State Health Policy. State community health worker models. Available at: <https://www.nashp.org/state-community-health-worker-models>. Accessed March 2, 2022.
26. Blackman K, Scotti S. Incorporating community health workers into state health care systems: options for policymakers. Available at: <https://www.ncsl.org/Portals/1/Documents/Health/CHWbrief2015.pdf>. Accessed June 18, 2021.
27. Families USA. How states can fund community health workers through Medicaid to improve people's health, decrease costs, and reduce disparities. Available at: <https://www.nationalcomplex.care/wp-content/uploads/2017/11/Community-Health-Workers-Brief.pdf>. Accessed June 16, 2021.
28. Centers for Disease Control and Prevention. Policy evidence assessment report: community health worker policy components. Available at: https://www.cdc.gov/dhds/pubs/docs/chw_evidence_assessment_report.pdf. Accessed June 16, 2021.
29. Athey S, Imbens GW. Design-based analysis in difference-in-differences settings with staggered adoption. Available at: https://www.nber.org/system/files/working_papers/w24963/w24963.pdf. Accessed June 16, 2021.
30. *Stata Statistical Software: Release 14*. College Station, TX: StataCorp LP; 2015.
31. Integrated Public Use Microdata Series. Current Population Survey: version 9.0 [data set]. Available at: <https://cps.ipums.org/cps>. Accessed June 16, 2021.
32. US Census Bureau. Appendix 10, occupation classification. Available at: <https://www2-census.gov/mutex.gmu.edu/programs-surveys/cps/methodology/Occupation%20Codes.pdf>. Accessed March 2, 2022.
33. Bureau of Labor Statistics. Inflation calculator. Available at: https://www.bls.gov/data/inflation_calculator.htm. Accessed November 2, 2021.
34. World Health Organization. Delivered by women, led by men: a gender and equity analysis of the global health and social workforce. Available at: <https://apps.who.int/iris/handle/10665/311322>. Accessed May 2, 2022.

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COVID-19 Among Non-Hispanic American Indian and Alaska Native People Residing in Urban Areas Before and After Vaccine Rollout—Selected States and Counties, United States, January 2020–October 2021

Dornell Pete, MPH, Scott L. Erickson, MPH, Melissa A. Jim, MPH, Sarah M. Hatcher, PhD, Abigail Echo-Hawk, MA, and Adrian E. Dominguez, MS

Objectives. To evaluate COVID-19 disparities among non-Hispanic American Indian/Alaska Native (AI/AN) and non-Hispanic White persons in urban areas.

Methods. Using COVID-19 case surveillance data, we calculated cumulative incidence rates and risk ratios (RRs) among non-Hispanic AI/AN and non-Hispanic White persons living in select urban counties in the United States by age and sex during January 22, 2020, to October 19, 2021. We separated cases into prevaccine (January 22, 2020–April 4, 2021) and postvaccine (April 5, 2021–October 19, 2021) periods.

Results. Overall in urban areas, the COVID-19 age-adjusted rate among non-Hispanic AI/AN persons ($n = 47\,431$) was 1.66 (95% confidence interval [CI] = 1.36, 2.01) times that of non-Hispanic White persons ($n = 2\,301\,911$). The COVID-19 prevaccine age-adjusted rate was higher (8227 per 100 000; 95% CI = 6283, 10 770) than was the postvaccine rate (3703 per 100 000; 95% CI = 3235, 4240) among non-Hispanic AI/AN compared with among non-Hispanic White persons (2819 per 100 000; 95% CI = 2527, 3144; RR = 1.31; 95% CI = 1.17, 1.48).

Conclusions. This study highlights disparities in COVID-19 between non-Hispanic AI/AN and non-Hispanic White persons in urban areas. These findings suggest that COVID-19 vaccination and other public health efforts among urban AI/AN communities can reduce COVID-19 disparities in urban AI/AN populations. (*Am J Public Health.* 2022;112(10):1489–1497. <https://doi.org/10.2105/AJPH.2022.306966>)

American Indian and Alaska Native (AI/AN) communities have borne a disproportionate burden of COVID-19. In March 2020, rates of COVID-19 infection, hospitalization, and death among AI/AN persons have been reported to be 1.7, 3.5, and 2.4 times those of non-Hispanic White persons, respectively.^{1–3}

The most recent analysis during January 31 through July 3, 2020 reported a COVID-19 incidence rate among AI/AN persons that was 3.5 times that of non-Hispanic White persons (594 per 100 000 vs 169 per 100 000, respectively) in a subset of 23 states with more than 70% complete race/ethnicity

data.⁴ However, these analyses did not specifically address AI/AN people living in US urban areas and were conducted before COVID-19 vaccine availability.

The health needs of urban AI/AN people have become increasingly amplified during the COVID-19 pandemic for several reasons. Historical and ongoing

health and socioeconomic inequities in urban settings have pervasive effects on the health of AI/AN people and, therefore, may play a critical role in the risk of COVID-19 exposure, transmission, morbidity, and mortality.

First, urban areas of today are located on the original homelands of AI/AN people, and according to the US Census, approximately 78% of AI/AN people in the United States live, work, and receive education and health care in urban areas.^{5,6} Moreover, federal legislation, including the Indian Relocation Act of 1957,⁷ incentivized AI/AN people to relocate from their tribal lands for better health care, education, and work; however, these services often did not materialize because of a lack of funding and priority.⁸ Second, urban environments pose a combination of COVID-19 exposure risks because of high population densities, reliance on public transportation, housing insecurity, and essential worker occupations that may not provide health insurance, paid sick leave, childcare, or options to work from home.⁹ Lastly, AI/AN populations often have a higher prevalence of underlying health conditions (e.g., diabetes, obesity, heart conditions), poverty, food and housing insecurity, homelessness, and limited access to quality health care, health insurance, and nutritious foods than other racial groups.¹⁰ These and other social determinants of health may make it difficult to follow public health guidelines to safely quarantine, work and go to school, and avoid close contact and crowded spaces to limit the spread of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2).

Despite the disproportionate effects of COVID-19 in the AI/AN population, AI/AN people have some of the highest rates of COVID-19 vaccination in the United States.^{11,12} Safe and effective

COVID-19 vaccines received US Food and Drug Administration Emergency Use Authorization on December 11 and 18, 2020, for Pfizer-BioNTech and Moderna, respectively, and February 27, 2021, for Janssen Pharmaceuticals, to reduce the burden of severe COVID-19 outcomes.¹³⁻¹⁵ According to the Centers for Disease Control and Prevention (CDC) COVID-19 data tracker, vaccination rates reached 48% by September 2021 in AI/AN people, which was higher than were rates in other racial groups (42% in Asians, 38% in Whites, and 30% in African Americans).^{3,12} However, to our knowledge, no studies have examined whether this has decreased the rate of COVID-19 among AI/AN persons compared with other races and ethnicities in the United States. Further study of the burden of COVID-19 among AI/AN persons in urban areas, particularly after vaccine rollout, is needed to inform national and local public health actions to reduce transmission, decrease disparities, and improve health outcomes in urban AI/AN communities.

We examined reports of laboratory-confirmed COVID-19 cases among urban non-Hispanic AI/AN persons from January 22, 2020, to October 19, 2021, and compared the period before vaccination (January 22, 2020–April 4, 2021) to after vaccination (April 5–October 19, 2021). We limited our analysis to urban counties from 40 states in the United States with 70% or more complete race/ethnicity information and more than 5 cases among non-Hispanic AI/AN persons and 5 cases among non-Hispanic White persons.

METHODS

Laboratory-confirmed COVID-19 cases were reported to the CDC through the

CDC COVID-19 case report form and the National Notifiable Disease Surveillance System from January 22, 2020, to October 19, 2021.^{16,17} We defined a laboratory-confirmed COVID-19 case as a positive test result for SARS-CoV-2, the virus that causes COVID-19, from a respiratory specimen, using real-time reverse transcription–polymerase chain reaction testing. We excluded probable cases and cases without information on race (n = 10 203 116), ethnicity (n = 8 527 491), county of residence (n = 405 050), and report date (n = 2 843 587) from this analysis, as well as cases among persons who repatriated to the United States from the city of Wuhan, China, and the Diamond Princess cruise ship COVID-19 outbreak.

We classified AI/AN race/ethnicity as non-Hispanic AI/AN alone or in combination with other races. We defined the comparison group as non-Hispanic White. We chose non-Hispanic White as the comparison group to avoid comparing rates among AI/AN persons to other marginalized populations that experience similar health disparities. Because all analyses reported here were limited to non-Hispanic populations, we have omitted the term “non-Hispanic” from this study when discussing both groups.

We classified an urban county as one that either (1) was identified as metropolitan using the National Center for Health Statistics Urban–Rural Classification Scheme (large central metro, large fringe metro, medium metro, small metro), or (2) was in the service area of the Urban Indian Health Institute.¹⁸ To improve the stability of rate estimates, we limited analyses to urban counties with more than 5 cases for both AI/AN and White persons and 70% or more complete race/ethnicity information. We defined a laboratory-confirmed

COVID-19 case as having “complete” race/ethnicity if it met both of the following criteria: (1) race was listed as 1 of the 5 Office of Management and Budget 1997 racial categories, and (2) ethnicity was listed as either Hispanic/Latino or non-Hispanic/Latino.¹⁹

We established 2 analysis periods—before vaccination (January 22, 2020–April 4, 2021) and after vaccination (April 5–October 19, 2021)—based on a cutoff date of April 5, 2021, when more than 25% of the AI/AN population in the United States achieved full vaccination coverage based on CDC data tracker data.³ This date and percentage vaccination coverage allowed us to evaluate before and after vaccination without the potential effects of waning immunity and new variants with the potential to evade vaccine-derived immunity. Additionally, we wanted to avoid potential diluting effects of the vaccine if we selected an earlier date and lower percentage vaccination coverage because so few people would have been fully vaccinated and the vaccine was limited to frontline health care workers and nursing home residents. The CDC data tracker defines full vaccination coverage as having received a dose of a single-shot COVID-19 vaccine or the second dose of the 2-dose COVID-19 vaccine series. To make comparisons between periods, we standardized the postvaccination period to the same urban geographic counties and states as the prevaccination period.

We used a generalized estimating equations (GEE) regression model to calculate cumulative incidence (cumulative cases per 100 000 population), risk ratios (RRs), and 95% confidence intervals (CIs) for AI/AN and White persons. We adjusted the overall estimates for age (categorical) and stratified

unadjusted estimates by age group (0–19 years, 20–54 years, and ≥ 55 years) and sex. We used GEE models, which perform well for estimating rates with correlated data, to account for clustering by county.²⁰ We used the CDC’s 2018 National Center for Health Statistics bridged-race population estimates as population denominators.²¹ We compared the cumulative incidence, RR, and 95% CI estimates of the postvaccination period with the prevaccination period. To examine the completeness of data for severe COVID-19 outcomes among AI/AN and White persons, we calculated the percentage of known and unknown hospitalization, intensive care unit (ICU) admission, and death status by dividing the number of cases with known (yes or no response) or unknown (missing or blank response) outcomes status by the total number of COVID-19 cases for that particular outcome. We set statistical significance at an α level of 0.05. We conducted and validated analyses using SAS version 9.4 (SAS Institute, Cary, NC) and R version 4.02 (RStudio, Boston, MA). We constructed maps using R version 4.02.

RESULTS

During January 22, 2020, through October 19, 2021, there were 31 192 253 laboratory-confirmed COVID-19 cases reported to the CDC in the United States. In the 1183 counties classified as urban, there were 58 362 cases among AI/AN persons and 3 274 534 cases among White persons. In addition, 326 urban counties (27.5%) in 40 states had more than 5 cases among AI/AN and White persons and 70% or more complete race/ethnicity (Figure 1). Among these 326 urban counties, there were 2 301 911 laboratory-

confirmed COVID-19 cases reported among AI/AN and White persons, of which 47 431 were among AI/AN persons and 2 254 480 were among White persons.

The overall cumulative incidence rate of COVID-19 after adjusting for age among urban-residing AI/AN persons during January 22, 2020, through October 19, 2021, was 12 360 per 100 000 population (95% CI = 10 230, 14 930), which was 1.66 (95% CI = 1.36, 2.01; $P < .05$) times that of urban-residing White persons (7468 per 100 000 population; 95% CI = 6881, 8106; Table 1). The median age was 34 years (interquartile range [IQR] = 21–51 years) among AI/AN persons and 40 years (IQR = 25–58 years) among White persons. For both AI/AN and White persons, most cases were aged 20 to 54 years (57.8% and 52.8%, respectively) and were female (54.6% and 52.7%, respectively; Table 1). Across the age groups, AI/AN persons were younger than White persons. Among all age and sex categories, COVID-19 incidence was significantly greater among AI/AN persons than among White persons (Table 1).

In the prevaccination period (January 22, 2020–April 4, 2021), 1 623 018 COVID-19 cases among AI/AN and White persons were reported for 345 urban counties in 40 states with more than 5 cases among both AI/AN and White persons and with 70% or more complete race/ethnicity data (Figure 2). Of these, 36 278 were AI/AN persons (age-adjusted cumulative incidence per 100 000 = 8227; 95% CI = 6283, 10 770) and 1 586 740 were White persons (cumulative incidence per 100 000 = 4416; 95% CI = 3982, 4897). Across the age groups, AI/AN persons were younger than were White persons. After adjusting for age, AI/AN

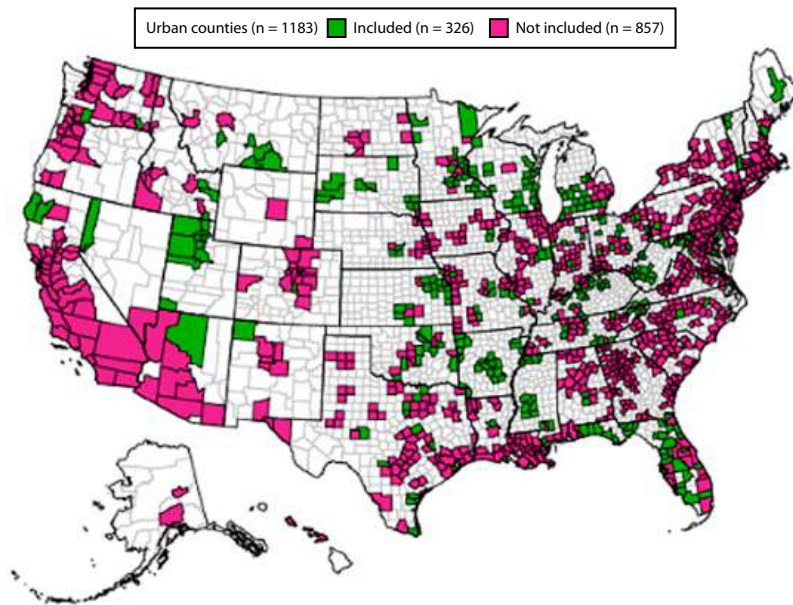


FIGURE 1— Aggregate Urban County-Level Analysis of COVID-19 Cases in Non-Hispanic American Indian/Alaska Native and Non-Hispanic White Persons: 326 US Counties and 40 US States, January 22, 2020–October 19, 2021

Note. Urban counties indicate 2013 National Center for Health Statistics Urban–Rural Classification Scheme for Counties (https://www.cdc.gov/nchs/data/series/sr_02/sr02_166.pdf) and Urban Indian Health Program/Urban Indian Health Network service counties (including nonurban counties: KS: Reno County; MT: Big Horn, Broadwater, Jefferson, Lewis and Clark, and Silver Bow counties; NV: Churchill and Douglas counties; OK: Pottawatomie County; SD: Brown, Hughes, and Stanley counties). The 40 states were AL, AZ, AR, CA, CO, FL, GA, ID, IL, IN, IA, KS, KY, LA, MA, ME, MD, MI, MN, MS, MO, MT, NE, NV, NJ, NM, NC, OH, OK, PA, SC, SD, TN, TX, UT, VT, VA, WA, WV, and WI.

people were 1.86 (95% CI = 1.41, 2.45; $P < .05$) times as likely to be infected with COVID-19 than were White persons during the prevaccination period. For each age and sex category, COVID-19 incidence was significantly greater among AI/AN persons than among White persons (Table 1).

In the postvaccination period April 5, 2021, through October 19, 2021, 1 001 032 cases among AI/AN and White persons were reported for the same geographic area as in the prevaccination period (data available for 322 urban counties in 37 states; Figure 2). Of these persons in the postvaccination period, 16 117 were AI/AN persons (cumulative incidence per 100 000 = 3703; 95% CI = 3235, 4240) and 984 915 were White persons (cumulative incidence per 100 000 = 2819; 95%

CI = 2527, 3144). After adjusting for age, during the postvaccination period, the rate of COVID-19 among AI/AN persons was 1.31 (95% CI = 1.17, 1.48; $P < .05$) times that among White persons. For each age and sex category, COVID-19 incidence was significantly greater among AI/AN persons than among White persons (Table 1).

Completeness of data on COVID-19–related hospitalization, ICU admission, and death were higher among White persons than AI/AN persons during our period of interest, including during the pre- and postvaccination periods (Table 2). During January 22, 2020, through October 19, 2021, hospitalization status, ICU admission status, and death status were known for 63.7%, 13.5%, and 59.3%, respectively, of White COVID-19 patients, whereas

60.0% of hospitalization status, 6.4% of ICU admission status, and 50.9% of death status were known for AI/AN COVID-19 patients. Because of the disproportionate amount of missing hospitalization, ICU admission, and death status data, we could not analyze COVID-19–related severe outcomes.

DISCUSSION

AI/AN persons experienced a disproportionate rate of COVID-19 than did White persons (RR = 1.66; 95% CI = 1.36, 2.01; $P < .05$) in US urban areas from January 22, 2020, to October 19, 2021. However, the disparity in the rate of COVID-19 comparing AI/AN with White persons was lower in the postvaccination period than in the prevaccination period. Given that AI/AN communities have some of the highest rates of COVID-19 vaccination in the United States,^{11,12} these findings suggest that COVID-19 vaccination and other public health efforts among AI/AN communities in urban areas may have been successful in reducing the COVID-19 disease burden.

The decreased rate of COVID-19 in AI/AN persons compared with White persons during the postvaccination period may be attributable to the COVID-19 vaccine, immunity from previous infection, and continued physical distancing and mask wearing in AI/AN communities.²² A previous study showed reduced disease burden of COVID-19 in fully vaccinated adults, regardless of race and ethnicity, compared with unvaccinated adults in 13 US jurisdictions, where the risk of COVID-19 infection, hospitalization, and deaths were significantly lower.²³ In addition, efforts by AI/AN communities and organizations such as the Urban Indian Health Institute, Tribal

TABLE 1— Laboratory-Confirmed COVID-19 Cases and Cumulative Incidence and RRs for Non-Hispanic American Indian/Alaska Native and Non-Hispanic White Persons in Urban Areas, by Age and Sex Groups, in the Overall, Pre- and Postvaccination Periods: United States, January 22, 2020–October 19, 2021

Characteristics	AI/AN, ^a No. (%)	AI/AN, ^a Cumulative Incidence ^b (95% CI)	Non-Hispanic White, No. (%)	Non-Hispanic White Cumulative Incidence, ^b (95% CI)	RR ^c (95% CI)
Overall (January 22, 2020–October 19, 2021; 326 urban counties)^d					
Total	47 431	12 360 (1 0230, 1 4930)	2 254 480	7 468 (6 881, 8 106)	1.66 ^e (1.36, 2.01)
Age group, y					
0–19	10 328 (21.8)	9 045 (7 804, 1 0480)	400 670 (17.8)	5 998 (5 486, 6 559)	1.51 ^e (1.28, 1.78)
20–54	27 423 (57.8)	15 080 (1 2500, 1 8200)	1 190 324 (52.8)	9 122 (8 325, 9 995)	1.65 ^e (1.36, 2.01)
≥55	9 680 (20.4)	11 860 (9 334, 1 5070)	6 63486 (29.4)	6 368 (5 954, 6 810)	1.86 ^e (1.46, 2.38)
Sex ^f					
Female	25 891 (54.6)	13 280 (1 1120, 1 5860)	1 188 188 (52.7)	7 751 (7 155, 8 404)	1.71 ^e (1.42, 2.06)
Male	21 352 (45.0)	11 610 (9 598, 1 4050)	1 063 320 (47.2)	7 153 (6 575, 7 782)	1.52 ^e (1.33, 1.99)
Before vaccination (January 22, 2020–April 4, 2021; 345 urban counties)^g					
Total	36 278	8 227 (6 283, 1 0770)	1 586740	4 416 (3 982, 4 897)	1.86 ^e (1.41, 2.45)
Age group, y					
0–19	7 129 (19.7)	5 652 (4 461, 7 162)	237 862 (15.0)	3 050 (2 684, 3 466)	1.85 ^e (1.44, 2.39)
20–54	21 149 (58.3)	10 070 (7 701, 1 3170)	842 644 (53.1)	5 372 (4 785, 6 031)	1.87 ^e (1.43, 2.47)
≥55	8 000 (22.0)	8 324 (6 155, 1 1260)	506 234 (31.9)	4 106 (3 780, 4 460)	2.03 ^e (1.50, 2.75)
Sex ^f					
Female	19 804 (54.8)	8 853 (6 871, 1 1410)	839 028 (52.9)	4 597 (4 157, 5 084)	1.93 ^e (1.49, 2.49)
Male	16 325 (45.2)	6 345 (4 662, 8 634)	745 912 (47.1)	2 761 (2 450, 3 112)	1.83 ^e (1.38, 2.43)
After vaccination (April 5, 2021–October 19, 2021; 322 urban counties)^h					
Total	16 117	3 703 (3 235, 4 240)	984 915	2 819 (2 527, 3 144)	1.31 ^e (1.17, 1.48)
Age group, y					
0–19	4 257 (26.4)	3 339 (2 957, 3 770)	214 166 (22.0)	2 867 (2 615, 3 143)	1.16 ^e (1.03, 1.32)
20–54	9 119 (56.6)	4 391 (3 757, 5 131)	517 309 (53.1)	3 419 (3 039, 3 847)	1.28 ^e (1.12, 1.47)
≥55	2 741 (17.0)	2 965 (2 617, 3 360)	253 440 (25.9)	2 165 (1 943, 2 413)	1.37 ^e (1.24, 1.51)
Sex ^f					
Female	12 292 (54.2)	3 993 (3 504, 4 550)	815 072 (52.5)	2 947 (2 647, 3 282)	1.35 ^e (1.21, 1.52)
Male	10 295 (45.4)	3 442 (2 976, 3 980)	733 442 (47.3)	2 779 (2 501, 3 089)	1.24 ^e (1.09, 1.40)

Note. AI/AN=American Indian and Alaska Native; CI=confidence interval; RR=risk ratio.

Source. National Notifiable Disease Surveillance System, Centers for Disease Control and Prevention COVID-19 case reports, 2018 National Center for Health Statistics bridged-race population estimates.

^aAlone or in combination with other races and non-Hispanic.

^bRate per 100 000 population.

^cRR for AI/AN vs non-Hispanic White persons.

^d40 states: AL, AZ, AR, CA, CO, FL, GA, ID, IL, IN, IA, KS, KY, LA, MA, ME, MD, MI, MN, MS, MO, MT, NE, NJ, NM, NV, NC, OH, OK, PA, SC, SD, TN, TX, UT, VT, VA, WA, WV, WI; 326 urban counties.

^eRR is statistically significant ($P < .05$).

^fOmits cases where sex is listed as missing, unknown, or other.

^g40 states: AL, AZ, AR, CA, CO, FL, GA, ID, IL, IN, IA, KS, KY, LA, ME, MD, MI, MN, MS, MO, MT, NE, NJ, NM, NV, NC, OH, OK, PA, SC, SD, TN, TX, UT, VT, VA, WA, WV, WI, WY; 345 urban counties.

^h37 states: AL, AZ, AR, CA, CO, FL, GA, ID, IL, IN, IA, KS, KY, ME, MD, MI, MN, MT, NE, NJ, NM, NV, NC, OH, OK, PA, SC, SD, TN, TX, UT, VT, VA, WA, WV, WI, WY; 322 urban counties.

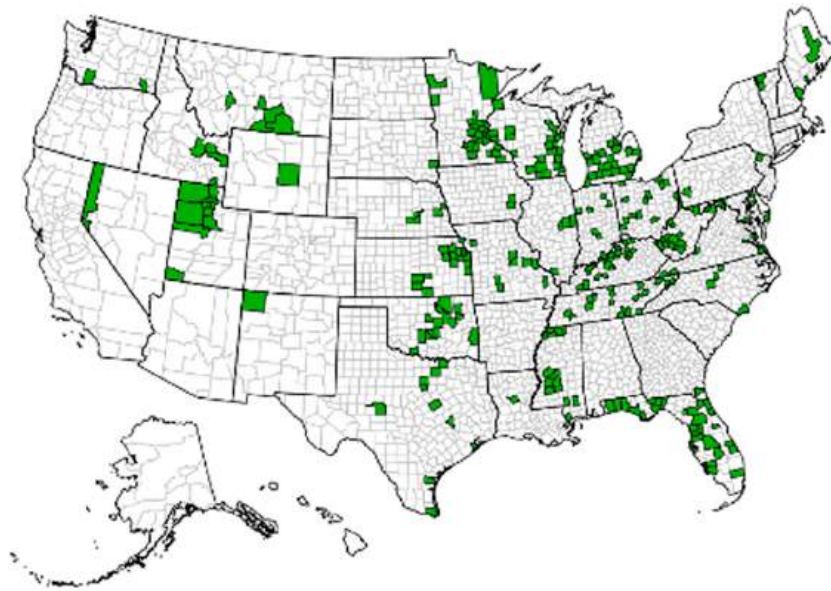


FIGURE 2— Urban Counties Included in the County-Level Analysis of COVID-19 Cases Before and After the Vaccination Period in Non-Hispanic American Indian/Alaska Native and Non-Hispanic White Persons: United States, January 22, 2020–October 19, 2021

Note. Urban counties indicate 2013 National Center for Health Statistics Urban–Rural Classification Scheme for Counties (https://www.cdc.gov/nchs/data/series/sr_02/sr02_166.pdf) and Urban Indian Health Program/Urban Indian Health Network service counties (including nonurban counties: KS: Reno County; MT: Big Horn, Broadwater, Jefferson, Lewis and Clark, and Silver Bow counties; NV: Churchill and Douglas counties; OK: Pottawatomie County; SD: Brown, Hughes, and Stanley counties). The 345 urban counties and 40 states in the prevaccine period (January 22, 2020–April 4, 2021) were AL, AZ, AR, CA, CO, FL, GA, ID, IL, IN, IA, KS, KY, LA, ME, MD, MI, MN, MS, MO, MT, NE, NJ, NM, NV, NC, OH, OK, PA, SC, SD, TN, TX, UT, VT, VA, WA, WV, WI, WY. The 322 urban counties and 37 states in the postvaccine period (April 5, 2021–October 19, 2021) were AL, AZ, AR, CA, CO, FL, GA, ID, IL, IN, IA, KS, KY, ME, MD, MI, MN, MT, NE, NJ, NM, NV, NC, OH, OK, PA, SC, SD, TN, TX, UT, VT, VA, WA, WV, WI, WY.

Health Boards, Tribal Health Clinics, and Indian Health Service facilities to increase COVID-19 vaccination uptake in urban and rural tribal settings through vaccination events and campaigns (e.g., For the Love of Our People²⁴) have likely played a critical role in decreasing COVID-19 risk in AI/AN persons. Many of these AI/AN community-led vaccination strategies have focused on protecting elders and the community and addressing vaccine hesitancy.

Although the resulting high rate of vaccination among AI/AN is an achievement, we found significantly higher rates of COVID-19 for each age and sex category of AI/AN persons compared with White persons in urban areas for the overall period we examined, including in the pre- and postvaccination

periods. Previous studies have shown that AI/AN populations often have a higher prevalence of underlying health conditions (e.g., diabetes, obesity, heart conditions) and limited access to quality health care and health insurance than do other racial groups;^{10,25–27} therefore, AI/AN persons with underlying conditions may be at increased risk for COVID-19 and severe outcomes. Additionally, reports on the impact of the COVID-19 pandemic among persons of color show higher risk and exposure to COVID-19 compared with White persons, as they are highly represented in low-wage essential work, are caregivers at home, and provide services for others,²⁸ including residing in highly populated urban areas and in overcrowded conditions as well as relying on public transportation—making

social distancing difficult.⁹ Therefore, continued efforts to reduce the risk of COVID-19 exposure and transmission through public health measures such as masking, physical distancing, up-to-date vaccination, and booster doses where appropriate remain important.^{29–31}

Higher percentages of unknown and missing COVID-19 severe health outcomes data in AI/AN persons demonstrate the need for more complete COVID-19 data for hospitalization, ICU admission, and death. Missing data regarding race/ethnicity, COVID-19 symptoms, underlying health conditions, and severe outcomes not only reduced the statistical power of this study but also precluded certain meaningful epidemiologic analyses of COVID-19 in urban AI/AN people.³²

TABLE 2— Reported Cases and Proportions of Known and Unknown COVID-19–Related Hospitalization, ICU Admission, and Death for Non-Hispanic American Indian/Alaska Native and Non-Hispanic White Persons in Urban Areas for the Overall, Pre-, and Postvaccination Periods: United States, January 22, 2020–October 19, 2021

Severe Outcomes	Overall (Jan. 22, 2020–Oct. 19, 2021) ^a		Before Vaccination (Jan. 22, 2020–Apr. 4, 2021) ^b		After Vaccination (Apr. 5, 2021–Oct. 19, 2021) ^c	
	AI/AN, ^d No. (%)	Non-Hispanic White, No. (%)	AI/AN, ^d No. (%)	Non-Hispanic White, No. (%)	AI/AN, ^d No. (%)	Non-Hispanic White, No. (%)
Total	47 431	2 254 480	36 278	1 586 740	16 117	984 915
Hospitalization						
Known ^e	28 471 (60.0)	1 435 572 (63.7)	25 203 (69.5)	1 148 136 (72.4)	7 801 (48.4)	464 554 (47.2)
Unknown ^f	18 960 (40.0)	818 908 (36.3)	11 075 (30.5)	438 604 (27.6)	8 316 (51.6)	520 361 (52.8)
ICU admission						
Known ^e	3 039 (6.4)	304 578 (13.5)	2 482 (6.8)	264 382 (16.7)	1 014 (6.3)	87 514 (8.9)
Unknown ^f	44 392 (93.6)	1 949 902 (86.5)	33 796 (93.2)	1 322 358 (83.3)	15 103 (93.7)	897 401 (91.1)
Death						
Known ^e	24 148 (50.9)	1 337 482 (59.3)	20 652 (56.9)	1 008 694 (63.6)	9 682 (60.0)	600 137 (60.9)
Unknown ^f	23 283 (49.1)	916 998 (40.7)	15 626 (43.1)	578 046 (36.4)	6 435 (40.0)	384 778 (39.1)

Note. AI/AN = American Indian and Alaska Native; ICU = intensive care unit.

Source. National Notifiable Disease Surveillance System, Centers for Disease Control and Prevention COVID-19 case reports.

^a40 states: AL, AZ, AR, CA, CO, FL, GA, ID, IL, IN, IA, KS, KY, LA, MA, ME, MD, MI, MN, MS, MO, MT, NE, NJ, NM, NV, NC, OH, OK, PA, SC, SD, TN, TX, UT, VT, VA, WA, WV, WI; 326 urban counties.

^b40 states: AL, AZ, AR, CA, CO, FL, GA, ID, IL, IN, IA, KS, KY, LA, ME, MD, MI, MN, MS, MO, MT, NE, NJ, NM, NV, NC, OH, OK, PA, SC, SD, TN, TX, UT, VT, VA, WA, WV, WI, WY; 345 urban counties.

^c37 states: AL, AZ, AR, CA, CO, FL, GA, ID, IL, IN, IA, KS, KY, ME, MD, MI, MN, MT, NE, NJ, NM, NV, NC, OH, OK, PA, SC, SD, TN, TX, UT, VT, VA, WA, WV, WI, WY; 322 urban counties.

^dAlone or in combination with other races and non-Hispanic.

^eHospitalization, ICU admission, and death status were considered known if the response was “yes” or “no” (not “missing” or “unknown”).

^fHospitalization, ICU admission, and death status were considered unknown if the response was “missing” or “unknown” (not “yes” or “no”).

Limitations

This study has several notable limitations. First, race and ethnicity data are disproportionately missing for racial minorities.³³ Second, population-based surveillance systems commonly misclassify AI/AN people as other races or ethnicities, resulting in an underestimate of AI/AN morbidity and mortality.³⁴ Third, our postvaccination period began April 5, 2021, when more than 25% of AI/AN people in the United States were fully vaccinated, and served as a conservative estimate of the postvaccination period. Fourth, the counties studied in the postvaccination period were standardized to urban counties of the prevaccination period; therefore,

not all the counties in the postvaccination period necessarily met the more than 5 cases of AI/AN and White persons and the 70% or more complete race/ethnicity data requirements that the overall and prevaccination period counties did, and there might have been more missing race/ethnicity information in the counties during the postvaccination period. Fifth, because the National Center for Health Statistics bridged-race population denominator estimates are reliable only for non-Hispanic AI/AN people, this study excludes people who identify as Hispanic AI/AN, which may lead to an undercount of total AI/AN cases.^{34,35} Sixth, our findings are observational, and we were not able to determine

causality. Finally, we excluded 72% (n = 857) and 70% (n = 831) of urban counties from the aggregate and time analyses, respectively, because of incomplete race/ethnicity data. Notably, the AI/AN populations from urban counties in the aggregate time frame of this study represent only 14.5% of all urban AI/AN individuals in the country—based on 2020 postcensal estimates of the AI/AN population. Therefore, these findings may not be generalizable to the overall national urban AI/AN population.

Conclusions

Our study highlights the disproportionate burden of COVID-19 among AI/AN persons in urban areas from January 22,

2020, through October 19, 2021, and before COVID-19 vaccines were available in the United States. Importantly, it also highlights a significant achievement by tribal public health professionals and communities, demonstrating a decreased disparity in COVID-19 rates among AI/AN compared with White persons before and after vaccination. Finally, this research contributes to the limited scientific literature on COVID-19 in urban AI/AN people. As others have noted, an urgent need for complete COVID-19 case surveillance data remains,^{4,33} and health and mortality status assessments for AI/AN populations are often hindered by a lack of complete and accurate data on race and ethnicity in surveillance and vital statistics systems.³⁴ An immediate starting point is to support health care providers, laboratories, and local, tribal, state, and federal agencies to consistently collect and report complete COVID-19 data. Complete data allow a full understanding of COVID-19 in vulnerable, yet resilient, communities to ensure they have the information needed to rapidly respond to COVID-19.

Specifically, complete COVID-19 data are needed in the National Notifiable Disease Surveillance System to fully characterize COVID-19 in AI/AN people, including more complete reporting of race/ethnicity, comorbid conditions, exposure information, symptoms, hospitalization, ICU admission, and death. Our findings can help inform national and local public health actions to reduce COVID-19 transmission, improve health outcomes, address equity in vaccination, and increase resiliency in urban AI/AN communities. *AJPH*

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CONTRIBUTORS

D. Pete assisted with the analysis and led the writing. S. L. Erickson completed the analyses. S. L. Erickson, M. A. Jim, S. M. Hatcher, and A. E. Dominguez assisted with results interpretation. S. L. Erickson, M. A. Jim, S. M. Hatcher, and A. Echo-Hawk assisted with writing. M. A. Jim formulated the data analyses. S. M. Hatcher assisted in developing the analysis methods. A. Echo-Hawk reviewed the article. A. E. Dominguez supervised the study.

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CONFLICTS OF INTEREST

The authors have no conflicts of interest to declare.

HUMAN PARTICIPANT PROTECTION

No protocol approval was necessary because no human participants were involved in this study.

REFERENCES

- Centers for Disease Control and Prevention. COVID-19 mortality among American Indian and Alaska Native Persons—14 states, January–June 2020. *MMWR Morb Mortal Wkly Rep*. 2020;69(49): 1853–1856. [Erratum in: *MMWR Morb Mortal Wkly Rep*. 2021;70(1):24]. <https://doi.org/10.15585/mmwr.mm6949a3>.
- Centers for Disease Control and Prevention. Coronavirus disease 2019 case surveillance—United States, January 22–May 30, 2020. *MMWR Morb Mortal Wkly Rep*. 2020;69(24):759–765. <https://doi.org/10.15585/mmwr.mm6924e2>
- Centers for Disease Control and Prevention. COVID data tracker. July 28, 2022. Available at: <https://covid.cdc.gov/covid-data-tracker>. Accessed October 14, 2021.
- Centers for Disease Control and Prevention. COVID-19 among American Indian and Alaska Native persons—23 states, January 31–July 3, 2020. *MMWR Morb Mortal Wkly Rep*. 2020;69(34): 1166–1169. <https://doi.org/10.15585/mmwr.mm6934e1>
- Urban Indian Health Commission. *Invisible Tribes: Urban Indians and Their Health in a Changing World*. Seattle, WA; 2007.
- US Census Bureau. The American Indian and Alaska Native population: 2010. Available at: <https://www.census.gov/library/publications/2012/dec/c2010br-10.html>. Accessed December 9, 2021.
- Jaimes MA. *The State of Native America: Genocide, Colonization, and Resistance*. Boston, MA: South End Press; 1992.
- James RD, West KM, Claw KG, et al. Responsible research with urban American Indians and Alaska Natives. *Am J Public Health*. 2018;108(12): 1613–1616. <https://doi.org/10.2105/AJPH.2018.304708>
- Dubay L, Aarons J, Brown KS, Kenney GM. How risk of exposure to the coronavirus at work varies by race and ethnicity and how to protect the health and well-being of workers and their families. December 2, 2020. Available at: <https://www.urban.org/research/publication/how-risk-exposure-coronavirus-work-varies-race-and-ethnicity-and-how-protect-health-and-well-being-workers-and-their-families>. Accessed January 12, 2022.
- Urban Indian Health Institute. Old UIHP profiles page. Available at: <https://www.uihi.org/old-uihp-profiles-page>. Accessed October 14, 2021.
- Hill L, Artiga S. COVID-19 vaccination among American Indian and Alaska Native People. April 9, 2021. Available at: <https://www.kff.org/racial-equity-and-health-policy/issue-brief/covid-19-vaccination-american-indian-alaska-native-people>. Accessed October 14, 2021.
- Silberner J. COVID-19: how Native Americans led the way in the US vaccination effort. *BMJ*. 2021; 374:n2168. <https://doi.org/10.1136/bmj.n2168>
- US Food and Drug Administration. FDA takes key action in fight against COVID-19 by issuing emergency use authorization for first COVID-19 vaccine. December 11, 2020. Available at: <https://www.fda.gov/news-events/press-announcements/fda-takes-key-action-fight-against-covid-19-issuing-emergency-use-authorization-first-covid-19>. Accessed October 14, 2021.
- US Food and Drug Administration. FDA takes additional action in fight against COVID-19 by issuing emergency use authorization for second COVID-19 vaccine. December 18, 2020. Available at: <https://www.fda.gov/news-events/press-announcements/fda-takes-additional-action-fight-against-covid-19-issuing-emergency-use-authorization-second-covid>. Accessed October 14, 2021.

15. US Food and Drug Administration. FDA issues emergency use authorization for third COVID-19 vaccine. December 18, 2020. Available at: <https://www.fda.gov/news-events/press-announcements/fda-issues-emergency-use-authorization-third-covid-19-vaccine>. Accessed October 14, 2021.
16. Centers for Disease Control and Prevention. Information for health departments on reporting cases of COVID-19. May 25, 2022. Available at: <https://www.cdc.gov/coronavirus/2019-ncov/php/reporting-pui.html>. Accessed October 14, 2021.
17. Centers for Disease Control and Prevention. NNDSS supports the COVID-19 response. May 9, 2022. Available at: <https://www.cdc.gov/nndss/action/covid-19-response.html>. Accessed October 14, 2021.
18. Ingram DD, Franco SJ. 2013 NCHS urban-rural classification scheme for counties. *Vital Health Stat 2*. 2014;(166):1-73
19. US Census Bureau. About the topic of race. Available at: <https://www.census.gov/topics/population/race/about.html>. Accessed October 14, 2021.
20. Hanley JA, Negassa A, Edwardes MD, Forrester JE. Statistical analysis of correlated data using generalized estimating equations: an orientation. *Am J Epidemiol*. 2003;157(4):364-375. <https://doi.org/10.1093/aje/kwf215>
21. Centers for Disease Control and Prevention. Bridged-race population estimates—data files and documentation. September 22, 2021. Available at: https://www.cdc.gov/nchs/nvss/bridged_race/data_documentation.htm. Accessed October 14, 2021.
22. Centers for Disease Control and Prevention. Racial and ethnic disparities in COVID-19 incidence by age, sex, and period among persons aged <25 years—16 US jurisdictions, January 1–December 31, 2020. *MMWR Morb Mortal Wkly Rep*. 2021;70(11):382-388. <https://doi.org/10.15585/mmwr.mm7011e1>
23. Centers for Disease Control and Prevention. Monitoring incidence of COVID-19 cases, hospitalizations, and deaths, by vaccination status—13 US jurisdictions, April 4–July 17, 2021. *MMWR Morb Mortal Wkly Rep*. 2021;70(37):1284-1290. <https://doi.org/10.15585/mmwr.mm7037e1>
24. Urban Indian Health Institute. For the love of our people. Available at: <https://fourpeople.uih.org>. Accessed February 17, 2022.
25. Melkonian SC, Jim MA, Haverkamp D, et al. Disparities in cancer incidence and trends among American Indians and Alaska Natives in the United States, 2010–2015. *Cancer Epidemiol Biomarkers Prev*. 2019;28(10):1604-1611. <https://doi.org/10.1158/1055-9965.EPI-19-0288>
26. Goins RT, Pilkerton CS. Comorbidity among older American Indians: the native elder care study. *J Cross Cult Gerontol*. 2010;25(4):343-354. <https://doi.org/10.1007/s10823-010-9119-5>
27. Denny CH, Holtzman D, Goins RT, Croft JB. Disparities in chronic disease risk factors and health status between American Indian/Alaska Native and White elders: findings from a telephone survey, 2001 and 2002. *Am J Public Health*. 2005;95(5):825-827. <https://doi.org/10.2105/AJPH.2004.043489>
28. Obinna DN. "Essential and undervalued: health disparities of African American women in the COVID-19 era." *Ethn Health*. 2021;26(1):68-79. <https://doi.org/10.1080/13557858.2020.1843604>
29. US Food and Drug Administration. Coronavirus (COVID-19) update: FDA takes additional actions on the use of a booster dose for COVID-19 vaccines. October 21, 2021. Available at: <https://www.fda.gov/news-events/press-announcements/coronavirus-covid-19-update-fda-takes-additional-actions-use-booster-dose-covid-19-vaccines>. Accessed November 10, 2021.
30. Brooks JT, Butler JC. Effectiveness of mask wearing to control community spread of SARS-CoV-2. *JAMA*. 2021;325(10):998-999. <https://doi.org/10.1001/jama.2021.1505>
31. Kwon S, Joshi AD, Lo CH, et al. Association of social distancing and face mask use with risk of COVID-19. *Nat Commun*. 2021;12(1):3737. <https://doi.org/10.1038/s41467-021-24115-7>
32. Centers for Disease Control and Prevention. Coronavirus disease 2019 case surveillance—United States, January 22–May 30, 2020. *MMWR Morb Mortal Wkly Rep*. 2020;69(24):759-765. <https://doi.org/10.15585/mmwr.mm6924e>
33. Labgold K, Hamid S, Shah S, et al. Measuring the missing: greater racial and ethnic disparities in COVID-19 burden after accounting for missing race/ethnicity data. *medRxiv* [Preprint October 2, 2020:2020.09.30.20203315]; update in: *Epidemiology*. November 30, 2020]. <https://doi.org/10.1101/2020.09.30.20203315>
34. Espey DK, Jim MA, Cobb N, et al. Leading causes of death and all-cause mortality in American Indians and Alaska Natives. *Am J Public Health*. 2014;104(suppl 3):S303-S311. <https://doi.org/10.2105/AJPH.2013.301798>
35. Arias E, Xu J, Curtin S, Bastian B, Tejada-Vera B. Mortality profile of the non-Hispanic American Indian or Alaska Native population, 2019. *Natl Vital Stat Rep*. 2021;70(12):1-27.



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SNAP and WIC Participation During Childhood and Food Security in Adulthood, 1984–2019

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 See also Gundersen, p. 1370.

Objectives. To examine the effects of childhood participation in the Supplemental Nutrition Assistance Program (SNAP) and the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) on adult food security in the United States.

Methods. We used data from the 1984 to 2019 waves of the Panel Study of Income Dynamics to follow a balanced panel of 1406 individuals from birth through ages 20 to 36 years. We measured food insecurity from 1999 to 2003 and 2015 to 2019 among those who resided in low-income households during childhood.

Results. Twenty-eight percent of individuals who resided in low-income households during childhood exhibited improved food security status from childhood to adulthood. Those who participated in SNAP and WIC during childhood had 4.16-fold higher odds (95% confidence interval [CI] = 1.91, 9.03) of being more food secure than those who were eligible for but did not receive SNAP or WIC, and those who participated in SNAP alone had 3.28-fold higher odds (95% CI = 1.56, 6.88).

Conclusions. Participation in social safety net programs such as SNAP and WIC during childhood helps to improve food security across the life course. Our findings add evidence regarding the long-term benefits of participation in SNAP and WIC during childhood. (*Am J Public Health.* 2022;112(10):1498–1506. <https://doi.org/10.2105/AJPH.2022.306967>)

In 2019 in the United States, 13.7 million households (representing 10.5% of the population) experienced food insecurity, including 2.4 million households (6.5% of households) in which children experienced food insecurity.^{1,2} In 2020, despite the overall level of food insecurity across US households remaining, similar to that of 2019, food insecurity among households with children increased to 14.8% (from 13.6% in 2019), and in 7.6% of households, children were food insecure.³

Childhood food insecurity is associated with numerous adverse outcomes including anxiety, depression, poorer diet quality, higher rates of diabetes

and obesity, and lower academic performance.^{4–8} The Supplemental Nutrition Assistance Program (SNAP) and the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), 2 of the largest federal food assistance programs, aim to improve nutrition and food security among low-income people in the United States.^{3,4} One in 9 US residents received SNAP benefits in 2019, and more than half of the children born each year receive WIC benefits.^{9,10} Evidence suggests that SNAP and WIC participation improves food security at the time benefits are received.^{5–12} However, the effect of program participation on longer-term

food security status (FSS) is largely unknown.

Whether SNAP and WIC participation during childhood promotes food security later in life is a key area of inquiry given the programs' scale and the high prevalence of food insecurity among low-income US residents. This is especially salient now given that SNAP enrollment during the first year of the COVID-19 pandemic increased 23% relative to 2019.¹¹ Several federal and state policy changes to both SNAP and WIC, including temporary expansion of SNAP eligibility, raising of SNAP benefits, and increased flexibility to waive program requirements, likely mitigated

early indicators of worsening food insecurity related to the pandemic.¹² In a national survey of low-income households in March 2020, 44% reported experiencing food insecurity.^{13–15} In the case of young children in particular, programs such as SNAP and WIC that ameliorate food insecurity could change their life course trajectories, although more longitudinal research on the effects of food insecurity during childhood is needed.

In this study, involving prospectively collected life course data from a large, nationally representative longitudinal survey in the United States, our primary aim was to quantify the impact of SNAP or WIC participation (or both) during childhood on adult food security outcomes among individuals who had ever resided in low-income households in childhood. We conducted our analysis at the individual level, assessing the relationship between participation in SNAP and WIC in childhood (ages 0–18 years) and FSS in adulthood once individuals had established their own households.

METHODS

We obtained data from the Panel Study of Income Dynamics (PSID), the world's longest-running nationally representative household panel survey.¹⁶ The study began in 1968 and has followed the members of the original sample and their descendants since that time, first annually and then (since 1997) biennially. For our study, we used data from the PSID main interview as well as the Child Development Supplement, which, starting in 1997, collected additional information about a cohort of children 0 to 12 years old in 1997 with follow-up waves in 2002 and 2007. To construct the analytic sample, we created a balanced panel of individuals who had SNAP and family

income information from their year of birth through the age of 18 years as well as WIC information from the PSID main interview or the Child Development Supplement.

We created a binary indicator for low income during childhood, coded as 1 if an individual was in a household whose income-to-needs ratio was less than or equal to 130% of the federal poverty level (the gross income threshold for SNAP) in any wave from ages 0 to 18 years. We limited the sample to individuals who were living independently as a reference person or spouse or partner in their own family unit in 2015, 2017, or 2019 (meaning that they had moved out of their parents' household and were economically independent) and who had resided in a low-income household during at least 1 time period during childhood ($n = 1406$).

Individuals who had not split off from their natal homes by 2019 were not included in the analytic sample because their FSS was that reported by their parents or guardians and they did not have the same detailed employment, race/ethnicity, or income information as their economically independent counterparts. Individuals still living in their natal homes were more likely to be in the youngest age category (20–26 years), to be male, and to have a high school education or less. The PSID is nationally representative of the US population when sample weights are applied.

The PSID and the Child Development Supplement collect in-depth information on demographic characteristics, income, and health status, following multiple generations of the same families over time. This enables analysis of firsthand, prospective reporting of income, SNAP and WIC participation, family composition, and social environment during childhood through adulthood.

We measured FSS using the US Department of Agriculture's 18-question Household Food Security Survey Module, which is scored to create a 4-category food security measure: high food security (score = 1), marginal food security (score = 2), low food security (score = 3), or very low food security (score = 4).¹⁷ FSS was measured in 1999, 2001, 2003, 2015, 2017, and 2019.

Outcomes for our analyses were 2 binary measures capturing changes in FSS from childhood (1999–2003) to adulthood (2015–2019), the first indicating that FSS had improved (more secure) and the second indicating that FSS had worsened (less secure). Changes in food security were based on average food security scores for up to 3 childhood waves (1999–2003) and average scores for up to 3 adulthood waves (2015–2019). Average scores were then categorized back into a 4-category average FSS variable: high (average score of 1.0; high food security in all waves), marginal (average score of 1.33–2.33; marginal food security in at least 1 wave), low (average score of 2.5–3.33; multiple waves of marginal, low, or very low food security with at least 1 wave of low food security), or very low (average score of 3.5–4.0; multiple waves of low or very low food security with at least 1 wave of very low food security).

Individuals were defined as having become more secure if their average FSS improved from childhood to adulthood. Individuals were coded 1 if they were more secure and 0 if their FSS worsened or stayed the same. Conversely, individuals were defined as being less secure if their average FSS worsened from childhood to adulthood. In this case, individuals were coded 1 if they became less food secure and 0 if their FSS improved or stayed the same. As a robustness

check, we also created binary measures of improved and worsened FSS by selecting the minimum, maximum, and single wave values from childhood and adulthood; the resulting trends were the same (Appendix A, available as a supplement to the online version of this article at <http://www.ajph.org>).

Family SNAP participation during childhood was measured in all available waves from an individual's birth through the age of 18 years. Multiple questions were aggregated to define whether the child's family received SNAP benefits in the previous year, how many months they used SNAP in the previous year, and receipt in the preceding month.

In the Child Development Supplement, primary caregivers were asked whether the target child received WIC benefits in the primary caregiver-child portion of the 1997 interview. Primary caregivers were asked whether they received benefits when pregnant with that child, as well as after the child was born. Because WIC benefits are available to eligible children 0 to 5 years old, we used information from the PSID main interview for 1999 to 2003 (at which point all children in the analytic sample were at least 5 years old) to capture additional WIC receipt for children who were younger than 5 years after 1997. We then created a binary indicator of whether these children received WIC benefits at any point when they were 0 to 5 years old. The key independent variable for the analyses was a 4-category variable that captured whether individuals received the following during childhood: (1) no SNAP or WIC benefits, (2) SNAP alone, (3) WIC alone, or (4) both SNAP and WIC.

Covariates included individual- and family-level measures taken from 2015 to 2019. Individual-level measures included age (20–26, 27–31, 32–36 years), sex

(male, female), race/ethnicity (non-Hispanic White, non-Hispanic Black, Hispanic, other), marital status (married, never married, divorced/separated/widowed), educational attainment (less than high school, high school or equivalent, some college, college degree or greater), employment (employed, unemployed, out of the labor force, nonworking student), and time since “launch” (the number of waves since individuals had split off from their parental family units). Family-level covariates included log of total family income, region of residence (Northeast, South, Midwest, West), metropolitan or nonmetropolitan status, and family unit size.

We used PSID-provided individual longitudinal survey weights in all of our analyses, which allowed us to generate nationally representative estimates and account for sample attrition, clustering, and strata. Initially, we generated weighted cross tabulations to examine participation in SNAP and WIC during childhood and transitions between food insecurity status in childhood and adulthood. Because of the potential for bidirectional associations, we tested whether receipt of SNAP or WIC was associated with higher odds of improved or worsened food security in adulthood. To do so, we estimated 2 logit models in which the outcome was the change in FSS (improved or worsened) from childhood to adulthood after adjustment for each of our individual- and family-level covariates.

As a robustness check, we also estimated multinomial logistic models adjusted for our covariates with a 4-category outcome variable in which 1 represented more secure, 2 represented less secure, 3 represented always high food security, and 4 represented always food insecurity (marginal, low, very low; see Appendix B, available

as a supplement to the online version of this article at <http://www.ajph.org>).

Analyses were conducted in 2020–2021 with Stata version 15 (StataCorp LLC, College Station, TX); all tests were 2 sided, and significance was set at $P < .05$. Survey weights and original sampling strata and clusters were applied to all analyses with *svyset* commands, and postestimation *margins* commands were used to generate predicted probabilities of improved or worsened FSS.

RESULTS

Characteristics of the study sample are described in Table 1, overall and by adult FSS; in the context of this table, food insecure is defined as having low or very low food security from 2015 to 2019. Nearly 47% of the sample received SNAP and WIC during childhood, with an additional 32% receiving SNAP alone and 5% receiving WIC alone. Individuals who experienced food insecurity in adulthood were significantly more likely to have received SNAP at some point during childhood. Individuals who experienced food insecurity in adulthood were also significantly more likely to have lower incomes and to be less educated, unmarried, and unemployed ($P < .01$).

According to weighted transitions between average FSS from childhood (1999–2003) to adulthood (2015–2019), 24.4% of the sample reported high food security at every time point. Of the total sample, 28% saw improved FSS from childhood to adulthood, whereas 32.6% had worsened FSS (Appendix C, Table C1, available as a supplement to the online version of this article at <http://www.ajph.org>).

Figure 1 shows the weighted distributions of SNAP receipt during different

TABLE 1— Characteristics of the Study Sample, Overall and by Adult Food Security Status: Panel Study of Income Dynamics, United States, 1984–2019

	Overall (n = 1406), % (95% CI) or Mean ±SE	Food Secure ^a (n = 866), % (95% CI) or Mean ±SE	Food Insecure ^a (n = 540), % (95% CI) or Mean ±SE	p ^b
Total	100	65	35	
SNAP and WIC benefits in childhood				< .01
None	16.5 (13.3, 20.4)	21.3 (16.8, 26.6)	7.7 (4.6, 12.5)	
SNAP alone	31.8 (27.4, 36.7)	31.1 (25.9, 36.8)	33.2 (27.0, 40.1)	
WIC alone	4.9 (3.1, 7.7)	5.54 (2.94, 10.2)	3.65 (1.9, 6.83)	
SNAP and WIC	46.8 (41.0, 52.7)	42.1 (35.3, 49.2)	55.5 (47.7, 62.9)	
SNAP benefits in childhood	78.6 (74.7, 82.0)	73.2 (67.4, 78.2)	88.7 (84.1, 92.1)	< .01
WIC benefits in childhood	51.6 (46.1, 57.2)	47.6 (41.1, 54.3)	59.1 (51.3, 66.5)	.01
Income, \$	57 310 ±2029	67 725 ±2942	37 965 ±1858	< .01
Sex				.09
Male	48.5 (43.8, 53.2)	51.3 (45.6, 57)	43.2 (35.7, 51)	
Female	51.5 (46.8, 56.2)	48.7 (49, 64.3)	56.8 (43, 54.4)	
Age, y				< .01
20–26	27.9 (24.3, 31.9)	22.0 (18.0, 26.5)	39.0 (31.3, 47.3)	
27–31	36.3 (32.5, 40.3)	38.7 (33.2, 44.5)	31.9 (26.6, 37.7)	
32–36	35.8 (32.3, 39.4)	39.3 (34.5, 44.4)	29.1 (23.1, 36.0)	
Waves since launch ^c	3.0 ±0.08	3.0 ±0.10	3.0 ±0.15	.85
Race/ethnicity				.24
Non-Hispanic White	50.8 (43.5, 58.1)	51.9 (43.7, 60.0)	48.7 (38.7, 58.8)	
Non-Hispanic Black	25.1 (19.0, 32.4)	22.5 (16.2, 30.4)	29.9 (20.8, 40.9)	
Hispanic	20.0 (15.0, 26.2)	22.0 (17.1, 27.9)	16.2 (9.4, 26.6)	
Other	4.1 (2.4, 6.9)	3.6 (1.8, 7.1)	5.1 (2.6, 9.8)	
Family size	2.46 ±0.06	2.50 ±0.07	2.37 ±0.08	.23
No. of children	0.88 ±0.05	0.88 ±0.07	0.89 ±0.07	.11
No. of adults	1.58 ±0.02	1.63 ±0.02	1.48 ±0.04	< .01
Education				< .01
< high school	10.5 (8.4, 13.2)	7.2 (5.1, 10.1)	16.7 (12.7, 21.6)	
High school or equivalent	38.0 (33.6, 42.6)	34.5 (29.4, 40.1)	44.5 (37.8, 51.4)	
Some college	31.7 (27.2, 36.6)	31.9 (26.3, 38.0)	31.4 (25.4, 38.1)	
≥ college	19.7 (16, 24.2)	26.4 (20.8, 32.8)	7.4 (4.5, 11.8)	
Employment status				< .01
Employed	76.2 (72.4, 79.5)	79.8 (75.9, 83.3)	69.3 (62.9, 75.1)	
Unemployed	12.9 (10.1, 16.3)	10.0 (7.16, 13.9)	18.2 (12.5, 25.6)	
Out of labor force	8.7 (6.9, 10.9)	7.1 (5.0, 10.0)	11.6 (8.6, 15.5)	
Student	2.3 (1.5, 3.7)	3.07 (1.9, 5.0)	0.9 (0.3, 3.1)	
Urbanicity				.46
Metropolitan	79.4 (75.1, 83.1)	78.3 (72.5, 83.1)	81.4 (74.3, 86.9)	
Nonmetropolitan	20.6 (16.9, 24.9)	21.7 (16.9, 27.5)	18.6 (13.1, 25.7)	
Region				.88
Northeast	11.2 (6.54, 18.6)	11.5 (6.4, 19.9)	10.6 (5.82, 18.7)	
Central	25.5 (20.4, 31.4)	24.8 (18.9, 31.7)	26.9 (18.6, 37.2)	
South	40.5 (34.2, 47.1)	41.5 (34.7, 48.7)	38.6 (30.7, 47.1)	
West	22.8 (16.9, 30)	22.2 (15.9, 30.1)	23.9 (15, 35.7)	

Continued

TABLE 1— Continued

	Overall (n = 1406), % (95% CI) or Mean ±SE	Food Secure ^a (n = 866), % (95% CI) or Mean ±SE	Food Insecure ^a (n = 540), % (95% CI) or Mean ±SE	p ^b
Marital status				< .01
Married	47.2 (43.3, 51.1)	53.4 (48.8, 58.0)	35.7 (28.8, 43.3)	
Never married	46 (42.2, 50.0)	40.8 (36.2, 45.6)	55.8 (48.9, 62.5)	
Divorced or widowed	6.75 (5.0, 9.2)	5.81 (3.7, 8.9)	8.5 (5.0, 14.0)	

Note. CI = confidence interval; SNAP = Supplemental Nutrition Assistance Program; WIC = Special Supplemental Nutrition Program for Women, Infants, and Children. Data are weighted.

^aFood secure refers to high or marginal food security status in adulthood; food insecure refers to low or very low food security status in adulthood.

^bBased on χ^2 test.

^cNumber of waves since individuals split off from their parental family units.

stages of childhood and WIC receipt from ages 0 to 5 years among individuals who received SNAP during childhood (n = 1180). The combination of SNAP and WIC in early childhood (ages 0–5 years) was common, showing the potential for a synergistic relationship between the 2 programs. Among those

who received SNAP in childhood, 45.6% did so at ages 0–5 years, 6–11 years, and 12–18 years, and 30.6% of them also received WIC benefits. To be included in this category, these individuals were required to have lived in households that received SNAP benefits during at least 3 years in childhood,

at least 2 of which had to be nonconsecutive. This indicates that SNAP receipt is less often a 1-time experience for low-income families and more often a safety net for those in need over time.

A total of 15.1% of children received SNAP benefits only when they were 0 to 5 years old, and 7.3% received both SNAP and WIC benefits from ages 0 to 5 years. Some children received WIC alone between ages 0 and 5 years and subsequently participated in SNAP in middle and late childhood; however, the proportion of children who received SNAP benefits in later stages of childhood was much lower if they did not also receive benefits at ages 0 to 5 years.

Table 2 presents associations of SNAP or WIC participation during childhood with becoming more food secure (model 1) or less food secure (model 2) 16 to 20 years later. Children who received both SNAP and WIC benefits had 4.16-fold higher odds (95% confidence interval [CI] = 1.91, 9.03) of improved FSS in adulthood than those who did not receive either. Receipt of SNAP alone in childhood was associated with 3.28-fold higher odds (95% CI = 1.56, 6.88) of improved FSS in adulthood. None of the combinations

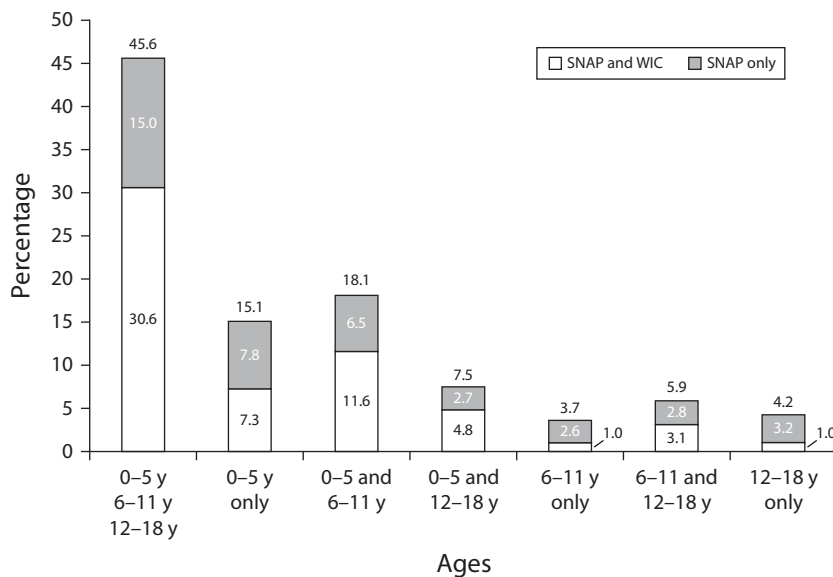


FIGURE 1— SNAP and WIC Participation Among Individuals Who Received SNAP in Childhood: Panel Study of Income Dynamics, United States, 1984–2019

Note. Supplemental Nutrition Assistance Program (SNAP) participation during different stages of childhood among children who received SNAP at any point during childhood. Participation in the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) occurs only during ages 0 to 5 years. Interpretation of the percentages in the figure is as follows: 15.1% of all children who ever received SNAP benefits received them only when they were 0 to 5 years old, and 7.3% of all children who received SNAP benefits during childhood received SNAP benefits when they were 0 to 5 years old and also received WIC benefits. The weighted sample size was 1180.

of SNAP and WIC receipt were associated with higher odds of worsened food security. Full model results are available in Appendix A, Table A3 (available as a supplement to the online version of this article at <http://www.ajph.org>).

Table 3 shows the predicted probabilities of becoming more or less food secure in adulthood on the basis of SNAP or WIC participation during childhood (as compared with not participating in either program). The predicted probability of being more food secure in adulthood was 33.9% for childhood SNAP and WIC recipients, as compared with 12.0% for those who did not receive either SNAP or WIC benefits (21.9% difference; $P < .001$). Receipt of SNAP alone was associated with a 29.2% predicted probability of being more food secure relative to nonreceipt of SNAP or WIC (17.2% difference; $P = .001$). These results were generally consistent with (and predicted

probabilities were nearly identical to) those from the multinomial logistic modeling approach used as a robustness check (Appendix B, Tables B2 and B3, available as a supplement to the online version of this article at <http://www.ajph.org>).

DISCUSSION

In this nationally representative, longitudinal study of the long-term effects of SNAP and WIC participation during childhood on adult FSS, we found that among individuals who resided in low-income households during childhood, receipt of SNAP alone and receipt of both SNAP and WIC were associated with significantly higher odds of improved FSS in adulthood. Furthermore, the predicted probabilities of becoming more food secure as an adult were 4 times higher in magnitude among those who received both SNAP and WIC and 3 times higher among

those who received SNAP alone than among those who did not receive either during childhood. Participation in WIC alone did not result in improved food security, but participation in both SNAP and WIC had an overall positive effect on FSS that was greater than that of participation in either program in isolation.

Although WIC is a widely used public safety net program, participation is limited to pregnant women and children younger than 5 years. WIC benefits are not intended to provide food for entire families, but when participants are also enrolled in SNAP the effects of the 2 programs may be synergistic.

Our findings uniquely add to the literature regarding the ways in which SNAP and WIC help participating families not only at the time of receipt but over the life course and across generations. Through the use of nationally representative, prospectively collected longitudinal data on income and federal food assistance program participation over 35 years, our study contributes new evidence regarding the long-term impact of SNAP and WIC participation on mitigating current and future food insecurity.

The mechanism by which SNAP and WIC receipt would have a positive impact on FSS over the long term was not explored in this study and is an important subject for future research. SNAP and WIC benefits offset food costs for participating families and may allow them to allocate those resources to other household needs that would contribute to positive trajectories for children, thereby affecting their long-term outcomes including future FSS. Possible mechanisms include being able to afford rent and having more stable housing, investing in educational activities, and having the ability to afford

TABLE 2— SNAP and WIC Participation in Childhood and Food Security Outcomes: Panel Study of Income Dynamics, United States, 1984–2019

	OR (95% CI)
Fully adjusted model: more secure (vs less secure or no change)	
SNAP alone	3.28 (1.56, 6.88)
WIC alone	1.87 (0.44, 7.92)
Both SNAP and WIC	4.16 (1.91, 9.03)
Fully adjusted model: less secure (vs more secure or no change)	
SNAP alone	1.38 (0.78, 2.46)
WIC alone	1.43 (0.73, 2.81)
Both SNAP and WIC	1.10 (0.60, 2.04)

Note. CI = confidence interval; OR = odds ratio; SNAP = Supplemental Nutrition Assistance Program; WIC = Special Supplemental Nutrition Program for Women, Infants, and Children. Logistic models adjusted for age, sex, race, marital status, educational attainment, employment status, time since launch, log of total family income, family unit size, region of residence, and metropolitan/nonmetropolitan status. The more secure outcome was coded as 1 if individuals became more secure (e.g., low food security in childhood and moderate food security in adulthood) and 0 if they became less secure or their food security status stayed the same. The less secure outcome was coded as 1 if individuals became less secure (e.g., high food security in childhood and moderate food security in adulthood) and 0 if they became more secure or their food security status stayed the same. The weighted sample size was 1406.

TABLE 3— SNAP and WIC Participation During Childhood and Food Insecurity Changes: United States, Panel Study of Income Dynamics, 1999–2019

	Predicted Probability, % (Difference)	P
Model 1: more secure (vs less secure or no change)		
Neither SNAP nor WIC	12.0 (Ref)	
SNAP alone	29.2 (17.2)	.001
WIC alone	19.7 (7.7)	.43
Both SNAP and WIC	33.9 (21.9)	<.001
Model 2: less secure (vs more secure or no change)		
Neither SNAP nor WIC	29.3 (Ref)	
SNAP alone	35.7 (6.4)	.25
WIC alone	36.4 (7.1)	.3
Both SNAP and WIC	31.3 (2.0)	.73

Note. SNAP = Supplemental Nutrition Assistance Program; WIC = Special Supplemental Nutrition Program for Women, Infants, and Children. Postestimation margins from logistic models were adjusted for age, sex, race, marital status, educational attainment, employment status, time since launch, log of total family income, family unit size, region of residence, and metropolitan/nonmetropolitan status. The more secure outcome was coded as 1 if individuals became more secure (e.g., low food security in childhood and moderate food security in adulthood) and 0 if they became less secure or their food security status stayed the same. The less secure outcome was coded as 1 if individuals became less secure (e.g., high food security in childhood and moderate food security in adulthood) and 0 if they became more secure or their food security status stayed the same. The weighted sample size was 1406.

medical care or medications.^{18–20} SNAP participants differed from their nonparticipating but eligible counterparts (e.g., participants tended to be younger and less educated), so the positive effects of SNAP and of SNAP and WIC in combination in this study may indicate that benefits are especially helpful in terms of not only purchasing food but providing financial stability, which has a positive influence on longer-term food security trajectories.^{21–23}

The protective effects of SNAP and the combination of SNAP and WIC are especially important now given the role of social safety net programs in mitigating food insecurity during the COVID-19 pandemic.²⁴ Despite early signs of record high levels of food insecurity, year-end estimates showed that food insecurity levels in 2020 were on par with levels in 2019.^{3,13} However,

disparities in food insecurity rates persist, particularly among households with children.³ Lack of access to in-person school and the economic fallout of the pandemic have been especially difficult for families with children, and although SNAP benefits and participation have increased, many families have not been able to access benefits.¹¹

Although temporary increases in SNAP benefits and administrative waivers that make it easier to enroll and maintain benefits have been critical during the pandemic, many of these changes are temporary.²⁵ Many families experienced food insecurity for the first time as a result of the adverse economic shocks brought on by the COVID-19 pandemic, and these families may be less likely to access benefits because they do not know that public benefits are available,

know that they are eligible, or know how to apply.^{26–28}

In addition, although SNAP benefits are helpful, they have often been insufficient to ensure a household's ability to purchase enough nutritious food to last throughout the month.²⁹ This may change in response to the recent revisions of the Thrifty Food Plan, which increased benefits by an average of 27% above prepandemic levels.^{30,31} Future research is needed to examine the effects of this benefit increase on food insecurity. WIC has also increased benefit allocations for fruits and vegetables during the pandemic in accordance with the American Rescue Plan Act of 2021, which could have a positive impact as well on both food security and diet quality among participating children.^{31,32}

Our findings indicate that there could be long-term consequences for today's children if current levels of food insecurity are not addressed. Participation in public safety net programs such as SNAP and WIC during childhood is key in helping families experiencing food insecurity put food on the table. SNAP has expanded rapidly during the pandemic, but more needs to be done to ensure that people who need SNAP benefits receive them and that benefits are sufficient to allow participants to purchase food consistent with a healthy diet.³³

Strengths and Limitations

Strengths of this study include the use of a nationally representative longitudinal panel survey with detailed income and SNAP participation data. These data are prospectively collected throughout all sample individuals' lives and provide consistent information on their environment from birth to present day. The genealogical design of the PSID provides

unparalleled information for life course research because children of sample members are followed once they leave their natal homes. This allows researchers to assume appropriate temporal order, minimize recall bias with prospective survey methods, and collect in-depth, self-reported information once individuals become householders themselves.

Several limitations of our study should also be considered. First, the initial measurement of food insecurity in the PSID occurred in 1999, and although we used all waves in which information was collected, FSS data were not collected from 2005 to 2013. Second, because of the biennial nature of PSID data collection after 1997, creating a continuous measure of SNAP participation at each age during childhood was not possible. Instead, a binary indicator of childhood SNAP receipt was included.

Third, because WIC benefits were measured at the child level and not at the household level, it is possible that household receipt of WIC was undercounted if siblings or other household members received WIC benefits. If so, this may have muted the potential effect of WIC benefit receipt during childhood on future FSS. Fourth, as a result of small cell sizes, binary measures of improved or worsened FSS did not differentiate the magnitude of FSS changes, which is an important area for future research. However, the majority of transitions in our study were within a single FSS level (e.g., marginal to high or marginal to low); dramatic transitions (e.g., from very low to high) were rare, mitigating some of this concern.

Finally, the present results may not be generalizable to children experiencing food insecurity today, as our sample comprised children at a period during which the economic environment, as

well as SNAP and WIC benefits, differed in key respects to the present day. The COVID-19 pandemic has created a particularly perilous economic situation for many low-income families, and SNAP and WIC benefits have undergone several key policy changes since 1984, when the oldest member of the analytic sample was born. These changes include program restrictions as a result of budget cuts in the early 1980s, increased access and decreased stigma from development of the Electronic Benefits Transfer between 1988 and 2004, increased benefits during the Great Recession via the 2009 American Recovery and Investment Act, and the recent revisions of the Thrifty Food Plan.^{34,35} More longitudinal research with contemporary cohorts is needed to examine the short- and long-term effects of SNAP and WIC participation on food security.

Public Health Implications

Our findings indicate that SNAP and WIC participation during childhood led to improved FSS in adulthood among individuals from low-income households eligible to participate in those programs. Although SNAP and WIC benefits may be increasing, they affect only families that are enrolled. Policies are needed to improve program access, minimize barriers to enrollment, and ensure adequacy of benefits so that today's children at risk for food insecurity can benefit from these important programs now and in the future. *AJPH*

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N. Insolera wrote the first draft of the article, J. A. Wolfson contributed to subsequent drafts, and A. Cohen and J. A. Wolfson critically reviewed the article. N. Insolera conducted the analyses. N. Insolera and J. A. Wolfson designed the analytic plan. All authors designed the study, developed the hypotheses, and contributed to the interpretation of the results.

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CONFLICTS OF INTEREST

The authors have no affiliation with any organization with a direct or indirect financial interest in the subject matter discussed in this article.

HUMAN PARTICIPANT PROTECTION

No protocol approval was needed for this study because secondary data were used.

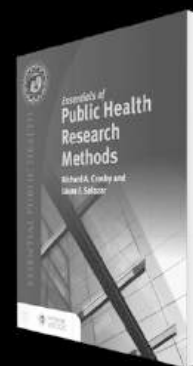
REFERENCES

1. Coleman-Jensen A, Rabbitt MP, Gregory CA, Singh A. Household food security in the United States in 2019. Available at: <http://www.ers.usda.gov/publications/pub-details/?pubid=99281>. Accessed March 12, 2021.
2. Feeding America. Map the meal gap. Available at: <http://map.feedingamerica.org>. Accessed March 24, 2017.

3. Coleman-jensen A, Rabbitt MP, Gregory CA, Singh A. Household food security in the United States in 2020. Available at: <http://www.ers.usda.gov/publications/pub-details/?pubid=102075>. Accessed November 10, 2021.
4. Gundersen C, Ziliak JP. Childhood food insecurity in the US: trends, causes, and policy options. *Future Child*. 2014;24(2):1–19. <https://doi.org/10.1353/foc.2014.0007>
5. Gundersen C, Ziliak JP. Food insecurity and health outcomes. *Health Aff (Millwood)*. 2015;34(11):1830–1839. <https://doi.org/10.1377/hlthaff.2015.0645>
6. Leung CW, Stewart AL, Portela-Parra ET, Adler NE, Laraia BA, Epel ES. Understanding the psychological distress of food insecurity: a qualitative study of children's experiences and related coping strategies. *J Acad Nutr Diet*. 2020;120(3):395–403. <https://doi.org/10.1016/j.jand.2019.10.012>
7. Seligman HK, Schillinger D. Hunger and socioeconomic disparities in chronic disease. *N Engl J Med*. 2010;363(1):6–9. <https://doi.org/10.1056/NEJMp1000072>
8. Leung CW, Farooqui S, Wolfson JA, Cohen AJ. Understanding the cumulative burden of basic needs insecurities: associations with health and academic achievement among college students. *Am J Health Promot*. 2021;35(2):275–278. <https://doi.org/10.1177/0890117120946210>
9. Food and Nutrition Service. Supplemental Nutrition Assistance Program participation and costs. Available at: <https://www.fns.usda.gov/pd/supplemental-nutrition-assistance-program-snap>. Accessed December 21, 2018.
10. Oliveira O, Frazao E. The WIC program: background, trends, and economic issues. Available at: <https://www.ers.usda.gov/publications/pub-details/?pubid=43927>. Accessed November 10, 2021.
11. US Department of Agriculture. Program data overview. Available at: <https://www.fns.usda.gov/pd/overview>. Accessed April 7, 2021.
12. Bipartisan Policy Center. Improving food and nutrition security during COVID-19, the economic recovery, and beyond. Available at: https://bipartisanpolicy.org/download/?file=/wp-content/uploads/2021/09/BPC-Health-Nutrition-Brief-1_R03-compressed.pdf. Accessed April 7, 2021.
13. Fitzpatrick KM, Harris C, Drawe G, Willis DE. Assessing food insecurity among US adults during the COVID-19 pandemic. *J Hunger Environ Nutr*. 2021;16(1):1–18. <https://doi.org/10.1080/19320248.2020.1830221>
14. Wolfson JA, Leung CW. Food insecurity and COVID-19: disparities in early effects for US adults. *Nutrients*. 2020;12(6):1648. <https://doi.org/10.3390/nu12061648>
15. Wolfson JA, Leung CW. Food insecurity during COVID-19: an acute crisis with long-term health implications. *Am J Public Health*. 2020;110(12):1763–1765. <https://doi.org/10.2105/AJPH.2020.305953>
16. University of Michigan, Institute for Social Research. PSID Main Interview User Manual: Release 2019. Available at: <https://psidonline.isr.umich.edu/data/Documentation/UserGuide2017.pdf>. Accessed April 7, 2021.
17. US Department of Agriculture, Economic Research Service. US Household Food Security Survey Module: three-stage design with screeners. Available at: <https://www.ers.usda.gov/media/8271/hh2012.pdf>. Accessed April 7, 2021.
18. Frank DA, Neault NB, Skalicky A, et al. Heat or eat: the Low Income Home Energy Assistance Program and nutritional and health risks among children less than 3 years of age. *Pediatrics*. 2006;118(5):e1293–e1302. <https://doi.org/10.1542/peds.2005-2943>
19. Berkowitz SA, Seligman HK, Choudhry NK. Treat or eat: food insecurity, cost-related medication underuse, and unmet needs. *Am J Med*. 2014;127(4):303–310.e3. <https://doi.org/10.1016/j.amjmed.2014.01.002>
20. Lee CY, Zhao X, Reesor-Oyer L, Cepni AB, Hernandez DC. Bidirectional relationship between food insecurity and housing instability. *J Acad Nutr Diet*. 2021;121(1):84–91. <https://doi.org/10.1016/j.jand.2020.08.081>
21. Singleton CR, Young SK, Kessee N, Springfield SE, Sen BP. Examining disparities in diet quality between SNAP participants and non-participants using Oaxaca-Blinder decomposition analysis. *Prev Med Rep*. 2020;19:101134. <https://doi.org/10.1016/j.pmedr.2020.101134>
22. Vega SS, Hinojosa MS, Nguyen J. Using Andersen's behavioral model to predict participation in the Supplemental Nutrition Assistance Program (SNAP) among US adults. *J Hunger Environ Nutr*. 2017;12(2):193–208. <https://doi.org/10.1080/19320248.2016.1255694>
23. Smith TM, Bertmann FMW, Pinar CA, et al. Factors associated with Supplemental Nutrition Assistance Program participation among the working poor: findings from 2012 American Community Survey. *J Hunger Environ Nutr*. 2017;12(2):169–180. <https://doi.org/10.1080/19320248.2016.1146196>
24. Bryant A, Follett L. Hunger relief: a natural experiment from additional SNAP benefits during the COVID-19 pandemic. *Lancet Reg Health Am*. 2022;10:100224. <https://doi.org/10.1016/j.lana.2022.100224>
25. Center on Budget and Policy Priorities. States are using much-needed temporary flexibility in SNAP to respond to COVID-19 challenges. Available at: <https://www.cbpp.org/research/food-assistance/states-are-using-much-needed-temporary-flexibility-in-snap-to-respond-to>. Accessed May 3, 2021.
26. Ziliak JP. Food hardship during the Covid-19 pandemic and Great Recession. *Appl Econ Perspect Policy*. 2020;43(1):132–152. <https://doi.org/10.1002/aapp.13099>
27. Ohri-Vachaspati P, Acciai F, DeWeese RS. SNAP participation among low-income US households stays stagnant while food insecurity escalates in the months following the COVID-19 pandemic. *Prev Med Rep*. 2021;24:101555. <https://doi.org/10.1016/j.pmedr.2021.101555>
28. Siddiqi SM, Cantor J, Dastidar MG, et al. SNAP participants and high levels of food insecurity in the early stages of the COVID-19 pandemic. *Public Health Rep*. 2021;136(4):457–465. <https://doi.org/10.1177/00333549211007152>
29. Whiteman ED, Chrisinger BW, Hillier A. Diet quality over the monthly Supplemental Nutrition Assistance Program cycle. *Am J Prev Med*. 2018;55(2):205–212. <https://doi.org/10.1016/j.amepre.2018.04.027>
30. US Department of Agriculture. Thrifty Food Plan. Available at: <https://www.fns.usda.gov/taxonomy/term/415>. Accessed May 3, 2021.
31. Congressional Research Service. The 2018 Farm Bill (P.L. 115-334): summary and side-by-side comparison. Available at: <https://crsreports.congress.gov/product/pdf/R/R45525>. Accessed May 3, 2021.
32. US Department of Agriculture, Food and Nutrition Service. Implementation of the Extending Government Funding and Delivering Emergency Assistance Act temporary increase in the CVW benefit for fruit and vegetable purchases. Available at: <https://www.fns.usda.gov/wic/extending-government-funding-and-delivering-emergency-assistance>. Accessed May 3, 2021.
33. Wolfson JA, Leung CW, Moran A. Meeting the moment: policy changes to strengthen SNAP and improve health. Available at: <https://www.milbank.org/quarterly/opinions/meeting-the-moment-policy-changes-to-strengthen-snap-and-improve-health>. Accessed May 3, 2021.
34. US Congress. American Recovery and Reinvestment Act of 2009. Available at: <https://www.govinfo.gov/app/details/STATUTE-123/STATUTE-123-Pg115>. Accessed May 3, 2021.
35. Caswell JA, Yaktine AL. History, background, and goals of the Supplemental Nutrition Assistance Program. Available at: <https://www.ncbi.nlm.nih.gov/books/NBK206907>. Accessed April 8, 2022.

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US Black–White Differences in Mortality Risk Among Transgender and Cisgender People in Private Insurance, 2011–2019

Landon D. Hughes, Wesley M. King, MPH, MEd, Kristi E. Gamarel, PhD, EdM, Arline T. Geronimus, ScD, Orestis A. Panagiotou, MD, PhD, and Jaclyn M. W. Hughto, PhD, MPH

See also Thomeer and Patterson, p. 1365.

Objectives. To compare survival by gender and race among transgender and cisgender people enrolled in private insurance in the United States between 2011 and 2019.

Methods. We examined Optum’s Clinformatics Data Mart Database. We identified transgender enrollees using claims related to gender-affirming care. Our analytic sample included those we identified as transgender and a 10% random sample of cisgender enrollees. We limited our sample to those 18 years or older who were non-Hispanic Black or White. We identified 18 033 transgender and more than 4 million cisgender enrollees. We fit Kaplan–Meier survival curves and calculated standardized mortality ratios while adjusting for census region.

Results. Black transfeminine and nonbinary people assigned male sex at birth were 2.73 times more likely to die than other Black transgender people and 2.38 and 3.34 times more likely than Black cisgender men and women, respectively; similar results were found when White transfeminine and nonbinary people assigned male sex at birth were compared with White cisgender cohorts.

Conclusions. Our findings highlight glaring inequities in mortality risks among Black transfeminine and nonbinary people assigned male sex at birth and underscore the need to monitor mortality risks in transgender populations and address the social conditions that increase these risks. (*Am J Public Health.* 2022;112(10):1507–1514. <https://doi.org/10.2105/AJPH.2022.306963>)

In US cisgender populations, increases in mortality risk among Black people have been well documented¹ and attributed to “weathering” (premature aging of Black people) because of biopsychosocial, economic, and environmental stressors (e.g., interpersonal and structural racism) that Black people differentially experience relative to White people over the life course.² Researchers have postulated that transgender and gender-diverse people of any race often experience early morbidity³ and mortality⁴ as a result of pervasive

transgender-related discrimination.⁵ Given the co-occurrence and mutual reinforcement of racial and antitransgender stigma, an intersectional approach suggests that Black transgender people may experience earlier health declines than their White transgender and Black cisgender counterparts, which could lead to premature death.^{6,7}

Recent literature also suggests that Black transgender women are at a particularly high risk of stress because of their exposure to systems that reify White supremacy, cisnormativity, and

related interpersonal and structural violence due to misogyny.^{8,9} Notably, several studies have documented the high rates of victimization, including homicide, experienced by Black transgender women, which may contribute to mortality inequities.^{10–12}

In this study, we sought to explore mortality differences among Black and White transgender and cisgender people by analyzing all-cause mortality rates among those enrolled in private insurance and Medicare Advantage plans between 2011 and 2019. We had 3 primary hypotheses.

First, given the increased risk of morbidity, social stigmatization, and victimization among transgender populations,^{5,13} we hypothesized that transgender individuals would have a greater risk of mortality at every age than their cisgender counterparts who shared their same race (i.e., White transgender people would be at a greater risk of mortality than their White cisgender counterparts). Second, given racial differences in mortality among the general population as a result of structural racism,^{1,14} we hypothesized that Black transgender people would be at a greater risk of mortality at every age than their White transgender counterparts. Third, given early evidence of a greater risk of mortality among transfeminine and nonbinary people assigned male sex at birth (TFN) than among transmasculine and nonbinary people assigned female sex at birth (TMN)⁴—and, in particular, the high rates of victimization experienced by Black transgender women¹⁰—we hypothesized that Black TFN people would be at a greater risk of mortality than Black TMN, White TFN, and White TMN people.

Deficiencies regarding routine and accurate collection of gender identity information in mortality data have obstructed research on mortality among transgender people in the United States.¹⁵ Therefore, researchers have turned to administrative health records as a viable source of mortality data on US transgender populations.^{16–18}

For example, analyzing medical claims from a large private insurer, researchers in one study found that, on average, transfeminine and nonbinary people assigned male sex at birth were more likely to die at nearly every age than cisgender men and women and were more likely to die overall than transmasculine and nonbinary people assigned female sex at birth.⁴ Despite

this contribution, the authors were unable to simultaneously examine racial and gender variations in mortality risk resulting from small sample sizes when stratifying by race and gender based on less robust algorithms identifying transgender people in insurance data.¹⁹ However, new methods have identified larger sample sizes when stratifying by race and gender that allow for more robust estimates of mortality risk among transgender populations stratified by race and gender.²⁰ To our knowledge, no studies have examined racial variations in the risk of all-cause mortality among transgender populations overall and between transgender and cisgender populations. Our research attempted to fill this gap.

METHODS

We analyzed administrative claims data from Optum's Clinformatics Data Mart Database, which includes deidentified insurance claims for commercially insured enrollees and those enrolled in Medicare Advantage plans from 2011 to 2019. These data include claims for approximately 84 million unique enrollees in the United States (disproportionately representing the South and Midwest) as well as information on medical claims (e.g., prescriptions, procedures, and diagnoses).

Our analytic sample included individuals 18 years or older and those identifying as non-Hispanic White or non-Hispanic Black. Our sample incorporated all enrollees we identified as transgender and a 10% random sample of cisgender enrollees. We used a 10% sample of cisgender enrollees because of data storage restrictions and the limited computational power of Stata MP (StataCorp LLC, College Station, TX) while maintaining a representative sample.

We excluded enrollees whose race was listed as Asian (n = 190 725), Hispanic (n = 482 608), or unknown (n = 742 534) and those who did not have a gender listed (n = 4357).

Measures

Identifying transgender enrollees and gender. The cisgender cohort was categorized as men and women according to their sex listed at enrollment. For the transgender cohort, we used an approach initially developed by Jasuja et al.¹⁹ (and further refined by Yee et al.²¹ and later Hughto et al.²⁰) to identify transgender enrollees and categorize their gender expression (hereafter referred to as gender) via claims data. Briefly, transgender enrollees and their gender were identified through a combination of *International Classification of Diseases, Ninth Revision (ICD-9)* and *10th Revision (ICD-10)* diagnostic codes specific to transgender individuals (e.g., gender dysphoria and gender identity disorder [ICD-9: 302.X; ICD-10: F64.X]), common procedural terminology codes for transgender-related surgical procedures (e.g., vaginoplasty, phalloplasty), and prescription claims for gender-affirming hormones.

This algorithm built on previous work incorporating transgender-related ICD codes alone²² by also including enrollees who received an endocrine disorder not otherwise specified diagnosis in conjunction with hormone prescriptions or transgender-specific surgeries.¹⁹ The endocrine disorder not otherwise specified diagnosis is often used instead of gender identity disorder in billing for transgender-affirming services to avoid the stigma of labeling the person as transgender or avoid insurance denials.¹⁹ Employing the Hughto et al.²⁰

algorithm, we then used a combination of claims for gender-affirming care and sex-specific care (i.e., procedures that could be performed only on males or females) to categorize transgender enrollees as TMN or TFN.

Race and ethnicity. Optum sourced information on enrollees' race and ethnicity from a nationally recognized supplier of consumer marketing data, including consumer-specific demographic, behavioral, and lifestyle data. Optum included the following categories: non-Hispanic Asian, non-Hispanic Black, Hispanic, non-Hispanic White, and unknown. Small sample sizes restricted the inclusion of non-Hispanic Asian enrollees in our study. Because Optum combined all Hispanic individuals into a single category regardless of race, we limited the sample to non-Hispanic White and non-Hispanic Black (hereafter referred to as White and Black) enrollees to ensure proper interpretation of our findings.

All-cause mortality. Optum collected information on enrollees' month of death from claims (e.g., "expired" discharge status of "death" as the reason for coverage discontinuation) and data from the Social Security Administration's Death Master File as well as the Centers for Medicare & Medicaid Services. Optum linked enrollment information to Social Security Administration and Centers for Medicare & Medicaid Services data via Social Security numbers along with an additional piece of information such as name or date of birth.

Statistical Analysis

The basic unit for our analyses was a person-year indexed to represent an enrollee's age at the first and last

observed times. We conducted all analyses over age. For cisgender enrollees, the survival period began the day of their enrollment or the day they reached the age of 18 years (if they were enrolled before that age) and ended when they disenrolled or died, whichever came first. As a means of accounting for immortal time bias,²³ transgender enrollees' observed period began when they were identified as transgender or when they reached the age of 18 years (if they were identified as transgender before that age) and ended when they disenrolled or died. Optum truncated date of birth information among those older than 89 years. Thus, all individuals who survived to 89.9 years were right censored at that age with no mortality event.

To test all 3 hypotheses by considering the risk of mortality at each age, we fit Kaplan–Meier survival curves to compare survival by gender and race. To compare overall mortality risks, we used the log-rank test for equality of survivor functions (see Table A, available as a supplement to the online version of this article at <http://www.ajph.org>) and calculated age-specific mortality rates per thousand enrollees along with standardized mortality ratios (SMRs) via direct standardization; members of the transgender cohort were compared with their cisgender counterparts and with their transgender counterparts who shared the same race. When comparing the transgender cohorts by race, we used the Black transgender cohort as the standard population. When comparing the transgender cohorts with cisgender cohorts sharing their same race, we used the transgender cohort as the standard population. When comparing the TFN and TMN cohorts with one another, we used the TFN cohort as the standard population.

Analyses showed that census region varied significantly by race; therefore, the data were weighted so that the Black and White transgender and cisgender groups would have identical distributions across all census regions. Stata MP version 14.2 was used in conducting all statistical analyses.

RESULTS

Table 1 provides demographic information for the transgender sample. The overall analytical sample included 2 876 073 enrollees, of whom 18 033 were identified as transgender (1321 Black TMN, 665 Black TFN, 10 475 White TMN, and 5572 White TFN). We found geographic variations among the Black and White cohorts, with the Black transgender and cisgender groups overwhelmingly residing in the South (66% and 69%, respectively); the White transgender and cisgender groups were mostly from the South but not to the extent of their Black counterparts (40% and 41%, respectively). The least represented region among the Black transgender and cisgender cohorts was the West (7% and 5%, respectively), whereas the least represented region among the White transgender and cisgender cohorts was the Northeast (9% and 8%, respectively).

We calculated the mean age at first observation by taking the average age we first observed each enrollee. The mean age at first observation was 41 years for Black and White transgender enrollees. Mean ages at first observation were 49 and 47 years for Black and White cisgender enrollees, respectively. We observed Black and White transgender enrollees for 4147 and 35 770 person-years, respectively.

Figure 1 presents Kaplan–Meier survival curves comparing the Black and

TABLE 1— Demographics of the Transgender Cohort: Optum Clinformatics, United States, 2011–2019

	Black		White	
	TFN (n = 665)	TMN (n = 1 321)	TFN (n = 5 572)	TMN (n = 10 475)
Person-years at risk	1 398	2 749	10 860	24 910
No. of deaths	49	24	252	147
Age distribution, %				
18–19 y	1	3	3	4
20–29 y	18	19	20	19
30–39 y	19	23	14	16
40–49 y	16	23	14	24
50–59 y	19	16	18	21
60–69 y	14	9	17	10
70–79 y	9	5	10	4
80–89 y	5	3	3	2
Death rate per 1000				
18–19 y	0	0	1	0
20–29 y	4	0	1	2
30–39 y	8	2	2	0
40–49 y	0	3	7	3
50–59 y	23	0	10	3
60–69 y	58	16	25	12
70–79 y	124	39	56	29
80–89 y	205	140	230	100
Region, %				
Midwest	20	18	27	24
Northeast	10	8	11	9
South	64	67	35	42
West	6	7	28	24

Note. TFN = transfeminine/nonbinary; TMN = transmasculine/nonbinary. Table includes only those who are non-Hispanic.

White transgender synthetic cohorts over age stratified by gender and weighted so that each group had the same regional distribution. Black TFN individuals exhibited an accelerated mortality rate relative to all other groups. Three quarters of the Black TFN synthetic cohort survived to age 55 years (95% confidence interval [CI] = 27, 64), and half survived to age 67 years (95% CI = 59, 72), whereas three quarters of Black TMN people survived to age 76 years (95% CI = 66, 78) and half survived to age 80 years

(95% CI = 76, 86), a difference of 21 and 13 years, respectively. Three quarters of the White TFN synthetic cohort survived to age 65 years (95% CI = 61, 69) and half survived to age 75 years (95% CI = 74, 77), whereas three quarters of White TMN people survived to age 73 years (95% CI = 72, 76) and half survived to age 83 years (95% CI = 81, 85; see Table A for the proportions surviving in each synthetic cohort by age).

Figure 2 presents Kaplan–Meier survival curves comparing the Black and White transgender synthetic cohorts

over age, again stratified by gender and weighted so that each group had the same regional distribution. Black TFN individuals exhibited an accelerated rate of mortality relative to their Black cisgender counterparts. A comparison of survival showed that, on average, 50% of the Black TFN cohort died by age 67 years, 16 years earlier than 50% of Black cisgender women and 11 years earlier than Black cisgender men. Survival among Black TMN people did not significantly differ from that among Black cisgender women, but they did fare slightly better than Black cisgender men (50% of Black TMN people survived to age 80 years, 2 years longer than Black cis men). On average, members of the White TFN cohort experienced worse mortality than their cisgender counterparts, with 50% dying before the age of 75 years, 10 years earlier than White cisgender women and 7 years earlier than White cisgender men. White TMN people did not have significantly different survival curves than either White cisgender men or White cisgender women.

Table 2 provides standardized mortality ratios and 95% confidence intervals stratified by age and weighted so that each group had the same regional distribution. We were unable to calculate age-specific rates for some groups because no deaths occurred in those groups during the study period, a limitation of our sample size. Overall, Black TFN individuals had a significantly greater risk of mortality than all other Black synthetic cohorts. After adjustment for age and regional distributions, Black TFN people were 2.73 times more likely to die than Black TMN people and 2.38 and 3.34 times more likely than Black cisgender men and women, respectively. Black TMN people did not exhibit a significantly different mortality rate overall or at any specific age than Black cisgender

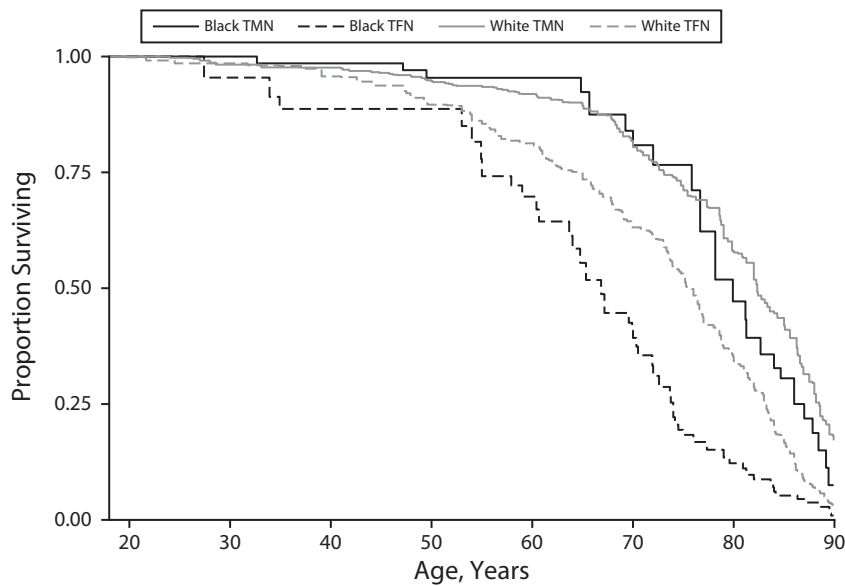


FIGURE 1— Proportion Surviving by Race/Ethnicity and Gender Among the Transgender Cohort: Optum Clinformatics, United States, 2011–2019

Notes. TFN = transfeminine/nonbinary; TMN = transmasculine/nonbinary. Analyses adjusted for census region.

men and women. Similarly, White TFN people were at a greater risk of mortality overall than White TMN people (SMR = 2.18; 95% CI = 1.57, 3.42), White cisgender men (SMR = 1.98; 95% CI = 1.43, 3.11), and White cisgender women (SMR = 2.56; 95% CI = 1.85, 4.03).

Black and White TFN people had the greatest disproportionate risk of mortality relative to their transgender peers between the ages of 30 and 39 years (SMRs = 4.56–4.67 in comparison with TMN people who share their race). Log-rank tests for equality confirmed the

overall risk findings outlined in Table 2 (for results of the log-rank tests, see Table B, available as a supplement to the online version of this article at <http://www.ajph.org>).

DISCUSSION

This study compared all-cause mortality rates among enrollees in private insurance and Medicare Advantage plans by race and gender from 2011 to 2019. As hypothesized, we found evidence of substantial mortality inequities that primarily affected TFN people. Like cisgender populations,²⁴ we found variation in terms of survival by sex assigned at birth, with those assigned male sex at birth dying at earlier ages than those assigned female sex. Specifically, White TFN people had a higher mortality risk across the study period than all other White groups, Black cisgender men, and Black cisgender women. Furthermore, Black TFN people had a higher mortality risk than all other Black groups and all other transgender groups. The magnitude of these

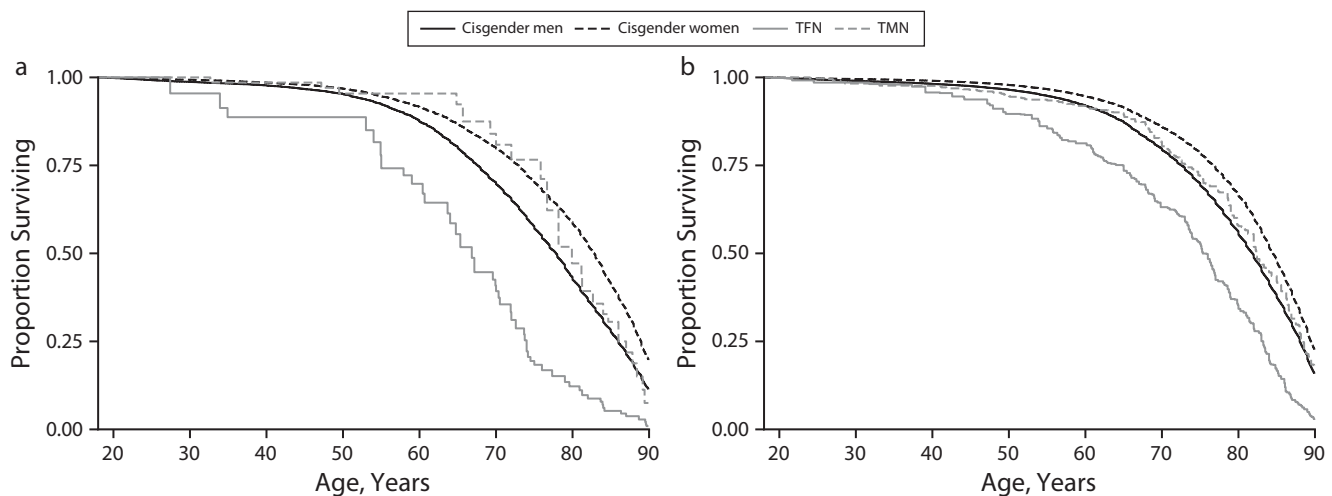


FIGURE 2— Proportion Surviving by Gender and Race/Ethnicity Among the Full Sample of (a) the Black Cohort and (b) the White Cohort: Optum Clinformatics, United States, 2011–2019

Notes. Cis = cisgender; TFN = transfeminine/nonbinary; TMN = transmasculine/nonbinary. Analyses adjusted for census region.

TABLE 2— Standardized Mortality Ratios by Age, Race/Ethnicity, and Gender: Optum Clinformatics, United States, 2011–2019

Age, y	TFN			TMN	
	TMN (95% CI)	Cis Men (95% CI)	Cis Women (95% CI)	Cis Men (95% CI)	Cis Women (95% CI)
Black					
20–29	NC	NC	NC	NC	NC
30–39	4.67 (1.00, 46.60)	7.13 (1.52, 71.11)	9.06 (1.93, 90.38)	NC	NC
40–49	NC	NC	NC	1.28 (0.28, 12.66)	1.85 (0.40, 18.29)
50–59	NC	2.76 (1.26, 7.19)	4.19 (1.91, 10.90)	NC	NC
60–69	3.67 (2.07, 7.02)	2.57 (1.45, 4.92)	4.14 (2.34, 7.93)	0.70 (0.26, 2.48)	1.13 (0.42, 4.00)
70–79	3.18 (1.92, 5.47)	2.65 (1.60, 4.55)	4.10 (2.48, 7.06)	0.83 (0.34, 2.57)	1.29 (0.53, 3.98)
80–89	1.47 (0.85, 2.59)	1.87 (1.08, 3.29)	2.18 (1.26, 3.84)	1.27 (0.74, 2.45)	1.49 (0.86, 2.86)
Overall	2.73 (1.48, 5.98)	2.38 (1.29, 5.22)	3.34 (1.81, 7.31)	0.86 (0.39, 2.62)	1.21 (0.55, 3.66)
White					
20–29	0.91 (0.20, 9.09)	1.74 (0.37, 17.41)	4.32 (0.93, 43.36)	1.91 (0.81, 5.74)	4.77 (2.01, 14.29)
30–39	4.56 (1.31, 25.50)	2.58 (0.74, 14.42)	5.22 (1.50, 29.23)	0.57 (0.04, 89.02)	1.15 (0.07, 180.43)
40–49	2.05 (0.99, 4.94)	3.82 (1.85, 9.19)	5.74 (2.78, 13.82)	1.86 (1.11, 3.36)	2.80 (1.67, 5.06)
50–59	3.61 (2.17, 6.46)	2.13 (1.28, 3.81)	3.19 (1.92, 5.71)	0.59 (0.34, 1.11)	0.88 (0.51, 1.65)
60–69	2.11 (1.54, 2.98)	1.76 (1.28, 2.48)	2.69 (1.96, 3.79)	0.83 (0.54, 1.32)	1.27 (0.83, 2.02)
70–79	1.92 (1.46, 2.56)	1.64 (1.25, 2.19)	2.34 (1.78, 3.11)	0.86 (0.59, 1.30)	1.22 (0.84, 1.85)
80–89	2.30 (1.80, 2.80)	2.30 (1.80, 2.80)	2.46 (1.93, 3.00)	1.00 (0.74, 1.50)	1.07 (0.79, 1.61)
Overall	2.18 (1.57, 3.42)	1.98 (1.43, 3.11)	2.56 (1.85, 4.03)	0.93 (0.60, 3.44)	1.27 (0.83, 4.71)

Note. CI = confidence interval; Cis = cisgender; NC = not calculated; TFN = transfeminine/nonbinary; TMN = transmasculine/nonbinary. Analyses adjusted for census region. Black transgender people were compared only with Black cisgender people, and White transgender people were compared only with White cisgender people.

inequities supports the need for greater attention toward the underlying conditions of premature mortality among transgender populations overall and within specific racial subgroups.

Our findings can also be understood in the context of the unrelenting social stigma experienced by transgender people in the United States, which stems from structural cissexism. A continuously growing body of literature has documented associations between multiple manifestations of cissexism (e.g., anti-transgender discrimination, harassment, interpersonal violence, hostile political environments) and adverse health outcomes among transgender populations.^{5,25} Cissexism can therefore be considered a fundamental cause of

population health inequities as anti-transgender stigma disrupts transgender people's access to resources, social relationships, and coping behaviors, in turn affecting their health.^{5,26}

The concept of intersectionality suggests that groups that are marginalized along multiple axes of identity experience effects of unique, compounded forms of stigma.^{6,12} Our findings are consistent with this theoretical framing, as we found that TFN people had the greatest mortality risk within racial groups and Black TFN people had the greatest mortality risk overall, reflecting possible effects of transmisogyny and transmisogynoir.^{27,28} Although our data do not allow for testing mechanisms through which cissexism, racism, misogyny, and other intersecting

oppression may drive mortality inequities, our findings suggest that future work examining the relationship between racism and cissexism may be particularly fruitful to explain differences in health outcomes between and within transgender racial and gender subgroups.

Our findings also suggest that weathering (early mortality and morbidity) caused by repeated socially structured stress occurs more rapidly among transgender people than their cisgender counterparts and more rapidly among Black transgender people than their White cisgender and transgender counterparts.² An increased relative risk of mortality (in comparison with White and cisgender cohorts) was apparent for most transgender cohorts

in early adulthood and persisted throughout older ages. Others have found that Black transfeminine people likely have a greater risk of homicide than the general population,¹⁰ and our work shows that this increased risk extends beyond homicide to all-cause mortality. Future research should focus on an older age range of Black transgender people (e.g., Medicare enrollees) and examine cause of death to better document the impact of intersectional socially structured stress and weathering in this population.

Limitations

In addition to highlighting the stark portrait of racially patterned risks of mortality within the transgender population and between transgender and cisgender populations, our analyses also raise important methodological and causal questions that apply to any use of claims data to analyze transgender populations. First, not all race data collected by Optum were self-reported; therefore, misclassification of race was possible. However, it is more likely that we excluded individuals because we were unable to ascertain their race than because their race was misclassified.²⁹

Second, the algorithm we used to identify transgender people likely coded some transgender people as “cisgender” people who are privately insured and (1) do not have access to gender-affirming care, (2) are not “out” to their providers, or (3) do not want gender-affirming medical care. Previous research suggests that the first 2 groups may be at increased risk of morbidity^{11,30} and possibly mortality,⁴ which may have biased our estimates toward the null.³¹ Not all transgender people desire gender-affirming medical care; however, evidence suggests that transgender people

experience high rates of discrimination regardless of medical interventions,³² which may have biased our results. Given the relatively small population of transgender people in the United States,³³ it is probable that this misclassification did not meaningfully bias mortality risks in the cisgender population.

We identified more TMN people than TFN people, likely as a function of those who seek sex-specific care; therefore, we may have excluded more people assigned male sex at birth who we were unable to classify as TFN. We were able to test our hypotheses only with data from those enrolled in private insurance, and thus our findings cannot be generalized to other populations. Finally, because claims data do not contain information on gender identity, we were unable to determine whether mortality patterns differed between nonbinary people and other gender-diverse groups, which is an important area for future research.

Public Health Implications

Our findings highlight glaring inequities in mortality risks among transgender people, particularly Black TFN people, and underscore the need for government agencies to increase the capacity to monitor mortality risks in transgender populations by routinely and accurately collecting gender identity information in death records.¹⁵ In addition, our results support advocates’ calls to collect gender identity data in death records and consider how gender and race shape mortality risks within transgender populations.^{10,15,34} This information is needed to conduct a more complete and inclusive analysis of mortality inequities among transgender populations that cannot be conducted with insurance claims data.

Furthermore, our findings highlight the need for action to reduce gender and racial mortality inequities. Policy-makers and funders should evaluate how best to distribute resources that promote longevity in the most affected population: Black transfeminine people. Such work will require engaging with Black transgender community organizations and other stakeholders to develop mechanisms supporting existing grassroots projects that promote transgender people’s well-being while centering and funding work with Black TFN people to address the material and social conditions that contribute to mortality risks in this population.^{9,10,34,35} **AJPH**

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CONTRIBUTORS

L. D. Hughes contributed to the conception of the article, analysis, interpretation, and acquisition of data and was the principal author. W. M. King, K. E. Gamarel, and A. T. Geronimus contributed to analysis, interpretation, and authorship. O. A. Panagiotou contributed to analysis, interpretation, and critical revision. J. M. W. Hughto contributed to the conception of the article, analysis, interpretation, and authorship.

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CONFLICTS OF INTEREST

The authors report no conflicts of interest.

HUMAN PARTICIPANT PROTECTION

No protocol approval was needed for this study because secondary data were used.

REFERENCES

- Cunningham TJ, Croft JB, Liu Y, Lu H, Eke PI, Giles WH. Vital signs: racial disparities in age-specific mortality among Blacks or African Americans—United States, 1999–2015. *MMWR Morb Mortal Wkly Rep.* 2017;66(17):444–456. <https://doi.org/10.15585/mmwr.mm6617e1>
- Geronimus AT, Pearson JA, Linnenbringer E, et al. Weathering in Detroit: place, race, ethnicity, and poverty as conceptually fluctuating social constructs shaping variation in allostatic load. *Milbank Q.* 2020;98(4):1171–1218. <https://doi.org/10.1111/1468-0009.12484>
- Hughes L, Shireman TI, Hughto J. Privately insured transgender people are at elevated risk for chronic conditions compared with cisgender counterparts. *Health Aff (Millwood).* 2021;40(9):1440–1448. <https://doi.org/10.1377/hlthaff.2021.00546>
- Hughes LD, King WM, Gamarel KE, Geronimus AT, Panagiotou O, Hughto J. Differences in all-cause mortality among transgender and non-transgender people enrolled in private insurance (2011–2019). *Demography.* 2022;59(3):1023–1043. <https://doi.org/10.1215/00703370-9942002>
- White Hughto JM, Reisner SL, Pachankis JE. Transgender stigma and health: a critical review of stigma determinants, mechanisms, and interventions. *Soc Sci Med.* 2015;147:222–231. <https://doi.org/10.1016/j.socscimed.2015.11.010>
- Wesp LM, Malcoe LH, Elliott A, Poteat T. Intersectionality research for transgender health justice: a theory-driven conceptual framework for structural analysis of transgender health inequities. *Transgend Health.* 2019;4(1):287–296. <https://doi.org/10.1089/trgh.2019.0039>
- Crenshaw K. Mapping the margins: intersectionality, identity politics, and violence against women of color. *Stanford Law Rev.* 1993;43:61.
- Sevelius JM. Gender affirmation: a framework for conceptualizing risk behavior among transgender women of color. *Sex Roles.* 2013;68(11–12):675–689. <https://doi.org/10.1007/s11199-012-0216-5>
- Lacomb-Duncan A, Jadwin-Cakmak L, Trammell R, et al. "... Everybody else is more privileged. Then it's us. . .": a qualitative study exploring community responses to social determinants of health inequities and intersectional exclusion among trans women of color in Detroit, Michigan. *Sex Res Soc Policy.* 2021 [Epub ahead of print]. <https://doi.org/10.1007/s13178-021-00642-2>
- Dinno A. Homicide rates of transgender individuals in the United States: 2010–2014. *Am J Public Health.* 2017;107(9):1441–1447. <https://doi.org/10.2105/AJPH.2017.303878>
- James SE, Herman JL, Rankin S, Keisling M, Mottet L, Anaf M. The report of the 2015 US Transgender Survey. Available at: <https://transequality.org/sites/default/files/docs/usts/USTS-Full-Report-Dec17.pdf>. Accessed June 24, 2021.
- Millar K, Brooks CV. Double jeopardy: minority stress and the influence of transgender identity and race/ethnicity. *Int J Transgend Health.* 2021;23(1–2):133–148. <https://doi.org/10.1080/26895269.2021.1890660>
- Progovac AM, Cook BL, Mullin BO, et al. Identifying gender minority patients' health and health care needs in administrative claims data. *Health Aff (Millwood).* 2018;37(3):413–420. <https://doi.org/10.1377/hlthaff.2017.1295>
- Satcher D, Fryer GE, McCann J, Troutman A, Woolf SH, Rust G. What if we were equal? a comparison of the Black-White mortality gap in 1960 and 2000. *Health Aff (Millwood).* 2005;24(2):459–464. <https://doi.org/10.1377/hlthaff.24.2.459>
- Haas A, Lane A, Blosnich JR, Butcher BA, Mortali MG. Collecting sexual orientation and gender identity information at death. *Am J Public Health.* 2019;109(2):255–259. <https://doi.org/10.2105/AJPH.2018.304829>
- Blosnich JR, Brown GR, Wojcio S, Jones KT, Bossarte RM. Mortality among veterans with transgender-related diagnoses in the Veterans Health Administration, FY2000–2009. *LGBT Health.* 2014;1(4):269–276. <https://doi.org/10.1089/lgbt.2014.0050>
- Boyer TL, Youk AO, Haas A, et al. Suicide, homicide, and all-cause mortality among transgender and cisgender patients in the Veterans Health Administration. *LGBT Health.* 2021;8(3):173–180. <https://doi.org/10.1089/lgbt.2020.0235>
- Quinn VP, Nash R, Hunkeler E, et al. Cohort profile: study of transition, outcomes and gender (STRONG) to assess health status of transgender people. *BMJ Open.* 2017;7(12):e018121. <https://doi.org/10.1136/bmjopen-2017-018121>
- Jasuja GK, de Groot A, Quinn EK, et al. Beyond gender identity disorder diagnoses codes: an examination of additional methods to identify transgender individuals in administrative databases. *Med Care.* 2020;58(10):903–911. <https://doi.org/10.1097/MLR.0000000000001362>
- Hughto J, Hughes LD, Yee K, et al. Improving data-driven methods to identify and categorize transgender individuals by gender in insurance claims data. *LGBT Health.* 2022;9(4):254–263. <https://doi.org/10.1089/lgbt.2021.0433>
- Yee K, Lind BK, Downing J. Change in gender on record and transgender adults' mental or behavioral health. *Am J Prev Med.* 2022;62(5):696–704. <https://doi.org/10.1016/j.amepre.2021.10.016>
- Proctor K, Haffer SC, Ewald E, Hodge C, James CV. Identifying the transgender population in the Medicare program. *Transgend Health.* 2016;1(1):250–265. <https://doi.org/10.1089/trgh.2016.0031>
- Levesque LE, Hanley JA, Kezouh A, Suissa S. Problem of immortal time bias in cohort studies: example using statins for preventing progression of diabetes. *BMJ.* 2010;340:b5087. <https://doi.org/10.1136/bmj.b5087>
- Case A, Paxson CH. Sex differences in morbidity and mortality. *Demography.* 2005;42(2):189–214. <https://doi.org/10.1353/dem.2005.0011>
- King WM, Hughto JMW, Operario D. Transgender stigma: a critical scoping review of definitions, domains, and measures used in empirical research. *Soc Sci Med.* 2020;250:112867. <https://doi.org/10.1016/j.socscimed.2020.112867>
- Hatzenbuehler ML, Phelan JC, Link BG. Stigma as a fundamental cause of population health inequalities. *Am J Public Health.* 2013;103(5):813–821. <https://doi.org/10.2105/AJPH.2012.301069>
- Krell EC. Is transisogyny killing trans women of color? *Transgend Stud Q.* 2017;4(2):226–242. <https://doi.org/10.1215/23289252-3815033>
- Bailey M. On misogynoir: citation, erasure, and plagiarism. *Fem Media Stud.* 2018;18(4):762–768. <https://doi.org/10.1080/14680777.2018.1447395>
- Polubriaginof FCG, Ryan P, Salmasian H, et al. Challenges with quality of race and ethnicity data in observational databases. *J Am Med Inform Assoc.* 2019;26(8–9):730–736. <https://doi.org/10.1093/jamia/ocz113>
- Hughes L, Gamarel KE, King WM, Goldenberg T, Jaccard J, Geronimus AT. State-level policy stigma and non-prescribed hormones use among trans populations in the United States: a mediational analysis of insurance and anticipated stigma. *Ann Behav Med.* 2022;56(6):592–604. <https://doi.org/10.1093/abm/kaab063>
- Kronk CA, Everhart AR, Ashley F, et al. Transgender data collection in the electronic health record: current concepts and issues. *J Am Med Inform Assoc.* 2022;29(2):271–284. <https://doi.org/10.1093/jamia/ocab136>
- Begun S, Kattari SK. Conforming for survival: associations between transgender visual conformity/passing and homelessness experiences. *J Gay Lesbian Soc Serv.* 2016;28(1):54–66. <https://doi.org/10.1080/10538720.2016.1125821>
- Meerwijk EL, Sevelius JM. Transgender population size in the United States: a meta-regression of population-based probability samples. *Am J Public Health.* 2017;107(2):e1–e8. <https://doi.org/10.2105/AJPH.2016.303578>
- Momen RE, Dilks LM. Examining case outcomes in US transgender homicides: an exploratory investigation of the intersectionality of victim characteristics. *Sociol Spectr.* 2021;41(1):53–79. <https://doi.org/10.1080/02732173.2020.1850379>
- Gyamerah AO, Baguso G, Santiago-Rodriguez E, et al. Experiences and factors associated with transphobic hate crimes among transgender women in the San Francisco Bay area: comparisons across race. *BMC Public Health.* 2021;21(1):1053. <https://doi.org/10.1186/s12889-021-11107-x>

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The Gap Between Anticipated and Current Life Satisfaction May Indicate Dissatisfaction Rather Than Hope

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Riley et al.¹ propose a measure of the difference between anticipated life satisfaction and current life satisfaction as a way of tracking population-level hope and its health effects. Morey² goes on to suggest that such a measure could be used to inform the development of

public health programs and policies that aim to enhance population well-being. Yet, no evidence supporting the validity of this “novel measure of hope” is provided.

Hope is synonymous with positive expectations about the future, and measures that assess hope should correlate negatively with hopelessness and positively with optimism and a positive outlook. To test this idea, I examined data from 3842 adults 28 to 84 years old drawn from the nationally representative Midlife in the United States (MIDUS) study.³ As in Riley et al.,¹ hope was measured according to the gap between anticipated and current life satisfaction, both assessed on a scale ranging from 0 (worst possible life) to 10 (best possible life).

Age- and sex-adjusted ordinary least squares regression models showed that those scoring higher on this measure of hope (i.e. by rating future life satisfaction as higher than current life satisfaction) were found to experience higher levels of hopelessness and lower levels of positive affect and current life satisfaction than others (Table A, available as a supplement to the online

version of this article at <http://ajph.org>). Hope was unrelated to dispositional optimism as measured with the Life Orientation Test–Revised.⁴

These findings are consistent with psychological research showing that anticipating improvements in life satisfaction is associated with dissatisfaction and distress,^{5,6} perhaps because one’s life conditions are not yet aligned with one’s expectations. This idea is further supported by research at the national level showing that larger gaps between anticipated and current life satisfaction are associated with lower levels of national prosperity and development.⁷ As such, when people envision dramatic improvements in their life circumstances, this may reflect a failure of expectations and dissatisfaction with current conditions.

If this suggestion is correct, it would mean that the counties identified by Riley et al.¹ as displaying the highest levels of hope may in fact be the areas where people are struggling most and in greatest need of well-being support. In contrast, counties with the lowest levels of “hope” (where current life satisfaction is approximately equal to anticipated life satisfaction) may be those where residents are content and anticipate stability.⁶ This is a concerning possibility and highlights the need for the validity of this new measure to be rigorously evaluated before it can be used to inform public health strategies. **AJPH**

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CONFLICTS OF INTEREST

The author reports no conflicts of interest.

REFERENCES

- Riley C, Herrin J, Lam V, et al. Trends and variation in the gap between current and anticipated life satisfaction in the United States, 2008–2020. *Am J Public Health*. 2022;112(3):509–517. <https://doi.org/10.2105/AJPH.2021.306589>
- Morey BN. A measure of hope: new questions for postpandemic rebuilding. *Am J Public Health*. 2022;112(3):345–347. <https://doi.org/10.2105/AJPH.2021.306668>
- Ryff CD, Almeida D, Ayanian J, et al. Midlife in the United States (MIDUS 2), 2004–2006. Available at: <https://www.icpsr.umich.edu/web/NACDA/studies/4652>. Accessed May 20, 2022.
- Scheier MF, Carver CS, Bridges MW. Distinguishing optimism from neuroticism (and trait anxiety,

self-mastery, and self-esteem): a reevaluation of the Life Orientation Test. *J Pers Soc Psychol*. 1994;67(6):1063–1078. <https://doi.org/10.1037/0022-3514.67.6.1063>

- Busseri MA, Peck E. Do (even) depressed individuals believe that life gets better and better? The link between depression and subjective trajectories for life satisfaction. *Clin Psychol Sci*. 2015;3(5):715–725. <https://doi.org/10.1177/2167702614547265>
- Choma BL, Busseri MA, Sadava SW. Deciphering subjective trajectories for life satisfaction using self-versus-normative other discrepancies, self-esteem and hope. *Eur J Pers*. 2014;28(2):107–119. <https://doi.org/10.1002/per.1889>
- Busseri MA. The global belief that “life gets better and better”: national differences in recollected past, present, and anticipated future life satisfaction around the world, across time, and in relation to societal functioning. *J Pers Soc Psychol*. 2022;123(1):223–247. <https://doi.org/10.1037/pspp0000415>

Riley and Roy Respond

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In our study “Trends and Variation in the Gap Between Current and Anticipated Life Satisfaction in the United States, 2008–2020,” we and our team proposed the gap between anticipated and current life satisfaction as an essential new measure to drive insight and action. The results of our study showed that this newly constructed measure remained largely unchanged for the United States population from 2008 through 2019 but increased dramatically in 2020. This change was driven by a sharp decline in current life satisfaction during the COVID-19 pandemic, with maintenance in anticipated life satisfaction. We interpreted this widening of the gap as suggestive of greater hope because it reflects a state in which

people have maintained their outlook on the future despite a decrease in their current satisfaction with their lives. This interpretation seems to align with Daly's understanding of hope as being “synonymous with positive expectations about the future.”

In our study, we also noted considerable variation in the gap between anticipated and current life satisfaction across counties. We further noted that many counties experienced an increase in this gap over time not because of a decrease in current life satisfaction but, rather, because of an increase in anticipated life satisfaction. These areas experienced an increase in the gap because the future outlook of their residents improved. We therefore remain unconvinced that the

gap may be identifying places in which people are experiencing dissatisfaction in response to a failure of expectations. Nonetheless, the findings of our study, as well as the analyses conducted by Daly, demonstrate the complexity in the relationships among current life satisfaction, anticipated life satisfaction, and their gap at the population level. These findings should serve as a call for more population-level research to understand such measures so that they can be used to guide actions in service to the well-being and hopefulness of people and places. **AJPH**

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CONTRIBUTORS

Both authors contributed to the conception and drafting of the letter.

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CONFLICTS OF INTEREST

The authors have received funding during the study to which this letter refers from the Institute for Healthcare Improvement and Heluna Health for work related to well-being measurement and its implementation.

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Erratum In: “Unanticipated Pandemic Outcomes: The Assault on Public Health”

In: Tremmel Freeman L. Unanticipated pandemic outcomes: the assault on public health. *Am J Public Health*. 2022;112(5):731–733. <https://doi.org/10.2105/AJPH.2022.306810>

On page 732, the launch of the We Stand with Public Health initiative was incorrectly attributed. It should read:

NACCHO is a key partner in the Johns Hopkins Bloomberg School of Public Health’s We Stand with Public Health effort that is working to bring attention to necessary actions to support public health.

This change does not affect the paper’s conclusions. [AJPH](#)

<https://doi.org/10.2105/AJPH.2022.306810e>

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Erratum In: “Experimental Forum 2: Two Years After the 2020 Food and Drug Administration Guidance on E-Cigarette Flavors”

In: Dasgupta N, Morabia A. Experimental forum 2: two years after the 2020 Food and Drug Administration guidance on e-cigarette flavors. *Am J Public Health*. 2022;112(7):995–998. <https://doi.org/10.2105/AJPH.2022.306921>

There was a typographical error in the first sentence of page 995. It should read:

There is intense interest in the April 2020 Food and Drug Administration (FDA) guidance document (“the Guidance”) on flavors in electronic cigarettes ([am.ajph.link/fda_guidance](https://www.fda.gov/oc/2020-04-20-fda-guidance-flavors-electronic-cigarettes)).

This change does not affect the paper’s conclusions. 

<https://doi.org/10.2105/AJPH.2022.306921e>

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Erratum In: “Scientific Publishing and the Tobacco Industry”

In: Morabia A. Scientific publishing and the tobacco industry. *Am J Public Health*. 2022;112(7):951. <https://doi.org/10.2105/AJPH.2022.306916>

Brad Rodu conducts research with funds from unrestricted grants from tobacco manufacturers to the University of Louisville, but Rodu stresses that the opinions he expressed in his comment to the *American Journal of Public Health* were his and did not represent the views of the tobacco industry or any other funding agency. On page 951, Rodu's name was misspelled and support for his research was misstated. The sentence should read:

We checked by asking Derek Yach, who was then the director of an organization funded by Philip Morris International, and Brad Rodu, who declares that his research is supported by unrestricted grants from tobacco manufacturers to the University of Louisville and by the Kentucky Research Challenge Trust Fund, to comment.

This change does not affect the paper's conclusions. [AJPH](https://doi.org/10.2105/AJPH.2022.306916)

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