Supplement 10

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Widespread Surveillance by the Child Protection System: Lasting Effects on Families

Christina N. Schmidt, BS, Monica Stretten, BA, and Heather Briscoe, MD

ABOUT THE AUTHORS

Christina N. Schmidt and Monica Stretten are with the School of Medicine, University of California, San Francisco. Heather Briscoe is with the Department of Pediatrics, University of California, San Francisco.

We commend Putnam-Hornstein et al. for their efforts to document rates of investigation and termination of parental rights by the child protective system in California.[1] The authors report that approximately one in two Black and Native American children were investigated over the course of their study, as compared with one in four White children. They also report that very few of these investigations resulted in termination of parental rights. Although the conversation surrounding child welfare systems often focuses on family separation, launching a child protective services (CPS) investigation is itself a significant intervention. Widespread surveillance of Black and Native American families contributes to significant trauma and perpetuates distrust in our social service systems.

The trauma resulting from a CPS investigation has been well documented in the literature. Families who experience an investigation often report significant stress and feelings of powerlessness, as well as adverse mental health outcomes.[2] Experiences of racism among child welfare–involved parents of color perpetuate feelings of disrespect, shame, fear, and judgment.[3]

Unsubstantiated investigations also seed distrust of the child welfare system and other social service programs. Even if a CPS investigation does not lead to family separation, fear of future reports contributes to "system" avoidance, resulting in decreased use of social services. Parents may strategically conceal information from social service workers, health care providers, and other mandated reporting systems, inhibiting access to important welfare services.[4]

Fears of a future investigation and separation are not unfounded, as repeated encounters with CPS are common. Families that CPS has investigated are more likely to experience a family separation if CPS launches a second investigation, even if the prior allegations were unsubstantiated.[5,6] The heightened risk of reinvestigation and family separation perpetuates the disproportionate rates of families of color involved in the child welfare system and reinforces the stark disparities in CPS investigations by race.

The child welfare system is designed to protect children and families. As Putnam-Hornstein et al. acknowledge, the findings of their study demonstrate that the design of the current system is flawed, resulting in detrimental effects on families of color who experience disproportionate family surveillance. Creating standardized workflows informed by multidisciplinary conversations to determine when and how to engage with CPS is a first step toward eliminating the bias involved in reporting child welfare cases. Bolstering preventive services that support families, rather than penalize them, is important in building trust and strengthening our communities. AJPH

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CONFLICTS OF INTEREST

The authors report no conflicts of interest.

REFERENCES

1. Putnam-Hornstein E, Ahn E, Prindle J, Magruder J, Webster D, Wildeman C. Cumulative rates of child protection involvement and terminations of parental rights in a California birth cohort, 1999–2017. *Am J Public Health.* 2021;111(6):1157–1163. https://doi.org/10.2105/AJPH.2021.306214
2. Merritt DH. How do families experience and interact with CPS? *Ann Am Acad Pol Soc Sci.* 2020; 692(1):203–226. https://doi.org/10.1177/0002716220979520
3. Merritt DH. Lived experiences of racism among child welfare-involved parents. *Race Soc Probl.* 2021; 13(1):63–72. https://doi.org/10.1007/s12552-021-09316-5
4. Fong K. Concealment and constraint: child protective services fears and poor mothers' institutional engagement. *Soc Forces.* 2019;97(4):1785–1810. https://doi.org/10.1093/sf/soy093
5. English DJ, Marshall DB, Brummel S, Orme M. Characteristics of repeated referrals to child protective services in Washington State. *Child Maltreat.* 1999;4(4):297–307. https://doi.org/10.1177/1077559599004004003
6. Connell CM, Bergeron N, Katz KH, Saunders L, Tebes JK. Re-referral to child protective services: the influence of child, family, and case characteristics on risk status. *Child Abuse Negl.* 2007;31(5):573–588. https://doi.org/10.1016/j.chiabu.2006.12.004

Putnam-Hornstein et al. Respond

Emily Putnam-Hornstein, PhD, Eunhye Ahn, MSW, John Prindle, PhD, Joseph Magruder, PhD, Daniel Webster, PhD, and Christopher Wildeman, PhD

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We thank Schmidt et al. for their thoughtful response to our *AJPH* article. Here we briefly expand on four topics they surfaced.

First, they noted that too little attention has been paid to the consequences of unnecessary child abuse and neglect investigations for families, especially low-income families and families of color. We agree. But we would add that unnecessary investigations also affect child safety. By asking child protection systems to dedicate resources to investigating and responding to so many reports under an increasingly broad umbrella of possible maltreatment, there is a real risk that we will miss children who are experiencing (or at risk of experiencing) serious harm.

Second and relatedly, we use the phrase "child protection system" intentionally. The current system is imperfect in its response, but what is reasonable to expect when we ask it to be all things for all children? The system was not designed, nor is it funded or situated, to assume responsibility for the general welfare (or, more recently, the "well-being") of children. It was established to investigate and intervene in relatively rare situations in which children are endangered by the inability or unwillingness of their parents to care for them.

Third, we agree that there must be more standardized efforts to "determine when and how to engage with [child protective services]." To that end, we believe that jurisdictions must reevaluate their methods for screening allegations of maltreatment and assessing risk. The tools typically used are rudimentary, often lack validation, and have left child protective services poorly equipped to effectively triage millions of children reported to have experienced alleged maltreatment each year.

Finally, we endorse Schmidt and colleagues' call to bolster prevention services to support families. But we are concerned that coupling primary prevention or concrete services with child protective services will create a context in which even more families, and especially families of color, are reported for reasons unrelated to child safety or harm. When it comes to societal goals of child welfare and child well-being, we believe that we must look to our health and public health systems, along with community providers. AJPH

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4. Fong K. Concealment and constraint: child protective services fears and poor mothers' institutional engagement. *Soc Forces.* 2019;97(4):1785–1810. https://doi.org/10.1093/sf/soy093
5. English DJ, Marshall DB, Brummel S, Orme M. Characteristics of repeated referrals to child protective services in Washington State. *Child Maltreat.* 1999;4(4):297–307. https://doi.org/10.1177/1077559599004004003
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COVER: What way forward for future pandemic planning? National, state, and city surveillance and survey programs would benefit from a unified national surveillance system for public health emergencies. The December 2021 issue of *AJPH* explores the complex answer to how this could be done on the basis of lessons from the COVID-19 pandemic. Who conducts such surveys, what modifications have already been made or are still needed, and how data collection might expand.
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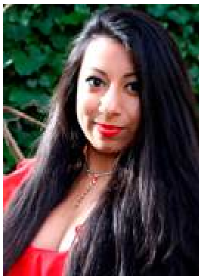

Surveillance and survey data are critical for informing effective and timely public health actions, particularly during pandemics like COVID-19 and other public health emergencies. Surveillance and survey programs track major life events such as births and deaths, disease distribution and wellness progression, as well as health care utilization across populations, geographies, and time. As our understanding about COVID-19 evolves, our surveillance and survey approaches must quickly adapt to meet the growing data needs of public health officials, researchers, and the public. These reformed programs will form the bedrock for a new generation of health informatics.

Because of COVID-19 safety concerns and varying stay-at-home orders imposed across the country, data collection and processing were disrupted, especially for programs that relied on person-to-person interactions or onsite manual reviews. As protocols and content got modified, surveillance and survey programs needed to address key dimensions of data quality: (1) accuracy and consistency, (2) timeliness, (3) efficiency and burden, and (4) relevance. These issues are raised in this special edition on COVID-19's impact on public health surveillance and survey programs in the United States.

First, programs needed to ensure data accuracy and consistency. For example, detailed death certification guidance and automated and manual coding instructions for cause of death had to be rapidly developed to help certifiers accurately record COVID-19 deaths. Furthermore, standardizing COVID-19 case definitions on death records is needed to yield more accurate and consistent comparisons across jurisdictions and over time.

Second, programs needed to ensure timely data dissemination. For example, to provide timelier data about the impact of COVID-19 on care providers, preliminary estimates from the National Health Care Surveys will be published via a data dashboard earlier than the release of final official data files. Federal health surveys may have an even more critical role in informing the public, as state-level pandemic dashboards are being decommissioned (https://n.pr/3hEH9cy). Within a media-rich public environment, timely data are now a public expectation, including small companies making occupational health decisions and large health care organizations predicting caseloads. Many data systems could benefit from clearer descriptions of how the data arose and how they should be analyzed.

Third, programs needed to ensure efficiency, striking a balance between minimizing burden to reluctant survey respondents and maximizing safety to collect critical pandemic-related data without sacrificing data quality. For example, like many other health surveys, the Medical Expenditure Panel Survey had to suspend almost all in-person field activities and pivoted to conducting most interviews by telephone, a less expensive option. Furthermore, multiple federal agencies collaborated quickly to launch two online data collection platforms to efficiently collect COVID-19–related information: the National Center for Health Statistics' Research and Development Survey and the Census Bureau's Household Pulse Survey.

Finally, programs needed to ensure data relevance by replacing less-prioritized content with new COVID-19–related items. Although changes to major surveys traditionally have phased in slowly to ensure data continuity, more dynamic surveys are required to monitor different aspects of emerging public health crises. For example, the National Health and Nutrition Examination Survey will include antibody testing to provide data on undiagnosed COVID-19 infections. The California Health Interview Survey integrated new COVID-19 items on anti-Asian rhetoric and hate incidents targeting Asian, Native Hawaiian, and Pacific Islander communities in California.

The essays in this special edition address what new research opportunities may be gained from collecting new COVID-19 information, how data quality and continuity may change through program design modifications, and what lessons are gained from this process that may inform future data strategies for other public health challenges. As more data become available, we can examine the fuller impact of COVID-19 on our data systems and the health of the nation. AJPH

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3 Years Ago

Public Health Surveillance for Zika Virus

Taking into account factors that influence both testing and reporting, it is reasonable to assume that Zika surveillance reports, like most case-based surveillance systems, substantially undercount the number of true infections. Moreover, who is screened, why, and where they live or have traveled all vary over time and among population groups. What tests are done, and when they are done relative to the time of exposure, also vary. All of these factors may depend on testing capacity, public health guidance, . . . as well as public and provider awareness and knowledge. Awareness and knowledge, in turn, depend on what the media says about these matters and individuals' access to different information sources, personal beliefs, and health services. As a consequence, case count trends as well as geographical and other differentials may reflect surveillance "artifacts" as much as real trends. . . . Differing criteria in epidemiological linkages in different jurisdictions make differences and changes in the data harder to interpret as real difference in incidence and prevalence.

From AJPH*, October 2018, p. 1361*

9 Years Ago

Self-Reported Influenza-Like Illness During the 2009 Pandemic

Standard surveillance for influenza in the United States involves health care providers describing patient visits for ILI [influenza-like illness] and submitting respiratory specimens for influenza diagnostic testing. The results from such health care–based surveillance conducted during the pH1N1 pandemic . . . indicate that activity peaked in late October 2009. . . . However, a majority of adults and almost half of children with ILI [in the CDC's Behavioral Risk Factor Surveillance System community survey conducted from September 2009 to March 2010] reported that they did not visit a health care provider for their illness and would not have been captured by health care-based influenza surveillance. Additionally, children, women, the oldest adult respondents, and adults in the Northeast and children in the South census regions were more likely to seek health care, suggesting that the epidemiology of ILI ascertained through routine influenza surveillance systems may differ substantially from that of cases identified using community surveillance.

From AJPH*, October 2012, p. e24*

Editor's Choice *Lau et al.* **2085**

Why Is It Important to Correctly Classify and Report SARS-CoV-2 Infections and COVID-19 Deaths?

Some countries classify the cause of death as COVID-19 with laboratory-confirmed tests, whereas other countries base this on symptomology. A study into the reported versus the estimated excess deaths during the COVID-19 pandemic was conducted in South Africa to determine the accuracy of surveillance in the country. Literature searches showed that South Africa significantly underestimated the deaths from COVID-19 during 2020. This was also observed during the HIV epidemic in South Africa, resulting in underfunding of resources for HIV prevention and treatment. Proper measures and universal definitions for reporting deaths from COVID-19 should be put in place to ensure that necessary policy and funding are provided for the prevention and treatment of COVID-19.

Citation. Ngcobo S, Rossouw TM, Madela-Mntla E. Why is it important to correctly classify and report SARS-CoV-2 infections and COVID-19 deaths? *S Afr J Public Health.* 2020;4(3):81–84. https://doi.org/10.7196/SHS.2020.v4.i3.134

Bangladesh Lower-Income Workers Suffer High Stress Levels Because of COVID-19 Pandemic

Paul et al. conducted a quantitative and qualitative survey of 576 low-income workers in several Bangladesh districts to assess stress levels. The researchers used the mean score of a 4-point Likert-type scale, where a score of 4 indicates extreme stress. Most (94.1%) of the participants reported being affected by the COVID-19 pandemic, with a mean stress score of 3.2 (+0.77). Daily workers who had to go out often searching for jobs reported being more affected by the pandemic than did unemployed respondents (odds ratio [OR] = 7.96). Industry workers, farmers, and day laborers reported higher stress than did unemployed respondents (ORs = 5.82, 3.03, and 2.65, respectively). The combined effect of fearing COVID-19 and lack of worker support from the government may have resulted in workers' higher levels of stress.

Citation. Paul A, Nath TK, Mahanta J, et al. Psychological and livelihood impacts of COVID-19 on Bangladeshi lower income people. *Asia Pac J Public Health.* 2021;33(1):100–108. https://doi.org/10.1177/1010539520977304

The Use of Quick Response (QR) Posters for COVID Contact Tracing

To bolster COVID-19 contact-tracing efforts, a smartphone app was launched in conjunction with QR code posters displayed in public venues. This intervention was created to encourage the population to keep a digital log of places visited in case of a positive COVID-19 case. Parkin et al. assessed the proportion of people frequenting a venue who scanned the QR code. From January to February 2021, the authors randomly selected 40 venues (e.g., cafes, restaurants, bars, churches, and supermarkets). Across venues, the proportion of visitors who scanned the QR code ranged from 0% to 50% (median 10.2%); the highest proportion of people scanning was in cafes, and the lowest was in bars. The authors emphasized the continued need for QR scanning by the population and recommended that venues take action to display posters clearly to facilitate public participation.

Citation. Parkin L, Singh A, Seddon E, et al. Audit of NZ COVID tracer QR poster display and use in Dunedin. *N Z Med J.* 2021;134(1531):67–76.

An Advanced SARS-CoV-2 Surveillance System in Canada

Surveillance metrics help government systems and policymakers determine the most effective response to a disease outbreak. Post et al. provide an advanced method that uses a longitudinal trend analysis design to capture changes in speed, acceleration, jerk, and persistence of the COVID-19 pandemic. Comparing the week of February 7 to 13, 2021 with February 14 to 20, 2021, Post et al. showed that the speed of the pandemic decreased from 8.4 new daily cases per 100 000 to 7.5 per 100 000 for the whole country. In individual provinces, over the same time, the speed decreased in both Ontario and Quebec, and increased in Nunavat. The model presented provides a better picture of day-to-day and week-to-week changes in the pandemic than do traditional surveillance measures.

Citation. Post L, Boctor MJ, Issa TZ, et al. SARS-CoV-2 surveillance system in Canada: longitudinal trend analysis. *JMIR Public Health Surveill.* 2021;7(5):e25753. https://doi.org/10.2196/25753

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Oral Histories of Civic Action to Address HIV/AIDS

Daniel M. Fox, PhD

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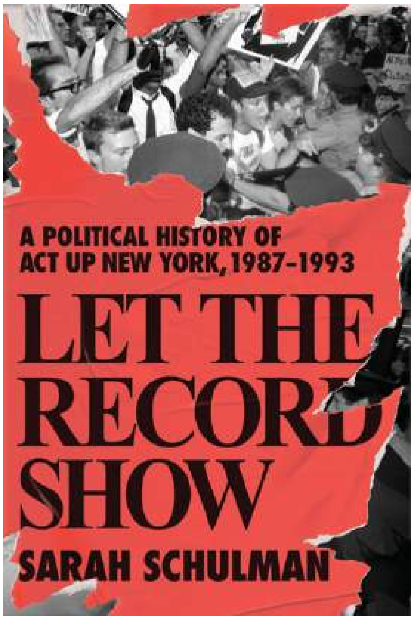

Let the Record Show: A Political History of ACT UP NEW YORK, 1987–1993
By Sara Schulman
702 pp.; $40.00
New York, NY: Farrar, Straus and Giroux, 2021 (hardcover)
ISBN: 978034185138

Since 1987, ACT UP (AIDS Coalition to Unleash Power) has, through civic action by its members in 148 chapters in the United States and other countries, advocated on behalf of public policy and health care interventions to prevent and treat HIV/AIDS. This massive book focuses on the most influential years of its history in a narrative based on oral history interviews with 188 members of ACT UP conducted over 17 years by Schulman and her colleagues. Schulman supplements these interviews with accounts of her own activism during the HIV/AIDS pandemic.

Schulman makes insightful observations throughout the book. For example, she opens the narrative by asserting that

> this is a story of a despised group of people . . . facing a terminal disease for which there were no treatments. Abandoned by their families, government, and society, they joined together and forced our country to change against its will . . . and [saved] incalculable numbers of future lives (p. 5).

Similarly, she describes how “one great thing that ACT UP accomplished was to give a face to AIDS” (p. 74). Another example: “the art of ACT UP created a new kind of person, one who was living with HIV (infected or not) and who could change the world. It reached for and confirmed power, both as self-perception and ultimately reality” (p. 319). She summarizes the achievements of ACT UP in a list of seven bullet points.

The persuasiveness of Schulman’s insights emerges through her thick descriptions of ACT UP leaders and members demonstrating in public and negotiating with powerful policymakers, especially in the federal government; members called this the “inside-outside strategy.”

I can attest to the strong impact of ACT UP’s advocacy as a result of my experience as a member of a special study section convened by the National Institutes of Health to devise and apply creative methods of evaluating the effectiveness of interventions in collaboration with members of affected communities. The financing and implementation of this research strongly influenced the uptake by American research-funding agencies and clinical researchers of methodology (devised mostly in other industrial countries) that was soon associated with the phrase “evidence-based medicine.”

The book has 29 chapters preceded by an informative preface and followed by a conclusion and Schulman’s “personal conclusion.” Schulman divides the chapters into four “books” titled Political Foundations, Art in the Service of Change, Creating the World You Need to Survive, and Desperation. Each chapter combines extensive quotations from the oral histories with analyses by Schulman and the colleagues who worked with her in conducting the interviews.

Inevitably, the book has several deficiencies. One is inattention to the strengths and limitations of the extensive literature about the history of the pandemic that has accumulated since the mid-1980s. For instance, Schulman and her colleagues understate support for ACT UP's agenda among senior policymakers in the federal government and the states as well as among influential journalists, even at the *New York Times* (of which Schulman is highly critical). Another deficiency is the lack of attention to the influence of ACT UP in other countries, especially in the Global South (and, in particular, Latin America).

Overall, however, the result is a compelling synthesis of stories about policy and politics during the HIV pandemic, with details about the personal lives of interviewees.

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AJPH Call for Papers
A PUBLICATION OF THE AMERICAN PUBLIC HEALTH ASSOCIATION
Ubiquitous Lead

The ***American Journal of Public Health (AJPH)***, in collaboration with the Centers for Disease Control and Prevention (CDC), intends to publish a supplemental issue on the topic of lead hazards, prevention–mitigation programs, and emerging sources of exposure. The supplement will address and contribute to the comprehensive understanding of currently known and emerging hazardous sources of lead exposure related to global trade, climate change, and infrastructure renewal. Original social, policy, research and evaluation articles, and perspectives are invited. Topics of interest include but are not limited to evidence-based promising practices that strengthen efforts to identify, measure, and mitigate lead exposure in communities; analyses of data demonstrating geographic distribution of lead exposures and associated social vulnerabilities; social determinants of lead exposure risk and consequences; blood lead level testing in affected communities; building capacity for prevention and working with agency partners; emerging sources of lead exposure; implications of COVID-19 on lead poisoning prevention and surveillance; lead poisoning as a major international health crisis; and data demonstrating the impact of lead on children and adults. The full Call for Papers is available at https://ajph.aphapublications.org/callforpapers.

Scholars in academia, historians, public health departments, the medical professions, health educators and evaluators, community and faith-based organizations, and governmental agencies are invited to submit manuscripts related to lead exposure prevention and mitigation. Potential authors should visit the *AJPH* website (https://www.ajph.org) to review the Instructions for Authors and specific guidelines for the various types of manuscripts. Importantly, submissions must include a cover letter formatted as requested in the Instructions for Authors. In all manuscripts, the number of words, references and tables/figures must correspond to a specific *AJPH* article format. All manuscripts will undergo standard peer review by the *AJPH* editors and peer referees as defined by *AJPH* policy. Manuscripts must be submitted to *AJPH* by **January 30, 2022,** and can be submitted at https://www.editorialmanager.com/ajph. For additional information about this supplement, contact: T. LeBlanc at tleblanc@cdc.gov.

Guest Editors: Tanya Telfair LeBlanc, PhD, MS; Erik Svendsen, PhD; and Paul Allwood, PhD, Centers for Disease Control and Prevention, Atlanta, GA
AJPH *Editor:* Jonathan I. Levy, ScD

Access and Analytics: What the Military Can Teach Us About Health Equity

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Note. The views expressed in this editorial are solely those of the authors and do not reflect the views of New York City Health + Hospitals, the New York University Grossman School of Medicine, or the Yale New Haven Health System.

See also Young et al., p. 2194.

Racial and ethnic minority groups have been disproportionately burdened by COVID-19 health outcomes, including infection, hospitalization, and death. Over the course of the pandemic, Black and Hispanic people in the general population have had more than two times the rate of infection and nearly five times the rate of hospitalization (Young et al.; p. 2194). Disparities in health outcomes are thought to be multifactorial but related in part to lack of access to health care coverage. To test the hypothesis that universal eligibility for health care may eliminate disparities in COVID-19 health outcomes among racial and ethnic groups, Mancuso et al. used an integrated database to analyze rates of COVID-19 testing, test positivity, and hospitalizations in the active component of the US military (AC)—a group with universal eligibility for health care. They found that members of the AC still had disparities in test positivity and hospitalizations, but at less than half the level of the general population. Specifically, they found that compared with White people, Black people (adjusted risk ratio [ARR] = 1.25; 95% confidence interval [CI] = 1.22, 1.27) and Hispanic people (ARR = 1.26; 95% CI = 1.24, 1.28) were at higher risk for infection and higher risk for hospitalization (ARR = 1.28; 95% CI = 1.08, 1.53; ARR = 1.21, 95% CI = 1.01, 1.45). The authors' analysis also showed that Black and Hispanic people in the AC had higher rates of COVID-19 testing than their White counterparts. These findings suggest that universal access to health care services advances health equity.

Although universal health care coverage is a necessary first step toward eliminating health care disparities, it is only one aspect of access to health care and does not imply equal quality of care. This study nonetheless provides an opportunity for scholars, policymakers, and the public to analyze the effect of universal coverage on health and health disparities. To better understand the relationship between access to health coverage and health outcomes, future work should consider other dimensions of health care access: timely use of health services, affordability, a usual source of care, and availability of culturally competent and capable providers.[1,2] These elements are salient when measuring disparities and designing interventions in the AC, given that in the general population, Black and Hispanic people are more likely to report delaying their care because of related costs and are more likely to go without a usual source of health care.[3] Identifying patterns of sources of care is particularly relevant for understanding populations with universal coverage, as even the insured can suffer negative health consequences and are less likely to receive necessary treatment for chronic conditions like hypertension without a usual source of care.[4] Furthermore, it is important to recognize that universal coverage is not commensurate with provider availability. Some members of the AC, who are beneficiaries of a military coverage option called Tricare, have struggled to establish care with private civilian practices, as only about 67% of primary care physicians accept this insurance.[5] Finally, systems that guarantee universal coverage should measure and aspire to increase the availability of culturally competent and concordant providers, as these features of health care access are known to affect health outcomes.[6]

One of the strengths of the study is its use of a large, structured data set for an enumerated population. Large data sets are promising for elucidating health disparities and potential areas for interventions.[7] However, as with any data enterprise, the accuracy, specificity, and completeness of the data are important to ensure that results are reliable and meaningful. This is particularly the case in health equity studies, where demographic categorizations related to race, ethnicity, and gender may not be standardized or may be noninclusive in their collection or reporting. Demographic groups that are less prevalent in the sample, such as Native Americans and gender minorities, are also at risk for loss of visibility or loss of privacy. Disparities in COVID-19 testing, infections, hospitalizations, and mortality have been identified among ethnic groups not explicitly described, such as among Asian Americans (in aggregate and among Asian American subgroups); therefore, data structures used to assess health disparities must be sufficiently detailed that select populations are not overlooked or excluded.[8]

In line with these challenges, Mancuso et al. note that further details related to race and ethnicity could not be provided beyond non-Hispanic White, non-Hispanic Black, Hispanic, and Other because ethnicity is not captured in a standard fashion across military branches. One area in which the Department of Defense may be able to improve its efforts to understand diversity, equity, and inclusion is in standardization of data fields for measurement of demographic factors across all military branches. The minimum standards developed by the US Department of Health and Human Services under the Affordable Care Act's Section 4302 on the collection of race and ethnicity data may serve as a starting point.[9] More robust data will be critical in efforts to quantify, intervene, and monitor for health disparities.

Universal eligibility for health care coverage is essential to eliminating health disparities in COVID-19 and beyond. However, coverage alone is insufficient, as disparities are influenced by many factors within and outside of formal health care institutions. Ongoing efforts to improve and standardize data structures will be necessary to produce accurate, actionable, and inclusive analyses around health disparities. Policymakers, health systems leaders, and community advocates have an opportunity to learn from Mancuso et al. about the power that universal access to care and reliable data collection can have on reducing health disparities and approaching equity for marginalized groups. AJPH

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CONFLICTS OF INTEREST

The authors have no conflicts of interest to disclose.

REFERENCES

1. Agency for Healthcare Research and Quality. Topic: access to care. Available at: https://www.ahrq.gov/topics/access-care.html. Accessed August 5, 2021.
2. Campbell SM, Roland MO, Buetow SA. Defining quality of care. *Soc Sci Med.* 2000;51(11):1611–1625. https://doi.org/10.1016/S0277-9536(00)00057-5
3. Kaiser Family Foundation. Key facts on health and health care by race and ethnicity. Available at: https://www.kff.org/report-section/key-facts-on-health-and-health-care-by-race-and-ethnicity-coverage-access-to-and-use-of-care. Accessed August 5, 2021.
4. Spatz ES, Ross JS, Desai MM, Canavan ME, Krumholz HM. Beyond insurance coverage: usual source of care in the treatment of hypertension and hypercholesterolemia. Data from the 2003–2006 National Health and Nutrition Examination Survey. *Am Heart J.* 2010;160(1):115–121. https://doi.org/10.1016/j.ahj.2010.04.013
5. Zoroya G. Civilian doctors wary of accepting military's Tricare. *USA Today*. April 3, 2013. Available at: https://www.usatoday.com/story/news/nation/2013/04/03/tricare-doctors-insurance/2047569. Accessed August 4, 2021.
6. Alsan M, Garrick O, Graziani GC. Does diversity matter for health? Experimental evidence from Oakland. June 2018. Available at: https://www.nber.org/system/files/working_papers/w24787/w24787.pdf. Accessed August 5, 2021.
7. Zhang X, Pérez-Stable EJ, Bourne PE, et al. Big data science: opportunities and challenges to address minority health and health disparities in the 21st century. *Ethn Dis.* 2017;27(2):95–106. https://doi.org/10.18865/ed.27.2.95
8. Chin MK, Doan LN, Chon SK, et al. Asian American subgroups and the COVID-19 experience: what we know and still don't know. Available at: https://www.healthaffairs.org/do/10.1377/hblog20210519.651079/full. Accessed August 5, 2021.
9. US Dept of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. HHS implementation guidance on data collection standards for race, ethnicity, sex, primary language, and disability status. Available at: https://aspe.hhs.gov/reports/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-disability-0. Accessed August 5, 2021.

Yes, Food Portion Sizes and People Have Become Bigger and Bigger. What Is to Be Done?

Carlos A. Monteiro, MD, PhD, and Geoffrey Cannon, MA

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See also Young and Nestle, p. 2223.

The food supply in the United States is a catastrophe, from the public health and other points of view. Its most visible result is obesity: in two decades, the prevalence of obesity among US adults has risen by more than 30% (from 30.5% to 42.4%) and the prevalence of severe obesity has almost doubled (from 4.7% to 9.2%).[1] Even more alarming are the figures for children. From the periods 1971–1974 to 2017–2018, among those aged 2 to 19 years, the prevalence of obesity nearly quadrupled (from 5.2% to 19.3%), and the prevalence of severe obesity rose sixfold (from 1% to 6.1%).[2] These are great warning signs.

A recent US government report dryly notes: "The typical American dietary pattern is not currently nor has it ever been aligned with recommendations issued by the Dietary Guidelines for Americans since their inception in 1980."[3]

THE GROWTH OF PORTION SIZES

One reason is the large portion sizes of many food products, as shown in important *AJPH* articles in 2002[4] and in this issue (p. 2223). The findings of these articles have vital implications for the United States and for other countries.

In their 2002 report, Young and Nestle showed that what they then named "market-place foods" evaded US official guidance. "Portion sizes began to grow in the 1970s, rose sharply in the 1980s, and have continued in parallel with increasing body weights."[4(p246)] Thus, for "French fries, hamburgers, and soda, current sizes are 2–5 times larger than the originals."[4(p246)] More examples of the swelling portion sizes of foods and drinks sold in retail stores or fast-food outlets are given. Thus: "In the mid-1950s, McDonald's offered only 1 size of French fries; that size is now considered 'Small.' . . . Today's 'Large' weighs the same as the 1998 'Supersize.' . . . Since 1999, a McDonald's 'Supersize' soda is nearly one third larger than the 'Large.'"[4(p248)]

Little has changed since 2002. The 2021 article by Young and Nestle, accurately identifying "market-place foods" as ultra-processed,[5] reports that since 2002 all companies in their sample "still sold portions of ultra processed foods in up to 5-times-larger sizes than when first introduced" (p. 2223). The authors also state that whereas the original size of a Coca Cola bottle was 6.5 ounces, it now has 6 sizes, from 7.5 to 24 ounces, all of which are marketed as single servings. They note that although McDonald's has eliminated its "supersizes," it still markets quart-sized sodas and double burgers. Generally, bigger sizes remain priced as better bargains than smaller sizes.

SO, WHAT TO DO?

Young and Nestle argue for policies designed to reduce portion sizes of ultra-processed foods and drinks. Such advice is understandable in the United States, where on average, for everybody aged older than two years, "Foods and beverages [such as] burgers and sandwiches, casseroles, pizza, snacks and sweets, and beverages (other than milk and 100% juice) contribute 50–60% of total energy intake."[3] Practically all these products, and others cited, are ultra-processed,[5] purchased ready-made and ready to eat, drink, heat, or snack anywhere, anytime, often alone, sold at retail stores and fast-food outlets.

The two reports by Young and Nestle are based on data from the United States, where fast-food and snacking habits are ingrained, and where those most in need of dietary advice may rarely if ever eat freshly prepared meals. In this context, consuming smaller portions and servings of ultra-processed food could be sensible advice, even though smaller products would remain devoid of intact food matrices; would still be energy-dense with combinations of fat, sugar, or salt; would continue to induce mindless snacking; and would discourage switching to whole and minimally processed foods and freshly prepared dishes and meals.

What then about other countries? Ultra-processed foods are made by transnational corporations whose policies and practices are worldwide. Rates of overweight and obesity are rising globally, as is the increase in the manufacture, marketing, sale, and consumption of ultra-processed foods, most dramatically in middle- and low-income countries.[6] But in many of these countries, long-evolved, established national and regional food systems and dietary patterns persist, although threatened by the incursion of transnationals. Regular freshly prepared meals enjoyed with family, friends, or colleagues, at home or in neighborhood restaurants, are still normal in countries such as Brazil, where we live.[7]

In such countries, reduced portion sizes of ultra-processed foods would at best have limited effect, and most likely would be counterproductive if they were marketed to promote their consumption. Generally, the most rational guideline, for global as well as personal health and well-being, is to protect and promote minimally processed foods and freshly prepared meals and to discourage the consumption of ultra-processed foods altogether,[8] together with statutory measures including fiscal policies and actions. These measures should make fresh and minimally processed foods cheaper and more available. Ultra-processed foods should be made more expensive and less available, if at all, especially in canteens and hospitals, other health settings, and in and near schools. Cosmetic additives should be banned or highly taxed.

Another important reason to avoid ultra-processed foods in any country has become more evident. Many such products are designed by their manufacturers to induce craving.
A substantial literature states that such effects amount to addiction. This is not surprising. Humans are not evolved or adapted to metabolize ultra-processed foods, which are artificial technical formulations. The common combination of fat and refined carbohydrates in ultra-processed foods does not exist in any naturally occurring food. According to a recent study, "As with addictive drugs, ultra-processed foods are the result of processing naturally occurring substances . . . and refining them into evolutionarily novel substances with unnaturally high levels of rewarding ingredients. They are then combined with additives that further amplify their effects and are quickly consumed [in ways that] rapidly and effectively activate reward/motivation systems in the brain."[9]

As with tobacco, there is no need to consume ultra-processed food products. Avoidance is the prudent and healthiest guideline.

Transnational food corporations operate worldwide, their ultra-processed products are increasingly consumed everywhere, obesity is now pandemic, and in most countries related disorders and diseases are rapidly increasing. Therefore, global action coordinated by the United Nations is necessary.[10] It is uncertain whether moves like those recommended here will gain traction after the UN Food Systems Summit held in September.[11] They should, because the declared purpose of the summit has been to transform food systems so as to achieve the UN Sustainable Development Goals by 2030.

In any case, recommended policies and actions for—and then issued by—the United Nations should not be limited to those that could be immediately feasible. The time for thorough change is needed, and will come. Foresight is needed, and the social, economic, political, and environmental contexts of the pandemic need to be included, as in any major public health initiative. Sometime in the future—perhaps, unfortunately, only when many millions more people have obesity and are suffering from diabetes or other related disabilities and diseases—there should be effective action.

Rudolf Virchow, the great 19th-century physician, pathologist, and social reformer, said of mass epidemics: "[P]alliatives will no longer do. If we wish to take remedial action, we must be radical."[12] Indeed we must.

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REFERENCES

1. US Centers for Disease Control and Prevention. Adult obesity facts. 2021. Available at: https://www.cdc.gov/obesity/data/adult.html. Accessed September 26, 2021.
2. Fryar C, Carroll M, Afful J. Prevalence of overweight, obesity, and severe obesity among children and adolescents aged 2–19 years: United States. US Centers for Disease Control and Prevention. 2021. Available at: https://www.cdc.gov/nchs/data/hestat/obesity-child-17-18/obesity-child.htm. Accessed September 26, 2021.

3. US Dept of Agriculture, US Dept of Health and Human Services. Scientific Report of the 2020 Dietary Guidelines Advisory Committee. Part D, chapter 1, pp. 4 and 52. 2020. Available at: https://www.dietaryguidelines.gov/2020-advisory-committee-report. Accessed September 15, 2021.
4. Young L, Nestle M. The contribution of expanding portion sizes to the US obesity epidemic. *Am J Public Health.* 2002;92(2):246–249. https://doi.org/10.2105/AJPH.92.2.246 https://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11818300&dopt=Abstract
5. Monteiro CA, Cannon G, Levy RB, et al. Ultra-processed foods: what they are and how to identify them. *Public Health Nutr.* 2019;22(5):936–941. https://doi.org/10.1017/S1368980018003762
6. Baker P, Machado P, Santos T, et al. Ultra-processed foods and the nutrition transition: global, regional and national trends, food systems transformations and political economy drivers. *Obes Rev.* 2020;21(12):e13126. https://doi.org/10.1111/obr.13126 https://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=32761763&dopt=Abstract
7. Monteiro CA, Cannon G. The impact of transnational "big food" companies on the South: a view from Brazil. *PLoS Medicine* 2012;9(7):e1001252.
8. Brazilian Ministry of Health. *Dietary Guidelines for the Brazilian Population.* Brasilia: Ministry of Health; 2014.
9. Gearhardt A, Schulte E. Is food addictive? A review of the science. *Ann Rev Nutr.* 2021; Epub ahead of print. https://doi.org/10.1146/annurev-nutr-110420-111710
10. Monteiro CA, Lawrence M, Millett C, et al. The need to reshape global food processing: a call to the United Nations Food Systems Summit. *BMJ Glob Health.* 2021;6(7):e006885. https://doi.org/10.1136/bmjgh-2021-006885 https://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=34321237&dopt=Abstract

11 United Nations. The Food Systems Summit, September 23, 2021, New York: Available at: https://www.un.org/en/food-systems-summit. Accessed September 15, 2021.

12. Virchow R. *Report on the Typhus Epidemic in Upper Silesia. Archiv für pathologische Anatomie und Physiologie und für klinische Medicin.* Vol 2. 1848: Berlin, Germany: George Reimer. In English: Virchow R (Rather L, edit) *Collected Essays on Public Health and Epidemiology*. Vol 1. 1985: Boston, MA: Science History Publications.

Reaffirming the Foundations of Public Health in a Time of Pandemic

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See also Young et al., p. 2194, Nicholas et al., p. 2212, Palermo et al., p. 2227, and Sterling et al., p. 2239.

Public health has been through an extraordinary period over the past two years. The novel coronavirus infection that became the COVID-19 global pandemic was first diagnosed on December 31, 2019. The pandemic spread rapidly, with much of the world affected by mid-2020. The contours of 2020 and 2021 globally were shaped almost entirely by the pandemic. Millions of people died, economies slowed, and unemployment reached record levels in many countries, all stemming from a pandemic that had been unknown two years ago. In the United States, COVID-19 was the third leading cause of death in 2020 and resulted in a downturn in life expectancy unprecedented since World War II.

Coincident with the overwhelming role that COVID-19 has played in shaping public life, the visibility of the public health field has skyrocketed in the time of the pandemic, with public health occupying the front pages of newspapers worldwide. This visibility for public health was long overdue and welcome. It also of course should create an opportunity for reflection and self-examination. Much remains to be written about the burden of COVID-19, about our response to it, and about what public health stands to learn from the moment. We look forward to those conversations emerging. In this editorial, the last of what has been a five-year series of Public Health of Consequence commentaries, we wanted, however, to pause and reflect less on how public health might wish to evolve in the aftermath of COVID-19 and more on the foundations of public health that remain central to the aspirations of the field despite and perhaps because of COVID-19. Four articles in this issue of *AJPH* serve to illustrate three core points that lie at the heart of public health.

PUBLIC HEALTH PRINCIPLES

First, we lean on the definition offered by the Institute of Medicine, according to which "public health is what we, as a society, do collectively to assure the conditions for people to be healthy."[1(p1)] Although this definition is many decades old, it captures the foundational observation that public health is about creating conditions for health. This has since been amplified in other writing.[2,3] The understanding that public health is fundamentally about conditions creates opportunities for innovative approaches that can contribute to those conditions.

The article by Palermo et al. (p. 2227) is an illustration of this. The authors examine the effects of a government-implemented cash plus program on experiences of violence and perpetration among Tanzanian adolescents and youths, and their findings show that the program reduced both females' experiences of sexual violence and males' perpetration of physical violence. The authors conclude that social protection can reduce violence by addressing poverty and multidimensional vulnerability, and they offer an example of how we can improve the health of populations by improving conditions. Although this is one very particular illustration, we hold it as a general example of the broader point about the foundations of public health: public health is what we do collectively, in this case through government efforts, to create conditions for health. That is as much true for violence prevention as it is for creating the conditions that mitigate the spread of disease during the time of COVID-19; moreover, it will be so for decades hence and can serve as well as one of the pillars of public health going forward.

Second, public health must centrally be concerned with health equity, with ensuring that all can live long, healthy lives. That we have a deeply unequal country on axes of health is indubitable,[4] and the gaps between health haves and health have nots have only widened during COVID-19.[5] This elevates the importance of focusing on the core purpose of public health to narrow these gaps.

The article by Young et al. (p. 2194) in this issue amply illustrates how deeply entrenched health inequities can be and how challenging, as a result, an effort to eradicate these inequities is. Young et al. demonstrate that, among active-component US military members, non-Hispanic Black Americans and Hispanic Americans have higher rates of COVID-19 infection and hospitalization even though active-duty military personnel all have access to universal health care and, in this case, had similar rates of testing. This speaks to the deeply entrenched forces that drive racial and ethnic health inequities, the impact of which extends well beyond what can be addressed through the availability of universal health care. It also points to the need for unrelenting commitment on the part of public health to eliminate health inequities, including making a concerted effort to take an anti–health inequity approach to counter the burden of poor health.[6]

Third, public health must stand on the side of those who are marginalized and vulnerable and whose health stands most to benefit through improvements to the conditions that generate health. According to the 1948 Universal Declaration of Human Rights, "Everyone has the right to a standard of living adequate for the health and well-being of [themselves] and [their] family."[7] It is the role of public health to focus on the "everyone" in that definition, turning our attention in particular to those individuals who are often left behind by other broader societal efforts.

Two articles in this issue remind us well of some of these populations. Nicolas et al. (p. 2212) document an increase in mortality rates among the homeless population in Los Angeles county between 2015 and 2019, showing that drug overdose was the leading cause of death in this population. Sterling et al. (p. 2239) show that home health care workers have worse general, physical, and mental health than low-wage workers not employed in home health, highlighting the health needs of a group that is growing in size and societal importance as our population ages but to which we seldom pay adequate attention. These articles both remind us of the role of public health to bear witness—and point to solutions—to the health burdens experienced by those who are far from the front pages of the public conversation and to relentlessly continue our efforts to both elevate their stories and urge approaches that can improve their health.

LOOKING AHEAD

We consider these three core purposes of public health—a focus on the conditions of the world around us, on eliminating health inequity, and on those who are marginalized and vulnerable—foundational to the field. This has, in our assessment, been the case since the origins of public health, has continued to be so during COVID-19, and will continue to be so for decades hence. A refocus on these forces can help sharpen our priorities and remind us of why we do what we do, even when we are living through the maelstrom of ideas occasioned by a global pandemic.

And it is in that vein, one of refocusing on foundations, that we will pause these commentaries, five years and 60 commentaries in. As the world slowly exits through COVID-19 it will be a time for reflection and careful reconsideration, grounded in the foundations of why we do what we do. We hope to do just that ourselves and to learn from the many other voices that have emerged in the past five years since we started writing these commentaries. We remain grateful to be part of the public health community, perhaps in this time more than ever, and the scholarship with purpose featured in the pages of *AJPH*.

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REFERENCES

1. Institute of Medicine. *The Future of Public Health.* Washington, DC: National Academy Press; 1988.
2. 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
3. Galea S, Annas GJ. Aspirations and strategies for public health. *JAMA.* 2016;315(7):655–656. https://doi.org/10.1001/jama.2016.0198
4. Galea S, Vaughan R. A public health of consequence: review of the May 2017 issue of *AJPH*. *Am J Public Health.* 2017;107(5):646–647. https://doi.org/10.2105/AJPH.2017.303726
5. Ahmad FB, Cisewski JA, Miniño A, Anderson RN. Provisional mortality data—United States, 2020. *MMWR Morb Mortal Wkly Rep.* 2021;70(14):519–522. https://doi.org/10.15585/mmwr.mm7014e1
6. Galea S, Vaughan R. Taking an anti-health inequity approach to counter the unfair burden of poor health. *Am J Public Health.* 2021:e1–e2. https://doi.org/10.2105/AJPH.2021.306451
7. United Nations. Universal Declaration of Human Rights. Available at: https://www.un.org/en/about-us/universal-declaration-of-human-rights. Accessed September 5, 2021.

Why Was COVID-19 Not the First Leading Cause of Death in the United States in 2020? Rethinking the Ranking List

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In the United States, COVID-19 was the third leading cause of death, after heart disease and cancer, during 2020, according to the provisional mortality data report released by the National Center for Health Statistics (NCHS) on March 31, 2021.[1,2] By contrast, COVID-19 was the leading cause of death, followed by dementia and Alzheimer's disease, ischemic heart disease, stroke, and lung cancer, in England and Wales in February 2021, according to the provisional mortality analysis released by the Office for National Statistics on March 18, 2021.[3] One month later, COVID-19 became the third leading cause of death.[4] Some people might wonder why the names of the categories used for rankings in the United States (e.g., cancer or heart disease) differed from those used in England and Wales (e.g., lung cancer or ischemic heart disease). That is, the countries did not use the same list in ranking the leading causes of death.

BROAD VERSUS SPECIFIC RANKING CATEGORIES

Rankings of the leading causes of death are the most commonly cited health statistics by mass media and health-related advocacy organizations in many countries because of their easy comprehensibility. However, different countries use different lists for their rankings. Some countries use *International Classification of Diseases, Tenth Revision* (*ICD-10*; Geneva, Switzerland: World Health Organization; 1992) codes (e.g., neoplasms, diseases of the circulatory system, diseases of the respiratory system) as a foundation for their rankings. By contrast, some countries use more specific categories (cancer of specific site, ischemic heart disease, diabetes mellitus, land transport accidents) as a foundation. As expected, the use of different lists results in different ranking orders, hindering valid international comparisons.

The rankings that the Office for National Statistics uses are different from those the NCHS uses. The Office for National Statistics includes 65 ranked categories in its list,[5] whereas the NCHS includes 51.[6] The NCHS list incorporates some broad categories such as cancer, heart disease, and unintentional injuries. These categories have 89, 31, and more than 100 three-character *ICD-10* codes, respectively. However, diabetes mellitus has five subcategories (*ICD-10* codes E10–E14), and COVID-19 has only one subcategory (*ICD-10* code U07.1).[6] These discrepancies lead to unfair comparisons between cancer and COVID-19.

MORE SPECIFIC AND ACTIONABLE INFORMATION

Furthermore, health policy decision makers require more specific and actionable information to determine the relative importance of different health problems and subsequently allocate resources appropriately. From the perspective of disease control and prevention, cancers of different sites are heterogeneous in terms of etiology, progression, screening capability, and treatment modalities. Grouping cancers of various levels of preventability and treatability into one category for mortality rankings cannot provide specific or actionable information.

Only 16 cancers are included in the avoidable mortality indicators used by the Organisation for Economic Co-operation and Development and Eurostat to assess the performance of health systems across member countries.[7,8] Nine cancers (oral, esophageal, stomach, liver, lung, mesothelioma, skin, bladder, and cervical) are classified as preventable through implementation of effective public health and primary prevention interventions, and eight cancers (cervical, colorectal, female breast, uterus, testicular, thyroid, Hodgkin's disease, and lymphoid leukemia) are classified as treatable (or amenable) through timely and effective health care interventions.[8]

Similarly, grouping unintentional injuries (accidents) into a single ranked category masks specific and actionable information. Prevention strategies and countermeasures are quite different for causes such as land transport accidents, falls, drownings, poisonings, and discharging of a firearm. The list should present external causes separately for ranking the leading causes of death, especially for younger people, for whom external causes are the primary causes of death.

PROPOSED STANDARD RANKING LIST

To solve the aforementioned comparability and specificity problems, a standard list for ranking the leading causes of death in the World Health Organization (WHO) member countries was proposed at the World Health Organization Family of International Classifications network meeting in 2004. The principles for constructing the standardized list include the following:

1. the grouping of causes should have an epidemiological basis for disease prevention and control;
2. residual categories (e.g., other, not specified) should be avoided, and only one such category should exist for all remaining causes;
3. a balance between aggregating and disaggregating causes should be sought;
4. broad and heterogeneous categories (such as cancer and unintentional injuries) should be avoided;
5. the list should consist of mutually exclusive diseases or groups of diseases;
6. the list should be based on the current *ICD* version; and
7. a list that meets these criteria will likely contain a range of 40 to 80 candidate categories.[9]

Despite the disapproval of the US delegates,[10] the WHO ranking list was approved by the organization and has been used by many countries and researchers.[11–13]

COVID-19 IN THE REVISED WHO RANKING LIST

If we apply the revised WHO ranking list[5] to 2020 provisional mortality data to determine the rankings of leading causes of death in the United States, COVID-19 becomes the leading cause of death, and several new specific causes such as ischemic heart disease, lung cancer, heart failure, and hypertension are among the top 10 leading causes (Table 1).

Using the same WHO list, we were able to compare the rankings of the United States in 2020 with those in England in February 2021, and the categories were as follows: COVID-19, dementia and Alzheimer's disease, ischemic heart disease, stroke, lung cancer, chronic lower respiratory tract diseases, symptoms and ill-defined conditions, influenza and pneumonia, and hematopoietic cancer. Notably, heart failure, hypertension, diabetes, and diseases of the urinary system were among the 10 leading causes of death in the United States but not in England.

We were also able to compare the rankings of the United States in 2019 with those of high-income countries in 2019 released by WHO; the categories were ischemic heart disease, dementia and Alzheimer's disease, stroke, lung cancer, chronic obstructive pulmonary disease, lower respiratory tract infections, colorectal cancer, kidney disease, hypertensive heart disease, and diabetes.[14] Accidental poisoning was the 10th leading cause in the United States but not in high-income countries overall.

COMPARABILITY WITHIN AND BEWEEN COUNTRIES

The main reason for preserving the broad categories in NCHS ranking list is to retain comparability across times for users at the national and local levels in the United States. The NCHS list was established at the 1951 Public Health Conference of Records and Statistics,[6] and sophisticated diagnostic tools were not widely available at that time (the first computerized tomography scanners were installed in the United States in 1973). One pragmatic consideration was the use of the broad category "cancer" instead of "cancer of specific site." This consideration also existed for the WHO ranking list, which used "stroke" instead of "cerebral infarction or cerebral hemorrhage." Furthermore, many countries other than United States still use broad categories in their rankings, probably with the similar consideration of comparability across time.

With regard to comparability between countries on specific causes of death, the NCHS has also published detailed cause-specific data on numbers of deaths and death rates.[15] If users are not able to find specific

TABLE 1— Ten Leading Causes of Death According to Two Ranking Lists: United States, 2020

Cause of Death (*ICD-10* Code)	No. of Deaths
National Center for Health Statistics list[a]	
Heart disease (I00–I09, I11, I13, I20–I51)	690 882
Cancer (C00–C97)	598 932
COVID-19 (U07.1)	435 323
Unintentional injuries (V01–X59, Y85–Y86)	192 176
Chronic lower respiratory diseases (J40–J47)	159 050
Stroke (I60–I69)	151 637
Alzheimer’s disease (G30)	133 382
Diabetes (E10–E14)	101 106
Influenza and pneumonia (J09–J18)	53 495
Kidney disease (N00–N07, N17–N19, N25–N27)	52 260
Suicide (U03, X60–X84, Y870)	44 834
World Health Organization list[b]	
COVID-19 (U07.1)	435 323
Ischemic heart diseases (I20–I25)	369 579
Dementia and Alzheimer’s disease (F01, F03, G30)	242 273
Chronic lower respiratory diseases (J40–J47)	159 050
Stroke (I60–I69)	151 637
Lung cancer (C33-C34)	143 041
Heart failure (I50–I51)	108 866
Hypertensive diseases (I10–I15)	104 527
Diabetes (E10–E14)	101 106
Diseases of the urinary system (N00–N39)	73 037
Accidental poisoning (X40–X49)	67 355

Note. ICD-10 = International Classification of Diseases, Tenth Revision (Geneva, Switzerland: World Health Organization; 1992).

[a] The numbers of deaths for 2020 were obtained from Ahmad and Anderson.[2]
[b] The numbers of deaths for specific causes were estimated according to specific cause (such as lung cancer)/broad cause (such as cancer) in 2019 obtained from CDC WONDER.

causes in that report, they can access CDC WONDER to determine numbers of deaths for four-character *ICD* codes.[16] The numbers of deaths for specific causes in Table 1 were retrieved from CDC WONDER.

In conclusion, ranking the leading causes of death is still a popular means of determining the relative importance of health problems and is a starting point for further comprehensive analyses of cause-specific mortality rates. Using more specific categories for rankings can provide more specific and actionable information for health policymakers. The United States should regularly provide the rankings of leading “specific” causes of death in addition to “broad” causes of death. AJPH

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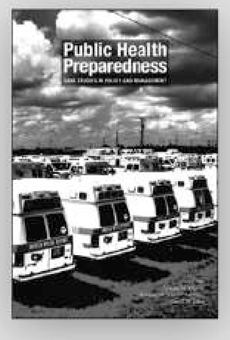
REFERENCES

1. Ahmad FB, Cisewski JA, Miniño A, Anderson RN. Provisional mortality data—United States, 2020. *MMWR Morb Mortal Wkly Rep.* 2021;70(14):519–522. https://doi.org/10.15585/mmwr.mm7014e1
2. Ahmad FB, Anderson RN. The leading causes of death in the US for 2020. *JAMA.* 2021;325(18):1829–1830. https://doi.org/10.1001/jama.2021.5469
3. Office for National Statistics. Monthly mortality analysis, England and Wales: February 2021. Available at: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/monthlymortalityanalysisenglandandwales/february2021#leading-causes-of-death. Accessed March 18, 2021.
4. Office for National Statistics. Monthly mortality analysis, England and Wales: March 2021. Available at: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/monthlymortalityanalysisenglandandwales/march2021#leading-causes-of-death. Accessed April 22, 2021.
5. Office for National Statistics. Leading causes of death in England and Wales. Available at: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/methodologies/userguidetomortalitystatistics/leadingcausesofdeathinenglandandwalesrevised2016. Accessed April 22, 2021.
6. Heron M. Deaths: Leading causes for 2019. *Natl Vital Stat Rep.* 2019;68(6):1–77. https://doi.org/10.15620/cdc:107021
7. *Health at a Glance 2019: OECD Indicators.* Paris, France: Organisation for Economic Co-operation and Development; 2019.
8. Organisation for Economic Co-operation and Development/Eurostat. Avoidable mortality: OECD/Eurostat lists of preventable and treatable causes of death (November 2019 version). Available at: https://www.oecd.org/health/health-systems/Avoidable-mortality-2019-Joint-OECD-Eurostat-List-preventable-treatable-causes-of-death.pdf. Accessed April 22, 2021.

9. Becker R, Silvi J, Ma Fat D, L'Hours A, Laurenti R. A recommended methodology for the derivation of leading causes of death. Available at: https://www.who.int/bulletin/volumes/84/4/297.pdf. Accessed April 22, 2021.
10. Rosenberg H, Anderson R. Leading causes of death: a tool for health assessment. Paper presented at: World Health Organization Family of International Classifications network meeting, Iceland, October 2004.
11. Becker R, Silvi J, Ma Fat D, L'Hours A, Laurenti R. A method for deriving leading causes of death. *Bull World Health Organ.* 2006;84(4):297–304. https://doi.org/10.2471/bit.05.028670
12. Griffiths C, Rooney C, Brock A. Leading causes of death in England and Wales: how should we group causes? *Health Stat Q.* 2005;28:6–17.
13. Hsiao AJ, Chen LH, Lu TH. Ten leading causes of death in Taiwan: a comparison of two grouping lists. *J Formos Med Assoc.* 2015;114(8):679–680. https://doi.org/10.1016/j.jfma.2013.12.003
14. World Health Organization. The top 10 causes of death. Available at: https://www.who.int/news-room/fact-sheets/detail/the-top-10-causes-of-death. Accessed May 7, 2021.
15. Xu JQ, Murphy SL, Kochanek KD, Arias E. Deaths: Final data for 2019. *Natl Vital Stat Rep.* 2021;70(8):1–86. https://doi.org/10.15620/cdc:106058
16. Centers for Disease Control and Prevention. CDC WONDER. Available at: https://wonder.cdc.gov. Accessed April 22, 2021.



Political Races, Religious Congregations, and Inefficacious Measures Amid the Second Wave of COVID-19 in India

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India is currently dealing with the period after the peak of the disastrous second wave of the COVID-19 pandemic. Daily reported cases are ebbing after reaching a peak of 0.4 million cases on May 7, 2021, with a positive test rate of approximately 22%.[1] Multiple reasons have been hypothesized for the second wave, the most common being the rapid transmission of the Delta variant of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), early relaxation of control measures, and ignorance of COVID-19–appropriate behavior.[2] The Union Health Ministry began reporting the unusual surge of cases in states such as Maharashtra, Punjab, and Kerala by the end of February 2021. The states were advised to "Test, Track, and Treat" by relying on RT-PCR (reverse transcription–polymerase chain reaction) rather than rapid antigen-based tests, accelerating vaccination, sending public health teams to affected areas for analysis, and promoting COVID-19–appropriate behavior. The state of Maharashtra, which reported the highest surge in cases, instituted multiple restrictive measures in early April that were equivalent to a complete lockdown, and the other states followed suit.[3]

CONGREGATING EVENTS AT START OF SECOND WAVE

During the months of March and April 2021, the states of Assam, Kerala, Tamil Nadu, and West Bengal and the union territory of Puducherry conducted elections whose candidates held political rallies consisting of large gatherings where COVID-19–appropriate behavior was defied; as a result, the states faced an unprecedented surge of new cases.[1,4] Of particular note are the massive political rallies in West Bengal, which imminent political leaders from the country's ruling party attended.[4] These events are linked to a massive surge of cases in West Bengal. There were 198 new cases on March 1, 2020, and a peak of 20 846 new cases on May 14, 2021, with a positivity rate of 29.75%.[1]

The Kumbh Mela (celebrated every 12 years) was held in early 2021 at Haridwar in Uttarakhand and contributed to the rising cases. The Union Health Ministry projected an attendance of 1 million people on regular days and about 5 million people on certain days for the holy bath at the banks of the Ganges River. Hosting the Kumbh Mela amid a pandemic was partly a calculated political and economic decision.[5] Even though the Health Ministry and the state government provided guidelines for the event—which included mandatory wearing of masks, maintaining social distance, obtaining medical certification, and mandatory RT-PCR reports for devotees—a blatant violation of norms was observed at the event, whose overall participants included 9.1 million devotees and a congregation of 6 million during April.[5] These events are linked to a rise in the number of new cases in Uttarakhand: from 69 cases on March 11, the day of the first holy bath, to a peak of 7749 new cases on May 12. A positivity rate of approximately 23% occurred in the last 15 days of the event.[1]

REPERCUSSIONS OF INDIA'S SECOND WAVE

As the upsurge of cases instigated the drastic second wave of COVID-19 in India, the health care system's inadequacies and lack of preparedness began to be exposed.[6] Many areas across the country faced shortages of hospital beds, ventilators, and oxygen supply owing to overloaded health care facilities.[6] A surge in oxygen demand peaked at 9000 metric tons as compared with 3095 metric tons during the first wave.[7] About 629 deaths have been linked to oxygen shortages across the country between April 6 and May

19, 2021—although the Union Health Ministry has reported no such deaths.[7,8] Prompt action and coordination between the state and the union government ensured that the states' oxygen demands were met by facilitating equitable distribution based primarily on the active case load.[7]

The availability of drugs such as Remdesivir was limited because of the increased demand, indiscriminate use, hoarding, and selling the drug at exorbitant prices.[9] Subsequently, the government banned exporting Remdesivir and implemented stricter regulations to ensure its proper use.[9]

The excess number of deaths attributable to COVID-19 during India's second wave remains enigmatic and has been estimated to be much higher than the official COVID-19 mortality data.[10] The five states of Andhra Pradesh, Bihar, Kerala, Madhya Pradesh, and Tamil Nadu cumulatively had more than 0.46 million excess deaths in the first five months of 2021, but the official COVID-19 death data accounted for only approximately 6% of these excess deaths.[10] Additionally, from March to July 2020, there were 989 deaths attributable to the strict lockdown during the first wave, of which 23% are owing to financial distress and starvation.[11]

Since the start of 2021, the government has focused on its nationwide vaccination drive. Currently in phase 3, the drive has resulted in the complete vaccination of approximately 147.50 million eligible citizens, which corresponds to roughly 15.69% of the total eligible population older than 18 years.[12] The accessibility and utility of AarogyaSetu—the contact-tracing application that the government developed—pose concerns: there have been approximately 202 million application downloads, suggesting it is currently inaccessible to 85% of the population.

CHALLENGES AHEAD FOR INDIA

Even though we could cite a multitude of reasons for India's second COVID-19 wave, it is necessary to undertake measures to prevent further damage and the emergence of an additional wave. First, the monitoring and sharing of genomic variations in SARS-CoV-2 need to be significantly increased to study the various strains in the community and their characteristics.[6] As of August 16, 2021, the Indian SARS-CoV-2 Genomics Consortium has sequenced only 0.23% of the reported COVID-19 cases as compared with the United Kingdom and Australia, which have sequenced and shared 11.1% and 49.9% of their COVID-19 cases, respectively.[13,14] The Delta variant continues to be the main variant of concern and is still responsible for a very high proportion of the vaccine breakthrough cases in India.[14] The emergence of Delta sublineages in India is currently being monitored, and there is no functional evidence of increased transmissibility.[14]

Second, key pandemic surveillance indicators data need to be made publicly available, which includes disaggregated data on new COVID-19 cases; deaths by age, sex, comorbidities, and vaccination status; transmission categories of cases; the number of hospitalized COVID-19 patients; COVID-19 clusters; influenza-like illnesses and severe acute respiratory illnesses; and COVID-19 among health care workers. These data will aid researchers and public health experts as they analyze the situation and tailor the response.[15]

Third, restrictions on movement similar to the lockdown of the first wave need to be evaluated with a focus on the burden placed on the population; prompt quantification of the morbidity and mortality that such measures cause is key to this evaluation.[11] The discussion on policy actions for COVID-19 control measures should be based in equity and should prioritize protecting lives and valuing the interests of vulnerable and the marginalized populations; efforts need to be made to reduce inequalities and disparities.[16]

Fourth, the COVID-19 pandemic's indirect consequences owing to disruptions in the delivery and utilization of routine services, including essential health and nutrition services, need to be addressed.[17] The government must ensure that the population-level health indicators are not affected drastically by the disruption of India's health care services. Modeling studies have already estimated a 15% and 18% increase in child and maternal mortality, respectively, in 2020 compared with 2019.[17] Also, prepandemic data show that the infant mortality decline has been stagnant and even reversed in some states in 2017 and 2018. Child nutrition indicators have not improved between 2015–2016 and 2019–2020; in some states, the proportion of underweight children and stunting has increased.[18,19] Early restoration of health care services is pivotal and requires triaging to identify priorities, succinct communication to the community, and increasing the health care workforce.[20]

Finally, the COVID-19 vaccination program's efforts need to be expanded. India has administered approximately 640 million vaccine doses, the highest number of doses administered worldwide but has completely vaccinated only 32.42% of the population older than 60 years; the United States, by comparison, has administered 369 million vaccines and has vaccinated 81.7% of the population older than 65 years.[12] Also, vaccination of the population older than 60 years declined in India after the beginning of phase 3 and has been down by nearly 50%.[12] The government must ensure equitable distribution of vaccines to the priority groups in both urban and rural areas, especially in areas where public health services are deficient, by employing the vast network of local and community health care workers to further improve vaccination coverage.[6]

CONCLUSIONS

As India recovers from the second wave and its repercussions, its causes must be promptly analyzed, and measures to prevent further damage and ensure preparedness must be instituted before there is a potential third wave of COVID-19.

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REFERENCES

1. India COVID Apex Research Team. COVID Today: tracking India’s pandemic response. Available at: https://covidtoday.in. Accessed August 30, 2021.
2. Thiagarajan K. Why is India having a COVID-19 surge? *BMJ*. 2021;373:n1124. https://doi.org/10.1136/bmj.n1124
3. Express Web Desk. COVID-19 second wave: here’s a list of states that have imposed full lockdown. May 9, 2021. Available at: https://indianexpress.com/article/india/covid-19-second-wave-heres-a-list-of-states-that-have-imposed-lockdowns-7306634. Accessed October 14, 2021.
4. Deka K. Is the Election Commission responsible for the second wave of COVID cases? April 29, 2021. Available at: https://www.indiatoday.in/india-today-insight/story/is-the-election-commission-responsible-for-the-second-wave-of-covid-cases-1796437-2021-04-29. Accessed October 14, 2021.
5. Jaswal S. BJP fired ex-Uttarakhand chief minister TS Rawat for restricting Kumbh gatherings. May 7, 2021. Available at: https://caravanmagazine.in/politics/bjp-fired-ex-uttarakhand-chief-minister-trivendra-singh-rawat-restricting-kumbh-gatherings. Accessed October 14, 2021.
6. The Lancet. India’s COVID-19 emergency. *Lancet*. 2021;397(10286):1683. https://doi.org/10.1016/S0140-6736(21)01052-7
7. Answers to Unstarred Question No. 243: acute shortage of oxygen during second wave of pandemic. 2021. Available at: https://www.theleaflet.in/wp-content/uploads/2021/07/AU243.pdf. Accessed October 14, 2021.
8. Priya A, Dash P, Ranaware K. The truth about oxygen deaths during COVID second wave. July 7, 2021. Available at: https://indianexpress.com/article/opinion/columns/covid-second-wave-oxygen-death-coronavirus-cases-7392219. Accessed October 14, 2021.
9. Bose J. What’s behind India’s Remdesivir shortage? Indiscriminate use, hoarding and black markets. April 11, 2021. Available at: https://www.hindustantimes.com/india-news/careless-use-hoarding-and-black-markets-behind-india-s-remdesivir-shortage-101618148086724.html. Accessed October 14, 2021.
10. Rukmini S. The challenge of saying how many excess deaths could be due to COVID-19. June 25, 2021. Available at: https://www.indiaspend.com/covid-19/deaths-first-wave-second-wave-pandemic-757701. Accessed October 14, 2021.
11. Aman, Thejesh GN, Ranaware K, Sharma K. Of denial and data. Deaths due to India’s COVID-19 national lockdown. Economic & Political Weekly. 2021;56(23). June 5, 2021. Available at: https://www.epw.in/journal/2021/23/insight/denial-and-data.html. Accessed October 14, 2021.
12. India Ministry of Health and Family Welfare. CoWIN dashboard. Available at: https://dashboard.cowin.gov.in/?lang=en. Accessed August 30, 2021.
13. GISAID. COVID-19 submission tracking. Available at: https://www.gisaid.org/index.php?id=208. Accessed August 30, 2021.
14. Indian SARS-CoV-2 Genomics Consortia. INSACOG Weekly Bulletin, No. 8. August 16, 2021. Available at: https://dbtindia.gov.in/sites/default/files/INSACOG%20Bulletin%20August%2016th.pdf. Accessed October 14, 2021.
15. Morgan OW, Aguilera X, Ammon A, et al. Disease surveillance for the COVID-19 era: time for bold changes. *Lancet*. 2021;397(10292):2317–2319. https://doi.org/10.1016/S0140-6736(21)01096-5
16. Rahman M, Ahmed R, Moitra M, et al. Mental distress and human rights violations during COVID-19: a rapid review of the evidence informing rights, mental health needs, and public policy around vulnerable populations. *Front Psychiatry*. 2021;11:603875. https://doi.org/10.3389/fpsyt.2020.603875
17. United Nations Children’s Fund. Direct and indirect effects of COVID-19 pandemic and response in South Asia. March 2021. Available at: https://www.unicef.org/rosa/reports/direct-and-indirect-effects-covid-19-pandemic-and-response-south-asia. Accessed October 14, 2021.
18. Drèze J, Gupta A, Parashar SA, Sharma K. Pauses and reversals of infant mortality decline in India in 2017 and 2018. November 8, 2020. Available at https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3727001. Accessed October 14, 2021.
19. Drèze J. New evidence on child nutrition calls for radical expansion of child development services. December 20, 2020. Available at: https://indianexpress.com/article/opinion/columns/new-evidence-on-child-nutrition-calls-for-radical-expansion-of-child-development-services-7107810. Accessed October 14, 2021.
20. World Health Organization. Second round of the national pulse survey on continuity of essential health services during the COVID-19 pandemic. April 23, 2021. Available at: https://www.who.int/publications/i/item/WHO-2019-nCoV-EHS-continuity-survey-2021.1. Accessed October 14, 2021.

Child Enrollment in States With and Without Continuous Coverage in Medicaid and CHIP During COVID-19

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COVID-19 threatens the health of children, yet it is important to recognize that children's health is at risk not only by the disease itself but by the policies that have been adopted before and during the pandemic. As unemployment has increased during the pandemic, so has the risk of uninsurance.[1] Loss of insurance coverage is particularly harmful for children because of the long-term health, education, and financial benefits of insurance.[2] Levels of health insurance coverage for children were decreasing even before COVID-19, outpacing similar negative trends in adult insurance coverage.[3] In an effort to improve children's coverage, 25 states adopted policies that extended continuous eligibility in the Children's Health Insurance Program (CHIP) and 23 states adopted continuous eligibility for Medicaid, allowing children to remain enrolled for a 12-month period even if temporary income changes would have made them ineligible for the program.[4]

Since the pandemic began, the federal government mirrored these state actions to stabilize Medicaid coverage through the Families First Coronavirus Response Act. The act provided enhanced funding for Medicaid, but it required states to not restrict eligibility standards and to provide continuous coverage without eligibility redetermination for enrollees through the remainder of the public health emergency. Although CHIP has been a policy success, its smaller enrollment and budget compared with Medicaid, recent lapses in federal funding, and fraying bipartisan support has resulted in a program that can be overlooked by policymakers.[5] This is what happened when Congress did not require CHIP to provide enrollment protections for enrollees through Families First. During the pandemic, a handful of states have adopted enrollment protections for their CHIP programs, but this has been a patchwork approach. Ultimately, the contrasting treatment of continuous eligibility regulations, combined with the fragmented insurance landscape across programs, complicates and threatens the health of enrollees.

We analyzed variation in Medicaid and CHIP enrollment changes across states that had implemented continuous eligibility policies prior to the COVID-19 pandemic. We aggregated data from the federal government's standardized monthly reports of Medicaid and CHIP enrollment figures across all the states. All states are required to report a range of data to the Centers for Medicare & Medicaid Services (CMS), including application, eligibility, and enrollment figures. We collected reported data from March to October 2020, when finalized reports by the CMS were last made available. We measured changes in child enrollment in two different ways—on a per capita basis and as a percentage change in enrollment over the time period of the study.

In total, child enrollment in Medicaid and CHIP increased by 6 881 004 from March to October 2020, with the majority of those gains occurring in Medicaid programs. Medicaid enrollment, which could not decrease because of the federal freeze, increased across all states. Medicaid programs across all the states experienced an average child enrollment increase of 10.6% (or 957 per 10 000 children) from March to October 2020.

Compared with Medicaid, there was much more volatility in CHIP enrollment across the states. This is a function of the lack of federal enrollment protections for these enrollees. Twenty-one states experienced declines in enrollment from March to October 2020. In total, CHIP enrollment increased by just 17 295 children from March to October 2020, an increase of 0.26%, or 8.6 per 10 000 children. It is unclear from the data whether enrollment in Medicaid accounts for part of the decrease in CHIP enrollment.

Adoption of a continuous enrollment policy prior to COVID-19 matters for child enrollment. States that had previously adopted policies to enhance child enrollment in Medicaid and CHIP experienced smaller changes in enrollment during COVID-19. States without a CHIP continuous enrollment policy prior to March 2020 experienced an enrollment increase of 1.2% (18.7 per 10 000 children), compared with a 0.11% decrease in states with a preexisting continuous enrollment policy in the program. Medicaid enrollment in states without a Medicaid continuous enrollment program increased on average by 12.6% (974 children per 10 000 children), compared with 10.7% (958 children per 10 000 children) in states with Medicaid continuous enrollment policy. States without continuous enrollment in either Medicaid or CHIP experienced a combined increased enrollment of 10.09% (941 per 10 000 children) across both programs.

There are several important policy implications from the analysis of child enrollment in Medicaid and CHIP during COVID-19. First, although CHIP and Medicaid are essential programs for ensuring children's health, particularly during crises, policy adoption prior to a crisis is also important in stabilizing health care access for children. States that had implemented continuous coverage prior to COVID-19—and that probably had a higher baseline for participation in their Medicaid and CHIP programs—experienced smaller gains and decreases in enrollment during the pandemic.

Second, the divergent trends in enrollment between CHIP and Medicaid highlight the different policies and protections between the two programs, with this fragmented insurance landscape introducing potential threats to coverage and health. CHIP policies, which can include premiums, copays, and lack of the Medicaid Early and Periodic Screening, Diagnostic and Treatment benefit, may be burdensome for families. Such challenges create the potential for coverage loss or disruptions among enrolled children and point to the benefits that policymakers effect by better aligning CHIP policies with Medicaid.

Lastly, federal policymakers should consider a broader application of maintenance of eligibility and disenrollment freeze policy across public programs during future crises. By placing a disenrollment freeze on Medicaid, but not on CHIP, policymakers increase the likelihood of enrollment shifting across programs. This can increase burden and complications for enrollees and their families, or lead to children dropping coverage. Indeed, the state of Utah recently announced that more than 6200 children lost coverage after the state ended the CHIP maintenance of effort requirements.

It is important for policymakers to be aware of the particular harms that COVID-19 presents to children's public health, especially disruptions in insurance coverage, which can have long-term negative effects. These findings underscore the coverage and health challenges posed by a fragmented insurance coverage system, despite policy intervention to minimize disenrollment. Fragmentation across programs introduces gaps and barriers to coverage that the most vulnerable may fall into. Greater policymaker recognition of the ways in which Medicaid and CHIP work together would not only ensure increased continuity in coverage for children, but also streamline state eligibility and enrollment systems. Continuous enrollment policies can be important bulwarks against the loss of insurance coverage for children. Yet the patchwork approach, both across states and programs, to adopting continuous enrollment policy jeopardizes children's public health. State and federal policymakers need to strengthen enrollment procedures to proactively protect the public health of all children. AJPH

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REFERENCES

1. US Bureau of Labor Statistics. Employment situation news release. 2020. Available at: https://www.bls.gov/news.release/archives/empsit_06052020.htm. Accessed December 4, 2020.
2. Wherry LR, Miller S, Kaestner R, Meyer BD. Childhood Medicaid coverage and later-life health care utilization. *Rev Econ Stat.* 2018;100(2):287–302. https://doi.org/10.1162/REST_a_00677
3. Moore-Petinak N, Singer PM. The uncertain future of children's health insurance: new and ongoing threats. *JAMA Pediatr.* 2020;174(10):924–925. https://doi.org/10.1001/jamapediatrics.2020.2566
4. Kaiser Family Foundation. State adoption of 12-month continuous eligibility for children's Medicaid and CHIP. 2020. Available at: https://www.kff.org/health-reform/state-indicator/state-adoption-of-12-month-continuous-eligibility-for-childrens-medicaid-and-chip/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D. Accessed January 29, 2021.
5. Oberlander J, Jones DK, Spivack S, Singer PM. In The Affordable Care Act's shadow: the fate of the Children's Health Insurance Program. *Health Aff (Millwood).* 2016;35(10):1835–1841. https://doi.org/10.1377/hlthaff.2016.0226

Talking About "Firearm Injury" and "Gun Violence": Words Matter

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For decades, discussions of the prevention of firearm injury have been stalled by the debate between gun rights and gun control. Over time, even the terms used can develop unintended connotations, such that word choice might promote trust or derail a conversation.[1] "Gun violence" is a common term but may be viewed by some as code for "gun control" because it is often used by groups supporting firearm regulations.[2] A 2019 survey of gun owners showed that approximately half saw "gun control" advocates as disrespectful to gun culture and aiming to confiscate all guns,[3] and many gun owners said they felt blamed for "gun violence" by gun control advocates.

"Firearm injury" is a term used within academic and public health publications and programs because of the impression that it is more neutral and encompasses all types of injury, but it may be less well understood by the general public. These differences in terminology have implications for public health interventions, patient care, and participation in research because the message—and messenger—helps shape narratives about what firearm injury is, who is affected, and what can or should change.

Firearms are used in a large proportion of suicides, homicides, and nonfatal assaults in the United States, and firearm-involved injury and death has been identified as a significant public health problem.[4] With newly available funding from federal agencies and foundations, clinicians and researchers are developing and studying public health approaches to preventing firearm suicides, firearm homicides, and unintentional shootings. This work has, however, been limited by the lack of a shared language as well as by institutional barriers.

Sensitivity over language is not a new challenge, and words matter throughout public health, clinical care, and advocacy. As part of their training, physicians, nurses, and other health professionals learn how to talk about death, how to approach discussions of substance use disorder, and how to have respectful conversations about gender identity and sexual orientation. Informed health care providers and public health professionals generally know the importance of engaging with patients and communities in ways that are aligned with patient-relevant values and preferences. The same should hold true for conversations about firearms.

Challenges related to language used in discussions and interventions for preventing firearm injury and death extend beyond clinical care to research, training, prevention, and policy efforts. Importantly, programs or messaging from one discipline's approach to preventing firearm injuries or deaths may inadvertently have consequences for another field. For example, public and media discussions of "gun violence" often omit or downplay deaths from self-inflicted violence (suicide),[5] contributing to public misperceptions that firearm homicide is more common than firearm suicide.[6]

A 2019 analysis showed that a single mass shooting was associated with a 15% increase in firearm-related legislative proposals[7]; policy work driven by a discussion of only one type of firearm injury may cause unexpected negative outcomes. For example, background check laws for firearm purchases or transfers were written to prevent acquisition of firearms by individuals who might be more likely to use them for homicides or other crimes. Although these laws may prevent some suicides by putting time and space between a person in crisis and lethal means, they have also had a negative impact on suicide prevention by making temporary firearm transfers between individuals more difficult.[8,9] Professionals working to prevent injury and violence need to learn to talk about risk and prevention in words that can have a positive impact across disciplines.

Here our goal is to present suggestions and opinions as a starting point for culturally respectful, conversation-promoting language related to firearms, suicide by firearm, and community violence involving firearms. Further refinements and clarifications will be needed, as will expansion to parallel areas such as intimate partner violence and specific populations at increased risk of firearm injury (e.g., military personnel and veterans, individuals with dementia). In addition, some communities or demographic groups may have specific slang or colloquial terms that should be considered.

We bring perspectives from varied organizations and disciplines. We reached our recommendations for messaging (Box 1) through public discussions with each other and with stakeholders from our respective disciplines as well as through existing guides. Although we may not agree with or endorse each other's approach on all topics, we share the common goal of preventing firearm-involved injuries and deaths. We seek to encourage public health professionals, health care providers, and researchers—including those working in health policy—to use shared, informed, nonjudgmental language as a critical first step in creating trust and sustainable collaboration.

LANGUAGE AROUND FIREARMS, OWNERSHIP, AND STORAGE

A starting point is the basic language of firearms (Box 1). In the United States, approximately 44% of adults live in a home with at least one firearm.[10] Firearm purchases spiked in 2020, driven in part by fears about the COVID-19 pandemic and social and political unrest.[11] The most commonly reported reason for firearm ownership is personal protection from other people (cited by 63% of US adults in 2021), followed by hunting (40%).[10] Firearm ownership is often tied to identity and personal freedom: 74% of owners say the right to own guns is essential, and 50% say ownership is important to their overall identity.[12]

Firearm ownership rates vary by race, ethnicity, gender, and political party;[10] ownership is most common among White Americans (38%) and men (45%, as compared with 18% among women).[10] Although US residents of all backgrounds are firearm owners and have been victims of firearm injury, race and firearms are deeply intertwined in the United States, including with respect to reasons for gun ownership,[13] epidemiology of injuries,[14] and how prevention efforts are discussed.[15] "Gun culture"[16] is not monolithic: it varies geographically and by factors such as support for various firearm-related policies and identification with various gun rights organizations or activities.[10] It is important to not make assumptions about an individual's firearm access, attitudes, or risk of injury based on demographic characteristics or political affiliation.

Injury prevention discussions should include an acknowledgment of the strong sense of personal responsibility and commitment to safety common among gun owners. We suggest using "firearm" rather than "weapon" (a term that few firearm owners would use). A basic understanding of the mechanics of a firearm can be helpful in showing familiarity with, and respect for, the owner.

Language about secure firearm storage, a core injury prevention strategy, also matters. "Locked" can have different meanings, as devices for home firearm storage vary by cost and technological complexity: some devices require the firearm to be unloaded (e.g., cable locks), whereas others can be used with a loaded firearm (e.g., lock boxes). Larger devices can store multiple firearms, including rifles or shotguns (e.g., safes). Individuals who want access to a firearm for personal defense may not want to store it unloaded and locked with the ammunition separate. In the case of these owners, storage devices that are specifically designed to stage defensive firearms to prevent unauthorized access (e.g., "quick access safes") may be more acceptable.

For most firearm injury prevention discussions, we suggest an approach that encourages autonomous decision making. For example, clinicians can explain the rationale for secure storage and suggest options from which to choose. Enlisting trusted messengers from within the firearms community may also be helpful.[9]

LANGUAGE AROUND SUICIDE AND FIREARMS

In the United States, firearms are the most common method of suicide death (approximately 50% of suicide fatalities are by firearm),[14] and suicide accounts for the majority (60%) of all firearm deaths.[14] The link between firearm access and risk of suicide death, well established in numerous studies, arises because of the often very short period between suicidal thought and action and the high lethality of firearms (90% fatality rate in suicide attempts).[17] Therefore, an evidence-based component of suicide prevention for an individual at increased risk for suicidal behavior is reducing access to firearms and other lethal methods.

In practice, this generally means counseling at-risk individuals, and their friends and family, about voluntarily reducing access, either through locking the firearm at home or temporarily storing the firearm out of the home with trusted individuals or at locations such as firearm ranges, retailers, or law enforcement agencies, recognizing that options may be limited or logistically complicated depending on state firearm laws. In jurisdictions where private transfer of a complete firearm is tightly regulated,[8] it is usually still possible for a trusted individual to legally take possession of key components, such as a firing pin or trigger mechanism. This counseling may be best received when it emphasizes words such as "voluntary" and "temporary"[9] and is delivered by trusted messengers.[18]

Key messages for firearm suicide prevention also include those used for suicide prevention in general,[19] such as that suicide is complex and typically the result of multiple causes (e.g., numerous simultaneous biological, psychological, social, and environmental contributors in the context of one or more life stressors) rather than just a "mental health problem" (Box 1). The phrase that someone "committed suicide" is not recommended, as it suggests that the death is criminal and perpetuates negative stigma related to mental illness and the immorality of suicide. The preferred terminology is to say the person "died by suicide," as this avoids judgment. Additional ways to talk about a death by suicide, although less preferable, are that people "killed themselves" or "took their life."

To further avoid passing judgment on suicidal behavior or help seeking, do not say that people "failed" because they survived or "succeeded" because they died. Public health professionals, health care providers, researchers, and the media are generally encouraged to avoid publicly mentioning details about specific deaths by suicide to reduce the possibility of contagion. Messaging should emphasize hope: research shows that less than 10% of those who survive a suicide attempt later die by suicide.[17] Finally, it is important to normalize times of mental distress as common and temporary to reduce stigma around help seeking. During times of crisis, individuals may have reduced coping or problem-solving skills, highlighting the importance of both ensuring a safe environment and providing practical, usable guidance and resources, including proactive resources specifically for firearm owners.

LANGUAGE AROUND COMMUNITY VIOLENCE AND FIREARMS

Community violence is understood as the intentional use of physical force, threatened or actual, to cause injury, harm, or death to an acquaintance or stranger, excluding an intimate partner or family member. This includes firearm shootings, stabbings, blunt-force assaults, and unnecessary use of force by authorities.

In the United States, homicide disproportionately affects young men from underrepresented racial and ethnic communities. It is the leading cause of death among Black males 1 to 44 years of age, and it is the second and third leading cause of death among Latino males 1 to 19 and 20 to 44 years of age, respectively.[14] According to a 2014 study, the rate of nonfatal shootings is 50 times higher among young Black Americans than among White Americans.[20] Such disparities are the result of structural racism and other structural inequities. Communities of color often face higher rates of unemployment, lower socioeconomic status, and increased exposure to violence, among other structural risk factors for victimization or perpetration of community firearm violence.[21]

Exposure to social networks that engage in community violence increases the likelihood of becoming both a victim and an individual who harms others,[22] making violence a cyclical phenomenon. Community violence involving firearms is deeply detrimental to individual well-being: exposure alone correlates with both worse physical health and higher levels of psychological distress.[23] It is important to acknowledge the likelihood of a lifetime of secondary exposure, even if it is a patient's first personal injury with a gunshot wound.

Trauma-informed and culturally competent services are invaluable for both neighborhoods and individuals exposed to firearm community violence. At the level of one-on-one interactions within health care settings, trauma-informed care means avoiding criminalization of those affected, including avoiding terms (e.g., "gang bangers") or behaviors that suggest blame or refer to patients' prior history of involvement with law enforcement or violence (Box 1).[15] Prioritizing the needs of victims over interrogation and information gathering requires that health care staff advocate for trauma-informed care among law enforcement. At the level of the community, recognition of and attention to the complex factors that increase risk of community firearm violence are needed.

CONVERSATION, COLLABORATION, AND A PATH FORWARD

Conversations about firearm injury are sensitive in the United States because

BOX 1— Examples of Recommended Terminology Related to Firearms

Rather Than . . .	Consider . . .	Rationale
	Firearms and firearm ownership	
"Gun"	"Firearm"	"Firearm" may be more neutral
"Restriction," "surrender," or "confiscation" (unless as an outcome of enforcement activity)	"Transfer," "relinquishment," or "temporary removal"	Avoids provocative language; distinguishes between enforcement and voluntary actions
"Assault weapon," "assault rifle," or "military-style rifle"	"AR15-style rifle," "AK-style rifle," "semiautomatic rifle," "Rifle"	Avoids terms that gun owners may perceive as pejorative or inaccurate
"Firearm safety counseling" to describe counseling about secure firearm storage	"Firearm responsibility," "prevention of unauthorized access," or "secure firearm storage" counseling	"Firearm safety" connotes safe firearm handling (e.g., how to safely use a firearm); focuses on access (vs storage) avoids linkage to storage-related laws
"Are your firearms locked up?"	"Do you prevent access of your firearms by unauthorized individuals" (e.g., untrained, unable to control firearms owing to strength/age, unable to understand risks, altered judgment or perception)	Shifts focus from the item to the at-risk user, drawing on standard principle of responsible firearm ownership (preventing unauthorized access)
"All guns should be stored unloaded and separate from ammunition"	Responsibly "stage" firearms intended for defensive purposes; responsibly "store" firearms used for hunting or recreation	Acknowledges that norms and preferences for staging or storage vary according to use (e.g., a personal defense weapon is often stored locked but loaded and quickly accessible)
	Suicide	
"Commit" suicide	"Die by" or "die of" suicide	"Commit" implies criminality of the act and assigns blame
"Successful" or "failed" suicide attempt	"Died by suicide," "completed suicide," "killed themselves," "survived an attempt"	Avoids assigning moral judgment to outcome of attempt or implying that suicide death is a good outcome
"X caused the suicide"; "it was out of the blue"	Acknowledge that suicide is complex with no single cause and that there are often warning signs	Avoids oversimplifying suicide and encourages awareness of warning signs
"Suicide is inevitable"; "they'll always find a way"	Acknowledge that suicide can be prevented and that most people who survive a suicide attempt do not later die by suicide	Supports rationale for reducing access to firearms and other lethal methods during often brief (hours or days) periods or risk to prevent death
Omitting practical tips for seeking or providing help	Emphasize that asking people about suicide does not increase their risk; provide basic suicide warning signs and hotline resources	Supports efforts to make it easy to give and find help
	Community violence	
"Gangs," "thugs," "gang bangers," or "ex-convicts"	"Group involved," "street affiliated," "formerly incarcerated," "justice involved," or "people who use violence"	Avoids stigmatizing perpetrators or victims on the basis of prior/potential criminality; avoids implying that victims "deserved it"
"Black-on-Black crime"	Describe the high relative risk of firearm injury and death among young Black and Hispanic men and the structural racism that underlies that reality	Avoids implying that inherent racial/ethnic differences are the risk factor (rather than structural inequities in housing, jobs, education, and prison sentences)
"Inner cities" or "urban communities" as code words for race or socioeconomic status	Talk about "communities that are disproportionately affected by violence"	Avoids stigmatizing people living in urban communities affected by gun violence
Jokes or statements about victims such as "they were just minding their own business"; suggesting that victims are withholding information by not revealing who shot them	In clinical settings, say "I'm sorry this happened to you" and provide time and space for patients to discuss the circumstances if and when they are ready	Follows principles of "trauma-informed care" in not forcing people to discuss circumstances if they are not ready
Implying that mental illness is the cause of all violence	Acknowledge the complex relationship between mental health and community violence exposure; note that the vast majority of people with mental health conditions do not engage in violent behavior and that people with mental health conditions are at increased risk of being the victim of crime	Avoids misdirection of resources and attention from the real underlying problems (e.g., prior firearm injury increases risk of substance use, depression, and anxiety; people with serious mental illness are more likely to be victims than perpetrators)
"Innocent victims"	Acknowledge that all victims are equally deserving of medical care and prevention efforts	Avoids implying that some people "deserve" to get shot and therefore that violence cannot be prevented

of the myriad points for potential disagreement or misunderstanding. Political, cultural, and demographic differences often complicate these conversations, as do differences stemming from public health or academic disciplines, such as a focus on a particular etiology of violence or specific negative outcomes. Over recent years, there has been a growing movement for collaboration across the spectrum of political backgrounds and belief systems to develop firearm injury prevention guidelines and best practices that are acceptable and effective for all.[4,24] To successfully change patterns of injury and help shift harmful stereotypes and narratives in public policy and media, we must use a common, shared language across fields, disciplines, and cultures, albeit with tailored messaging when appropriate.

Engagement of affected communities—those with "lived experiences"—is critical in developing productive, collaborative conversations and programming. An example of cross-disciplinary collaboration and agreement on messaging is work by the National Shooting Sports Foundation and the American Foundation for Suicide Prevention[24] in which suicide prevention information was developed and distributed to firearm retailers nationwide. Walk The Talk America is an organization working to prevent firearm suicide by educating firearm owners about mental health treatment and by educating mental health providers about firearms, along with other programs. These programs, among others, provide promising models for collaboration and shared language; although evidence of effectiveness in terms of behaviors or violence outcomes is lacking, the firearms community has, reportedly, been generally supportive of the messages used. Other organizations and initiatives emphasize the responsibility attached to firearm ownership as a key method for prevention of suicide and other injuries from firearms.

In the realm of community firearm violence, examples of engaging those with "lived experiences" include programs with "violence intervention specialists," or community health workers seen as trusted messengers because of their own history of community work, victimization, or involvement in violent activities.[25] The Health Alliance for Violence Intervention is an organization that empowers and trains violence intervention specialists through hospital-based violence intervention programs. These specialists work with interdisciplinary health teams to provide support to violently injured patients during "teachable moments" and, using a trauma-informed approach, work with at-risk individuals to address recurrent victimization and other negative outcomes.

Additional tailored messaging is important for other etiologies of firearm injury and for specific populations. For mass shootings, for example, there are media guidelines recommending avoiding naming the perpetrator or assuming that the incident was caused by mental illness. Similarly, there are recommendations for both media and prevention professionals related to intimate partner violence. Firearm injury prevention messaging might also be tailored for populations such as children, adolescents, and adults with substance use disorders. In the case of children, for example, what does "safe storage" of home firearms mean, and what are the best ways for clinicians to talk with parents?

Talking about firearm injury prevention, suicide, and community violence can be difficult, and the language we use matters in how messages are received and in whether stereotypes or stigmas are perpetuated. Mutual understanding of language may help clinicians, researchers, and the public better work together to prevent firearm injuries and deaths.

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CONTRIBUTORS

M. E. Betz and M. L. Ranney drafted the editorial. All of the authors participated in developing the concept of the editorial and provided substantial edits.

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The authors declare no conflicts of interest.

REFERENCES

1. LaFrance A. How "gun control" became a taboo phrase. Available at: https://www.theatlantic.com/technology/archive/2016/01/word-choice-and-gun-culture/423108. Accessed January 20, 2021.
2. National Public Radio. Loaded words: how language shapes the gun debate. Available at: https://www.npr.org/sections/itsallpolitics/2013/02/26/172882077/loaded-words-how-language-shapes-the-gun-debate. Accessed June 25, 2021.
3. Siegel MB, Boine CC. The meaning of guns to gun owners in the US: the 2019 National Lawful Use of Guns Survey. *Am J Prev Med*. 2020;59(5):678–685. https://doi.org/10.1016/j.amepre.2020.05.010
4. Bulger EM, Kuhls DA, Campbell BT, et al. Proceedings from the Medical Summit on Firearm Injury Prevention: a public health approach to reduce death and disability in the US. *J Am Coll*

Surg. 2019;229(4):415–430.e12. https://doi.org/10.1016/j.jamcollsurg.2019.05.018

5. Amnesty International. Gun violence: key facts. Available at: https://web.archive.org/web/20210623190539/ https:/www.amnesty.org/en/what-we-do/arms-control/gun-violence. Accessed June 25, 2021.
6. Morgan ER, Rowhani-Rahbar A, Azrael D, Miller M. Public perceptions of firearm- and non–firearm-related violent death in the United States: a national study. *Ann Intern Med.* 2018;169(10):734. https://doi.org/10.7326/M18-1533
7. Luca M, Malhotra D, Poliquin C. The impact of mass shootings on gun policy. Available at: https://www.hbs.edu/ris/Publication%20Files/16-126_f03b33c6-5698-41d2-8b8e-2f98120e3dbc.pdf. Accessed June 25, 2021.
8. McCourt AD, Vernick JS, Betz ME, Brandspigel S, Runyan CW. Temporary transfer of firearms from the home to prevent suicide: legal obstacles and recommendations. *JAMA Intern Med.* 2017;177(1):96–101. https://doi.org/10.1001/jamainternmed.2016.5704
9. Pallin R, Siry B, Azrael D, et al. "Hey, let me hold your guns for a while": a qualitative study of messaging for firearm suicide prevention. *Behav Sci Law.* 2019;37(3):259–269. https://doi.org/10.1002/bsl.2393
10. Pew Research Center. Key facts about Americans and guns. Available at: https://www.pewresearch.org/fact-tank/2021/05/11/key-facts-about-americans-and-guns. Accessed June 14, 2021.
11. Kravitz-Wirtz N, Aubel A, Schleimer J, Pallin R, Wintemute G. Public concern about violence, firearms, and the COVID-19 pandemic in California. *JAMA Netw Open.* 2021;4(1):e2033484. https://doi.org/10.1001/jamanetworkopen.2020.33484
12. Parker K, Horowitz J, Igielnik R, Oliphant B, Brown A. America's complex relationship with guns. Available at: http://www.pewsocialtrends.org/2017/06/22/americas-complex-relationship-with-guns. Accessed June 25, 2021.
13. O'Brien K, Forrest W, Lynott D, Daly M. Racism, gun ownership and gun control: biased attitudes in US Whites may influence policy decisions. *PLoS One.* 2013;8(10):e77552. https://doi.org/10.1371/journal.pone.0077552
14. Centers for Disease Control and Prevention. Web-based Injury Statistics Query and Reporting System. Available at: http://www.cdc.gov/injury/wisqars/index.html. Accessed June 25, 2021.
15. Armstrong M, Carlson J. Speaking of trauma: the race talk, the gun violence talk, and the racialization of gun trauma. *Palgrave Commun.* 2019;5(1):1–11. https://doi.org/10.1057/s41599-019-0320-z
16. Yamane D. The sociology of US gun culture. *Sociol Compass.* 2017;11(7):e12497. https://doi.org/10.1111/soc4.12497
17. Harvard University. Means matter. Available at: https://www.hsph.harvard.edu/means-matter. Accessed June 25, 2021.
18. Anestis MD, Bond AE, Bryan AO, Bryan CJ. An examination of preferred messengers on firearm safety for suicide prevention. *Prev Med.* 2021;145:106452. https://doi.org/10.1016/j.ypmed.2021.106452
19. American Foundation for Suicide Prevention. Reporting on suicide prevention. Available at: https://afsp.org/reporting-on-suicide-prevention. Accessed January 20, 2021.
20. Kamm AR. African-American gun violence victimization in the United States: response to the Periodic Report of the United States to the United Nations Committee on the Elimination of Racial Discrimination. Available at: https://tbinternet.ohchr.org/Treaties/CERD/Shared%20Documents/USA/INT_CERD_NGO_USA_17803_E.pdf. Accessed January 20, 2021.
21. Thomas P, Duffrin M, Duffrin C, Mazurek K, Clay SL, Hodges T. Community violence and African American male health outcomes: an integrative review of literature. *Health Soc Care Community.* 2020;28(6):1884–1897. https://doi.org/10.1111/hsc.13065
22. Papachristos AV, Braga AA, Hureau DM. Social networks and the risk of gunshot injury. *J Urban Health.* 2012;89(6):992–1003. https://doi.org/10.1007/s11524-012-9703-9
23. Smith JR, Patton DU. Posttraumatic stress symptoms in context: examining trauma responses to violent exposures and homicide death among black males in urban neighborhoods. *Am J Orthopsychiatry.* 2016;86(2):212–223. https://doi.org/10.1037/ort0000101
24. Brassard B. NSSF-AFSP Suicide Prevention Partnership. Available at: http://www.nssfblog.com/nssf-afsp-suicide-prevention-partnership. Accessed January 20, 2021.
25. National Gang Center. Cure Violence: the interrupters. Available at: https://www.nationalgangcenter.gov/Blog/25/Cure-Violence-The-Interrupters. Accessed February 10, 2021.

Using Statewide Electronic Health Record and Influenza Vaccination Data to Plan and Prioritize COVID-19 Vaccine Outreach and Communications in Wisconsin Communities

Jessica Bonham-Werling, MBA, Allie J. DeLonay, MS, Kristina Stephenson, BS, Korina A. Hendricks, MPH, Lauren Bednarz, MPH, Jennifer M. Weiss, MD, MS, Matthew Gigot, MPH, and Maureen A. Smith, MD, PhD, MPH

The University of Wisconsin Neighborhood Health Partnerships Program used electronic health record and influenza vaccination data to estimate COVID-19 relative mortality risk and potential barriers to vaccination in Wisconsin ZIP Code Tabulation Areas. Data visualization revealed four groupings to use in planning and prioritizing vaccine outreach and communication based on ZIP Code Tabulation Area characteristics. The program provided data, visualization, and guidance to health systems, health departments, nonprofits, and others to support planning targeted outreach approaches to increase COVID-19 vaccination uptake. (*Am J Public Health*. 2021;111(12):2111–2114. https://doi.org/10.2105/AJPH.2021.306524)

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COVID-19 vaccine outreach is critical to overcoming barriers to vaccination. Vaccine hesitancy, including concerns about side effects and doubts about effectiveness,[1] is persistent despite proven safety and efficacy among millions of people. Successful outreach requires understanding the characteristics, needs, and challenges of communities so that investments are targeted to promote rapid vaccination.

INTERVENTION

In December 2020, the University of Wisconsin Neighborhood Health Partnerships Program and Health Innovation Program partnered with the Wisconsin Collaborative for Healthcare Quality (WCHQ) to build an outreach prioritization tool, using electronic health record (EHR) and influenza vaccination uptake data to support community-level understanding of COVID-19 mortality risk and vaccination barriers. Throughout the pandemic, quantifying COVID-19 mortality risk by geographic area has been useful for planning and directing resources to vulnerable communities.[2] The tool estimates relative mortality risk and potential barriers to vaccination for COVID-19 in Wisconsin ZIP Code Tabulation Areas (ZCTAs) and characterizes each ZCTA according to a rural–urban geodisparity model (see the supplemental material, available as a supplement to the online version of this article at http://www.ajph.org). Rather than a continuous score that assumes a rural disadvantaged area is the same as an urban disadvantaged area, this model accounts for differences in the sources of variation in and between rural and urban populations and goes beyond economic factors to incorporate information on health care capacity and health needs.

We calculated COVID-19 relative mortality risk using EHR data submitted to WCHQ by 22 health systems in June 2018. These data include 3.75 million patient records representing 65% of primary care providers in the state. We derived mortality risk using a model published in *Nature Medicine*[3] that incorporated sociodemographic, behavioral, and health condition factors.

Potential barriers to COVID-19 vaccination include hesitancy, access, and

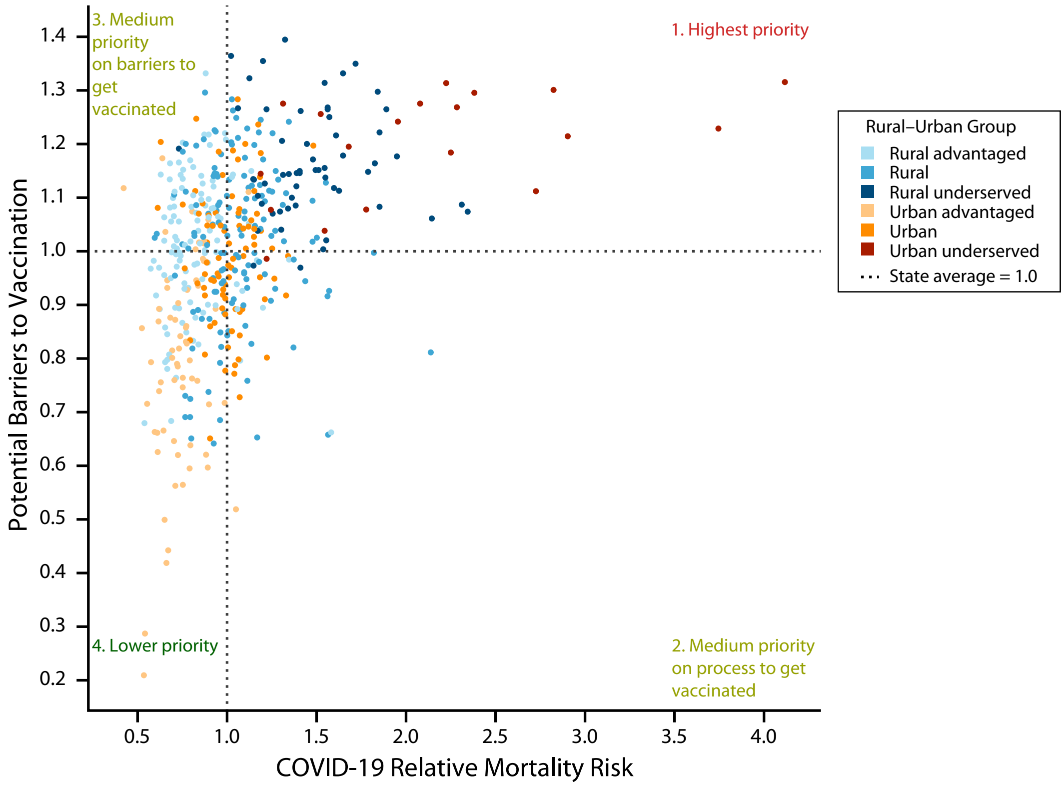

FIGURE 1— **COVID-19 Relative Mortality Risk and Barriers to Vaccination by Wisconsin ZIP Code Tabulation Area: February 2021**

trust in health care. We estimated these barriers by using ZCTA-level 2019–2020 seasonal influenza vaccination data from the Wisconsin Department of Health Services Immunization Registry. We divided each ZCTA's influenza vaccination rate by the average rate for all ZCTAs to derive relative vaccination rates. Although there are distinctions between COVID-19 and influenza vaccination, influenza vaccination rates are a useful proxy to anticipate potential barriers to COVID-19 vaccination.[4] A nationwide survey in June 2020 found that being previously vaccinated for influenza was a "potent predictor of intent to obtain a COVID-19 vaccine."[1(p1082)]

PLACE AND TIME

We designed the tool in December 2020 and made it available via a public Web site in February 2021. We developed and validated it with experts in EHR and public health data and biostatistics. Before launch, staff at WCHQ, the Wisconsin Department of Health Services, and local health departments through the Wisconsin Public Health Research Network reviewed the tool.

PERSON

We directed the tool and guidance to decision makers from health systems, health departments, nonprofits, and other organizations.

PURPOSE

The purpose of the tool was to understand where and how to prioritize COVID-19 vaccination outreach efforts in Wisconsin communities.

IMPLEMENTATION

When we plotted the Wisconsin ZCTAs by COVID-19 relative mortality risk and potential barriers to vaccination, we identified four unique groupings of ZCTAs relative to state averages. These groupings (Figure 1; https://nhp.wisc.edu/covid-19) can be used to target and prioritize outreach investments; plan communication timing, volume, and channel; and develop messaging to increase vaccine uptake among ZCTA residents.

Group 1, "highest priority," comprised 151 ZCTAs, representing 95% of underserved communities. They have the highest estimated COVID-19 relative mortality risk and highest barriers to vaccination. They would benefit from rapid vaccination and early targeting with the highest volume of communications from multiple channels and sources to overcome barriers while also making vaccination processes and timelines clear. Investing in partnerships with trusted organizations and individuals (e.g., churches, employers, and community organizations) may be a powerful action that builds trust and overcomes potential barriers in these communities.[5]

Group 2, “medium priority on process to get vaccinated,” comprised 60 ZCTAs, representing primarily rural and urban communities that are neither advantaged nor disadvantaged. They have higher than average COVID-19 relative mortality risk but lower than average barriers to vaccination. These communities should be vaccinated as quickly as possible but have fewer barriers and may require a more moderate volume of communications focusing primarily on vaccination processes.

Group 3, “medium priority on barriers to get vaccinated,” comprised 116 ZCTAs, representing 50% of rural advantaged communities. They have lower than average COVID-19 relative mortality risk but higher than average barriers to vaccination. Moderate communications addressing potential barriers could be beneficial, especially through partnerships with trusted individuals and organizations.

Group 4, “lower priority,” comprised 151 ZCTAs, representing 84% of urban advantaged communities. Their COVID-19 relative mortality risks and barriers to vaccination are both lower than average. These communities need basic communications on processes and timelines but may not require extra effort to motivate vaccination.

To disseminate the tool and guidance, we issued a press release and social media communications. The Wisconsin Public Health Research Network assisted in dissemination to local health departments. Two webinars and a downloadable toolkit with the webinar recording and materials were available at http://www.hipxchange.org/COVID-19VaccineOutreach.

EVALUATION

The two webinars had more than 150 attendees from various health systems, local and state health departments, community organizations, universities, and businesses. The Web site had 563 views in February 2021, which was a 54% increase in traffic compared with the previous six months. As of July 2021, there have been 1410 webinar views, and individuals from state, national, and international health organizations and universities have downloaded the toolkit.

Based on follow-up with webinar attendees, they used the tool to gain insights into populations served, plan programs supporting vaccine administration to vulnerable populations, and advocate community health workers’ involvement in vaccination education in high-mortality, high-barrier neighborhoods. We also supplied data to researchers and community organizations to support grant applications for COVID-19 vaccination and testing outreach.

In addition, the Wisconsin Department of Health Services recently released COVID-19 vaccination data at the ZCTA level. There was a strong correlation (0.81) between flu vaccination and receiving one or more doses of the COVID-19 vaccine.

ADVERSE EFFECTS

There were no adverse effects associated with the outreach prioritization tool, but there are some limitations to our tool. Not every person is reflected in the WCHQ data, so mortality risk for a ZCTA may be over- or underreported. Individuals with barriers to accessing health care are especially likely to be missing from the data. Only a single year of influenza vaccination data was available at the ZCTA level; data over several years could enhance understanding of potential barriers and trends related to vaccine uptake.

SUSTAINABILITY

The use of EHR data and seasonal influenza vaccination data could be applied to future vaccination campaigns to target those with the highest relative mortality risk from an infectious disease and higher barriers to vaccination. Other states with regional health improvement collaboratives could similarly use their data to inform public health decision making.

PUBLIC HEALTH SIGNIFICANCE

Communicating about new vaccines is challenging. Using local data to understand the characteristics of communities can inform targeting, message development, appropriate channels to maximize impact,[6] and investment allocation. It may also provide a basis for collaboration and consistency in messaging across stakeholders (e.g., public health, health care, the press, community organizations) contributing to vaccine outreach and communications.

Increasing vaccine uptake is critical to saving lives and improving the social and economic conditions affected by the COVID-19 pandemic. There is also an opportunity to invest in underserved communities to increase trust in health officials, improve uptake of other vaccines, and benefit health beyond the scope of COVID-19.[7] AJPH

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CONFLICTS OF INTEREST

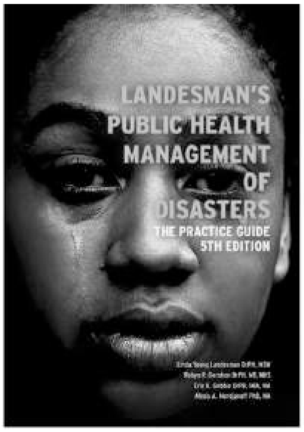
The authors have no conflicts of interest to declare.

HUMAN PARTICIPANT PROTECTION

Institutional review board review was not required because the project does not constitute research as defined under 45 CFR 46.102(d). This project was certified as quality improvement through the University of Wisconsin-Madison Health Sciences institutional review board self-certification tool.

REFERENCES

1. Ruiz JB, Bell RA. Predictors of intention to vaccinate against COVID-19: results of a nationwide survey. *Vaccine*. 2021;39(7):1080–1086. https://doi.org/10.1016/j.vaccine.2021.01.010
2. Smith CD, Mennis J. Incorporating geographic information science and technology in response to the COVID-19 pandemic. *Prev Chronic Dis*. 2020;17:E58. https://doi.org/10.5888/pcd17.200246
3. Jin J, Agarwala N, Kundu P, et al. Individual and community-level risk for COVID-19 mortality in the United States. *Nat Med*. 2021;27(2):264–269. https://doi.org/10.1038/s41591-020-01191-8
4. Rouw A, Wexler A, Dawson L, Kates J, Artiga S. State variation in seasonal flu vaccination: implications for a COVID-19 vaccine. November 2, 2020. Available at: https://www.kff.org/coronavirus-covid-19/issue-brief/state-variation-in-seasonal-flu-vaccination-implications-for-a-covid-19-vaccine. Accessed February 23, 2021.
5. National Academies of Sciences Engineering and Medicine. *Strategies for Building Confidence in the COVID-19 Vaccines*. Washington, DC: National Academies Press; 2021. https://doi.org/10.17226/26068
6. Quinn SC, Jamison AM, Freimuth V. Communicating effectively about emergency use authorization and vaccines in the COVID-19 pandemic. *Am J Public Health*. 2021;111(3):355–358. https://doi.org/10.2105/AJPH.2020.306036
7. Ojikutu BO, Stephenson KE, Mayer KH, Emmons KM. Building trust in COVID-19 vaccines and beyond through authentic community investment. *Am J Public Health*. 2021;111(3):366–368. https://doi.org/10.2105/AJPH.2020.306087



Implementing a Methadone Delivery System in New York City in Response to COVID-19

Alex Harocopos, PhD, MSc, Michelle L. Nolan, MPH, MPhil, Gail P. Goldstein, MPH, Shivani Mantha, MPH, Madeleine O'Neill, MPH, and Denise Paone, EdD

Opioid agonist medication, including methadone, is considered the first-line treatment for opioid use disorder. Methadone, when taken daily, reduces the risk of fatal overdose; however, overdose risk increases following medication cessation. Amid an overdose epidemic accelerated by the proliferation of fentanyl, ensuring continuity of methadone treatment during the COVID-19 pandemic is a vital public health priority. (*Am J Public Health*. 2021;111(12):2115–2117. https://doi.org/10.2105/AJPH.2021.306523)

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We describe an innovative methadone delivery system (MDS) implemented in New York City (NYC) in response to the COVID-19 pandemic.

INTERVENTION

Following the relaxation of federal regulations for methadone provision in response to COVID-19, NYC's Department of Health and Mental Hygiene (DOHMH) partnered with New York State's Office of Addiction Services and Supports (OASAS) in collaboration with the Coalition of Medication-Assisted Treatment Providers and Advocates to implement an MDS. Designed to accommodate patients receiving methadone treatment for opioid use disorder, the MDS provides curbside medication delivery. Informed by clinical practice (e.g., length of engagement in treatment, housing status, and toxicology screening), patients receive a 1- to 28-day supply of methadone. Patients who receive methadone delivery continue to engage with staff at their opioid treatment program (OTP) via telehealth services.

PLACE AND TIME

Implemented in April 2020, the MDS delivers to patient homes, isolation hotels, and other congregate settings across four NYC boroughs: Manhattan, Bronx, Brooklyn, and Queens.

PERSON

The MDS serves NYC methadone patients with confirmed or suspected COVID-19, patients advised to quarantine, and patients with an underlying health condition known to increase risk of severe illness from COVID-19. This list of conditions evolved over the course of the pandemic and followed guidance issued by the New York City Department of Health and Mental Hygiene (DOHMH). To allow maximum flexibility, patients also can be referred by the medical director at their OTP. In January 2020, there were approximately 28 000 NYC residents enrolled in 66 OTPs across NYC. About half were aged 45 years and older, and many had co-occurring morbidities that made them susceptible to severe COVID-19 illness.[1,2]

PURPOSE

The MDS serves two purposes. First, delivering methadone to patients at high risk for severe COVID-19 illness, or those required to quarantine or isolate, ensures continuity of opioid use disorder treatment, which is critical for avoiding opioid withdrawal and reducing the risk of overdose.[3] Second, the MDS is an important COVID-19 mitigation strategy, because it provides medication to individuals receiving methadone treatment who are advised to isolate or quarantine, so that they can follow quarantine protocols.

IMPLEMENTATION

MDS policies and procedures were developed by NYC's DOHMH, OASAS, and the Coalition of Medication-Assisted Treatment Providers and Advocates, and were disseminated to OTPs operating in NYC. Procedures for delivering methadone to hotels used for isolation and de-densification of NYC shelters were developed with NYC's Department of Homeless Services. Protocols for delivery to isolation hotels supported by other agencies were adapted to each agency's workflow. Webinars were offered to OTP medical directors to promote the initiative, and information sheets were sent for dissemination to OTP patients. Although no structure for this type of collaboration existed before program implementation, DOHMH's Incident Command Structure enabled staff to be activated to support this initiative.

To date, a rotation of more than 80 staff have participated in the program either on a full-time or part-time basis, the majority of whom have contributed their time in kind. Grant funding was used to purchase lockboxes in which to transport the methadone. As the program progressed, we were also able to use grant funding to pay for three dedicated coordinators. Relaxing regulations regarding the transportation and storage of methadone, as well as allowing pharmacies to dispense methadone to treat opioid use disorder, would decrease staff costs.

Eligible patients give their consent to be enrolled in the MDS and to have their medication delivered, and their home OTP refers them to OASAS. OASAS staff receive the consent form, which includes patient details along with a medication order, and input the data into REDCap Cloud, a secure data management system. Once the information has been entered, the patient is considered enrolled and included on the delivery schedule.

OASAS then assigns enrolled patients to 1 of 10 "guest" OTPs (GOTPs). Located in each of the four boroughs served by the initiative and used to centralize pickup points for couriers and drivers, GOTPs were selected based on their hours of operation and staff capacity to manage additional dispensing. GOTPs communicate with home OTPs to confirm patients' medication orders before preparing doses for delivery. On the morning of the scheduled delivery, GOTPs call patients directly to ensure that they are available to take receipt of the medication. When contact is made, patients are provided with a passcode, which is used to verify their identity when the medication is delivered.

MDS coordinators assign deliveries to a team consisting of a driver and a courier. Once the team has received its daily assignment, the courier calls the GOTP to confirm the medication pickup schedule. The driver collects the courier from their residence in a city-owned vehicle, and together they drive to the GOTP to pick up the medication, which is dispensed in lockboxes labeled with the patient's name, New York State central registry number, and date of birth. A naloxone kit is provided with the initial methadone delivery. On receipt of the medication from the GOTP, MDS couriers sign a chain of custody form in REDCap Cloud to confirm they have collected the methadone. The courier then contacts each of their assigned patients to provide a time estimate for medication delivery. Medication is typically delivered between the hours of 8:30 AM and 1:00 PM. Because of logistical constraints, patients are unable to select a time slot for medication delivery. In a handful of instances, patients opted to discontinue delivery because the medication arrived later than they preferred.

cApproximately five minutes before arrival, couriers call patients to alert them of their arrival and remind them to wear a face covering. MDS patients meet the courier curbside to accept their medication, adhering to physical-distancing guidelines. Patients identify themselves by name and give the passcode provided by the GOTP. Once the patient receives their medication, the courier completes the chain of custody form using the passcode in lieu of a patient signature. DOHMH sends chain of custody forms to OASAS and home OTPs for billing and regulatory purposes. Once a patient has finished their doses, lockboxes are retrieved, sanitized, and returned to the GOTPs for future use.

EVALUATION

Between April 20 and December 31, 2020, the MDS made 3264 deliveries to 686 individuals. A total of 2954 deliveries were made to patients' homes, 179 to isolation hotels, and 131 to other congregate settings. When indicated by clinical practice, patients were provided with methadone delivery on a daily basis. We conducted brief telephone surveys with 46 OTPs to explore MDS use. Findings suggest that MDS is primarily used to support people in quarantine or isolation. Reasons for OTPs (n = 8) not participating in MDS included having a current "designated other" on file who could collect medication on the patient's behalf, implementing extended take-homes for patients to minimize clinic visits, and a preference to continue seeing patients in person.

ADVERSE EFFECTS

To our knowledge, there have been no adverse effects among participants of the MDS.

SUSTAINABILITY

In response to the COVID-19 public health emergency, the Drug Enforcement Administration issued an exemption to existing regulations that allowed alternative methadone delivery methods. Additionally, the Substance Abuse and Mental Health Services Administration permitted states to request blanket exceptions for take-home medication, providing more flexibility on the number of required clinic visits. The MDS should continue for the duration of the declared public health emergency; however, the program's longevity will largely depend on whether regulations implemented under the public health emergency declaration are extended.

PUBLIC HEALTH SIGNIFICANCE

To our knowledge, the MDS is the first program of its kind. The MDS was implemented to ensure that patients received methadone while reducing the risk of transmitting SARS-CoV-2 (severe acute respiratory syndrome coronavirus). Although initiated as a result of the pandemic, changes to dosing schedules and methadone delivery have challenged long-held practices regarding methadone dispensing. In tandem, many clinicians providing methadone treatment have also increased their use of telemedicine, leading some to call for a more patient-centered approach to clinical care, with less reliance on toxicology testing to guide clinical decision making.[4] OTPs typically referred patients to the MDS who were in isolation or quarantine, and few patients were enrolled in the program for more than 28 days; a patient-centered approach would increase flexibility in access to methadone, including delivery.

When the public health emergency is over, reverting to more restrictive methadone dispensing and denying patients extended take-home doses may deter people from remaining in treatment.[5] Preliminary reports suggest that the transition to increased take-home doses has been well tolerated.[4,6] It is imperative, therefore, that treatment outcomes associated with the changes in regulations be rigorously evaluated and the evidence used to inform clinical practice and federal and state policy.

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CONFLICTS OF INTEREST

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HUMAN PARTICIPANT PROTECTION

Institutional review board approval was not required because the data were collected for program evaluation purposes and presented in aggregate.

REFERENCES

1. New York State Department of Health, Office of Addiction Services and Supports. Client Data System. Available at: https://apps.oasas.ny.gov/portal/page/portal/OASAS_APPS. Accessed June 17, 2020.
2. Rosen D, Smith ML, Reynolds CF III. The prevalence of mental and physical health disorders among older methadone patients. *Am J Geriatr Psychiatry.* 2008;16(6):488–497. https://doi.org/10.1097/JGP.0b013e31816ff35a
3. Sordo L, Barrio G, Bravo MJ, et al. Mortality risk during and after opioid substitution treatment: systematic review and meta-analysis of cohort studies. *BMJ.* 2017;357:j1550. https://doi.org/10.1136/bmj.j1550
4. Joseph G, Torres-Lockhart K, Stein MR, Mund PA, Nahvi S. Reimagining patient-centered care in opioid treatment programs: lessons from the Bronx during COVID-19. *J Subst Abuse Treat.* 2021;122:108219. https://doi.org/10.1016/j.jsat.2020.108219
5. Frank D. A chance to do it better: methadone maintenance treatment in the age of COVID-19. *J Subst Abuse Treat.* 2021;123:108246. https://doi.org/10.1016/j.jsat.2020.108246
6. Figgatt MC, Salazar Z, Day E, Vincent L, Dasgupta N. Take-home dosing experiences among persons receiving methadone maintenance treatment during COVID-19. *J Subst Abuse Treat.* 2021;123:108276. https://doi.org/10.1016/j.jsat.2021.108276

Impact of the COVID-19 Pandemic on Public Health Surveillance and Survey Data Collections in the United States

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The COVID-19 pandemic highlighted the need for strengthened surveillance data to accurately track the distribution of infectious diseases for informing public health responses to improve infection prevention and control. Comprehensive surveillance for COVID-19 would rapidly identify infected cases, trace contacts, and monitor disease trends over time. Ongoing surveillance is also important for monitoring longer-term epidemiological trends—including infection incidence and mortality rates—across subpopulations that may be at significantly higher risk for severe disease and death, thereby improving population-specific interventions.[1] To track the progression of COVID-19, we inevitably ask the question: is a unified national surveillance system needed to respond effectively to this pandemic and future public health emergencies?

The answer may be unexpectedly complex when considering the different aspects of the pandemic that need to be tracked. In the United States, to monitor COVID-19–associated cases and deaths, complete census data at the aggregate and individual levels are gathered from separate systems. For example, COVID-19 cases (which may include death data) can come from notifiable infectious disease systems[2] and all deaths from vital statistics systems.[3] The most accurate death counts come from death certificates. To track hospitalizations with suspected and confirmed COVID-19 cases, for instance, data on all cases from more than 6000 hospitals are reported weekly and compiled in the Unified Hospital Time-Series Dataset by federal public health agencies.[4] Also used are commercial databases of health insurance claims and electronic health records from stand-alone hospital systems.

However, to better understand the epidemiology of COVID-19 among in-care populations, more information about the care episode, patient, and provider is often needed than what is available in highly structured and coded data gathered via standard surveillance reporting. Instead of relying on surveillance systems that are designed to provide near real-time data, collecting sampled data is a necessary alternative for gathering more in-depth information, even if these data are slower to process and are collected in selected geographic areas. Ideally, sampled data are collected from a representative subset of a population that would allow statistical estimates to be produced and inferences to be made from the sampled data to the population as a whole. As examples, in-depth data from claims and electronic health records are electronically extracted from a representative sample of hospitals through the National Hospital Care Survey[5] and a sample of patient records is abstracted in hospitals in selected states through the COVID-19–Associated Hospitalization Surveillance Network (COVID-NET).[6]

Because many individuals with COVID-19 can be asymptomatic or exhibit mild symptoms like those of a common cold, millions of Americans may have undiagnosed infections.[7] To more fully understand the epidemiology and burden of the pandemic, information about undiagnosed COVID-19 cases is needed. A national sample survey that has the capacity to conduct antibody tests, such as the National Health and Nutrition Examination Survey,[8] can offer additional information.

Similar population-based COVID-19 seroepidemiological surveys are conducted in other countries.[9] Alternatively, state and local-level surveys may produce more precise estimates on information about the pandemic experience specific to geographic areas, such as the California Health Interview Survey[10] and the New York City Department of Health surveys, among others. Indeed, many insightful findings have recently originated from single locations.[11,12]

Given the existing fragmented data collection systems, Hennessee et al. (p. 2127) describe how this complex infrastructure has led to drastic variations in surveillance practices, for example, in the analysis and public reporting of newly confirmed COVID-19 cases. On the other hand, building a single surveillance and survey infrastructure may be a tall order. Some challenges come to mind. Public health data, including case definitions of "suspected" and "confirmed" COVID-19 disease, are not collected or recorded in a standardized manner across all systems. Many systems do not allow for metadata on the type of test used to detect infection (e.g., antigen, polymerase chain reaction, and antibody). Data systems are not interoperable and lack common data vocabulary to allow seamless data exchange. Adequate data privacy, protection, and security need to be improved and put in place to promote public confidence. And currently there exists no unique national patient identifier to facilitate data linkage across systems to track progression of COVID-19 at the patient level over time. One step toward a single repository to compile multiple data sources is the Centers for Disease Control and Prevention (CDC) COVID Tracker, a "one-stop shop" for visualizing data from core surveillance and survey systems to share critical COVID-19–related information.[13] The CDC also recently created a new National Center for Epidemic Forecasting and Outbreak Analysis, which will forecast and track hotspots for COVID-19 and other emerging public health threats.[14]

In the meantime, a key objective is to ensure that accurate, reliable, and timely data continue to be produced from existing surveillance and survey systems, ranging from vital statistics and health care encounter data to population-based surveys that include interviews or physical examinations. In this issue, *AJPH* asks those who conduct some of the nation's long-standing surveillance and survey programs how COVID has affected their operations and what design modifications have been made to continue collecting data and perhaps even to expand their data collection in response to the pandemic.

- **Mortality Data**. To track the impact of COVID-19 on US mortality, Ahmad et al. (p. 2133) describe how, within weeks of the first reported US cases, the National Center for Health Statistics (NCHS) made unprecedented strides to successfully develop death record certification guidance, adjust internal data processing systems, modernize vital statistics systems to increase interoperability, and quickly stand up a system to release daily updates of COVID-19 death counts.
- **National Health Care Surveys**. Ward et al. (p. 2141) describe how, during COVID-19, survey operations had to be quickly modified to continue collecting the nation's data in ambulatory, hospital, and long-term care settings. For example, all in-person onsite interviews and health record abstraction were halted and replaced by telephone interviews. New COVID-19–related items were added regarding providers' experiences in delivering care during the pandemic, including telemedicine visits, shortages of personal protective equipment, inability to care for patients who tested positive for COVID-19, and knowledge of fellow providers or staff in their practice testing positive for COVD-19.
- **National Health and Nutrition Examination Survey (NHANES)**. Paulose-Ram et al. (p. 2149) describe how NHANES was suspended for a period of time because of COVID-19 and was able to resume operations in mid-2021. The newly designed NHANES 2021–2022 survey has changed its field operations to safely collect data at participants' homes and in mobile examination centers while adding new items on COVID-19, most notably, antibody testing that will provide data to produce national estimates on both natural infection and vaccine-induced immunity to the COVID-19 virus.
- **Medical Expenditure Panel Survey (MEPS)**. Zuvekas and Kashihara (p. 2157) describe how the MEPS successfully responded to challenges posed by COVID-19 by reengineering its field operations to complete data collection without in-person interviews and maintain data release schedules. Several enhancements were made to MEPS—such as adding survey items on telehealth visits, delays in accessing care because of

COVID-19, and social determinants of health—to allow research on COVID-19's impact on health care consumers, employers, and the US health care system.

- **National Health Interview Survey (NHIS)**. Blumberg et al. (p. 2167) describe how the NHIS responded to COVID-19 challenges with operational changes to continue production in 2020. Because of expected delay in releasing the 2020 NHIS data files, the NCHS turned to two new online data collection platforms: the NCHS Research and Development Survey and the Census Bureau's Household Pulse Survey. The latter shows how a new rapid response survey can be launched expediently by an intergovernmental cooperative effort to assess the impact of the pandemic on individuals and households.
- **California Health Interview Survey (CHIS)**. Ponce et al. (p. 2122) describe how the CHIS navigated challenges posed by COVID on data collection from a representative sample of California's adults, adolescents, and children; integration of new COVID-19–related modules, particularly items specific to anti-Asian rhetoric and hate incidents targeting Asian, Native Hawaiian, and Pacific Islander communities; new monthly releases of preliminary COVID-19 data through a dashboard; and future implications of findings from this period of data collection.
- **New York City Health Surveys**. Levanon Seligson et al. (p. 2176) describe how New York City's Department of Health and Mental Hygiene has rapidly changed its existing surveys, such as the long-standing Community Health Survey, and added new ones like the Healthy NYC and the SARS-CoV-2 serosurvey to better understand the impact of the pandemic on physical health, mental health, and social determinants of health among New York City residents. Furthermore, seven New York City Health Opinion Polls were conducted in one year between March 2020 and March 2021 to collect information on COVID-19–related knowledge, attitudes, and opinions, including vaccine intentions.

Collectively, these national, state, and city surveillance and survey programs have demonstrated agility, resilience, innovation, and commitment in their efforts to meet their mission while incorporating new COVID-19–related items to monitor the pandemic and implementing new data collection, processing, and dissemination plans to release data in an even more timely manner. As more data become available, we will be able to further examine the impact on data quality from changes made to the nation's surveillance and survey systems, as well as the fuller extent and impact of COVID-19 on the health of the nation. This collection of experiences is expected to assist future surveillance and survey managers in pandemic contingency planning. AJPH

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CONFLICTS OF INTEREST

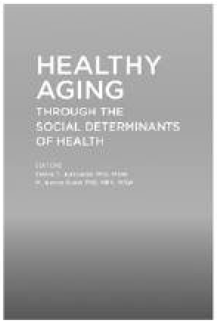
The authors have no conflicts of interest to disclose.

REFERENCES

1. World Health Organization. Public health surveillance for COVID-19: interim guidance. Available at: https://www.who.int/publications/i/item/who-2019-nCoV-surveillanceguidance-2020.8. Accessed September 4, 2021.
2. Centers for Disease Control and Prevention. National Notifiable Diseases Surveillance System. Surveillance case definitions for current and historical conditions. Available at: https://ndc.services.cdc.gov. Accessed September 4, 2021.
3. Centers for Disease Control and Prevention, National Center for Health Statistics. Weekly updates by select demographic and geographic characteristics. Provisional death counts for Coronavirus Disease 2019 (COVID-19). Available at: https://www.cdc.gov/nchs/nvss/vsrr/covid_weekly/index.htm. Accessed September 4, 2021.
4. Centers for Disease Control and Prevention. COVID data tracker. New hospital admissions. Available at: https://covid.cdc.gov/covid-data-tracker/#new-hospital-admissions. Accessed September 4, 2021.
5. Centers for Disease Control and Prevention, National Center for Health Statistics. National Hospital Care Survey. COVID-19 data from selected hospitals. Available at: https://www.cdc.gov/nchs/covid19/nhcs.htm. Accessed September 4, 2021.
6. Centers for Disease Control and Prevention. Coronavirus Disease 2019 (COVID-19)-Associated Hospitalization Surveillance Network (COVID-NET). Available at: https://www.cdc.gov/coronavirus/2019-ncov/covid-data/covid-net/purpose-methods.html. Accessed September 4, 2021.
7. Kalish H, Klumpp-Thomas C, Hunsberger S, et al. Undiagnosed SARS-CoV-2 seropositivity during the first 6 months of the COVID-19 pandemic in the United States. *Sci Transl Med.* 2021;13(601): eabh3826. https://doi.org/10.1126/scitranslmed.abh3826
8. Centers for Disease Control and Prevention, National Center for Health Statistics. National Health and Nutrition Examination Survey. Available at: https://www.cdc.gov/nchs/nhanes/index.htm. Accessed September 4, 2021.
9. Pollán M, Pérez-Gómez B, Pastor-Barriuso B, et al. Prevalence of SARS-CoV-2 in Spain (ENE-COVID): a nationwide, population-based seroepidemiological study. *Lancet.* 2020;396(10250):

535–544. https://doi.org/10.1016/S0140-6736(20)31483-5

10. University of California at Los Angeles. California Health Interview Survey. Available at: https://healthpolicy.ucla.edu/chis/Pages/default.aspx. Accessed September 4, 2021.
11. Brown CM, Vostok J, Johnson H, et al. Outbreak of SARS-CoV-2 infections, including COVID-19 vaccine breakthrough infections, associated with large public gatherings—Barnstable County, Massachusetts, July 2021. *MMWR Morb Mortal Wkly Rep.* 2021;70(31):1059–1062. https://doi.org/10.15585/mmwr.mm7031e2
12. Griffin JB, Haddix M, Danza P, et al. SARS-CoV-2 Infections and hospitalizations among persons aged ≥16 years, by vaccination status—Los Angeles County, California, May 1–July 25, 2021. *MMWR Morb Mortal Wkly Rep.* 2021;70(34):1170–1176. https://doi.org/10.15585/mmwr.mm7034e5
13. Centers for Disease Control and Prevention. COVID data tracker. Available at: https://covid.cdc.gov/covid-data-tracker/#cases_casesper100klast7days. Accessed September 4, 2021.
14. Centers for Disease Control and Prevention. Press release: CDC stands up new disease forecasting center. Released August 18, 2021. Available at: https://www.cdc.gov/media/releases/2021/p0818-disease-forecasting-center.html. Accessed September 4, 2021.



COVID-19 Rapid Response: How the California Health Interview Survey Adapted During the Global Pandemic

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See also Lau et al., p. 2085.

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As a large, well-established population survey, the California Health Interview Survey (CHIS), housed at the University of California Los Angeles Center for Health Policy Research, was well poised to adapt to the changing conditions and challenges presented by the COVID-19 pandemic. Our goal was to continue to provide equity-focused data products relevant to public health,[1,2] but with a more rapid data processing timeframe to meet the immediate insights needed during the pandemic.

For nearly 20 years, CHIS has been collecting information on a population-representative sample of California's adults, adolescents, and children. CHIS annually collects data from approximately 20 000 households. In 2019, CHIS transitioned from a landline and cell phone random-digit-dial methodology to a dual-mode administration that takes place on the Web or by telephone.[3] CHIS employs an address-based sample design with mail recruitment inviting sampled individuals to complete a Web survey (mail push to Web). A phone number is provided in each mail invitation to allow interested respondents to alternatively complete the survey with a trained interviewer. This was important to reduce coverage bias because approximately 5% of the state's population have no computers with Internet access.[4] Up to six calls are made for nonresponse follow up with an offer of a computer-assisted telephone interview, in which interviewers follow a script provided by a software application.

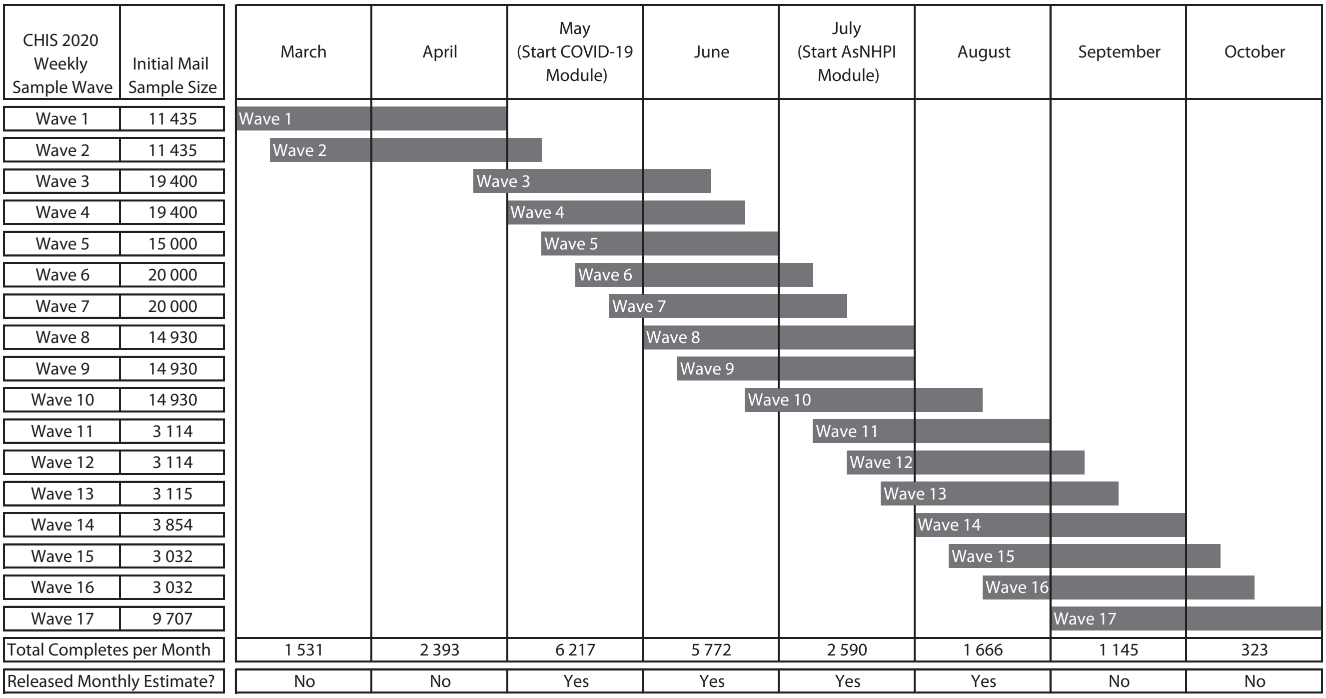
To ensure coverage of respondents with limited English proficiency, in addition to English, CHIS is administered in Spanish, Cantonese, Mandarin, Korean, Tagalog, and Vietnamese.[5] The two principal objectives of CHIS are to provide a large enough sample to yield robust health estimates for local jurisdictions (large and medium counties and county groups among smaller counties) and to provide statewide surveillance of racial/ethnic disparities in health status, health care coverage, and health care utilization. Both objectives are strongly aligned with the policy data demands of understanding the unequal toll of the pandemic on California counties and on racial/ethnic groups.

The culmination of decades of survey administration, the recent CHIS redesign and stakeholder engagement[1] provided a solid base in adapting survey operations in 2020. We describe the data collection and data release adaptations CHIS made in response to the COVID-19 pandemic, consider the implications of these changes on data quality, and discuss future implications on data collection for population-based surveys such as the CHIS.

PANDEMIC IMPACTS ON 2020 DATA COLLECTION

CHIS 2020 data collection commenced in early March 2020 contemporaneously with the beginning of stay-at-home orders in California. The first completed surveys were received on March 9, just 10 days before California issued a statewide stay-at-home order on March 19, 2020.[6] Nearly 96% of all CHIS 2020 data collection occurred after these orders took effect. CHIS 2020 adult data collection concluded on October 31, 2020.

CHIS 2020 data collection was divided into 17 mailing waves with a total sample of 190 428 (Figure 1). More than 85% of the data collection was completed with the first 10 waves of sample mail outs (n = 161 640), spanning the beginning of the stay-at-home orders through the first major surge of COVID-19 infections within California from late June through August. Each of these individual mailing sample waves was selected to



CHIS 2020 Weekly Sample Wave	Initial Mail Sample Size
Wave 1	11 435
Wave 2	11 435
Wave 3	19 400
Wave 4	19 400
Wave 5	15 000
Wave 6	20 000
Wave 7	20 000
Wave 8	14 930
Wave 9	14 930
Wave 10	14 930
Wave 11	3 114
Wave 12	3 114
Wave 13	3 115
Wave 14	3 854
Wave 15	3 032
Wave 16	3 032
Wave 17	9 707

	March	April	May (Start COVID-19 Module)	June	July (Start AsNHPI Module)	August	September	October
Total Completes per Month	1 531	2 393	6 217	5 772	2 590	1 666	1 145	323
Released Monthly Estimate?	No	No	Yes	Yes	Yes	Yes	No	No

FIGURE 1— **California Health Interview Survey 2020 Sample Sizes and Data Collection Periods by Sample Wave and Month**

Note. AsNHPI = Asian, Native Hawaiian, and Pacific Islander.

independently provide coverage across the state and, when aggregated together, to provide a comprehensive picture of the California population, with a goal of 20 000 total completed adult surveys. However, as the cycle of waves progressed, cooperation in some geographic areas differed from the projections used to design the sample. Therefore, modifications were made to the design of later waves to reduce the sample in areas that were performing better than expected and increase the sample in areas that were underperforming.

While CHIS internally addressed adaptation of day-to-day operations given the stay-at-home orders (e.g., ensuring remote access to secure data), our data collection partner, SSRS, a full-service survey research firm located in Pennsylvania, continued to operate its mail and printing services as essential services.[7] This allowed the production and mailing of recruitment materials to proceed unimpeded by widespread pandemic shutdowns. Though telephone data collection only accounts for approximately a tenth of total CHIS interviews, SSRS was able to transition their telephone interviewing operation in a matter of days to a decentralized, home-based model allowing inbound computer-assisted telephone interviewing and outbound nonresponse follow-up to continue.

When we examined the impact of the pandemic on CHIS data collection results, the average completion rate for CHIS 2020 was 11.4%. For comparison, CHIS 2019 only achieved an average 8.7% completion rate. Despite state and local leadership loosening some restrictions over the course of the year,[8] completion rates were relatively consistent across the waves of sample mail outs. The latter, smaller waves of data collection had slightly lower completion rates (average of 10.4%), but given that many of these waves began in July at the initial peak of infections in California, this decline in completion rates in the latter waves is most likely attributable to increasing proportions of workloads in harder-to-survey counties where we were falling short of annual county-level targets. Even the least effective waves of 2020 data collection outpaced the most effective waves of 2019. There was also a noticeable shift in the timing and mode of completed surveys in CHIS 2020 relative to CHIS 2019. Nearly 50% of all completed adult surveys per wave were completed in the two weeks following the initial invitation letter, a noticeable increase from 33% in 2019. Overall, computer-assisted telephone interview completes accounted for 10.9% of all completed adult surveys in 2019 but only 7.7% in 2020. The revised sample design and data collection strategy allowed CHIS to take advantage of the increased number of Californians reachable at home because of the stay-at-home orders. The strong health focus of CHIS may have been a more salient factor to many respondents given the spotlight on public health during the pandemic.

The CHIS sample design is intended to support annual estimates for California and many individual counties by aggregating all interviews conducted across all weekly sample waves. The need for timely data during the pandemic and the strong response observed during this time warranted examining the feasibility of producing more timely subannual estimates. We employed a strategy that pooled all interviews conducted across sample waves within a given calendar month (Figure 1). The monthly totals were determined to be sufficient for statewide estimates, as well as for large substate regions and demographic subgroups. Given that the sample distribution in later waves was modified to compensate for underperforming areas across the state to reach annual targets, the unweighted sample in these later waves tends to be less representative of the statewide population. To help compensate for the geographic differences in the sample over time, we included substate geographic variables as raking dimensions during weighting. Accounting for the yield of completed surveys each month and the geographic changes in the sample distribution, CHIS decided to release monthly estimates for May, June, July, and August, but not for September and October.

ADAPTING QUESTIONNAIRE TO REFLECT COVID-19 NEEDS

With an increasing number of COVID-19 cases and public health guidelines across the state, CHIS resolved to add COVID-19–related questions with the planning for a specific COVID-19 module beginning in mid-March 2020. Without ample time to conduct iterative cognitive pretesting, the CHIS team at UCLA consulted various experts involved in monitoring the pandemic. We explored COVID-19–related questions from surveys in the United States and Canada including those shared on the Centers for Disease Control and Prevention COVID-19 Community Survey Question Bank, which at the time of our instrument development offered a comprehensive set of potential questions for community surveys. Through several revisions, CHIS finalized a nine-item COVID-19 module in April 2020 with indicators on COVID-19 concerns, testing, and diagnoses; financial and social impacts of the pandemic; personal acceptance of the COVID-19 vaccine; and reasons why respondents had no insurance (Appendix A, available as a supplement to the online version of this article at http://www.ajph.org). Simultaneously, the UCLA Asian American Studies Center and CHIS began collaborating on a module intended to capture the impacts of the COVID-19 pandemic among Asian, Native Hawaiian, and Pacific Islander (AsNHPI) communities. Responding to the rise of anti-Asian rhetoric and hate incidents targeting the AsNHPI community, the AsNHPI module measures the prevalence of anti-Asian bias and perceived association between COVID-19 and Asians, the economic and social impacts of COVID-19 specifically on AsNHPI communities, and perceptions among AsNHPI communities on how national, local, and academic institutions handled the pandemic. CHIS began fielding the AsNHPI 12-item module in July 2020 (Appendix B, available as a supplement to the online version of this article at http://www.ajph.org).

These two novel modules underwent multiple rounds of collaborative development with stakeholders at the UCLA Fielding School of Public Health, UCLA Geffen School of Medicine, the UCLA Asian American Studies Center, and the California Department of Public Health. With its data collection partner, SSRS, the CHIS team expeditiously developed and implemented the general COVID-19 module on May 5, 2020, and the COVID-19 AsNHPI module on July 2, 2020. As these questions were fielded, modifications were made to adapt to the changing practices and guidelines surrounding COVID-19, including expanding the universe of the indicator on whether the respondent was ever tested from a subset of adults who saw a clinician related to COVID-19 symptoms to all respondents to reflect the growing availability of testing that did not require clinician recommendation.

NEW DISSEMINATION APPROACHES FOR COVID-19 DATA

Given that CHIS is designed as an annual survey, the COVID-19 module presented two challenges: (1) Could the data be made public almost in real time? and (2) How can data be presented so that they are generally understood and differentiated from the annual data products?

The sample yields from the first months after the May implementation of the COVID-19 module were robust and well-distributed enough across the state to release statewide preliminary monthly estimates. However, there were few protocols in place for producing and releasing preliminary estimates monthly. CHIS worked with SSRS to abbreviate the typical data processing procedures, including expediting the timeline for geocoding and race upcoding needed to produce population survey weights, allowing CHIS to produce monthly population estimates in a publicly accessible data dashboard.

The dashboard on preliminary monthly estimates containing data collected in May was launched in September 2020, with subsequent releases of June data in October 2020, July data in November 2020, and August data in December 2020. Users were able to access preliminary estimates for the majority of the new COVID-19 indicators at the state level and apply demographic filters including racial/ethnic subgroups, insurance status, and household size to illustrate how these sociodemographic indicators affected the prevalence of indicators in the COVID-19 modules, including the types of difficulties experienced because of COVID-19 and whether the respondent had ever been tested for COVID-19. Furthermore, because COVID-19 resources and responses were at the local level, CHIS generated substate estimates by pooling data collected from May through August 2020. CHIS established 18 substate groupings with enough sample size to produce data estimates at a more granular level including data at the county level for seven larger California counties including Los Angeles, Santa Clara, and Alameda. With these substate estimates, users could access data for various indicators in the COVID-19 module and apply health and sociodemographic filters to create a visual illustration of how these covariates are distributed across a map of California (Appendix C, available as a supplement to the online version of this article at http://www.ajph.org). For the COVID-19 AsNHPI module, pooled data from July through October were used to create estimates on these special topics for the AsNHPI population and were added to the dashboard in February 2021 (Appendix D, available as a supplement to the online version of this article at http://www.ajph.org).

FUTURE IMPLICATIONS AND TAKEAWAYS

The urgency of providing health data during the COVID-19 pandemic necessitated a way to share CHIS findings with the public in real time. Although the design of the CHIS remains an annual survey, the 2020 CHIS demonstrated for the first time the viability of pooling completed surveys conducted across weekly sample waves within a calendar month to produce monthly statewide estimates. Fluctuations in sample sizes and changes in the geographical distribution of the sample across the weekly sample waves created some challenges in producing stable monthly estimates or allowing for an accurate comparison or progression of indicators across several months.

In planning for 2021, CHIS has improved the consistency of sample releases across the survey administration year to help ensure adequate sample sizes are available from month to month to produce monthly COVID-19 preliminary estimates through the bulk of 2021. In the future, CHIS will also consider how to implement real-time measures to assess the representativeness of the raw sample yield to improve the quality of monthly estimates with less reliance on geographical and demographic raking factors in the weighting processes to correct for month-to-month variation in the sample design.

The scientific value is largely to inform other surveys that reporting preliminary monthly estimates from an annual population-based survey is possible, albeit limited to a subset of indicators. A monthly data collection sampling approach is necessary to produce monthly estimates, but, to our knowledge, these provisional estimates from other surveys were conducted in English only or in English and Spanish only and, thus, were limited in coverage of racial/ethnic and language diversity.[9,10]

COVID-19 exposed longstanding inequities shaped by socioeconomic conditions and opportunities. Our preliminary monthly COVID-19 dashboard was the first time CHIS released monthly data within three months of data collection, compared with a standard release of annual data 10 months after data collection. CHIS has had a two-decade commitment to measuring these socioeconomic conditions to augment public health's understanding of the inequities in population health. For this reason, we pursued a strategy to release estimates with a large set of sociodemographic filters to inform policies to address these inequities, but the tradeoff with more data granularity was a longer release time. As the annual CHIS 2020 is currently being processed, CHIS will further assess the data quality of the 2020 monthly estimates and streamline processes to optimize the release of monthly estimates. CHIS will also consider other measures that might benefit from subannual estimates. The demonstrated feasibility of the COVID-19 dashboard has established the foundations for potential future use of dashboards as a platform for communicating and democratizing more timely critical health and health-related data. AJPH

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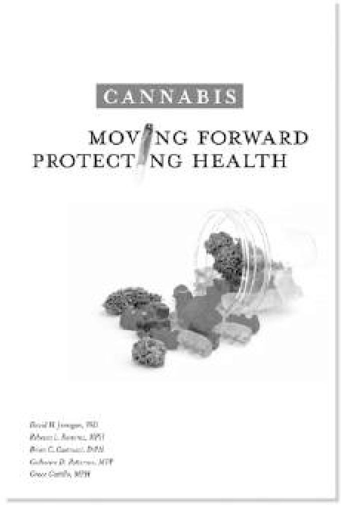
Note. All views presented in the article are the views of the authors.

CONFLICTS OF INTEREST

The authors have no conflicts of interest to report.

REFERENCES

1. Brown ER, Holtby S, Zahnd E, Abbott GB. Community-based participatory research in the California Health Interview Survey. *Prev Chronic Dis.* 2005;2(4):A03.
2. Ponce NA. Centering health equity in population health surveys. *JAMA Health Forum.* 2020;1(12):e201429. https://doi.org/10.1001/jamahealthforum.2020.1429
3. Wells BM. CHIS 2019–2020 redesign: rationale, empirical evaluation, and trends. October 2020. Available at: https://healthpolicy.ucla.edu/chis/design/Documents/CHIS2019-2020-Redesign-WorkingPaper-Oct2020.pdf. Accessed March 1, 2021.
4. US Census Bureau. American Community Survey, 2019 American Community Survey 1-year data file. 2020. Available at: https://www2.census.gov/programs-surveys/acs/summary_file/2019/data/1_year_by_state. Accessed April 14, 2021.
5. Ponce NA, Lavarreda SA, Yen W, Brown ER, DiSogra C, Satter DE. The California Health Interview Survey 2001: translation of a major survey for California’s multiethnic population. *Public Health Rep.* 2004;119(4):388–395. https://doi.org/10.1016/j.phr.2004.05.002
6. Arango T, Cowan J. Gov. Gavin Newsom of California orders Californians to stay at home. *New York Times*. March 19, 2020. Available at: https://www.nytimes.com/2020/03/19/us/California-stay-at-home-order-virus.html. Accessed April 15, 2021.
7. Marroni S. What are essential and non-essential businesses during coronavirus shutdown? Here’s what Pa. Gov. Wolf says. *PennLive*. March 17, 2020. Available at: https://www.pennlive.com/news/2020/03/what-are-essential-and-non-essential-businesses-during-coronavirus-shutdown-heres-what-pa-gov-wolf-says.html. Accessed April 15, 2021.
8. Bollag S. New California coronavirus rules will let more counties reopen, Gavin Newsom says. *Sacramento Bee.* May 18, 2020. Available at: https://www.sacbee.com/news/politics-government/capitol-alert/article242818586.html. Accessed April 15, 2021.
9. US Census Bureau. Household Pulse Survey technical documentation. Available at: https://www.census.gov/programs-surveys/household-pulse-survey/technical-documentation.html. Accessed October 19, 2021.
10. Societal Experts Action Network. Welcome to the Societal Experts Action Network (SEAN) COVID-19 survey archive. Available at: https://covid-19.parc.us.com/client/index.html. Accessed October 19, 2021.



Considerations for Improving Reporting and Analysis of Date-Based COVID-19 Surveillance Data by Public Health Agencies

Ian Hennessee, MPH, Julie A. Clennon, PhD, MSc, Lance A. Waller, PhD, MS, Uriel Kitron, PhD, MPH, and J. Michael Bryan, PhD, MPH

See also Lau et al., p. 2085.

More than a year after the first domestic COVID-19 cases, the United States does not have national standards for COVID-19 surveillance data analysis and public reporting. This has led to dramatic variations in surveillance practices among public health agencies, which analyze and present newly confirmed cases by a wide variety of dates.

The choice of which date to use should be guided by a balance between interpretability and epidemiological relevance. Report date is easily interpretable, generally representative of outbreak trends, and available in surveillance data sets. These features make it a preferred date for public reporting and visualization of surveillance data, although it is not appropriate for epidemiological analyses of outbreak dynamics. Symptom onset date is better suited for such analyses because of its clinical and epidemiological relevance. However, using symptom onset for public reporting of new confirmed cases can cause confusion because reporting lags result in an artificial decline in recent cases.

We hope this discussion is a starting point toward a more standardized approach to date-based surveillance. Such standardization could improve public comprehension, policymaking, and outbreak response. (*Am J Public Health*. 2021;111(12):2127–2132. https://doi.org/10.2105/AJPH.2021.306520)

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The COVID-19 pandemic has placed pressure on public health agencies to produce and report surveillance data at an unprecedented speed and granularity.[1] While the Centers for Disease Control and Prevention publishes guidelines for collecting COVID-19 surveillance information, there is limited information on standard practices for analysis and public reporting of date-based surveillance data.[2,3] This has led to dramatic variations in reporting practices among health departments. For example, 30% of health departments use report date for visualizing new COVID-19 cases in epidemic (epi) curves, 22% use test date, 12% use symptom onset date, 16% display multiple dates such as report date and symptom onset date, and 20% do not define what dates are used or do not show epi curves.

The choices that health departments make regarding date-based analysis and reporting of COVID-19 cases have important consequences for public comprehension and trust, policymaking, and outbreak response. For example, until July 2020, all epi curves included in the Georgia Department of Public Health (GDPH) Daily COVID-19 Status Reports showed new cases by symptom onset date. Although this approach was in keeping with standard epidemiological practice,[4] it resulted in an apparent downward trend in recent cases because of incomplete reporting of cases whose symptoms started recently.[5] This led to public confusion and incorrect conclusions about Georgia's progress in reducing infections in the early months of the epidemic.[6,7] Discrepancies in dates used across different reporting platforms have caused further confusion.[6]

This article discusses considerations for reporting and analysis of date-based surveillance data, using a longitudinal COVID-19 surveillance data set from GDPH as an example. This data set included 862 153 confirmed COVID-19 cases as of April 11, 2021.[5] We hope this discussion will contribute to the development of more standardized approaches for analysis and presentation of date-based COVID-19 surveillance data across jurisdictions. Such standardization could improve public comprehension, policymaking, outbreak response, and communication.

WHICH DATES TO USE FOR SURVEILLANCE AND REPORTING

Confirmed COVID-19 cases follow a basic timeline from infection date to symptom onset date (for symptomatic individuals), test date, and, finally, report date. Figure 1 presents this timeline, along with median lags between each date from GDPH COVID-19 surveillance data and published reports. These dates are commonly used for epidemiological analysis and public reporting of routine COVID-19 surveillance data. The strengths and weaknesses of each are discussed in the following paragraphs.

Report Date

Report date (i.e., the date a confirmed case was reported to the health department) is generally available in surveillance data sets. For example, it is available for more than 99% of confirmed COVID-19 cases in Georgia. Report date is easily interpretable for decision-makers and the lay public because there is no need to account for reporting lags (Figure 2a). In addition, report date is usually representative of outbreak trends, especially when a running average is presented. These features make it a preferred choice for public reporting and visualization of new confirmed COVID-19 cases via epi curves, maps, and tables. This is the date that is used by the World Health Organization, Centers for Disease Control and Prevention, and many state and local health departments.[8,9] Report date is also a suitable choice for summary metrics (e.g., 14-day community transmission rates) where reporting lags associated with other dates could otherwise complicate interpretation.

However, report date is the least epidemiologically relevant date because it is not directly related to the occurrence of disease in individuals or patterns of disease in populations. Epidemiological analyses of outbreak dynamics (e.g., contact tracing, investigations of transmission chains, cluster or hotspot analyses, estimation of the effective reproductive number) require precise characterization of temporal relationships between cases. Using report date for such analyses could introduce systematic or random

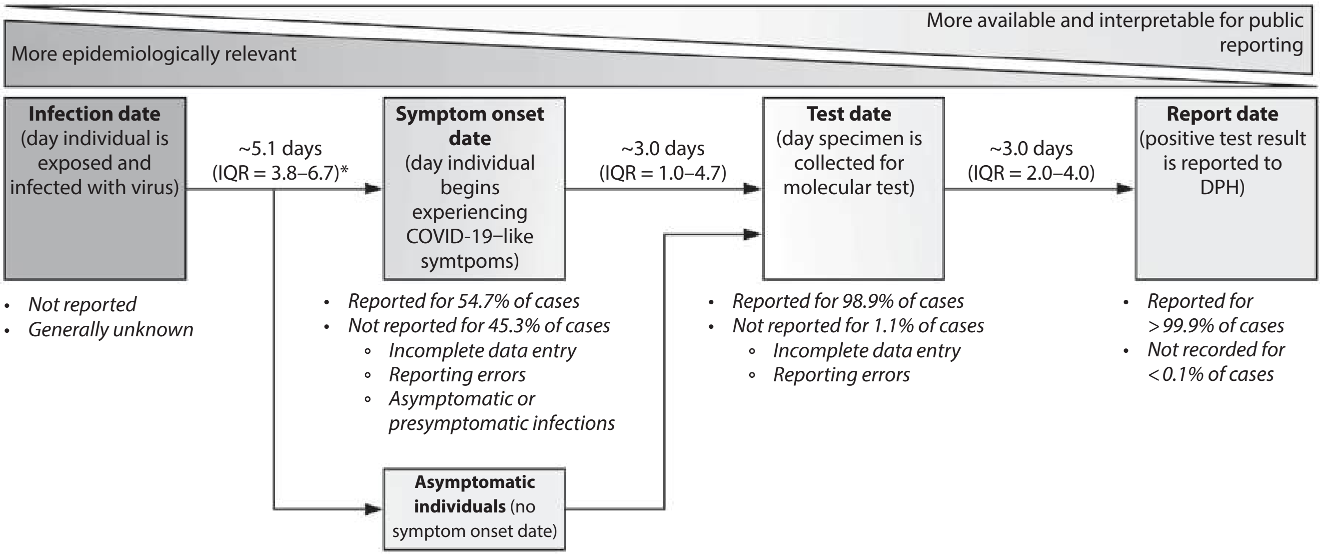

FIGURE 1— **Timeline of Confirmed COVID-19 Cases for Date-Based Surveillance: Georgia**

Note. DPH = Department of Public Health; IQR = interquartile range. Dates follow a timeline of infection date on the left to report date on the right, with median and IQR differences depicted between each date. The incubation period is from Lauer et al.[15] All other dates are derived from Georgia DPH surveillance data as of April 11, 2021. Dates on the left are more epidemiologically relevant in that they are reflective of the occurrence and patterns of disease in individuals and populations. However, they are potentially less available and interpretable for public reporting because of large reporting lags. Dates on the right are less epidemiologically relevant but more appropriate for reporting and public presentation of surveillance data because of higher availability in surveillance data sets and minimal reporting lags.

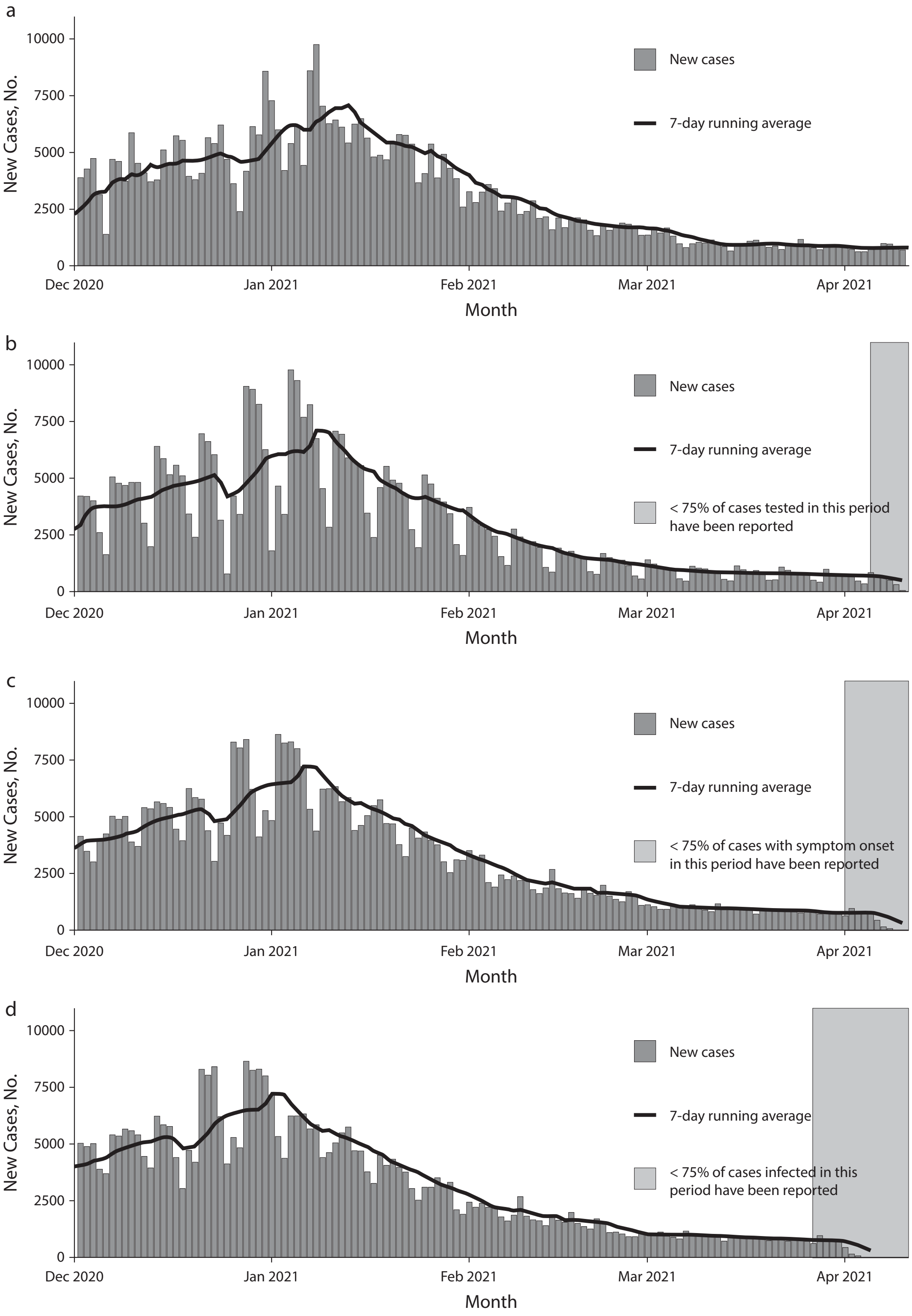

FIGURE 2— **Comparisons of Epidemic Curves for Confirmed COVID-19 Cases by (a) Report Date, (b) Test Date, (c) Symptom Onset Date, and (d) Estimated Infection Date: Georgia, December 1, 2020–April 11, 2021**

Note. Missing symptom onset dates were imputed using generalized additive models, and infection dates were estimated as symptom onset dates minus a median incubation period of 5.1 days. Reporting lags when < 75% of cases were likely to have been reported are shown with gray boxes on the right of each plot.

error.[10] Variations in reporting practices can also introduce artificial trends in surveillance data, such as a weekend drop or spikes from resolved reporting backlogs.[11]

Test Date

Test date (i.e., the day a positive molecular test was first performed for a confirmed case) may be less biased by the previously mentioned variations in reporting practices and is more clinically relevant. Test date is available in electronic laboratory records, so it is timelier than dates requiring patient interviews. More than 98% of confirmed cases in Georgia include test date (Figure 1). For these reasons, some health departments report confirmed COVID-19 cases by test date. However, positive COVID-19 cases in Georgia have a median lag of 3 days between test date and report date, and median lags were as long as 5 days during parts of the outbreak. These lags may cause confusion when test date is used for public presentation of surveillance data because incomplete reporting results in an artificial decline in recent cases. Test date is not a recommended date for most analyses of transmission dynamics because it may not directly align with the clinical course of infections or patterns of disease in populations. In addition, many testing centers have irregular operating dates, and health care utilization often changes depending on the day of the week.[12] This could introduce artificial “weekend effects” or other irregularities in epi curves that use test date (Figure 2b).

Symptom Onset Date

Symptom onset date (i.e., the date an individual first began experiencing COVID-19–like symptoms before a positive diagnostic test) is usually reportable on COVID-19 case report forms or collected during case interviews.[13] Because symptomatic individuals are most infectious at or just before their symptoms begin, symptom onset date approximates the time period when individuals were most likely to infect close contacts.[14] This makes it an appropriate date for epidemiological analyses related to transmission dynamics. Because symptoms generally appear a median of 5 days after infection, symptom onset date can be used to estimate infection date for contact tracing, outbreak response, or other epidemiological analyses of infection dynamics when the date of infection is unknown.[15,16]

Symptom onset date is not ideal for public reporting because the inherent lag from onset to report creates an artificial downward trend in recent cases (Figure 2c). Symptom onset date also must be collected via case report forms or contact-tracing interviews, which can cause further delays in reporting. The public and decision-makers may misinterpret reporting lags as true downward trends. This can negatively affect public trust and potentially lead to misinformed policy decisions.[6,7] Unlike previous pandemics such as HIV and severe acute respiratory syndrome coronavirus 1 (SARS-CoV-1), a high proportion of SARS-CoV-2 infections are asymptomatic.[17] Reporting all COVID-19 cases by symptom onset date obscures this fact and may cause confusion. In addition, public digestion of COVID-19 epidemiological data is dramatically higher than in previous pandemics.[1,18] This makes it more imperative to clearly present data and avoid potential ambiguities from dates with long reporting delays.

Limitations of using symptom onset date include underreporting, potential recall bias, and inapplicability to asymptomatic or presymptomatic individuals. This can lead to issues with reliability and a high degree of absence from surveillance data sets. In Georgia, for example, symptom onset date is only available for 55% of confirmed COVID-19 cases. Despite these limitations, various methods can be used to impute symptom onset date and assess bias. GDPH and other health departments derive symptom onset date for missing observations by using a decision tree of other available dates, and other approaches include predictive regression models and multiple imputation.[5,19]

Infection Date

Infection date (i.e., when an individual was exposed to and infected with SARS-CoV-2) is the most epidemiologically relevant date because of its direct relationship to disease patterns in populations. When available, it is an ideal date for contact tracing,[14] outbreak investigations,[20] and spatiotemporal analyses of transmission dynamics.[21,22] However, individuals often do not know the date they were infected, and it is not collected as part of most COVID-19 surveillance systems. This reduces its applicability to analyses that use routine surveillance data. It can be estimated by using symptom onset date, but many estimation methods homogenize substantial heterogeneities in incubation periods.[23,24] Long lags between infection and report dates also complicate the interpretation of epi curves that use infection date (Figure 2d). In Georgia, for example, most cases are reported more than 10 days after infection (Figure 1). Therefore, infection date is not recommended for use in public presentation of surveillance data.

PUBLIC HEALTH IMPLICATIONS

More than a year after the first domestic COVID-19 cases, the United States still does not have national standards for jurisdiction-level analysis and reporting of date-based COVID-19 surveillance data. A more standardized approach could increase public confidence and enable better harmonization of indicators and reporting methods across jurisdictions.[25] This is increasingly important in the current context when strengthened surveillance and reporting are required to inform reopening decisions, maintain public confidence, and rapidly detect and respond to recurrent outbreaks.

The choice of which date to use for public reporting or epidemiological analysis should be guided by a balance between interpretability and epidemiological relevance. In general, report date is preferable for use in public reporting, while symptom onset date is the best choice for many epidemiological analyses of transmission dynamics when infection date is not available. Some health department dashboards, such as that of GDPH, now give users an option to view epi curves by date of report and by date of symptom onset. This may reduce public confusion, but additional efforts are needed to identify best practices for reporting and visualization of surveillance data.[5,18]

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CONTRIBUTORS

All authors contributed to the conceptualization of the work as a part of the spatial epidemiology COVID-19 Emory–GDPH collaboration led by J. A. Clennon and J. M. Bryan. I. Hennessee conducted the analyses and wrote the first draft of the essay. J. A. Clennon, L. Waller, U. Kitron, and J. M. Bryan provided critical feedback and edits to drafts, and all authors approved the final version.

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CONFLICTS OF INTEREST

The authors have no potential conflicts of interest to declare.

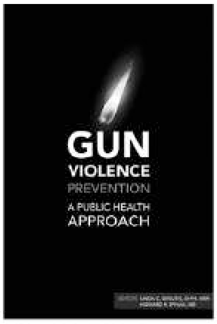
HUMAN PARTICIPANT PROTECTION

De-identified case data were analyzed with the purpose of informing the GDPH’s pandemic response. GDPH therefore determined that this analysis was exempt from GDPH institutional review board review and approval.

REFERENCES

1. 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
2. Centers for Disease Control and Prevention. Information for health departments on reporting cases of COVID-19. 2021. Available at: https://www.cdc.gov/coronavirus/2019-ncov/php/reporting-pui.html. Accessed April 22, 2021.
3. Pearce N, Vandenbroucke JP, VanderWeele TJ, Greenland S. Accurate statistics on COVID-19 are essential for policy guidance and decisions. *Am J Public Health.* 2020;110(7):949–951. https://doi.org/10.2105/AJPH.2020.305708
4. Centers for Disease Control and Prevention. Interpretation of epidemic (epi) curves during ongoing outbreak investigations. 2015. Available at: https://www.cdc.gov/foodsafety/outbreaks/investigating-outbreaks/epi-curves.html. Accessed April 12, 2021.
5. Georgia Department of Public Health. Georgia Department of Public Health daily status report. 2021. Available at: https://dph.georgia.gov/covid-19-daily-status-report. Accessed April 12, 2021.
6. Mariano W. “Confused and scared”: Georgians frustrated over shifting virus data. *Atlanta Journal–Constitution.* April 23, 2020. Available at: https://www.ajc.com/news/state–regional-govt–politics/confused-and-scared-georgians-frustrated-over-shifting-virus-data/k9oUbZDE3z6iyouWQBF7gJ. Accessed April 29, 2020.
7. Newkirk M. Georgia massaged virus data to reopen, then voided mask orders. *Bloomberg.* July 17, 2020. Available at: https://www.bloomberg.com/news/articles/2020-07-17/georgia-massaged-virus-data-to-reopen-then-voided-mask-orders. Accessed July 20, 2020.
8. Centers for Disease Control and Prevention. United States COVID-19 Cases, Deaths, and Laboratory Testing (NAATs) by State, Territory, and Jurisdiction. 2021. Available at: https://www.cdc.gov/coronavirus/2019-ncov/cases-updates/cases-in-us.html. Accessed April 22, 2021.
9. Surveillance strategies for COVID-19 human infection. Geneva, Switzerland: World Health Organization; May 10, 2020.
10. Rasmussen SA, Goodman RA. *The CDC Field Epidemiology Manual.* New York, NY: Oxford University Press; 2019. https://doi.org/10.1093/cid/ciz065
11. Cohen J. Transient drops in reported new coronavirus cases: “Sunday effect.” *Forbes.* April 27, 2020. Available at: https://www.forbes.com/sites/joshuacohen/2020/04/27/transient-drops-in-reported-new-coronavirus-cases-sunday-effect/?sh=3cc9f115811a. Accessed May 1, 2020.
12. Marcilio I, Hajat S, Gouveia N. Forecasting daily emergency department visits using calendar variables and ambient temperature readings. *Acad Emerg Med.* 2013;20(8):769–777. https://doi.org/10.1111/acem.12182

13. Centers for Disease Control and Prevention. Investigating a COVID-19 case. 2020. Available at: https://www.cdc.gov/coronavirus/2019-ncov/php/contact-tracing/contact-tracing-plan/investigating-covid-19-case.html. Accessed July 1, 2020.
14. Cheng H-Y, Jian S-W, Liu D-P, et al. Contact tracing assessment of COVID-19 transmission dynamics in Taiwan and risk at different exposure periods before and after symptom onset. *JAMA Intern Med.* 2020;180(9):1156–1163. https://doi.org/10.1001/jamainternmed.2020.2020
15. Lauer SA, Grantz KH, Bi Q, et al. The incubation period of coronavirus disease 2019 (COVID-19) from publicly reported confirmed cases: estimation and application. *Ann Intern Med.* 2020;172(9):577–582. https://doi.org/10.7326/M20-0504
16. Pan A, Liu L, Wang C, et al. Association of public health interventions with the epidemiology of the COVID-19 outbreak in Wuhan, China. *JAMA.* 2020;323(19):1915–1923. https://doi.org/10.1001/jama.2020.6130
17. Petersen E, Koopmans M, Go U, et al. Comparing SARS-CoV-2 with SARS-CoV and influenza pandemics. *Lancet Infect Dis.* 2020;20(9):e238–e244. https://doi.org/10.1016/S1473-3099(20)30484-9
18. Chiolero A, Anker D. Data are not enough to reimagine public health. *Am J Public Health.* 2020;110(11):1614. https://doi.org/10.2105/AJPH.2020.305907
19. Nguyen CD, Carlin JB, Lee KJ. Model checking in multiple imputation: an overview and case study. *Emerg Themes Epidemiol.* 2017;14(1):8. https://doi.org/10.1186/s12982-017-0062-6
20. Li Q, Guan X, Wu P, et al. Early transmission dynamics in Wuhan, China, of novel coronavirus-infected pneumonia. *N Engl J Med.* 2020;382(13):1199–1207. https://doi.org/10.1056/NEJMoa2001316
21. Pei S, Kandula S, Shaman J. Differential effects of intervention timing on COVID-19 spread in the United States. *Sci Adv.* 2020;6(49):eabd6370. https://doi.org/10.1126/sciadv.abd6370
22. Lau MSY, Grenfell B, Thomas M, Bryan M, Nelson K, Lopman B. Characterizing superspreading events and age-specific infectiousness of SARS-CoV-2 transmission in Georgia, USA. *Proc Natl Acad Sci U S A.* 2020;117(36):22430–22435. https://doi.org/10.1073/pnas.2011802117
23. Fareed N, Swoboda CM, Chen S, Potter E, Wu DTY, Sieck CJ. US COVID-19 state government public dashboards: an expert review. *Appl Clin Inform.* 2021;12(2):208–221. https://doi.org/10.1055/s-0041-1723989
24. McAloon CG, Wall P, Griffin J, et al. Estimation of the serial interval and proportion of pre-symptomatic transmission events of COVID-19 in Ireland using contact tracing data. *BMC Public Health.* 2021;21(1):805. https://doi.org/10.1186/s12889-021-10868-9
25. Tarantola D, Dasgupta N. COVID-19 surveillance data: a primer for epidemiology and data science. *Am J Public Health.* 2021;111(4):614–619. https://doi.org/10.2105/AJPH.2020.306088



Advancements in the National Vital Statistics System to Meet the Real-Time Data Needs of a Pandemic

Farida B. Ahmad, MPH, Robert N. Anderson, PhD, Karen Knight, MS, Lauren M. Rossen, PhD, and Paul D. Sutton, PhD

See also Lau et al., p. 2085.

The National Center for Health Statistics' (NCHS's) National Vital Statistics System (NVSS) collects, processes, codes, and reviews death certificate data and disseminates the data in annual data files and reports.

With the global rise of COVID-19 in early 2020, the NCHS mobilized to rapidly respond to the growing need for reliable, accurate, and complete real-time data on COVID-19 deaths. Within weeks of the first reported US cases, NCHS developed certification guidance, adjusted internal data processing systems, and stood up a surveillance system to release daily updates of COVID-19 deaths to track the impact of the COVID-19 pandemic on US mortality.

This report describes the processes that NCHS took to produce timely mortality data in response to the COVID-19 pandemic. (*Am J Public Health*. 2021;111(12):2133–2140. https://doi.org/10.2105/AJPH.2021.306519)

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The National Center for Health Statistics' (NCHS's) National Vital Statistics System (NVSS) collects official death certificate data through contracts with 57 jurisdictions (the 50 states, the District of Columbia, New York City, and 5 US territories).[1] NCHS works closely with jurisdictions to improve the speed and quality of how death statistics are reported by preparing standards for data collection, developing death certification guidance and training, and providing continual feedback on data provided. NCHS collects, processes, codes, and reviews death certificate data and disseminates the data in annual data files and reports. In recent years, improvements to the data quality and timeliness of data, combined with enhancements to the ongoing processing and coding of these data, have made it possible to conduct more timely public health surveillance on deaths from causes such as influenza and pneumonia, drug overdose, and suicide.

With the global rise of COVID-19 in early 2020, NCHS mobilized to rapidly respond to the growing need for reliable, accurate, and complete real-time data on COVID-19 deaths. Within weeks of the first reported US cases, NCHS developed certification guidance, adjusted internal data processing systems (i.e., cause-of-death coding, auditing, review), and stood up a surveillance system to release daily updates of COVID-19 deaths to track the impact of the COVID-19 pandemic on US mortality. This report describes the processes that NCHS undertook to produce timely mortality data in response to the COVID-19 pandemic.

DATA SOURCE

COVID-19 mortality surveillance for the NVSS relies on death certificate data reported by US jurisdictions. Figure 1 outlines the data flow of death certificate data from the time it is completed by local officials to its inclusion in mortality data files. Death certificates are completed by using a standardized form, in part by a funeral director and in part by a certifier (i.e., physician, medical examiner, or coroner). The funeral director provides demographic information about the decedent based on information obtained from family members or other informants. The certifier reports information about a decedent's death, including the place, time, manner, and cause of death. The primary cause and other conditions in the chain of events leading to the decedent's death are written in literal text, or free text, by the certifier. Certifiers use their best medical judgment based on available information in providing cause-of-death information and may

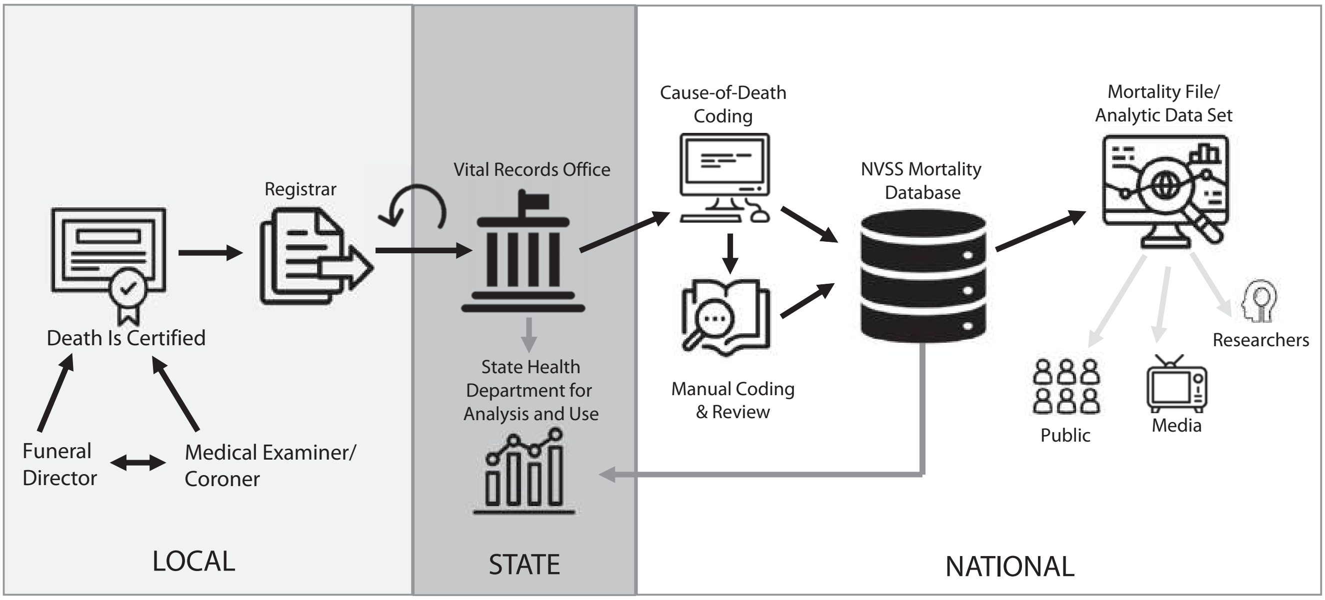

FIGURE 1— **The Data Flow Process of Death Certificate Data From Certification to Publication in the National Vital Statistics System (NVSS)**

include the terms “probable” or “presumed” when circumstances are compelling within a reasonable degree of certainty but a definitive diagnosis cannot be made.[2] Laboratory confirmation of infectious diseases such as influenza and COVID-19 is encouraged, but not required. Guidance for certification and coding of COVID-19 deaths is consistent with standardized guidance for all other causes of death.[2]

DATA PROCESSING

NCHS began preparing the NVSS mortality system to accept, code, analyze, and report COVID-19 deaths in a standardized method in February 2020. To help certifiers accurately record cause-of-death information on the death certificate in the case of a COVID-19–related death, NCHS issued preliminary guidance on March 4, 2020, and full guidance on April 2, 2020.[2,3] The guidance documents gave certifiers detailed instructions and examples, while aligning the guidance with established certification practices for all causes of death. Ongoing outreach to vital registration offices and death certifiers, through webinars, online video tutorials, and targeted trainings, is continuing to help ensure that COVID-19 deaths are being accurately reported on death certificates.

NCHS processes, reviews, and codes mortality data through a complex network of automated and manual steps. After death records are received from the jurisdictions, cause-of-death information is coded by NCHS according to the *International Classification of Diseases, Tenth Revision* (*ICD-10*), which standardizes disease classification and the designation of underlying cause of death.[4,5] Analysts use *ICD-10* codes when tabulating deaths by cause of death. Deaths are assigned the *ICD-10* code U07.1 when coronavirus disease 2019 or COVID-19 is reported as a cause that contributed to death on the death certificate.[6] In 92% of these deaths, COVID-19 is the underlying cause of death.[7] A second *ICD-10* code, U07.2, issued by the World Health Organization (WHO) to code deaths without laboratory confirmation, is not used by NCHS because laboratory test results are not routinely reported on death certificates in the United States and, therefore, use of this code could not be implemented in a consistent, reliable manner.[6] Differences in access to testing, accuracy of test results, and the reporting of test results would present bias, potentially labeling large numbers of COVID-19 deaths as unconfirmed because they lack laboratory confirmation.

For the majority of death records (approximately 75%), cause-of-death information can be electronically processed and coded automatically within minutes. Because COVID-19 was a novel cause of death, 100% of initial COVID-19 records were reviewed and coded manually by trained nosologists. By April 2020, autocoding methods were developed to code uncomplicated death certificates that referenced COVID-19. However, throughout 2020, approximately 70% to 75% of death records involving COVID-19 still needed to be manually coded by a trained nosologist because of the complexity of the records, many of which had multiple conditions listed.[8] By January 2021, NCHS had received, processed, and coded more than 350 000 death records listing COVID-19 as an underlying or contributing cause. Insight from these records informed further improvements to the autocoding system, allowing for about 80% of COVID-19 records to be machine-coded within minutes of receipt.

The length of time to complete the manual coding for COVID-19 deaths can vary considerably depending on the number of records requiring this step, ranging from 6 days in August 2020 to 29 days in January 2021. This length of time, or backlog, is greater when there is a surge in deaths requiring manual coding. During these surge periods (e.g., April 2020, September 2020, and December 2020), the NVSS death data lag between the time of death and when data were available temporarily grew from 1 to 2 weeks to 4 to 5 weeks as jurisdictions faced delays to complete death certificates and NCHS was challenged with completing all of the manual coding necessary. In each instance, NCHS staff monitored the number of records awaiting manual coding and percent completeness by jurisdiction to identify when targeted intervention (e.g., additional staffing, modifications to automated coding procedures) was needed to reduce the data lag.

NCHS staff routinely monitor death data for completeness and data quality and provide feedback to states to improve reporting. In March 2020, NCHS data acquisition staff began conducting a weekly review of potentially miscoded COVID-19 deaths (e.g., instances in which the literal text did not correspond with the assigned *ICD-10* code) and a monthly audit of death records with nonspecific literal text. Vital registration offices were asked to seek clarification from certifiers and to submit amended death certificates to NCHS when appropriate.

DATA RELEASE

The NVSS's COVID-19 mortality surveillance system releases real-time provisional death data through daily, weekly, and ad-hoc data files and analyses. Provisional data are nonfinal death certificate data that have been received, coded, and processed by NCHS but are subject to revision until data are finalized. The COVID-19 surveillance system has expanded since the beginning of the pandemic, initially only providing provisional death counts by demographic and geographic characteristics, then adding data on racial and ethnic disparities and analyses with innovative statistical methods. In addition to data file releases, NCHS has released preliminary analyses in numerous publications and plans to continue publishing summary analyses with provisional and final data.

Daily data releases include national and state weekly and monthly counts of total deaths, COVID-19 deaths, and deaths that involve pneumonia and influenza, from January 2020 through the most current full week.[9] Weekly data files, updated each Wednesday, include death counts by demographic characteristics (e.g., age, sex, race/ethnicity), geography (e.g., state, county), and select causes of death (Figure 2).[10,11] Excess deaths, a measure of the mortality burden related to the COVID-19 pandemic, are also tabulated for release on a weekly basis.[12] In accordance with NCHS standards for data disclosure, subnational data (i.e., data at the region, state, or county level) are suppressed when counts for individual data cells are between 1 and 9 to minimize the risk of identifying rare cases.

Provisional Death Counts

Before the COVID-19 pandemic, provisional mortality data were published on a quarterly or monthly basis through the Vital Statistics Rapid Release program, for the purposes of public health surveillance of overall mortality and mortality attributable to specific causes of death such as drug overdose.[13,14] Depending on the cause of death, provisional data have historically been published with a 3- to 9-month lag (length of time between the date of death and date of report), to ensure that data were sufficiently complete for purposes of surveillance. Provisional mortality data from the NVSS are also used for near-real-time pneumonia and influenza mortality surveillance, where data are published with a 1-week lag after the time of death.[15] Pneumonia is a common contributing cause of death among COVID-19 patients, and COVID-19 could have been mistaken for influenza in the early days of the pandemic before testing being widely available, so the existing pneumonia and influenza mortality surveillance platform provided the first indication of increased deaths.

In April 2020, NCHS began publishing provisional mortality data on deaths with COVID-19 listed as an underlying or contributing cause, total deaths, and related causes of death (i.e., pneumonia

Causes of Death	Demographic Detail	Time Detail	Geographic Detail
• COVID-19 • Pneumonia and Influenza • Other Selected Causes of Death • External Causes of Death (With 6-Month Lag)	• Sex • Age • Race/Hispanic Origin • Educational Attainment	• Cumulative for Pandemic • Yearly • Monthly • Weekly	• National • HHS Region[a] • Jurisdiction/State[a] • Hospital Referral Region[a] • Health Service Area[a] • County[a]

FIGURE 2— Available Detail for National Vital Statistics System Provisional COVID-19 Death Counts: United States, January 2020–June 2021

[a] Subnational counts under 10 are suppressed.

and influenza) for the United States and by jurisdiction (50 states, District of Columbia, New York City, and Puerto Rico). Death counts, aggregated by the week and month the death occurred, have been released every weekday except on federal holidays. Counts are published along with an estimate of the percentage of expected death records received (i.e., total number of death records received compared with the average number of death records received for the same time period in 2017–2019) to give data users an indication of data completeness. Analyses of COVID-19 death counts suggest that provisional mortality data from the NVSS lag behind other published counts (e.g., Centers for Disease Control and Prevention's [CDC's] COVID Data Tracker), based on aggregated state data, by approximately 2 weeks.

In mid-April 2020, NCHS also began publishing counts of death by demographic and geographic characteristics on a weekly basis. The expanded set of data included death counts by age, sex, race/ethnicity, and place of death by state. Death counts by county and county-specific race/ethnicity data were also released. Over time, additional routine data files were added for COVID-19 death characteristics by weekly and monthly aggregates and for death counts by leading causes of death. In addition, ad-hoc data files were periodically added and updated in response to data requests from government agencies and public health researchers on specific topics such as deaths by single year of age, sickle cell deaths, diabetes deaths, and COVID-19 deaths by educational attainment and race/ethnicity (https://www.cdc.gov/nchs/covid19/covid-19-mortality-data-files.htm). NCHS has continued to expand the breadth of publicly available data sets in response to the ever-present need to understand how COVID-19 affects trends in mortality.

Racial/Ethnic Disparities in COVID-19 Mortality

When health disparities were identified early in the pandemic, there was an urgent need for accurate mortality data on race and ethnicity.[16] Whereas CDC case surveillance data include race/ethnicity for 76% of deaths, more than 99% of NVSS deaths include race/ethnicity. In April and May 2020, the majority of COVID-19 deaths in the United States were occurring in just a few large urban areas, most notably New York City. These areas have a larger percentage of residents who are non-Hispanic Black, non-Hispanic Asian, or Hispanic, and a smaller percentage of residents who are non-Hispanic White. To account for the geographic clustering of COVID-19 deaths, weighted population distributions, which more closely matched the areas initially most affected by COVID-19 deaths, were provided to reflect differential risk within the areas most affected by COVID-19 deaths.[11] As the pandemic became more widespread across the United States, there was less need to align the population distributions with the specific geographic areas experiencing COVID-19 outbreaks and mortality, and the focus of the health disparities data centered on age distributions by race/ethnicity. A Health Disparities dashboard was developed to present data by race/ethnicity and age, with raw counts and percentages and with standardized age distributions.[11] Age-standardized distributions show what disparities would look like, assuming that all of the groups had the same age distribution as the 2000 standard population.

Innovative Statistical Methods

In addition to the need for data to describe the direct impact of COVID-19 through death counts, the pandemic gave urgency to the need for data on the indirect impact of the pandemic on mortality. In response, NCHS began incorporating new statistical methods to provide more context around provisional data beyond COVID-19, through excess deaths analysis and nowcasting techniques to adjust for lags in reporting.

NCHS began publishing data on excess deaths related to COVID-19 in late April 2020 to provide information about the more complete burden of mortality potentially related to the COVID-19 pandemic, including deaths that may be directly or indirectly attributed to COVID-19.[12] Excess deaths are the number of deaths among persons who have died from all causes in excess of the expected number of deaths for a given place and time period. Expected numbers of deaths are estimated on the basis of the number of deaths occurring in the same weeks of previous years (e.g., 2015–2019), accounting for seasonal patterns in the number of deaths. The excess deaths visualization page shows excess deaths for the United States and for states, by age, race/ethnicity, and cause of death. Data from the excess deaths analysis show that the largest percentage increases in deaths from January to October 2020 were seen among adults aged 25 to 44 years and among Hispanic or Latino persons.[17]

As researchers and officials sought to further understand the broader societal impacts of the pandemic, NCHS developed nowcasting methods to predict trends in injury-related causes of death, which lag behind other causes of death in terms of reporting. Death certificate data related to injuries are historically delayed in being reported to NCHS because of the longer time needed to investigate such deaths.[18] Nowcasting methods built upon historical analyses of the timeliness of provisional data for drug overdose and other injury-related causes of death and previous methods to adjust provisional drug overdose death counts for reporting lags.[19,20] Nowcasting results showed sharp increases in drug overdose deaths from February through May 2020.[21] Transportation-related deaths were predicted to decline in March and April, then rise sharply through September 2020. The analysis also showed that suicide deaths, which were widely believed to have increased during the pandemic, did not in fact increase but instead declined in March through May. The nowcasting methodology allowed for the early release of predicted injury-related data, with a shorter lag than previously required. It is important to note that the estimates produced with nowcasting methods are predicated on several assumptions, many of which will need to wait for final data before they can be fully evaluated. However, with further development, future nowcasting analyses look to be a promising method that may be applied to additional outcomes of interest.

Publications With Provisional and Final Data

NCHS staff have produced several reports by using provisional data to provide an early signal about changing trends in mortality. In October 2020, a *Morbidity and Mortality Weekly Report* article described trends in COVID-19 death rates by race/ethnicity.[22] In February 2021, a Vital Statistics Rapid Release program report on provisional life expectancy estimates for January through June 2020 signaled a decrease in life expectancy in the United States and for non-Hispanic Black or African American persons and Hispanic or Latino persons.[23] The authors plan to produce an updated report with life expectancy estimates for the entire year.[24] Early estimates of 2020 deaths were published in a March 2021 *Morbidity and Mortality Weekly Report*, which provided overall and COVID-19 associated death rates by demographic characteristics.[25] The report also provided a ranking of causes of death, showing that COVID-19 was the third-leading cause of death in 2020.

Once the 2020 data are complete (in approximately July 2021), NCHS will begin preparing annual data files with record-level data, statistical reports with official mortality rates and life expectancy calculations, and additional topic-specific analyses. Once finalized, 2020 data will be added to CDC Wide-ranging Online Data for Epidemiologic Research (WONDER), a database that allows users to instantly access NCHS data sets through dynamic queries. Users accessing final death data through WONDER will be able to create customized queries for death data, giving them a greater range of data access than currently possible through the NVSS's COVID-19 surveillance data platform, which is based on provisional data. Final leading cause of death rankings will show how COVID-19 ranks among traditional leading causes of death such as heart disease and cancer. Final life expectancy tables will estimate the long-term effect of the pandemic on years lived, while cause-specific trend data will show whether there were changes in patterns for other causes of death aside from COVID-19. These routine, annual NCHS mortality reports, which will provide official statistics documenting the effect of the pandemic on mortality in the United States, will be supplemented with additional COVID-19–related reports.

Comparing NVSS Data With Other Sources

NVSS death counts do not always match death counts in other surveillance systems because of the way deaths are collected, tabulated, and reported. Figure 3 shows how NVSS death counts, reported by date of death, compare with CDC's COVID Data Tracker[26] death counts, reported by the date the deaths were reported. NVSS surveillance data are tabulated according to the jurisdiction of occurrence and date of death, not by the decedent's state of residence or by the date the death was reported. Some local and state health departments only report laboratory-confirmed COVID-19 deaths on their Web sites. NCHS death counts and death counts reported in other sources may also differ because of how COVID-19 deaths are defined and reported.[26–28] Reporting lags, attributable to the time it takes to complete and submit death records and the time needed for NCHS to process, code, and tabulate data, may also account for differences between NCHS counts and counts from other sources.

Mortality statistics from the NVSS have long been the definitive source of information for identifying and monitoring chronic diseases and other public health issues. In recent years, provisional NVSS data have also been used for surveillance of infectious disease, like influenza,[15] and emerging public health problems, like drug overdose.[14] The COVID-19 pandemic has further increased the utility of provisional data as public health officials and researchers race to understand and measure the impacts of the pandemic. NVSS mortality data offer several advantages over newer surveillance systems developed in response to the pandemic, such as the longevity and stability of the vital statistics system, the completeness of the data, and the level of detailed information (e.g., demographic detail, cause-of-death information). With decades of death data with standardized data elements for all deaths in the United States, NVSS provides complete data on all causes of death, including the underlying and contributing causes of death, along with additional elements including but not limited to age, sex, race/ethnicity, county of residence, educational attainment, and place of death. The collection of death data by using standardized death certificates and the standardized central cause-of-death coding by NCHS allow for reliable comparisons across geographies and over time. Demographic and geographical information about decedents allow researchers to measure and identify health disparities both within the context of COVID-19 and with overall mortality. Trend analysis, using decades of previous NVSS death data, can show the effects of the pandemic in context of patterns over time.

FUTURE OF NATIONAL VITAL STATISTICS SYSTEM MORTALITY DATA

At the start of the COVID-19 pandemic, NCHS rapidly activated and subsequently refined a surveillance system to provide robust, real-time death data to the public. The pandemic was the catalyst for the expansion and improvements to the existing surveillance system, but the foundations for the system were laid over decades of strong partnerships with jurisdictions and the medical examiner and coroner community and steady investments in electronic death registration systems. NCHS continues to expand on this crucial foundation-building work by improving interoperability and further

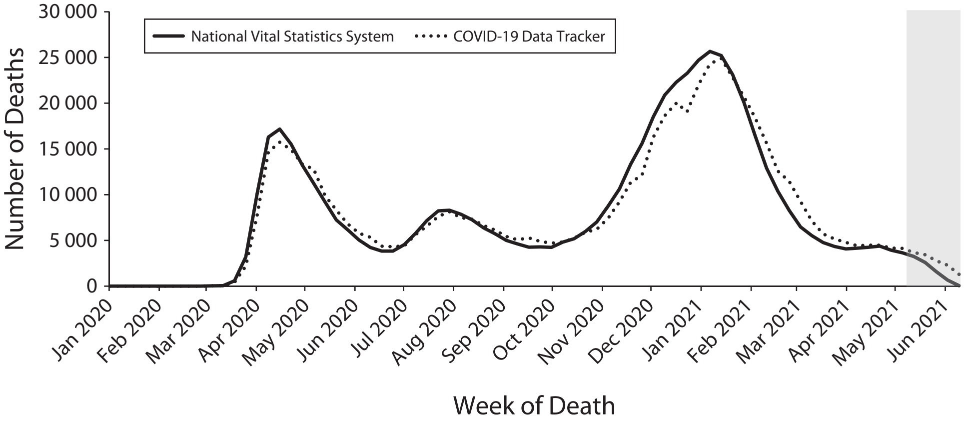

FIGURE 3— Weekly COVID-19 Death Counts as of June 10, 2021: United States

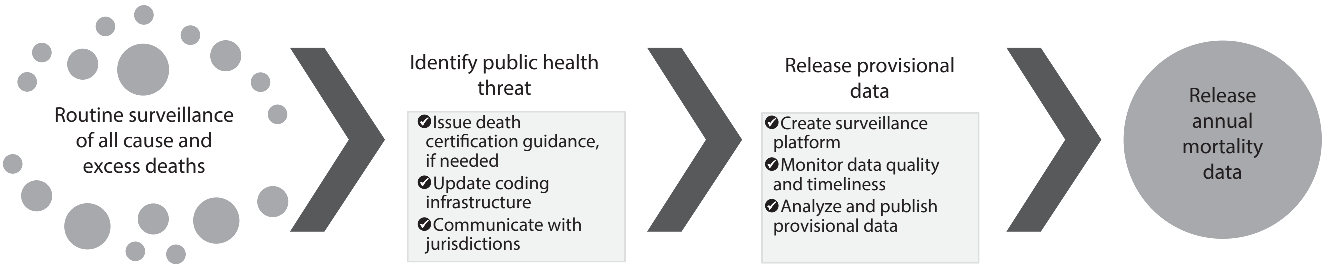

FIGURE 4— National Vital Statistics System Response Framework for Public Health Emergencies

investments into modernizing the NVSS data system. NVSS modernization initiatives focus on modernizing the entire system to create more interoperability between medical examiner and coroner systems and state electronic death registration system platforms, and between the state electronic death registration system platforms and NCHS. An interoperable platform that needs minimal manual intervention can eventually provide even more timely and higher-quality data.

In the past year, NCHS transformed and adapted the NVSS to provide rapid surveillance data in response to a national and global emergency. NCHS now has a framework for the detection and surveillance of emerging public health threats (Figure 4). Routine surveillance of all-cause and excess deaths can help identify concerning shifts in mortality trends. When a public health concern is identified, either through routine surveillance or through the public health community, NCHS can rapidly publish detailed death certification guidance, develop cause-of-death coding instructions for automated and manual coding, and closely monitor incoming records for the relevant deaths. An initial surveillance reporting platform might only include total counts of death, but as the public health crisis evolves, the platform would be adapted to make additional data available. Researchers will be able to leverage decades of final mortality data and real-time provisional mortality data to analyze the effect of emerging public health threats on mortality in the United States. NCHS is committed to improving access to timely and high-quality mortality data through improved interoperability and automation of data infrastructure, innovative analysis, and expanded data releases. AJPH

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Note. The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the CDC.

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NCHS would like to acknowledge the extra efforts of the vital statistics jurisdictions in their continued collaboration with NCHS and provision of data during the pandemic. Deployments to address the pandemic locally or outbreaks affected availability of staff in some jurisdictions. Despite these challenges, many jurisdictions were able to increase frequency of reporting and quickly address the need for additional training and follow up with certifiers. Their commitment to timely data submission made it possible for NCHS to expand existing surveillance efforts and shorten reporting delays to produce relevant and real-time mortality data.

CONFLICTS OF INTEREST

The authors report no conflicts of interest.

HUMAN PARTICIPANT PROTECTION

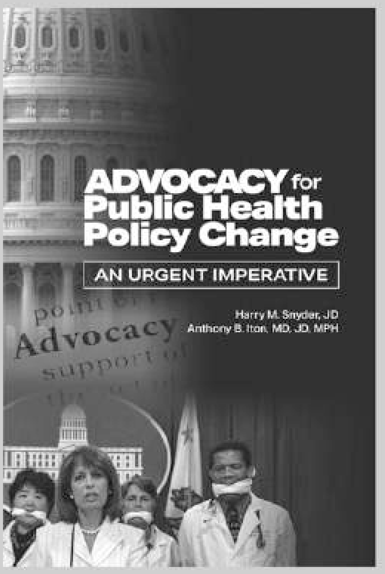
The activities captured in this article are a descriptive narrative of the National Vital Statistics System and do not include any data captured from the system itself. Thus, this body of work does not meet the definition of research as defined by the Revised Common Rule 45 CFR 46 and is therefore not subject to review by an institutional review board. However, the contents have undergone review and approval by the Office of the Associate Director for Science at NCHS.

REFERENCES

1. National Center for Health Statistics, Centers for Disease Control and Prevention. National Vital Statistics System. 2021. Available at: https://www.cdc.gov/nchs/nvss/index.htm. Accessed June 10, 2021.
2. National Center for Health Statistics, Centers for Disease Control and Prevention. Guidance for certifying COVID-19 deaths. March 4, 2020. Available at: https://www.cdc.gov/nchs/data/nvss/coronavirus/Alert-1-Guidance-for-Certifying-COVID-19-Deaths.pdf. Accessed June 10, 2021.
3. National Center for Health Statistics, Centers for Disease Control and Prevention. Guidance for certifying deaths due to COVID–19. April 2020. Available at: https://www.cdc.gov/nchs/data/nvss/vsrg/vsrg03-508.pdf. Accessed June 10, 2021.
4. *International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (ICD–10).* Geneva, Switzerland: World Health Organization; 2009.
5. National Vital Statistics System. Part 2a. Instructions for classifying the underlying cause of death. In: *NCHS Instruction Manual.* 2021.

Available at: https://www.cdc.gov/nchs/nvss/manuals/2a-2021.htm. Accessed June 10, 2021.

6. National Center for Health Statistics, Centers for Disease Control and Prevention. New *ICD* code introduced for COVID-19 deaths. March 24, 2020. Available at: https://www.cdc.gov/nchs/data/nvss/coronavirus/Alert-2-New-ICD-code-introduced-for-COVID-19-deaths.pdf. Accessed June 10, 2021.
7. National Center for Health Statistics, Centers for Disease Control and Prevention. Technical notes. 2021. Available at: https://www.cdc.gov/nchs/nvss/vsrr/covid19/tech_notes.htm. Accessed June 10, 2021.
8. National Center for Health Statistics, Centers for Disease Control and Prevention. COVID-19 death data and resources. 2021. Available at: https://www.cdc.gov/nchs/nvss/covid-19.htm. Accessed June 10, 2021.
9. National Center for Health Statistics, Centers for Disease Control and Prevention. Daily updates of totals by week and state. 2021. Available at: https://www.cdc.gov/nchs/nvss/vsrr/COVID19/index.htm. Accessed June 10, 2021.
10. National Center for Health Statistics, Centers for Disease Control and Prevention. Weekly updates by select demographic and geographic characteristics. 2021. Available at: https://www.cdc.gov/nchs/nvss/vsrr/covid_weekly/index.htm. Accessed June 10, 2021.
11. National Center for Health Statistics, Centers for Disease Control and Prevention. Health disparities: race and Hispanic origin. 2021. Available at: https://www.cdc.gov/nchs/nvss/vsrr/covid19/health_disparities.htm. Accessed June 10, 2021.
12. National Center for Health Statistics, Centers for Disease Control and Prevention. Excess deaths associated with COVID-19. 2021. Available at: https://www.cdc.gov/nchs/nvss/vsrr/covid19/excess_deaths.htm. Accessed June 10, 2021.
13. Ahmad FB, Cisewski JA. Quarterly provisional estimates for selected indicators of mortality, 2018–quarter 2, 2020. National Vital Statistics System, Vital Statistics Rapid Release Program. National Center for Health Statistics. 2021. Available at: https://www.cdc.gov/nchs/nvss/vsrr/mortality.htm. Accessed June 10, 2021.
14. Ahmad FB, Rossen LM, Sutton P. Provisional drug overdose death counts. National Center for Health Statistics. 2021. Available at: https://www.cdc.gov/nchs/nvss/vsrr/drug-overdose-data.htm. Accessed June 10, 2021.
15. Centers for Disease Control and Prevention, National Center for Immunization and Respiratory Diseases. U.S. influenza surveillance system: purpose and methods. 2020. Available at: https://www.cdc.gov/flu/weekly/overview.htm#Mortality. Accessed June 10, 2021.
16. Webb Hooper M, Nápoles AM, Pérez-Stable EJ. COVID-19 and racial/ethnic disparities. *JAMA*. 2020;323(24):2466–2467. https://doi.org/10.1001/jama.2020.8598
17. Rossen LM, Branum AM, Ahmad FB, Sutton P, Anderson RN. Excess deaths associated with COVID-19, by age and race and ethnicity—United States, January 26–October 3, 2020. *MMWR Morb Mortal Wkly Rep*. 2020;69(42):1522–1527. https://doi.org/10.15585/mmwr.mm6942e2
18. Ahmad FB, Dokpesi P, Escobedo L, Rossen L. Timeliness of death certificate data by sex, age, and geography. Vital Statistics Rapid Release; no 9. Hyattsville, MD: National Center for Health Statistics; June 2020.
19. Bastos LS, Economou T, Gomes MFC, et al. A modelling approach for correcting reporting delays in disease surveillance data. *Stat Med*. 2019;38(22):4363–4377. https://doi.org/10.1002/sim.8303
20. Greene SK, McGough SF, Culp GM, et al. Nowcasting for real-time COVID-19 tracking in New York City: an evaluation using reportable disease data from early in the pandemic. *JMIR Public Health Surveill*. 2021;7(1):e25538. https://doi.org/10.2196/25538
21. Rossen LM, Hedegaard H, Warner M, Ahmad FB, Sutton PD. Early provisional estimates of drug overdose, suicide, and transportation-related deaths: nowcasting methods to account for reporting lags. Vital Statistics Rapid Release; no 11. Hyattsville, MD: National Center for Health Statistics; February 2021. https://doi.org/10.15620/cdc:101132
22. Gold JA, Rossen LM, Ahmad FB, et al. Race, ethnicity, and age trends in persons who died from COVID-19—United States, May–August 2020. *MMWR Morb Mortal Wkly Rep*. 2020;69(42):1517–1521. https://doi.org/10.15585/mmwr.mm6942e1
23. Arias E, Tejada-Vera B, Ahmad F. Provisional life expectancy estimates for January through June, 2020. Vital Statistics Rapid Release; no 10. Hyattsville, MD: National Center for Health Statistics; February 2021.
24. Arias E, Tejada-Vera B, Ahmad F, Kochanek KD. Provisional life expectancy estimates for 2020. Vital Statistics Rapid Release; no 15. Hyattsville, MD: National Center for Health Statistics. July 2021. DOI: https://dx.doi.org/10.15620/cdc:107201
25. Ahmad FB, Cisewski JA, Miniño A, Anderson RN. Provisional mortality data—United States, 2020. *MMWR Morb Mortal Wkly Rep*. 2021;70(14):519–522. https://doi.org/10.15585/mmwr.mm7014e1
26. Centers for Disease Control and Prevention. COVID Data Tracker. Trends in number of COVID-19 cases and deaths in the US reported to CDC, by state/territory. Available at: https://covid.cdc.gov/covid-data-tracker. Accessed February 23, 2021.
27. Dong E, Du H, Gardner L. An interactive web-based dashboard to track COVID-19 in real time. *Lancet Infect Dis*. 2020;20(5):533–534. https://doi.org/10.1016/S1473-3099(20)30120-1
28. Wu J, McCann A, Collins K, Harris R, Huang J, Almukhtar S. Coronavirus in the U.S.: latest map and case count. *New York Times*. Available at: https://www.nytimes.com/interactive/2020/us/coronavirus-us-cases.html. Accessed June 10, 2021.



COVID-19 Pandemic Impact on the National Health Care Surveys

Brian W. Ward, PhD, Manisha Sengupta, PhD, Carol J. DeFrances, PhD, and Denys T. Lau, PhD

See also Lau et al., p. 2085.

While underscoring the need for timely, nationally representative data in ambulatory, hospital, and long-term-care settings, the COVID-19 pandemic posed many challenges to traditional methods and mechanisms of data collection.

To continue generating data from health care and long-term-care providers and establishments in the midst of the COVID-19 pandemic, the National Center for Health Statistics had to modify survey operations for several of its provider-based National Health Care Surveys, including quickly adding survey questions that captured the experiences of providing care during the pandemic.

With the aim of providing information that may be useful to other health care data collection systems, this article presents some key challenges that affected data collection activities for these national provider surveys, as well as the measures taken to minimize the disruption in data collection and to optimize the likelihood of disseminating quality data in a timely manner. (*Am J Public Health*. 2021; 111(12):2141–2148. https://doi.org/10.2105/AJPH.2021.306514)

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For almost 50 years, the National Center for Health Statistics (NCHS) has collected, analyzed, and disseminated data on health care utilization in the United States. These data have been used to generate nationally representative statistical information and answer key questions about the US health care and long-term-care systems that are of interest to health care policymakers, public health professionals, and health services researchers. To meet its mission, NCHS conducts the National Health Care Surveys (https://www.cdc.gov/nchs/dhcs/index.htm), a family of surveys covering a wide spectrum of health care delivery settings, from ambulatory and outpatient to hospital and long-term-care providers.

While the number of provider and establishment surveys in the National Health Care Surveys family has varied over past decades, there are 5 ongoing data collections as of 2021:

- National Ambulatory Medical Care Survey (NAMCS): annual survey of office-based physicians and community health centers (CHCs; including federally qualified health centers), which collects practice-level and patient visit data;
- National Electronic Health Records Survey (NEHRS): annual survey of office-based physicians on their use and experiences with electronic health records (EHRs);
- National Hospital Ambulatory Medical Care Survey (NHAMCS): annual survey of hospital emergency departments (EDs), which collects organization-level survey and patient visit data;
- National Hospital Care Survey (NHCS): survey of hospitals providing organization-level and patient visit data from hospitals on inpatient discharge and visits to EDs; and
- National Post-acute and Long-term Care Study (NPALS; formerly the National Study of Long-Term Care Providers): biennial study designed to provide national and state-level data on multiple long-term-care sectors using survey data on adult day services centers (ADSCs) and residential care communities (RCCs), along with administrative data on home health, hospice, long-term-care hospitals, inpatient rehabilitation facilities, and nursing homes.

These 5 provider- and establishment-based surveys cover a broad spectrum of health care settings and have a combination of design features that make them unique. They are used by policymakers, public health professionals, researchers, and provider and consumer organizations to answer important health care questions and inform policy, research, and practice. These surveys can be used to address health care access and utilization, quality of care, patterns of screening and treatment provided for specific conditions, disparities in health care, and diffusion of pharmaceutical therapies and health care technology. In some instances, these surveys are the only national data source of patient visits made to care settings (e.g., physician offices and CHCs) or that collect characteristics of settings (e.g., ADSCs and RCCs). The majority can be used to analyze trends in health care over time. They have been at the forefront of helping monitor new health information technologies; for example, data from NEHRS are used to monitor interoperability of EHR systems[1] and regulatory or administrative burdens associated with these systems (as detailed in the 21st Century Cures Act).[2] The absence of fielding these surveys would result in loss of vital data that serve as critical tools for understanding health care delivery and utilization and their impact on public health in the United States.

These surveys are voluntary, and each shares features designed to allow for nationally representative estimates for health care providers. The 2020 and 2021 data collections of the National Health Care Surveys have been significantly challenged by the COVID-19 pandemic, as health and long-term-care providers and establishments continue to serve the nation and battle the pandemic on the front lines. There exists a delicate balance between minimizing data collection burden to these already-overwhelmed care providers and safely collecting health care data that are critically important for monitoring the pandemic and informing health care policies in a timely manner.

This article details strategies that the NCHS has undertaken to mitigate the potential adverse impacts of interrupting NCHS health care survey data collection from across service delivery systems during the COVID-19 pandemic. These strategies allow the NCHS to carry out each of the National Health Care Surveys and add new COVID-19 questions to increase research capacity, while ensuring safety of survey participants, data quality, and timely public dissemination of health care data and statistical information.

AMBULATORY CARE SETTING

NCHS conducts 2 provider-based surveys that collect data on the ambulatory care setting. Both of these were affected by COVID-19.

National Ambulatory Medical Care Survey

Traditionally, NAMCS is conducted in person by US Bureau of Census field representatives (FRs), who administer a computer-assisted personal interview (referred to as the “induction interview”) with a sampled office-based physician, CHC director, or advanced practice provider, followed by manual abstraction of medical records for patient visits made to that physician or provider during a predetermined calendar week.[3] In-person methods have been historically used for NAMCS (and NHAMCS) because at the time of the survey’s creation in the 1970s, electronic data systems were not widely available, and in-person collection was considered one of the only manners for collecting detailed health care data uniformly from sampled physicians. The 2020 NAMCS office-based physician component was originally scheduled to begin in March 2020 but needed to be delayed to mid-May because of the initial wave of COVID-19 spreading across the United States (Box 1). Furthermore, because of certain geographic areas being affected differently by COVID-19, real-time data[4] were used to determine which US counties had (at the time) a high number or rate of positive cases. In these “hotspot” locations, the start of fielding was delayed an additional 4 weeks.

In addition to the delay in fielding NAMCS, there were other challenges. Many physician offices were initially closed or only conducting telemedicine visits, making in-person, on-site abstraction of patient visit data difficult to conduct. Lengthy data abstraction at the sites of care would also pose significant risk for FRs and survey respondents. As a consequence, the administration of the induction interview with sampled providers had to be changed to computer-assisted telephone interviews (CATI). Field representatives for the NAMCS tried to complete manual abstraction of patient visit data for the first quarter of the 2020 NAMCS data collection, which ended in mid-August 2020. The preliminary rate for abstraction for the first quarter of 2020 data collection was 24% compared with 36% in 2019.

As the toll of COVID-19 increased and safety concerns further escalated, in July 2020, NCHS made the decision to continue induction interviews using only CATI and cease all manual abstraction of patient visit data after the first quarter of data collection. The impact of this decision was that there would be no national estimates nor patient visit data available for 2020. While

BOX 1— Impact of the COVID-19 Pandemic on the National Health Care Surveys: United States, 2021

Timing or Stoppage of Fielding	Changes to Survey Content	Changes to Methods or Modes of Data Collection	Response Rates	Risk and Health Considerations	Changes to Data Dissemination
National Ambulatory Medical Care Survey: Physician Component					
Delayed ∼6 wk, with additional 4-wk delay for areas with high COVID-19 counts or rates; visit abstraction ended after 2020 Q1	+5 COVID-19 interview questions (with subquestions) in second half of 2020 and all of 2021	Physician induction interview conducted primarily over phone as opposed to in person; visit data ended after Q1	Preliminary response rates for 2020 physician induction interview: 40.1% in Q1, 49.9% in Q2, 52.9% in Q3, 54.0% in Q4	In-person data collection moved to CATI for physician induction interview	Estimates from the physician induction interview COVID-19 questions released on the NCHS Dashboard
National Ambulatory Medical Care Survey: Community Health Center (CHC) Component					
No delays; visit abstraction continued for entire 2020 survey	+5 COVID-19 interview questions (with subquestions) in second half of 2020 and all of 2021	CHC facility and provider induction interview conducted primarily over phone as opposed to in person; no change in collection of visit data	Preliminary response rates for 2020 provider induction interview: 74.0% in first half	In-person data collection moved to CATI for CHC facility and provider induction interviews; remote abstraction available for visit abstraction (if needed)	None
National Electronic Health Records Survey					
Fielding delayed from fall and winter 2020 to spring 2021	+7 interview questions on telemedicine in 2020	None	Fielding recently ended; response rate not yet available	No risk or health considerations	None
National Hospital Ambulatory Medical Care Survey					
Fielding delayed ∼1 wk, with additional 4-wk delay for areas with high COVID-19 counts or rates	+4 COVID-19 interview questions (with subquestions) in 2021	None	Preliminary response rates for 2020 hospital induction interview: 63.7% in P1, 63.8% in P2, 68.9% in P3 of 2020; for 2020 ED visit abstraction 50.3% in P1, 76.0% in P2, 72.3% in P3	In-person data collection moved to CATI for hospital induction interview; reliance on remote abstraction for ED visit data	None
National Hospital Care Survey (NHCS)					
Fielding delayed ∼2 mo	+7 COVID-19 interview questions (with subquestions) in 2020 and 2021	None	Not finalized	No risk or health considerations	Selected preliminary estimates from NHCS 2020 UB-04 claims visit-level data released on the NCHS Dashboard
National Post-acute and Long-term Care Study					
Survey component fielding delayed 2 mo from October 2020 to December 2020	+7 COVID-19 questions (with subquestions) to ADCS and RCC questionnaires	None	Not finalized; currently at ∼50% for RCCs and ∼43% for ADSCs	No risk or health considerations	Selected preliminary estimates from the COVID-19 questions released on the NCHS Dashboard

Note. ADSC = adult day services center; CATI = computer-assisted telephone interviewing; ED = emergency department; NCHS = National Center for Health Statistics; P = period; Q = quarter; RCC = residential care communities.

considered, remote abstraction was not deemed feasible because of the technical requirements that needed to be in place at physician offices.

The impact of COVID-19 on the CHC component of the NAMCS differed from the office-based physician component. First, data collection with CHCs was originally scheduled to start in summer 2020; therefore, lessons learned from the NAMCS physician component helped inform the switch to CATI-based induction interviews with CHC directors immediately. Unlike the physician component, as weekly monitoring of the response and abstraction rates occurred in CHCs, NCHS decided that manual abstraction of patient visits to sampled CHC providers would continue on site throughout 2020. This decision was made while coordinating with the US Census Bureau to ensure both intra-agency and federal, state, and local safety measures were being followed to protect both FRs and participants. While preliminary response and abstraction rates were lower than in previous years (i.e., 74% for the first half of 2020 vs 84% for 2019), the rates remained at levels that would generate reliable national estimates, unlike what was seen during the first quarter of visit data collection among physicians.

The practice-level induction interview portion of NAMCS offered a unique opportunity to collect provider-reported data on their clinical experiences during that time. As a consequence, 5 new survey questions about experiences with COVID-19 were added to both the office-based physician and CHC components (Appendix A and Appendix B, respectively, available as supplements to the online version of this article at http://www.ajph.org). These questions asked providers about the following issues:

- shortages of personal protective equipment;
- their ability to test patients for COVID-19 or refer them to a testing site;
- how often patients who tested positive for COVID-19 were turned away from the office or CHC;
- whether any physicians, providers, or their staff tested positive for COVID-19; and
- use of telemedicine.

Because of the timing of the creation and approval of these new COVID-19 questions, the items were included in all 2020 NAMCS induction interviews for CHCs but were only fielded in the second half of the 2020 NAMCS office-based physician induction interviews. Furthermore, these questions were scheduled for the entire 2021 NAMCS data collection. To provide more timely data about experiences and impact of COVID-19 on physicians, preliminary results from the new COVID-19 questions were published on the NCHS COVID-19 Data Dashboard[5] before the release of the final 2020 NAMCS data file.

National Electronic Health Records Survey

NEHRS is conducted through a joint partnership between NCHS and the Office of the National Coordinator for Health Information Technology.[6] NEHRS is a nationally representative, office-based physician survey about EHR adoption and capabilities, burden associated with EHRs, and progress physicians have made toward meeting the policy goals of the Health Information Technology for Economic and Clinical Health Act. Similar to NAMCS, NEHRS was recognized as a potential data source to collect information about physicians' clinical experience during COVID-19. New NEHRS questions (Appendix C, available as a supplement to the online version of this article at http://www.ajph.org) were developed to ask about the use of telemedicine in physician offices during 2020 because of the expected increase in telehealth visits[7] and recognition that more services would be made available through telehealth.[8]

The fielding of 2020 NEHRS was scheduled to occur during fall and winter 2020; however, the start of its fielding was ultimately delayed until March 2021. The reason for this delay was 2-fold: to allow time to revise the survey instrument to include new questions on telemedicine and to ensure that the fielding period avoided November and December, when NEHRS has traditionally yielded lower response rates. Because NEHRS is conducted using a combination of self-administered Web and postal mail responses, there are no safety concerns associated with the administration of this survey. Once NEHRS began, the response rates were monitored on a weekly basis to determine if any adjustments to the fielding schedule or survey operations may be needed.

HOSPITAL-BASED CARE SETTINGS

NCHS conducts 2 surveys that collect data from the hospital-based care setting, both of which were affected by COVID-19.

National Hospital Ambulatory Medical Care Survey

NCHS conducts 2 separate national surveys of hospital-based care settings. The first is NHAMCS, which collects data on the utilization and provision of ambulatory care services in sampled hospital EDs throughout the United States via in-person manual abstraction of ED visits by US Bureau of the Census FRs.[3] Fielding of the 2020 NHAMCS was delayed by 1 week until the end of May 2020, close to when NAMCS fielding also began. Similar to NAMCS, NHAMCS fielding was delayed for sampled hospitals located in counties with a high number or rate of positive COVID-19 cases; in these “hotspot” locations, NHAMCS fielding was delayed further by about 4 weeks until June.

Like other National Health Care Surveys, NHAMCS’s traditional approach to conduct in-person induction interviews and manual data abstraction of ED patient visits was not possible because of COVID-19 hospital safety protocols that prohibited FRs from entering the facilities. Therefore, FRs used CATI to administer the NHAMCS induction interview by phone. In addition, NCHS had to change the abstraction of medical records for ED visits from on-site conducted by FRs to various manners of remote abstraction (depending upon the individual infrastructure at each participating hospital), which ranged from hospitals mailing encrypted CDs to US Census regional offices, to submitting records electronically through their secure online portals, and even to having their own staff perform abstraction while being guided over the phone by a FR. Each of these individual methods was vetted by NCHS to ensure strict data security protocols were followed. While limited remote abstraction methods had been established in previous years, the COVID-19 pandemic pushed their expansion. Because remote abstraction methods circumvented COVID-19 restrictions and the sampled hospitals were being extra-accommodating, ED patient visit data for NHAMCS were collected throughout the entire 2020 calendar year. Weekly monitoring of progress showed that while the preliminary response and abstraction rates were lower than in previous years, they continued to remain above 50% and would ultimately generate 2020 national estimates when NHAMCS data collection was completed in May 2021.

Finally, new COVID-19 questions about hospital ED experiences providing care during the COVID-19 pandemic were developed and added to the NHAMCS induction interview with the sampled hospitals (Appendix D, available as a supplement to the online version of this article at http://www.ajph.org). These questions ask about

- shortages of COVID-19 testing,
- creation of COVID-19 testing areas outside the ED,
- ability to test patients for COVID-19, and
- whether any hospital clinical staff tested positive for COVID-19.

To allow for uninterrupted continuation of 2020 NHAMCS data collection, NCHS decided not to include these COVID-19 questions until the 2021 NHAMCS data collection, which was scheduled to start in spring 2021.

National Hospital Care Survey

The other hospital-based care survey is the NHCS, which leverages electronic health data (primarily EHRs and UB-04 administrative claims) to collect data on patient care in hospital-based inpatient settings and EDs to describe patterns of health care delivery and utilization in the United States.[9] As with NAMCS and NHAMCS, NHCS collects 2 levels of data: facility and patient visit. But unlike the other 2 surveys, NHCS patient visit data are extracted electronically from health records without needing any in-person manual abstraction. This extraction method remained unchanged during the pandemic because the automated data collection method presented no safety concerns to data collection agents or hospital responders. However, there still was concern regarding increased burden to the sampled hospital participants. The additional care requirements related to COVID-19 have disproportionately increased hospital burden of the provision of care throughout the United States,[10] yet all hospitals are experiencing a strain on their resources and being asked to participate in more data collection and surveillance systems at the federal level than ever before. In recognition of these additional burdens, fielding of the NHCS was delayed by approximately 2 months uniformly across all US regions.

In addition to patient-level data collection, NHCS includes an annual hospital Web-based interview to collect self-reported, hospital-level data about hospital utilization (e.g., number of staffed beds and average length of stay), general information (e.g., primary service type, mergers), and data reporting (e.g., annual visit counts). For the 2020 NHCS hospital interview, new COVID-19 questions were created and added to ask about the sampled hospital’s clinical experiences during the pandemic (Appendix E, available as a supplement to the online version of this article at http://www.ajph.org). These questions cover the following issues related to COVID-19:

- shortages of testing,

- creation of testing areas outside the hospital,
- need to turn patients away to other facilities,
- whether any hospital clinical staff tested positive, and
- the number of COVID-19 patients treated during the 2020 calendar year.

Data from the hospital interview have in the past been used primarily for developing weights for the NHCS patient visit data; however, because of the addition of new COVID-19 questions, NCHS is exploring plans to release some of these data to the NCHS Research Data Center (https://www.cdc.gov/rdc/index.htm) for researchers to access.

Given the pressing need for more timely hospital-based data, NCHS began dissemination of rapid, more "real-time" NHCS preliminary patient visit data from inpatient and ED claims for about 50 sampled hospitals. Preliminary unweighted data are released via the NCHS COVID-19 Data Dashboard (https://www.cdc.gov/nchs/covid19/nhcs.htm) and provide estimates on COVID-19 hospital encounters by week, COVID-19 screenings, intubation or ventilator use, mortality, and other related estimates. These preliminary data will serve as another data resource to help inform the monitoring of the COVID-19 pandemic and its impact on hospital utilization.

POSTACUTE AND LONG-TERM-CARE SETTINGS

NPALS is NCHS' initiative to estimate the supply and use of paid, regulated postacute and long-term-care services providers and their policy-relevant characteristics and practices.[11] Administrative data from the Centers for Medicare and Medicaid Services are acquired for home health, nursing home, hospice, inpatient rehabilitation, and long-term-care hospital sectors. Multimode surveys (i.e., Web and mail questionnaires followed by CATI for nonresponse follow-up) are used to collect information from ADSCs and RCCs. Given the disproportionate toll the COVID-19 pandemic has taken on long-term-care sectors including ADSCs and RCCs, operational adjustments in NPALS timing and protocol became essential for the 2020 wave of the survey component.

When COVID-19 started affecting long-term-care providers, questionnaire items were already finalized and ready for the approval process. However, as NPALS is the only federal study that collects national and state-level data on ADSCs and RCCs, new questions were quickly added that ask for

- the number of COVID-19 cases, hospitalizations, and deaths among ADSC and RCC services users and staff;
- availability of personal protective equipment and testing kits;
- changes in visitation procedures;
- use of telemedicine; and
- general infection-control policies and practices.

These new questions to the ADSC and RCC questionnaires[12,13] (Appendix F and Appendix G, respectively, available as supplements to the online version of this article at http://www.ajph.org) will allow analysis of challenges faced in long-term-care settings during the pandemic. The process of adding new questions and restructuring tasks (e.g., onboarding and training of field staff) to be conducted virtually shifted the original schedule by 2 months, which necessitated that data collection begin in December 2020. To reduce burden on respondents, telephone calls to verify contact information for target respondents (i.e., the director, administrator, owner, operator) were eliminated.

Over the past several years, response rates for NPALS (as with other health surveys) have declined, and it is expected that response rates may be further affected by the COVID-19 pandemic. As such, existing questions were removed to prioritize COVID-19 questions without increasing the length of NPALS survey instruments. The COVID-19 crisis resulted in several ADSCs closing temporarily and others providing services through alternative methods. To address these scenarios, prospective respondents were advised to complete the survey to the best of their ability, even with services at a center being temporarily or permanently suspended, reduced, or offered through alternative methods, and potentially fewer people receiving services on a regular basis. It is premature to assess response rates, but indications are that the number of ADSCs and RCCs out of business may be higher in 2020 than in earlier years. For instance, a total of 157 ADSCs and 127 RCCs reported as out of business at the end of the 2016 NPALS, whereas, for the 2020 wave, 236 ADSCs and 120 RCCs reported being out of business by the last month of data collection.

For the 2020 wave of the NPALS survey component, before processing of the final data, preliminary data were released on the NCHS COVID-19 Data Dashboard so more timely estimates of the COVID-19 variables could be made available. It is expected that a more stringent evaluation process will be needed to assess final data quality for 2020 relative to earlier NPALS waves, such as examining whether US state differences in response reflect the incidence and impact of COVID-19. On the administrative data side, it is expected that some data may not be "complete" as some surveys of nursing homes have been placed on hold, and requirements to submit assessments during the COVID-19 pandemic may have been waived.

SUMMARY

The COVID-19 pandemic has brought to the forefront the need for reliable, quality, and timely data to monitor the epidemiology of this disease and to inform both national and state policies and guidelines. Nationally representative health care data are particularly valuable as they provide an understanding of health care access and utilization throughout the United States. Collectively, the National Health Care Surveys have been modified and adapted quickly to provide these critical data and help our understanding of care provided in ambulatory, hospital, postacute, and long-term-care settings, as well as other concerns that COVID-19 has brought to light. For example, it has been made clear that social determinants of health (e.g., poverty, physical environment) have a substantial effect on COVID-19 outcomes.[14–16] The National Health Care Surveys result in data that can be used to study these differences: in addition to general care provided for COVID-19, there are patient and services user characteristics and social determinants of health data collected in NAMCS, NHAMCS, NHCS, and NPALS that will allow for study of these inequalities.

When one is using data from these surveys to study health care provided during the COVID-19 pandemic, it is important to understand how the pandemic itself affected data collection. As detailed previously, NCHS needed to adapt traditional data collection strategies for all 5 National Health Care Surveys. All surveys experienced some delays in fielding and a movement to or reliance on remote modes of data collection such as CATI. As such, somewhat lower response rates were expected compared with previous years of data collection. The most notable adjustment made was specific to NAMCS, in that data collection of patient visits in the office-based physician component ended after the first quarter of fielding. As such, there will not be a visit data file available for this component.

Other adjustments NCHS made to the surveys are poised to create a capacity for new research. In each of the surveys, questions were added that will capture the experiences of providing health care during the pandemic. To our knowledge, these questions are not available on other national data sets. They will ultimately be made available to researchers to perform their own data analyses. Furthermore, releases of data from NAMCS, NHCS, and NPALS via the NCHS COVID-19 Data Dashboard marks the first time preliminary estimates were made available from the National Health Care Surveys. While finalized data sets will also be made public or placed in the NCHS Research Data Center, through these preliminary estimates, NCHS is able to provide information to policy- and decision-makers in a timelier manner. Furthermore, it has also created a mechanism that NCHS plans to use in future years—not just for COVID-19, but for other health care topics as well.

While most of these adjustments were to ensure that data collection continued during COVID-19, NCHS expects some to continue on an ongoing basis. The option of using CATI to collect interview data for NAMCS and NHAMCS will continue in the future, in addition to using traditional in-person survey interviews. The use of remote abstraction will continue for NHAMCS as well, allowing hospitals to participate with more flexibility. Finally, while the NCHS COVID-19 Data Dashboard has provided a platform for NAMCS, NHCS, and NPALS to release preliminary estimates for the first time, the exploration of additional mechanisms for releasing preliminary estimates on opioid misuse and abuse, chronic conditions, and other health care topics is also being pursued.

Our experiences conducting the National Health Care Surveys during the COVID-19 pandemic provide several lessons that are important to consider, not only for these surveys but also for other researchers who may themselves be collecting data during the current or future pandemics. The first lesson is to be prepared for potential disruptions and have a willingness to adapt. Each of the National Health Care Surveys, in some way, had their data collections disrupted. However, NCHS adjusted, whether it was to delay or stagger the timing of data collection, to use new modes of survey administration, or even pull certain components of surveys from the field. Ensuring your surveys and data collection systems can make needed adjustments will allow data collection to continue during these challenging times when this collection may be needed more than ever.

Second, topical survey questions or data elements relevant to the study's population of interest should be included where possible, to collect data on COVID-19 or whatever future crises may arise. This will increase research capacity when one is using the resulting data and ultimately lead to new information that can inform policy and guidelines.

The third lesson is that novel data dissemination methods are also needed. While data collection is critical, disseminating the information to key stakeholders and the public in a timely manner is also important as it allows for informed decisions to be made more rapidly. Finally, the lessons learned from conducting the National Health Care Surveys during the COVID-19 pandemic are not just applicable to NCHS's current health care data collections but also for future years. Applying the lessons learned from COVID-19 will be important to ensure that NCHS's National Health Care Surveys are sustainable in the future and continue to be a source of reliable and quality data during any future pandemics. Using these lessons learned will allow researchers not only to continue to collect the data needed for monitoring health care during the COVID-19 pandemic but also to be prepared to better meet the data needs for any future pandemics.

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The authors report no conflicts of interest.

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REFERENCES

1. Office of the National Coordinator for Health Information Technology. Connecting health and care for a nation: a shared nationwide interoperability roadmap. Final version 1.0. Available at: https://www.healthit.gov/sites/default/files/hie-interoperability/nationwide-interoperability-roadmap-final-version-1.0.pdf. Accessed July 6, 2021.
2. 21st Century Cures Act, Pub L No. 114-125 (December 13, 2016).
3. National Center for Health Statistics. About the ambulatory health care surveys: National Ambulatory Medical Care Survey. Available at: https://www.cdc.gov/nchs/ahcd/about_ahcd.htm. Accessed January 25, 2021.
4. John Hopkins University. Coronavirus Resource Center. Available at: https://coronavirus.jhu.edu. Accessed April 22, 2020.
5. National Center for Health Statistics. COVID-19 data from the National Center for Health Statistics. Available at: https://www.cdc.gov/nchs/covid19/index.htm. Accessed January 24, 2021.
6. National Center for Health Statistics. National Electronic Health Records Survey. Available at: https://www.cdc.gov/nchs/nehrs/about.htm. Accessed January 24, 2021.
7. Koonin LM, Hoots B, Tsang CA, et al. Trends in the use of telehealth during the emergence of the COVID-19 pandemic—United States, January–March 2020. *MMWR Morb Mortal Wkly Rep*. 2020;69(43):1595–1599. https://doi.org/10.15585/mmwr.mm6943a3
8. Department of Health and Human Services. Centers for Medicare & Medicaid. CY 2021 Medicare Physician Fee Schedule Final Rule (FR Doc. 2020–26815). *Fed Regist.* 2020;85(248): 84472–85377.
9. National Center for Health Statistics. National Hospital Care Survey. Available at: https://www.cdc.gov/nchs/nhcs/index.htm. Accessed January 24, 2021.
10. Miller IF, Becker AD, Grenfell BT, Metcalf CJE. Disease and healthcare burden of COVID-19 in the United States. *Nat Med.* 2020;26(8):1212–1217. https://doi.org/10.1038/s41591-020-0952-y
11. National Center for Health Statistics. National Post-acute and Long-term Care Study: about NPALS. Available at: https://www.cdc.gov/nchs/npals/about_npals.htm. Accessed January 27, 2021.
12. National Center for Health Statistics. National Post-acute and Long-term Care Study: 2020 Adult Day Services Center questionnaire. Available at: https://www.cdc.gov/nchs/npals/2020-NPALS-ADSC-Questionnaire-Center.pdf. Accessed February 5, 2021.
13. National Center for Health Statistics. National Post-acute and Long-term Care Study: 2020 Residential Care Community questionnaire. Available at: https://www.cdc.gov/nchs/npals/2020-NPALS-RCC-Questionnaire-Community.pdf. Accessed February 5, 2021.
14. Wojcik O, Miller CE, Plough AL. Aligning health and social systems to promote population health, well-being, and equity. *Am J Public Health.* 2020;110(suppl 2):S176–S177. https://doi.org/10.2105/AJPH.2020.305831
15. Abrams EM, Szefler SJ. COVID-19 and the impact of social determinants of health. *Lancet Respir Med.* 2020;8(7):659–661. https://doi.org/10.1016/S2213-2600(20)30234-4
16. Khazanchi R, Beiter ER, Gondi S, et al. County-level association of social vulnerability with COVID-19 cases and deaths in the USA. *J Gen Intern Med.* 2020;35(9):2784–2787. https://doi.org/10.1007/s11606-020-05882-3

The National Health and Nutrition Examination Survey (NHANES), 2021–2022: Adapting Data Collection in a COVID-19 Environment

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See also Lau et al., p. 2085.

The National Health and Nutrition Examination Survey (NHANES) is a unique source of national data on the health and nutritional status of the US population, collecting data through interviews, standard exams, and biospecimen collection.

Because of the COVID-19 pandemic, NHANES data collection was suspended, with more than a year gap in data collection. NHANES resumed operations in 2021 with the NHANES 2021–2022 survey, which will monitor the health and nutritional status of the nation while adding to the knowledge of COVID-19 in the US population.

This article describes the reshaping of the NHANES program and, specifically, the planning of NHANES 2021–2022 for data collection during the COVID-19 pandemic. Details are provided on how NHANES transformed its participant recruitment and data collection plans at home and at the mobile examination center to safely collect data in a COVID-19 environment. The potential implications for data users are also discussed. (*Am J Public Health*. 2021;111(12):2149–2156. https://doi.org/10.2105/AJPH.2021.306517)

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The National Health and Nutrition Examination Survey (NHANES), conducted by the Centers for Disease Control and Prevention's (CDC's) National Center for Health Statistics (NCHS), has been monitoring the nation's nutrition and health for more than 5 decades. It collects data that can best or only be obtained by direct physical examination, clinical and laboratory tests, personal interviews, and related measurement procedures. The examinations are conducted in mobile examination centers (MECs) that travel to various locations throughout the country, providing a standardized environment for the health examinations. The information collected also includes data that cannot easily be reported by sample persons themselves or by their health care providers. NHANES data are used to estimate the prevalence of diagnosed and undiagnosed disease, including acute and chronic conditions, nutritional intake and status, chemical exposures, and much more.[1]

Since 1999, NHANES has been collecting data every year without disruption. However, in early 2020 with the emergence of SARS-CoV-2 (the virus that causes COVID-19), there was much uncertainty about virus transmission, infection, morbidity and mortality, and mitigation and prevention measures. Its impact on NHANES overall, and specifically on staff and participants, was unknown. NHANES is a complex data collection operation.[2] Field staff travel full-time to survey locations throughout the country, where COVID-19 exposure risk varied widely. Also, survey respondents, amid general public health warnings and guidance, were expected to be increasingly reluctant to open their doors for interviews or come to an MEC for fear of COVID-19 exposure. As a result, in March 2020, NHANES data collection efforts were stopped because of safety-related concerns.

As of June 2021, NHANES data collection had been suspended for 15 months. This disruption has led to a gap in the availability of recent NHANES data to inform public health research, programs, and policies. During this time, extensive efforts were made by NCHS staff to evaluate the data collected on an incomplete 2019–2020 survey sample, examine nonresponse bias, adjust sample weights, and create a combined 2017–March 2020 prepandemic analytic data set for researchers. The first set of data files were publicly released in May 2021, along with an Analytic Guidance and Brief Overview report that describes the creation of the data file and provides guidance for its analytic use.[3] A subsequent report further details the 2017–March 2020 prepandemic data file and provides key health estimates.[4]

Significant efforts were also made to return to data collection in 2021, considering prevalent COVID risk assessment. Assessing the level of risk remains complicated given the varying levels of risk across states, counties, and communities in the United States. Multiple vaccines also became authorized for use, beginning with the end of 2020.[5] However, conditions throughout the country still vary in terms of risk, incident case numbers, and morbidity and mortality rates. Given that the course of the pandemic in 2021 is unknown and the infection rates are anticipated not to be zero, several changes to the survey were necessary. The principles that guided these changes included the following:

1. ensure safety of survey participants and field staff,
2. reduce contact time with participants in the home and the MEC,
3. reduce respondent burden to maximize response rates,
4. maintain essential data collection to continue to monitor the nation's health, and
5. add COVID-19 content to further the understanding of the epidemiology of the disease based on a national sample.

This article describes the reshaping of the NHANES program and, specifically, the planning of NHANES 2021–2022 for data collection during the COVID-19 pandemic. The implications for data users are also discussed.

CHANGES TO THE SAMPLE DESIGN

Starting in 2023, NHANES is expected to undergo a substantial survey redesign.[6] Therefore, NHANES 2021–2022 will be the last cycle of a continuous survey that began in 1999 collecting data annually and publicly releasing data every 2 years. Over its history, NHANES has oversampled certain subgroups to ensure adequate sample sizes to obtain precise estimates for these groups. However, a 2-year sample has limited analytic utility to provide estimates for subgroups with lower percentage population distribution (e.g., non-Hispanic Asian persons). Often, a 2-year sample needs to be combined with adjacent 2-year samples to increase sample sizes to create a single estimate from the combined data set.[7] However, it may not be appropriate to combine the 2021–2022 data with the 2017–March 2020 data files, given that the 2017–2020 data were collected before the COVID-19 pandemic and there will be more than a 1-year gap between data collections.[3] NHANES 2023 will also be a new, redesigned survey. Therefore, NHANES 2021–2022 will, in effect, be a 2-year stand-alone survey. However, this does not preclude comparison of estimates from 2021 to 2022 with estimates from earlier survey cycles, depending on the research question and data available.

Operating in a COVID-19 environment also required the oversampling strategies to be reexamined. One consideration is the number of dwelling unit (DU) contacts required to complete eligibility screening. Oversampling increases this number, as the likelihood that any DU includes an eligible person decreases with oversampling and more DUs must be screened. Reducing the number of contacts is an important safety measure.

Given these factors, for NHANES 2021–2022, it was decided that the selection probability will only depend on age, regardless of gender, race, Hispanic origin, and household income level. The new 2021–2022 sampling strategy will decrease the number of households screened (from ∼13 000 to ∼7000), leading to fewer in-person encounters for field staff. Specifically, in a sampled DU, all children aged 19 years and younger and all persons aged 60 years and older will be eligible to participate. For persons aged 20 to 59 years, 1 or 2 persons will be eligible, depending on the total number of persons in the household aged 20 to 59 years. The reduction in the number of households screened does not change the targeted total examined sample of ∼10 000 persons across the 30 primary sampling units (PSUs).

With no oversampling by race/ethnicity and income, there will be fewer sampling domains compared with earlier designs.[8] This will result in national estimates with increased precision, smaller expected variances, and lower design effects than estimates from the previous design. This will also provide effective sample sizes necessary for key NHANES health outcomes that can be estimated with a 2-year sample. Further detail on assessing precision and statistical reliability of an estimate have been published elsewhere.[7]

As mentioned previously, the target number of examined persons will remain 10 000 across the 2-year period. The sample will be obtained from 30 PSUs that were selected out of over 3000 US counties. The first 15 PSUs and the later 15 PSUs will each be nationally representative. Table 1 provides a comparison of selected sample design parameters from the 2021–2022 and 2015–2018 survey samples.

As of June 2021, the dress rehearsal for the 2021–2022 survey has begun. Data collection at the first true PSU is targeted to begin soon afterward. To complete data collection in all 30 PSUs, the survey operations for this cycle will extend into 2023. Given the uncertainties of the COVID-19 pandemic, it is possible that start dates for specific PSUs may need to be shifted. If there are substantial delays with several PSUs due to such prevailing situations, NHANES may shift focus to complete only the first 15 PSUs in 2021–2022 to obtain 1 year of data collection targeting at least 5000 examined persons.

DATA COLLECTION

Prior to starting data collection in any NHANES location, to ensure the safety of all field staff and participants, COVID risk levels are closely monitored and field staff, who will be following all CDC recommendations, are encouraged to obtain available COVID-19 vaccines. Various data sets are used to compute metrics and risk-level measures similar to those developed by the Harvard Global Health Institute in their COVID Risk Level map and COVID suppression guidance.[9] In particular, NHANES uses the average of new daily cases of COVID-19 per 100 000 people over the last 7 days to classify counties in green (< 1 case), yellow (1–9 cases), orange (10–24 cases), and red (> 24 cases) risk levels. In-person data collection will only occur after assessment of a county's risk level and vaccination rates, field staff vaccination rates, and the latest CDC guidance. Given that this is an evolving pandemic with new guidance emerging periodically, we do not include here the specific terms for decision-making.

Identifying Eligible Persons

Historically, NHANES household interviewers attempt to make in-person contact at all selected DUs within each survey location. In the current COVID-19 pandemic environment, this face-to-face contact creates a potential risk of exposure for both the household interviewer and the household member. These risks are further amplified for DUs that are not single-family homes or do not have exterior-facing entrances (condominiums, apartments, dormitories, etc.).

For NHANES 2021–2022, eligibility screening will be carried out using a multimode approach. Sampled DUs will be mailed an invitation letter asking them to complete a short survey online

TABLE 1— Selected Sample Design Parameters: United States, National Health and Nutrition Examination Survey, 2015–2018 and 2021–2022

Characteristic	2015–2018[8]	2021–2022
Age of noninstitutionalized civilian target population	All ages	All ages
Geographic area	United States[a]	United States[a]
Sample design	4-y, stratified, clustered 4-stage samples	2-y, stratified, clustered 4-stage samples
Number of study locations	60	30
Domains for oversampling	Predesignated: 87 domains of gender–age groups for non-Hispanic Black persons; non-Hispanic, non-Black Asian persons; and Hispanic persons, and income–gender–age groups for other persons	Predesignated: 3 domains of age groups (0-19, 20-59, ≥ 60 y)
	Oversampled: Hispanic persons; non-Hispanic Black persons; non-Hispanic, non-Black Asian persons; low-income White and other persons (at or below 185% of federal poverty level); children aged 0–11 y; and adults aged ≥ 80 y	Oversampled: younger (0–19 y) and older (≥ 60 y) age groups
Number of examined persons	18 248	10 000 (targeted)

[a] Includes 50 states and the District of Columbia. US territories are not included in the National Health and Nutrition Examination Survey sample.

or via a toll-free number. Nonrespondents will receive a series of follow-up reminders, including a postcard, a paper copy of the eligibility screener, and a final reminder letter. Households that choose not to self-respond will receive an in-person visit by a household interviewer.

Household interviewers will contact all identified eligible household members to further explain the survey, gain their cooperation, and schedule personal interviews. Contact approaches will vary by the information provided by each household in their screener questionnaire (e.g., telephone number).

Changes to Household Interviewing

For eligible persons, NHANES conducts personal interviews followed by physical examinations and laboratory testing. Since 1999, the household interview has been conducted by trained interviewers in the participant's home using a computer-assisted personal interview system where demographic, socioeconomic, dietary, and health-related information has been collected.[10] For NHANES 2021–2022, those eligible and agreeing to participate will schedule a telephone appointment to complete the home interview. However, it may be conducted in the home if preferred, and all current CDC safety guidelines are followed.

Participation in the NHANES survey is voluntary, and prior to the start of the household interview, participants (sample persons, or SPs) are asked to provide verbal consent to participate. They are also sent, via postal mail or delivery by hand, a packet of materials that include a paper copy of the consent brochure, which will be reviewed with the household interviewer as part of scheduling the MEC appointment.

As in previous years, the interview will consist of the SP Questionnaire, which collects individual health-related data, and the Family Questionnaire, used to collect information at the household level (e.g., total family combined income and housing characteristics).[11] However, to decrease respondent burden on the phone and to increase interview completion, significant reductions to both the SP and Family Questionnaires were made to reduce the total phone interview time to under 60 minutes. Decisions on specific questions were made only after decisions were made on exam content to align all content. The SP Questionnaire was cut by over 50% and the Family Questionnaire by about a quarter. Based on 2019–2020 completion times for in-person interviewing, the expected median times for the 2021–2022 SP Questionnaire will range from between 10 and 25 minutes, depending on a person's age, and median administration time for the Family Questionnaire will be approximately 10 minutes. However, it is expected that the phone interviewing will add additional time to the estimated times, given the need for more explanations in lieu of using hands cards that were shown to participants with the additional information.

Given the change in mode of administration as well as the uncertainties of collecting data in a COVID-19 environment, it is not clear what level of response may be expected in 2021–2022. To increase participation in the SP interview, NHANES has introduced a $25 participant incentive. Historically, incentives have only been provided for MEC participation. However, the overall incentive totals have not been modified (ranging from $130 to $175 based on participant's age plus additional transportation and other allowance, if applicable). For the 2021–2022 survey, the timing of receipt of incentives has been shifted to better align with participant burden.

In addition to dropping some SP and Family questions, certain in-home data collections will be discontinued since the interview will now be conducted via phone. These include home water sample collection to test for fluoride, home dietary salt collection to test for iodine, and infant formula ingredients collection. In addition, information on dietary supplement use during the past 30 days, which was traditionally collected at the home interview, will be collected after the Day 1, 24-hour dietary recall over the telephone. Table 2 provides a summary of the changes to the household interviewing component.

Because of the COVID-19 pandemic and the anticipated survey redesign for 2023 onward, no new content was solicitated for the 2021–2022 survey cycle. Survey content in 2021–2022 is significantly condensed and modified to adapt to the pandemic–postpandemic environment. Stakeholders and collaborating agencies were consulted in the planning activities of the 2021–2022 survey content. Public solicitation on new content is planned to be resumed for NHANES 2023 and beyond.

Health Examinations at the Mobile Examination Center

To return NHANES to data collection in a COVID-19 environment, critical decisions had to be made about what exam content could be conducted in 2021–2022. These decisions were first guided by the safety of staff and participants, and whether any change could

TABLE 2— National Health and Nutrition Examination Survey 2021–2022 Household Interview Content: United States

Modified	Added	Cycled Out
All Sample Person questions conducted via phone or in-person	COVID-19	Over 50% of Sample Person questions
All Family questions conducted via phone or in-person		∼23% of Family questions
Dietary supplement use (past 30 days) moved to post exam interview with Day 1 24-h dietary phone interview		Home dietary salt collection to test for iodine
		Home water sample collection to test for fluoride
		Human papillomavirus (HPV) oral rinse
		Infant formula ingredients collection

Note. Refer to NHANES Web site for 2019–2020 Sample Person and Family Questionnaire Instruments.[11]

reduce the amount of time a participant and health examiner would spend in close contact in the MEC. Another consideration was which measures could be collected during a 2-year survey, to yield statistically reliable estimates overall and for certain subgroups. Additional attention was given to whether data on certain topics (e.g., hearing, oral health) that were collected in previous cycles were needed in the 2021–2022 data collection and whether a potential gap in available data was acceptable, or if continued data collection in 2021–2022 on those variables was truly necessary from a public health perspective. However, data that contribute to key national health outcomes that only come from NHANES examination data (e.g., anthropometry for obesity, blood pressure for undiagnosed hypertension, fasting plasma glucose for undiagnosed diabetes) would continue to be collected. Lastly, data collected on new content during 2019–2020 were also considered for dropping, since they no longer could be combined across the 4-year period from 2019 to 2022. Table 3 provides the specific MEC content for the 2021–2022 survey cycle that was unchanged, modified, added, or cycled out.

Similar to the mode changes of the SP and Family questionnaires, the mode of some of the MEC data collection also had to change. Specifically, the Day 1 Dietary Interview, which was historically administered in person at the MEC,[10] will now be conducted by telephone (as has been the case for the Day 2 Dietary Interview since continuous NHANES began; see section on Dietary Assessment for more detail[10]). Additionally, to further reduce contact between SPs and staff, most MEC interview questions will be self-administered by participants using the audio-computer-assisted self-interview (ACASI) system using a touch screen computer. Table 4 summarizes the overall mode changes.

Mobile Examination Center Modifications

As stated previously, NHANES examinations are conducted in MECs that travel to 15 survey locations annually. Each MEC is made up of 4 interconnected semitrailers.[2] Because of COVID-19 concerns, these trailers were all

TABLE 3— National Health and Nutrition Examination Survey 2021–2022 Mobile Examination Center (MEC) Examination Content: United States

Unchanged	Modified	Added	Cycled Out
Body measures	Balance—Modified Romberg Test	COVID-19 Screening Questionnaire and Serology	Audiometry
Blood pressure	Day 1 Dietary Interview via phone		Cognitive functioning
Dual-energy x-ray absorptiometry (DEXA)—whole body	MEC Interview via ACASI		DEXA—spine and femur
Liver elastography			Oral health
Phlebotomy			Words-in-noise

Note. ACASI = audio-computer-assisted self-interview. Refer to NHANES Procedure Manuals for 2017–2018[12] and 2019–2020[10] for further details on each content area.

TABLE 4— Mode of Data Collection Components: United States, National Health and Nutrition Examination Surveys, 2019–2020 and 2021–2022

Order	Component	2019–2020	2021–2022
1	Household Screener and Relationship Questionnaire	In-person	Multimode
2	Sample Person and Family Questionnaires	In-person	Telephone
3	Mobile Examination Center (MEC) Exam: Interview portion	In-person, some ACASI	Primarily ACASI
4	Day 1 Dietary Interview	In-person (at MEC)	Telephone (post MEC)
5	Day 2 Dietary Interview	Telephone (post MEC)	Telephone (post MEC)
6	Food Consumer Behavior Survey	Telephone (post MEC)	Telephone (post MEC)

ACASI = audio-computer-assisted self-interview.

refurbished. Several rooms were enlarged, and additional waiting rooms were created to allow for greater social distancing between participants and staff. Each trailer has 1 or more independent HVAC systems. In addition to implementing practices recommended by the CDC, NHANES replaced several HVAC units with systems that use Minimum Efficiency Reporting Values—13 filters, which have been shown to remove viruses from circulated air. A needlepoint bipolar ionization system was installed in all remaining trailers. This duct-mounted system has been shown to enhance the efficiency of existing HVAC filters. These changes will enhance the MEC ventilation systems to maintain optimal air circulation and quality.

A limited number of staff and participants will be allowed on the MECs at any one time to maintain as much social distancing as possible. All staff will be encouraged to be vaccinated. Personal protective equipment will be worn by all staff, who will maintain strict disinfection and risk-mitigating strategies following CDC guidelines. Staff will be required to conduct daily self-assessments of symptoms prior to work. Unvaccinated staff will receive COVID-19 polymerase chain reaction (PCR) testing on a weekly basis. Any staff who test positive or are determined to be in close contact with a positive individual will remain in isolation until cleared based on CDC guidance or by their medical provider. NHANES will take all necessary actions to inform participants and other NHANES staff of possible exposure.

Prior to participant entry to the MEC for a scheduled exam, NHANES staff will conduct body temperature checks and ask COVID-19 screening questions to all participants.[13] Body temperature at or above 100.4°F or affirmative responses to specific questions will necessitate cancellation and rescheduling of the appointment. Lastly, all participants will also be required to wear masks.

Dietary Assessment

Data on dietary intake and dietary supplement use as well as food consumer behavior will be collected following the MEC visit and will be conducted over the telephone.

The dietary intake component of NHANES, called What We Eat in America, is conducted as a partnership between the US Department of Agriculture (USDA) and the US Department of Health and Human Services. Under this partnership, NHANES uses the USDA's Automated Multiple Pass Method (AMPM) to collect 24-hour dietary recalls by trained dietary interviewers.[14] Since 2002, NHANES has successfully collected an in-person Dietary Interview in the MEC (Day 1) followed by a second interview over the telephone (Day 2) using the AMPM as described previously.[15]

As noted previously, in 2021–2022, the mode of the Day 1 Dietary Interview will be changed to telephone to limit face-to-face contact with respondents. The Day 2 Dietary Interview will remain unchanged (by phone). The methodology of dietary data collection will otherwise remain the same as described previously.[15]

The Dietary Supplement Questionnaire to collect information on 30-day supplement use, which used to be collected as part of the SP Questionnaire at home, will be administered after the Day 1 Dietary Interview over the phone. The 24-hour dietary supplement use data collected during 24-hour recall (Day 1 and Day 2) will not be included during 2021–2022. As collected in earlier NHANES cycles, the Flexible Consumer Behavior Survey Phone Follow-Up Questionnaire will be administered over the phone after the second dietary interview is completed.

COVID-19–Specific Content

NHANES is unique in that it collects data through interviews, in-person examination, and biospecimen collection. This offers a great opportunity to add COVID-19–specific content to obtain a more comprehensive understanding of the epidemiology of COVID-19 in the United States. There are 2 main COVID-related areas of content in 2021–2022 (Appendix, available as a supplement to the online version of this article at http://www.ajph.org). First, as part of the SP Questionnaire, questions were added on previous infection status and severity of symptoms, infection and antigens testing, vaccination, COVID-related hospitalizations, history of weakened immune system, and whether any household member ever tested positive for COVID-19. These questions are asked again at examination. Second, participants who receive phlebotomy at the MEC will have their blood samples tested for the SARS-CoV-2 nucleocapsid protein as well as the spike protein. Antibodies to the nucleocapsid protein indicate only natural infection regardless of vaccination status, whereas antibodies to the spike protein indicate either natural infection or vaccination.[16] Thus, a key contribution of NHANES 2021–2022 will be that the data collected from both of these antibody tests could provide nationally representative prevalence data on both natural COVID-19 infection and vaccine-induced immunity to the virus.

The science and knowledge of the disease, the virus, and immunity continue to develop. Therefore, NHANES will need to quickly adapt and add or modify the COVID-19 content, as needed.

DATA RELEASE AND ANALYSIS

The goal of NHANES 2021–2022 is to collect and publicly release a 2-year sample with data from 30 PSUs on about 10 000 examined persons. If successful, these data, like other NHANES 2-year data, would be made available on the NHANES Web site. Survey sample weights would be provided to account for any survey nonresponse. Data users should use the sample weights to account for the complex survey design in the estimation of variance.

Because of the COVID-19 pandemic, data collection may only occur in about 15 PSUs with a reduced examined sample size. Although the sample will be nationally representative, with such a small number of PSUs, estimates for the single year of data may be relatively unstable (i.e., have large variance estimates). Releasing only 1 year of data increases the possibility of disclosure of a participant's identity and, as a result, the single year of data would not be released publicly because of confidentiality or disclosure risk and instead would only be accessible via the NCHS Research Data Center.[17]

The expected sample sizes of screened and examined persons have been computed on the basis of past NHANES experience with response rates,[18] but these were prior to COVID-19. The overall examination response rate for NHANES 2021–2022 is hard to predict during the COVID-19 pandemic environment. It is especially hard to know how these response rates will be affected by general population concerns because of COVID-19, or the changes to the sample design, operations, and MEC procedures. Nonresponse bias will be examined as data are collected, as well as after all data collection has been completed prior to data release.

Prior to analyzing data, regardless of whether it is a 2-year 2021–2022 sample or only a 1-year sample, data users will need to review all data documentation and understand changes to the questions and exams from prior cycles. Data users should read the NHANES Analytic Guidelines and relevant documentation on the survey overall and specific data files to be used in their analysis. They will also need to determine the adequate sample sizes needed to obtain statistically reliable estimates for the health outcomes of interest for the population and for specific subgroups. Note that the change in sample design, where there will be no oversampling by race and Hispanic origin and income, will affect sample sizes for specific subgroups. Additionally, any comparisons made between the 2021–2022 cycle and earlier NHANES cycles need to consider the impact of COVID-19 during the data collection period as well as the changes described in this article to the survey overall (e.g., data collection mode differences). Analytic details will be provided in data documentation and publications that accompany the data release.

CONCLUSIONS

Over many decades, NHANES has been a unique source of national data on the health and nutritional status of the US population through standard exams and biospecimen collection. After more than a 1-year gap in data collection, in June 2021 NHANES began the dress rehearsal for the 2021–2022 survey cycle and plans to resume full operations soon thereafter. NHANES has transformed its participant recruitment and data collection plans to collect data in a COVID-19 environment as safely as possible. Data collection for the 2021–2022 sample is expected to occur through 2023, with data release beginning in mid-to-late 2023. NHANES's success will be determined by each person who participates in the survey, as well as all the NHANES partners who continue to see the survey's value and provide support through funding, staffing, and other means. NHANES 2021–2022 will continue to monitor the health and nutritional status of the nation while adding to the knowledge of COVID-19 in the US population. AJPH

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CONTRIBUTORS

R. Paulose-Ram and N. Ahluwalia conceptualized the study and drafted the article. J. E. Graber and D. Woodwell provided significant input, review, and editing. All authors read and approved the final article.

CONFLICT OF INTEREST

The authors have no conflicts of interest to disclose.

HUMAN PARTICIPANT PROTECTION

Centers for Disease Control and Prevention research on human participants complies with the Health and Human Services Policy for Protection of Human Research Subjects. All National Health and Nutrition Examination Survey procedures and protocols have been reviewed and approved by the National Center for Health Statistics Research Ethics Review Board.

REFERENCES

1. National Center for Health Statistics. About the National Health and Nutrition Examination Survey. Available at: https://www.cdc.gov/nchs/nhanes/about_nhanes.htm. Accessed March 3, 2021.
2. Centers for Disease Control and Prevention. National Health and Nutrition Examination Survey: plan and operations, 1999–2010. Available at: https://www.cdc.gov/nchs/data/series/sr_01/sr01_056.pdf. Accessed March 9, 2021.
3. Centers for Disease Control and Prevention. The National Health and Nutrition Examination Survey 2017–March 2020 Pre-Pandemic Data Files: brief overview and analytic guidance. Available at: https://wwwn.cdc.gov/nchs/nhanes/continuousnhanes/overviewbrief.aspx?cycle=2017-2020. Accessed November 1, 2021.
4. Stierman B, Afful J, Carroll MD, et al. *National Health and Nutrition Examination Survey 2017–March 2020 Prepandemic Data Files—Development of Files and Prevalence Estimates for Selected Health Outcomes.* Hyattsville, MD: National Center for Health Statistics; 2021. National Health Statistics Reports no. 158. https://doi.org/10.15620/cdc:106273
5. Centers for Disease Control and Prevention. Different COVID-19 vaccines. Available at: https://www.cdc.gov/coronavirus/2019-ncov/vaccines/different-vaccines.html. Accessed November 1, 2021.
6. National Center for Health Statistics. Board of Scientific Counselors—presentations. NHANES reimagined for a changing data world. Available at: https://www.cdc.gov/nchs/about/bsc/bsc_presentations_january2020.htm. Accessed March 9, 2021.
7. Centers for Disease Control and Prevention. National Health and Nutrition Examination Survey: analytic guidelines, 2011–2016. Available at: https://wwwn.cdc.gov/nchs/data/nhanes/analyticguidelines/11-16-analytic-guidelines.pdf. Accessed March 9, 2021.
8. Centers for Disease Control and Prevention. National Health and Nutrition Examination Survey 2015–2018: Sample design and estimation procedures. Available at: https://www.cdc.gov/nchs/data/series/sr_02/sr02-184-508.pdf. Accessed April 3, 2021. Accessed June 23, 2021.
9. GlobalEpidemics. Explore your COVID-19 risk level. Available at: https://globalepidemics.org/key-metrics-for-covid-suppression. Accessed April 3, 2021.
10. Centers for Disease Control and Prevention. National Health and Nutrition Examination Survey: interview procedures manuals, 2019–2020. Available at: https://wwwn.cdc.gov/nchs/data/nhanes/2019-2020/manuals/2020-Interviewer-Procedures-Manual-508.pdf. Accessed November 1, 2021.
11. Centers for Disease Control and Prevention. National Health and Nutrition Examination Survey: NHANES questionnaire instruments, 2019–2020. Available at: https://wwwn.cdc.gov/nchs/nhanes/continuousnhanes/questionnaires.aspx?BeginYear=2019. Accessed March 9, 2021.
12. Centers for Disease Control and Prevention. National Health and Nutrition Examination Survey: NHANES procedure manuals, 2017–2018. Available at: https://wwwn.cdc.gov/nchs/nhanes/continuousnhanes/manuals.aspx?BeginYear=2017. Accessed March 9, 2021.
13. Centers for Disease Control and Prevention. CDC facilities COVID-19 screening. Available at: https://www.cdc.gov/screening/index.html. Accessed June 23, 2021.
14. Moshfegh AJ, Rhodes DG, Baer DJ, et al. The US Department of Agriculture Automated Multiple-Pass Method reduces bias in the collection of energy intakes. *Am J Clin Nutr.* 2008;88(2):324–332. https://doi.org/10.1093/ajcn/88.2.324
15. Ahluwalia N, Dwyer J, Terry A, Moshfegh A, Johnson C. Update on NHANES Dietary Data: focus on collection, release, analytical considerations, and uses to inform public policy. *Adv Nutr.* 2016;7(1):121–134. https://doi.org/10.3945/an.115.009258
16. Centers for Disease Control and Prevention. Interim guidelines for COVID-19 antibody testing. Available at: https://www.cdc.gov/coronavirus/2019-ncov/lab/resources/antibody-tests-guidelines.html. Accessed April 3, 2021.
17. Centers for Disease Control and Prevention. NCHS Research Data Center (RDC). Available at: http://www.cdc.gov/rdc. Accessed March 9, 2021
18. Centers for Disease Control and Prevention. NHANES response rates and population totals. Available at: https://wwwn.cdc.gov/nchs/nhanes/ResponseRates.aspx. Accessed June 23, 2021.

The Impacts of the COVID-19 Pandemic on the Medical Expenditure Panel Survey

Samuel H. Zuvekas, PhD, and David Kashihara, MS

See also Lau et al., p. 2085.

The COVID-19 pandemic caused substantial disruptions in the field operations of all 3 major components of the Medical Expenditure Panel Survey (MEPS). The MEPS is widely used to study how policy changes and major shocks, such as the COVID-19 pandemic, affect insurance coverage, access, and preventive and other health care utilization and how these relate to population health.

We describe how the MEPS program successfully responded to these challenges by reengineering field operations, including survey modes, to complete data collection and maintain data release schedules. The impact of the pandemic on response rates varied considerably across the MEPS. Investigations to date show little effect on the quality of data collected. However, lower response rates may reduce the statistical precision of some estimates.

We also describe several enhancements made to the MEPS that will allow researchers to better understand the impact of the pandemic on US residents, employers, and the US health care system.
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The Medical Expenditure Panel Survey (MEPS) is a family of large-scale federal health surveys conducted annually since 1996 by the Agency for Healthcare Research and Quality (AHRQ). The MEPS is widely used to study health care utilization and costs, health insurance coverage and premiums, access, and quality of health care in the United States.[1–3] The MEPS-Household Component (MEPS-HC) collects detailed information on individuals in approximately 14 000 households through multiple rounds of in-person interviews. The MEPS-HC is closely linked to the National Health Interview Survey (NHIS), conducted annually by the National Center for Health Statistics, deriving its sample from the NHIS. The MEPS-HC provides less detail on health status and medical conditions than the NHIS but substantially greater detail on income, health insurance coverage, and, especially, health care utilization and spending, with information about every health care encounter and prescription drug fill for each household member over a 2-year period. This detail can be used to assess the consequences of health policy changes and major shocks, like the Great Recession and the COVID-19 pandemic, on health insurance coverage, access to care, patterns of preventive and other health care utilization, and how these all relate to population health. The MEPS-HC is also unique among major federal health surveys in collecting information on every household member to provide a more complete picture of the effects of policy changes and shocks on families.

The closely related MEPS-Medical Provider Component (MEPS-MPC) collects payment data from an annual sample of hospitals, doctors, home health agencies, and pharmacies that provided treatment to MEPS-HC households in the previous calendar year. It is designed to produce more detailed and accurate information on spending for health care encounters and prescription drug fills reported in the MEPS-HC than MEPS-HC respondents can typically provide. MEPS-MPC data are not separately released but instead are used as the principal source of expenditures in the person-level and event-level MEPS-HC calendar-year public use files (PUFs).

The MEPS-Insurance Component (MEPS-IC) is a separate, large-scale multimode (telephone, mail, Web) annual survey of more than 40 000 private-sector employers and more than 3000 state and local governments. The

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survey produces national and state-level estimates on topics such as health insurance offerings, enrollments, types of coverage, premium amounts, and employee out-of-pocket contributions in tabular format and in an annual chartbook.[4]

Field interviews for the MEPS-HC, MEPS-MPC, and MEPS-IC components are conducted, respectively, by Westat (www.westat.com), RTI International (www.rti.org), and the US Census Bureau (www.census.gov/programs-surveys/meps.html). AHRQ itself maintains a large, interdisciplinary staff of statisticians, economists, sociologists, and other researchers to provide overall direction for the MEPS, develop sampling strategies, design survey instruments, monitor data collection, develop and oversee data editing and imputation with contractors, perform quality control, and produce statistical reports. In keeping with recommendations of the National Academy of Sciences Committee on National Statistics,[5] a robust intramural research program is an integral part of the MEPS program, with researchers involved in all aspects of survey work, in addition to producing peer-reviewed publications. AHRQ and the National Center for Health Statistics coordinate efforts on the MEPS and NHIS through the Department of Health and Human Services Data Council, which oversees surveys and other data collection efforts across the department. Additional information about the MEPS programs, including survey questionnaires, summary data tables, publications, and PUFs, can be found at https://www.meps.ahrq.gov/mepsweb.

The COVID-19 pandemic caused substantial disruptions in the field operations of all 3 MEPS components, as with all federal surveys. The countrywide shutdowns that began in mid-March 2020 led to the immediate suspension of all in-person and call center–based interviewing at the height of data collection. The MEPS program responded by reengineering, often radically, many aspects of field operations to complete data collection. We describe these disruptions and the program responses in detail for each of the MEPS components, including their effects on response rates and data quality. The challenges of conducting the MEPS during the COVID-19 pandemic also led to innovations in content, providing new opportunities for analyses. We describe these enhancements, including content specifically added to study the impact of the pandemic on the health care system, employers, and US residents.

FIELDING THE SURVEY DURING COVID-19

We outline how the MEPS program managed the disruptions in field operations caused by the COVID-19 pandemic in each of the 3 major components of the survey.

Household Component

The MEPS-HC uses an overlapping panel design to make nationally representative estimates for the civilian, noninstitutionalized population. Each year, a new panel of households is drawn from a subsample of households responding to the NHIS and interviewed in person 5 times ("rounds") using computer-assisted personal interviewing (CAPI) to collect 2 full calendar years of data. Normally, 2 overlapping panels are fielded at the same time and combined to make calendar-year estimates and PUFs (Figure 1). In the "spring" field period running from January to June 2020, 3 panels were fielded simultaneously: round 1 of the new panel—panel 25—which began that calendar year; round 3 of panel 24, which began the previous year; and round 5 of panel 23, which began 2 years previously. The round 5 reference period normally ends December 31 of the previous year.

In response to the COVID-19 pandemic, Westat suspended all in-person field activities on March 17, 2020 (Box 1).[6] The MEPS-HC field staff immediately pivoted to conducting remaining spring interviews entirely by telephone. Interviewers were already familiar with telephone-based interviewing procedures because a small percentage (6%–7%) of interviews were conducted by telephone in prior years.

Before the suspension of in-person interviewing, 73% of round 5 interviews had been completed, and additional telephone-based interviewing achieved the usual high (98%) response rate (Table 1) conditional on households completing previous interviews. Respondents contacted for round 5 interviews previously participated in both the NHIS and 4 rounds of MEPS, so high levels of cooperation and ease of locating respondents were expected. A conditional response rate of 91% was achieved for round 3, with 35% of the interviews completed after the in-person field suspension. This was slightly lower than the usual 95% response rates for round 3. Because of the success in completing the round 3 and 5 interviews by telephone, the impact on the overall response rate for the 2019 full-year PUFs of the MEPS was minimal.

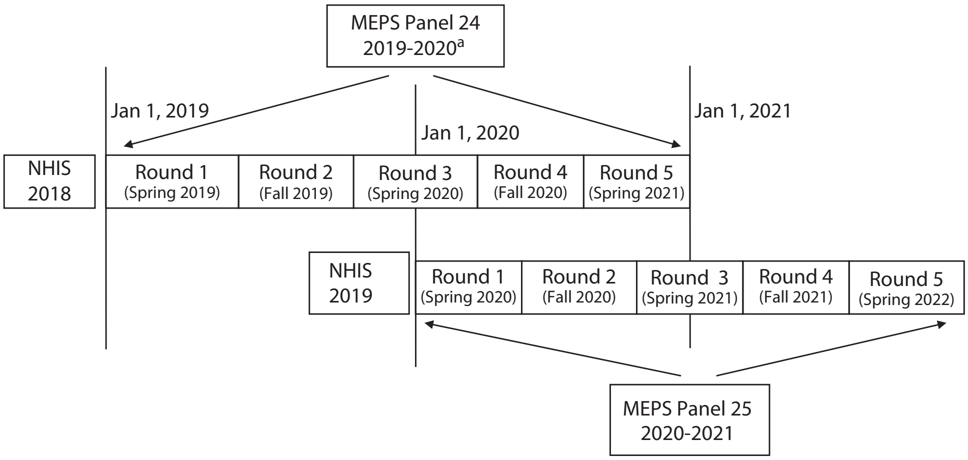


FIGURE 1— Overlapping Panel Design of the Medical Expenditure Panel Survey (MEPS)-Household Component: United States, 2019–2020

Note. NHIS = National Health Interview Survey. The figure depicts the standard 2-panel overlapping design of the MEPS used since 1996 and originally planned for the 2020 data collection year. Annually released full-year PUFs from 1997 through 2019 combine data from multiple rounds from each of 2 panels, as depicted. Subsequently, panel 23 was extended 4 additional rounds covering 2 additional calendar years, 2020 and 2021. As a result, the 2020 full-year PUFs will be composed of data from 3 panels (the Appendix and Figure A, available as supplements to the online version of this article at http://www.ajph.org, provide additional details).

[a] Panel 24 was subsequently extended 4 additional rounds covering 2 calendar years, 2021 and 2022 (the Appendix and Figure A provide additional details).

By contrast, the round 1 response rate fell substantially below normal (Table 1). The greater drop in round 1 response rate was likely because of both greater difficulty in locating some respondents by telephone only and greater reluctance of new sample members to respond during the COVID-19 crisis. Response rates for the 2 rounds normally fielded during the fall MEPS-HC data collection (panel 25, round 2 and panel 24, round 4), which runs from July through December, also fell in 2020 (Table 1). As a result, the overall response rate in the 2020 full-year PUFs of the MEPS-HC is expected to be lower than in previous years.

The spring 2021 data collection (Figure A, available as a supplement to the online version of this article at http://www.ajph.org) proceeded mostly by telephone, with in-person interviewing limited to lower risk areas and where respondents and interviewers felt comfortable. Even in safer areas, interviewers mostly made contact in person to arrange a subsequent telephone interview. A greater proportion of interviews were conducted in person beginning in May 2021, with Westat planning to return to in-person interviewing in fall 2021.

Initial analyses found little evidence of nonresponse bias because of the drops in response rates, including the large drop in round 1. There were no differences in response rates by age, race/ethnicity, sex, and health status, but there were small differences by education in round 1. Standard reweighting procedures will account for this when producing the 2020 annual weights. The switch from in-person to telephone interviewing affected the conditional response rates of other key aspects of the MEPS-HC. Most importantly, at the end of the in-person interview, sample members (or their parents) complete authorization forms (AFs), allowing the MEPS-MPC contractor to contact providers and pharmacies to collect more complete payment and other information. The signed AFs are often just handed to the interviewer. Telephone-based interviewing precludes this simple route for distributing and collecting AFs. Consequently, Westat developed mail-based alternatives to distribute and collect the AFs from households,[6] subsequently adding contactless in-person drop-offs to improve response rates. Supplemental self-administered questionnaires (SAQs) are also mailed to adult household members ahead of scheduled interviews during certain rounds. These are often collected by interviewers during in-person interviews. Again, the switch to telephone interviewing put more of the onus on MEPS-HC households, and response rates suffered accordingly. Because some forms are still being collected and receipted, final response rates for both the AFs and SAQs for 2020 are not yet available.

BOX 1— Medical Expenditure Panel Survey (MEPS) Data Collection Modes Before and After the COVID-19 Pandemic Hit, by Major Component

MEPS Component	Usual Data Collection Mode	COVID-19 Data Collection Mode
MEPS-HC: nationally representative panel survey of households (5 rounds covering 2 calendar years each panel) with detailed demographic characteristics, health care utilization and spending, and health insurance coverage	Main instrument: in-person CAPI interviews	• Spring 2020: All telephone-based CAPI after March 17 • Fall 2020: almost all telephone-based CAPI interviewing; limited in-person interviews, some door-to-door contacts to schedule telephone interviews
	Supplemental paper and pencil SAQs and other forms: interviewers collect during interview or returned by mail by respondent	• Spring 2020: respondents returned survey by mail only • Fall 2020: respondents returned survey mostly by mail, some pickup by field interviewers
MEPS-MPC: follow-back surveys of hospitals, office-based doctors, home health agencies, and pharmacies identified by MEPS-HC respondents where signed authorization forms were obtained	Call-center based CATI	Home-based telework CATI
	Abstraction from hard copy medical and billing records in RTI call center and entered into CATI system	Home-based telework abstraction from electronic records or scanned from hard copy records received at call centers
MEPS-IC: annual, nationally representative employer surveys of business locations and of state and local governments covering health insurance offerings, number of enrolled employees, and average health insurance premiums, copays and deductible amounts.	• Telephone (CATI) prescreener • Self-administered paper forms • Self-administered web form • Telephone (paper and CATI) follow-up • Personal visits • Respondents were offered a choice between mail (paper) response and web response. Most cases were sent paper forms with a link to the survey website.	• Telephone (CATI) prescreener • Self-administered paper forms • Self-administered web form • Telephone (paper and CATI) follow-up • 2020 respondents were initially only offered web response. Once the survey processing facility (NPC) opened some survey form packages were mailed, completed and returned. No personal visits were conducted in 2020.

Note. CAPI = computer-assisted personal interviewing; CATI = computer-assisted telephone interviewing; HC = Household Component; IC = insurance component; MPC = Medical Provider Component; NPC = US Census Bureau's National Processing Center; RTI = RTI International; SAQ = self-administered questionnaires.

Medical Provider Component

The MEPS-MPC collects billing and medical record information for office-based doctors, hospitals, home health agencies, and pharmacies for MEPS-HC sample members with signed AFs. In 2020, the MEPS-MPC collected data for encounters that occurred in 2019. Before the pandemic, this work was conducted exclusively in call centers using a combination of computer-assisted telephone interviewing (CATI) and abstraction from hard copy records mailed, faxed, or sent electronically by providers (Box 1). Some data collection is completed entirely through telephone interviews. Mostly, however, initial telephone contacts request records, and data collection is completed through abstraction. The hospital records abstraction is particularly labor intensive and often requires subsequent telephone contacts. Abstractors generally complete hard copy summary sheets from the records they are abstracting, which are then entered into the CATI system.

RTI shut down all telephone and abstraction activities on March 17, 2020, in response to the pandemic, and the call centers remain closed.[7] RTI developed new procedures for staff to complete the MEPS-MPC while teleworking through remote access to RTI systems. The more complicated issue was billing and medical record abstraction, which could not be completed by hard copy review in employees' homes for logistical and confidentiality reasons. Instead, hard copy records were scanned by a few employees at the call center. Abstractors then electronically highlighted key information in PDF documents and then entered them into the CATI system. This electronic highlighting and abstraction proved more cumbersome than hard copy abstraction.

Historically, MEPS-MPC obtains high rates of cooperation from providers, but providers were also hard hit by the COVID-19 pandemic, further slowing production (Table 1). Many doctor offices temporarily closed, and some provider staff working from home could

TABLE 1— **Survey Response Rates by Medical Expenditure Panel Survey (MEPS) Component and Data Collection Year: United States, 2018–2020**

MEPS Component	Data Collection Year		
	2018	2019	2020
Conditional response rate[a]			
MEPS-HC			
Round 1 (spring)	72.9	71.2	61.7
Round 3 (spring)	95.0	94.6	91.3
Round 5 (spring)	97.8	98.3	97.7
Round 2 (fall)	92.9	92.5	78.5
Round 4 (fall)	96.7	96.2	85.5
Conditional response rate[b]			
MEPS-MPC[c]			
Hospital	87.0	87.7	57.3
Office-based doctors	82.0	82.4	65.3
Home health agencies	85.0	84.9	80.2
Noncorporate pharmacies	84.8	83.3	65.8
Corporate pharmacies	86.1	89.2	80.7
Unconditional response rate[d]			
MEPS-IC			
Private sector	67.8	59.2	56.3
State and local governments	83.0	82.1	75.2

Note. HC = Household Component; IC = Insurance Component; MPC = Medical Provider Component.

[a] The round-specific household response rate is conditional on the household having responded previously to either the National Health Interview Survey (round 1) or previous MEPS-HC rounds (rounds 2–5; Table A, available as a supplement to the online version of this article at http://www.ajph.org, provides sample sizes).

[b] The provider response rate is conditional on having signed the authorization form from the MEPS-HC sample member and case fielded in the MPC. The denominator for the response rate calculation is the unique combination of the provider and the MEPS sample person.

[c] MEPS-MPC collects data for health care encounters and prescription fills that occurred in the previous calendar year. Because of budget limitations, a stratified subsample of office-based doctors is fielded each year.

[d] The response rate was calculated using unique private-sector establishments (a single firm may have multiple establishments) or unique state and local government entities.

not immediately access records. Hospitals were especially overwhelmed, with staff simply not having time to respond. Although the MEPS-MPC data collection picked up considerably through the summer and fall 2020, response rates were still substantially lower in 2020 (Table 1). The final MEPS-MPC sample from 2020 (covering events that occurred in 2019) has proportionally fewer cases with Medicaid coverage compared with earlier years. However, this is accounted for in the expenditure editing and imputation processes and, in extensive reviews of the final 2019 MEPS expenditure estimates, no systematic biases were uncovered.

Insurance Component

The MEPS-IC collects information about health insurance offered by both private and nonfederal public sector employers. We focus discussion on the private sector, but data collection from governments is similar.

MEPS-IC data are collected and processed by the US Census Bureau in stages: research, telephone prescreener, mailout, personal visits, and telephone follow-up. After the 2020 sample was drawn from the US Census Bureau's Business Register, research to update telephone numbers and other contact information was to commence. In mid-March 2020, the pandemic forced the closure of the Census Bureau telephone centers, and the research operation was canceled. After a delay, the Census Bureau distributed laptops to their analysts, enabling them to complete research from home (April 2020–June 2020).[8]

The brief telephone prescreener calls (June 2020–August 2020)[8] to determine whether a business offered health insurance to its employees were similarly conducted from home. If the business did not offer insurance, characteristics of the business were collected, and the survey ended. To facilitate communication with businesses operating remotely, interviewers collected e-mail addresses for future contacts with businesses that offered insurance.

From June through October, businesses that offered insurance or did not respond to the prescreener would typically be mailed an advanced letter and would subsequently receive survey forms along with a letter indicating an option to respond via the Web.[8] Because of COVID-19, the Census Bureau's National Processing Center was temporarily closed on March 18, 2020 and was unable to mail hard copy forms. By early May, automated processes were available that allowed the National Processing Center to mail advance letters notifying businesses of their inclusion in the survey and asking them to respond by Web. A similar "eBlast" e-mail was also sent to businesses. Later in the summer, the National Processing Center was finally able to mail some survey forms. However, emphasis in data collection shifted from a choice of paper or Web to primarily Web.

Personal visits (normally conducted August–December)[8] were canceled because of COVID-19. These visits are expensive and reserved for the largest nonresponders. Although the response rate for the largest employers was higher in 2020 compared to 2019, it might have been even higher had personal visits not been eliminated. The final response rate for the largest employers was still substantially below the rates of 2018 and earlier years.

The telephone follow-up operation, normally fielded from September 2020 through February 2021, was extended several weeks to compensate for lower response rates to the prescreener and e-mails.[8] The combined mitigation efforts resulted in a surprisingly small drop in the private-sector response rate from 59.2% in 2019 to 56.3% in 2020 (Table 1).

NEW SURVEY CONTENT

We describe the new content added to the MEPS in direct response to the disruptions in the field operations, as well as new MEPS content relevant for understanding the effects of the COVID-19 pandemic.

Longer Panels

Because of the substantial drop in round 1 response rates in 2020 and the anticipated effects of similar drops in the NHIS response rates on the MEPS-HC, Westat proposed extending data collection for the panel that was originally scheduled to rotate out of the survey after the round 5 interviews (panel 23, which started in 2018). Westat rapidly developed and tested a round 6 instrument that could be fielded in fall 2020. Because of the high likelihood that the COVID-19 pandemic would continue to limit in-person field operations and concerns about response rates in newer panels, AHRQ subsequently decided to extend the MEPS panels that began in 2018 (panel 23) and 2019 (panel 24) to 4 full years of data collection instead of the normal 2, budget permitting (Figure A and the Appendix provide additional details, available as supplements to the online version of this article at http://www.ajph.org). These extended panels have the dual benefits of increasing MEPS-HC sample sizes and allowing entirely new analyses to take advantage of the longer panels. Because data were collected for these panels before the COVID-19 pandemic, these extended panels will be particularly important for studying the consequences of the pandemic, including longer-run effects on health care utilization and the health of US residents.

Telehealth Visits

Many hospitals, doctor offices, and other health care providers transitioned to deliver some or all health care virtually by telephone or Internet in response to the pandemic even before the countrywide shutdowns in mid-March 2020. Supporting this move to telehealth-based care, Medicare, Medicaid, and most private insurers substantially relaxed previously tight restrictions on payment for telehealth visits,[9,10] but the MEPS-HC instrument had not previously explicitly probed respondents on telehealth visits. For 2020, interviewers were prompted to probe for visits that occurred by telephone or video (the Appendix provides additional details). Starting with 2021 interviews, the event reporting modules in the MEPS were substantially redesigned to include better probes for telehealth encounters and allow explicit identification of telehealth visits, including mode (telephone, video, or other). Data on these telehealth visits will be available beginning with the 2020 full-year PUFs for the MEPS-HC (Appendix).

COVID-19–Specific Content

Three questions were added to the MEPS-HC instrument for the fall 2020, spring 2021, and fall 2021 interviews that asked whether any medical care, dental care, or prescription drugs were delayed "because of the coronavirus pandemic." Beginning in fall 2021, MEPS-HC respondents will also be asked whether each person in the household had received a COVID-19 vaccination.

Two new questions were added to the 2021 MEPS-IC survey to further measure the consequences of the pandemic. The first asks about the teleworking capabilities of the employer's staff. The second asks employers if their business had a net increase or net decrease in the number of employees because of the pandemic. The

MEPS-IC is pretesting additional questions about incentives employers offered to employees to receive COVID-19 vaccinations and the impact of the pandemic on employers and employees.

Other Content

A new Social and Health Experiences SAQ was fielded in spring 2021 through a budget supplement for the MEPS-HC. A Web option was provided and strongly encouraged to improve response rates. The questionnaire asks each adult about social and behavioral determinants of health, including housing security, quality and affordability, food security, transportation challenges, general well-being, family and community support, personal safety, and adverse circumstances during childhood. This SAQ was planned long before the COVID-19 pandemic but will provide additional context for understanding the effect of the pandemic and how it varied across the population. Likewise, the main MEPS-HC instruments for 2020 and 2021 contain a US Department of Agriculture–funded supplement on food security that was previously included in the 2016 and 2017 MEPS.

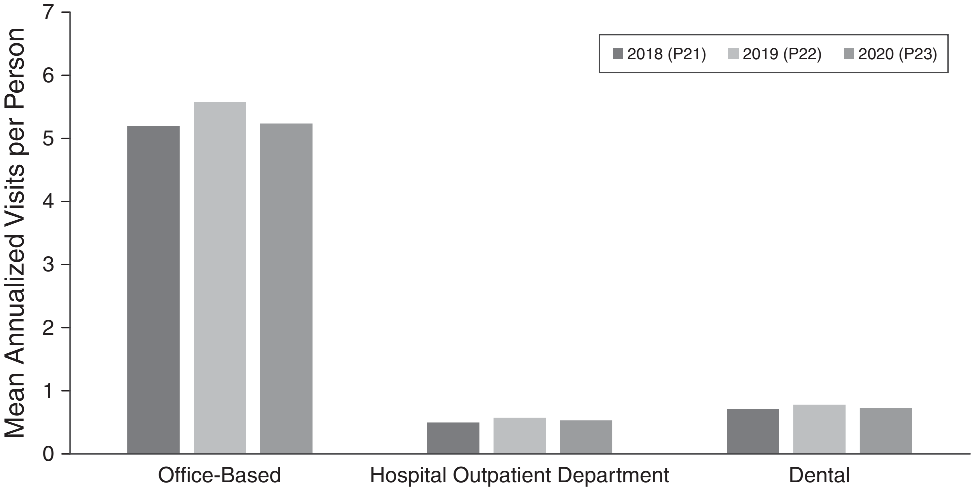
DATA QUALITY COLLECTED ON THE COVID-19 PANDEMIC

Initial investigations of the effects of COVID-19 on data quality focused on MEPS-HC reports of health care utilization for 2 main reasons. First, household reports of every office-based visit, hospital stay or visit, home health, prescription drug fill, and all other health care utilization serve as the basic building blocks of expenditure estimates, the most important domain in the MEPS-HC.

Second, reporting of health care events may be particularly sensitive to a switch from in-person to telephone-based interviews. The process of eliciting all health care encounters and prescription drugs and recording details—including dates, health care conditions associated with visits or medications, and payment details—is complex. To speed this process and improve recall, MEPS-HC respondents are encouraged to keep records and have them available during interviews. These records include bills, explanation of benefit forms, pill bottles, and special calendars to record the dates of all visits. Past validation studies demonstrate a strong correlation between use of records and the quality of MEPS-HC reports.[11–14] Telephone-based interviewing likely makes using these records during interviews more cumbersome. For example, the respondent cannot simply hand a pill bottle to the interviewer to record an unusual or complicated drug name. Respondents may also be more reluctant to collect or use records during a telephone-based interview or may not have had access to them because of the pandemic.[6] Indeed, there is evidence that use of records declined overall.[6]

We examined whether the switch from in-person to telephone-based interviewing affected the quality of health care utilization data by comparing the number of visits reported in interviews conducted exclusively by telephone after March 17, 2020, to interviews conducted by standard MEPS procedures after March 17 of the 2 previous spring interview cycles. Figure 2 compares the mean number of visits reported in the spring 2020, round 5 interviews conducted after March 17 to round 5 interviews conducted after March 17 the 2 previous years. The round 5 reference period ends on December 31, 2019, for the spring 2020 interviews, so the pandemic should not affect actual health care utilization. We found that the mean annualized number of office-based visits, visits to hospital outpatient departments, and dental visits were all comparable across all 3 years with no statistically significant differences. We similarly found no evidence of a mode effect in the switch from in-person to strictly telephone-based interviewing in rounds 1 and 3 and in multivariable regression models of all 3 rounds (see Appendix for additional details). Separate analyses performed by the MEPS-HC contractor, Westat, confirm these results.[6] In separate assessments, AHRQ and RTI found that the quality of the payment data collected in the MEPS-MPC in 2020 was like previous years (Appendix).

Our evaluations of both household reports of health care utilization and the quality of payment data from the MEPS-MPC are encouraging. However, challenges remain. In particular, the lower response rates in the MEPS-MPC (Table 1) mean that fewer events and prescription drugs reported by MEPS-HC households for 2019 have complete payment information available from providers. As a result, more payment data must be imputed, reducing the accuracy of MEPS-HC 2019 expenditure variables and estimates released in 2021. RTI reports that the 2021 data collection is going more smoothly, with higher response rates than in 2020. However, because of the challenges of collecting the necessary AFs from MEPS-HC sample members, the number of providers RTI can contact is



	2018		2019		2020	
	No.	Mean (SD)	No.	Mean (SD)	No.	Mean (SD)
Office-based visits	3323	5.20 (13.76)	3487	5.58 (17.64)	3727	5.24 (15.80)
Hospital outpatient department	3323	0.50 (6.23)	3487	0.57 (5.23)	3727	0.53 (4.11)
Dental visits	3323	0.71 (2.05)	3487	0.78 (1.98)	3727	0.73 (2.19)

FIGURE 2— Household Reporting of Pre–COVID-19 Visits in Medical Expenditure Panel Survey (MEPS)-Household Component Round 5 Interviews Conducted After March 17 by Data Collection Year: United States, 2018–2020

Note. The figure represents the authors' analyses of confidential MEPS-household component files. Usual reference period is from the date of round 4 interview to December 31 of the year before round 5 data collection. Adjusted Wald test of 2020 vs 2019 means: $P = .50$ office-based; $P = .78$ hospital outpatient department; $P = .39$ dental visits. Visits were annualized to account for slightly unequal average.

smaller than in past years. Thus, there will again be fewer events with complete payment data available from the MEPS-MPC, and more imputation will likely occur in the 2020 PUFs of the MEPS-HC.

Investigation of the quality of reporting in these and all other domains of the MEPS is ongoing (see Appendix for more details).

CONCLUSIONS

The COVID-19 pandemic created and continues to create many challenges for the MEPS program. Our contractors and partners worked creatively to revamp field operations in each of the main MEPS components by switching data collection modes, staffing operations with teleworkers, or both. That they were able to achieve the response rates they did during 2020 and maintain the data release schedules for data already collected is a testament to their hard work and dedication. We have also been encouraged by the quality of the data obtained despite substantial changes in data collection. At the same time, the statistical precision of some estimates may be reduced because of lower response rates in 2020 than in previous years, which continued in 2021. Of particular concern, the difficulties created by the pandemic increased the amount of imputation that was required to produce the expenditure variables in the 2019 full-year PUFs of the MEPS-HC and will do so again in the 2020 PUFs. AHRQ and its contractors are continuing intensive efforts to assess the quality of MEPS data collected during the pandemic using both qualitative and quantitative methods and to develop any necessary mitigation strategies for producing PUFs and other products.

The challenges of collecting data during the pandemic have also accelerated work on developing new methods and technologies for the MEPS of households, providers, and employers. For example, the MEPS-HC contractor is working on a system of collecting AFs electronically with electronic signatures to improve AF response rates whether MEPS-HC interviews are conducted in person or by telephone. Similarly, the MEPS is expanding the use of machine-learning methods to automate portions of the labor-intensive record abstraction in each of its surveys. The encouraging results of our analyses of the quality of MEPS-HC data collected through less costly telephone interviews opens new possibilities for extending MEPS panels on an ongoing basis. We are also examining whether additional portions of the MEPS-HC can be moved to the Web. A major lesson of the pandemic is that the MEPS, like other federal surveys, must become more flexible to better anticipate and respond to similar challenges in the future, while maintaining its core strengths that justify a continued large public investment.

Since its inception in 1996, the MEPS has been used in a wide range of economic, health services research, clinical, and public health studies, including those published in *AJPH*.[15–19] The MEPS is designed to support in-depth analyses of how socioeconomic characteristics, health insurance coverage, access to care, patterns of preventive and other health care utilization and spending, and population health all relate to one another. Meeting the challenges of the COVID-19 pandemic has created additional opportunities for analyses using the MEPS. We are particularly excited about the possibilities created by the planned 4-year panels. The 2-year duration in all previous panels of the MEPS-HC constrains both the topics that can be studied and the statistical methods that can be successfully applied to the MEPS-HC. In particular, the longer panels support examining the longer-run impacts of policy changes and shocks on access, health care utilization, health behaviors, and health of individuals and families and thus will allow analyses of sample members before, during, and after the COVID-19 pandemic.

Explicitly adding telehealth events to the MEPS-HC is also long overdue and particularly important for understanding health care utilization during the pandemic. Finally, the new COVID-19 questions and other new content in conjunction with the extended panels will greatly enhance the ability of the MEPS to study the consequences of the COVID-19 pandemic on US residents, their employers, and the health care system.

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CONTRIBUTORS

S. H. Zuvekas conducted statistical analyses and drafted the initial portions related to the Medical Expenditure Panel Household Component and Medical Provider Component. D. Kashihara conducted the analyses and drafted the initial sections related to the Medical Expenditure Panel Insurance Component. Both authors contributed to the overall conceptualization and design of the work, the drafting of the introduction and discussion sections, and subsequent revisions of all sections of the article.

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CONFLICTS OF INTEREST

The authors report no conflicts of interest.

HUMAN PARTICIPANT PROTECTION

All analyses were conducted under the protocol "Secondary Analysis of Confidential Data from the Medical Expenditure Panel Survey" (CRRI 0504015) and approved by the Advarra institutional review board.

REFERENCES

1. Weil A. We'd be in the dark without AHRQ. October 15, 2015. Available at: https://www.healthaffairs.org/do/10.1377/hblog20151015.051225/full. Accessed April 14, 2021.
2. Cohen SB, Cohen JW. The capacity of the Medical Expenditure Panel Survey to inform the Affordable Care Act. *Inquiry.* 2013;50(2):124–134. https://doi.org/10.1177/0046958013513678
3. Cohen JW, Cohen SB, Banthin JS. The Medical Expenditure Panel Survey: a national information resource to support healthcare cost research and inform policy and practice. *Med Care.* 2009;47(7 supp 1):S44–S50. https://doi.org/10.1097/MLR.0b013e3181a23e3a
4. Agency for Healthcare Research and Quality. MEPS insurance component chartbook 2019. October 2020. Available at: https://www.meps.ahrq.gov/data_files/publications/cb24/cb24.pdf. Accessed October 21, 2021.
5. National Academies of Sciences, Engineering, and Medicine. *Principles and Practices for a Federal Statistical Agency*. 7th ed. Washington, DC: National Academies Press; 2021. https://doi.org/10.17226/25885
6. Westat. *MEPS COVID-19 Data Quality Report*. Contract# HHSA-290-2016-00004I. Task Order# 75Q80119F32016, Deliverable # 1A.01 Final Report. Rockville, MD: Westat; March 15, 2021.
7. Dowd D, Saleska E, Bell S, et al. MEPS MPC COVID impacts: 2019 cycle. Paper presented at: the Agency for Healthcare Research and Quality; March 11, 2021; Rockville, MD.
8. Livesay M, Tarsia B, Winder S, Davis K. 2020 MEPS insurance component data collection. Slides presented at: the Agency for Healthcare Research and Quality Seminar; February 22, 2021; Rockville, MD.
9. US Department of Health and Human Services. Telehealth: delivering care safely during COVID-19. July 15, 2020. Available at: https://www.hhs.gov/coronavirus/telehealth/index.html#waivers. Accessed April 14, 2021.
10. Patel SY, Mehrotra A, Huskamp HA, Uscher-Pines L, Ganguli I, Barnett ML. Variation in telemedicine use and outpatient care during the COVID-19 pandemic in the United States. *Health Aff (Millwood).* 2021;40(2):349–358. https://doi.org/10.1377/hlthaff.2020.01786
11. Zuvekas S, Biener A, Hicks W. The effects of survey enhancements on the quality of reporting in the Medical Expenditure Panel Survey, 2008–2015. *J Surv Stat Methodol.* 2020;8(3):589–616. https://doi.org/10.1093/jssam/smz014
12. Zuvekas SH. The effects of recall length and reporting aids on household reporting of health care events in the Medical Expenditure Panel Survey. *J Econ Soc Meas.* 2011;36(4):321–343. https://doi.org/10.3233/JEM-2011-0348
13. Hill SC, Zuvekas SH, Zodet MW. Implications of the accuracy of MEPS prescription drug data for

health services research. *Inquiry.* 2011;48(3): 242–259. https://doi.org/10.5034/inquiryjrnl_48.03.04

14. Kashihara D, Wobus D. The effect of reporting aid use on the accuracy of household-reported medical expenditure data. Available at: http://www.asasrms.org/Proceedings/y2007/Files/JSM2007-000563.pdf. Accessed October 27, 2021.
15. Bachhuber MA, Hennessy S, Cunningham CO, Starrels JL. Increasing benzodiazepine prescriptions and overdose mortality in the United States, 1996–2013. *Am J Public Health.* 2016;106(4):686–688. https://doi.org/10.2105/AJPH.2016.303061
16. Caldwell JT, Ford CL, Wallace SP, Wang MC, Lois M, Takahashi LM. Intersection of living in a rural versus urban area and race/ethnicity in explaining access to health care in the United States. *Am J Public Health.* 2016;106(8): 1463–1469. https://doi.org/10.2105/AJPH.2016.303212
17. Aldridge MD, Kelley AS. The myth regarding the high cost of end-of-life care. *Am J Public Health.* 2015;105(12):2411–2415. https://doi.org/10.2105/AJPH.2015.302889
18. Abdus S, Mistry KB, Selden TM. Racial and ethnic disparities in services and the Patient Protection and Affordable Care Act. *Am J Public Health.* 2015;105(suppl 5):S668–S675. https://doi.org/10.2105/AJPH.2015.302892
19. Lau DT, Kirby JB. The relationship between living arrangement and preventive care use among community-dwelling elderly persons. *Am J Public Health.* 2009;99(7):1315–1321. https://doi.org/10.2105/AJPH.2008.151142

National Health Interview Survey, COVID-19, and Online Data Collection Platforms: Adaptations, Tradeoffs, and New Directions

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See also Lau et al., p. 2085.

High-quality data are accurate, relevant, and timely. Large national health surveys have always balanced the implementation of these quality dimensions to meet the needs of diverse users.

The COVID-19 pandemic shifted these balances, with both disrupted survey operations and a critical need for relevant and timely health data for decision-making. The National Health Interview Survey (NHIS) responded to these challenges with several operational changes to continue production in 2020. However, data files from the 2020 NHIS were not expected to be publicly available until fall 2021. To fill the gap, the National Center for Health Statistics (NCHS) turned to 2 online data collection platforms—the Census Bureau's Household Pulse Survey (HPS) and the NCHS Research and Development Survey (RANDS)—to collect COVID-19–related data more quickly.

This article describes the adaptations of NHIS and the use of HPS and RANDS during the pandemic in the context of the recently released Framework for Data Quality from the Federal Committee on Statistical Methodology. (*Am J Public Health*. 2021;111(12):2167–2175. https://doi.org/10.2105/AJPH.2021.306516)

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Accurate, relevant, timely—there are many dimensions of high-quality data, but these 3 are specifically included in the mission statements of several federal statistical agencies, including the US National Center for Health Statistics (NCHS).[1] Yet, even achieving these 3 requires tradeoffs. For example, accurate data take time to collect, evaluate, and analyze, and speeding up any of these processes presents risks to accuracy. Attaining and maintaining the right balance is the goal when producing official statistics.

The COVID-19 pandemic disrupted this balance. The data critical to inform programs and policies during the pandemic were not necessarily part of the core content of long-established federal household interview surveys. Even when these data were collected, established practices and guidelines for data processing and reporting, long considered necessary for ensuring accuracy, were too slow for urgent response needs. In this article, we describe efforts at NCHS to adapt to these changing needs and circumstances for data collected from the National Health Interview Survey, a survey typically conducted in person at participants' homes. We also describe 2 online data collection platforms—the Census Bureau's Household Pulse Survey (HPS) and the NCHS Research and Development Survey (RANDS)—that NCHS used to collect COVID-19–related data more quickly. But, first, we recognize that accuracy, relevance, and timeliness are not the only characteristics of high-quality data.

DIMENSIONS OF DATA QUALITY

High-quality data are essential for making data-driven decisions. NCHS follows US Office of Management and Budget directives and policies that ensure high-quality data are produced by federal statistical agencies.[2] With the changing world of data sources, analytic methods, and data uses, the conceptualization of quality has similarly been evolving among data programs throughout the federal government.

In September 2020, the Federal Committee on Statistical Methodology (FCSM) released a data quality framework that provides guidance to federal statistical agencies on assessing the quality of data.[3] FCSM is an interagency committee dedicated to improving the quality of federal statistics. Building on a 20-year foundation,[4–6] the new FCSM framework includes 3 domains of quality. Are the data useful? Are the data objective? Have the data been produced with integrity? Within these domains, multiple dimensions of data quality—including accuracy, relevance, and timeliness—can be considered when one is answering these questions (Figure 1).

Data with high utility have timeliness and relevance. They can also be easily obtained by data users (accessibility) when expected (punctuality) and can be disaggregated by time, geography, demographics, or other necessary characteristics (granularity). Data with high objectivity have accuracy and make use of common definitions and methods so that the data align with other relevant data (coherence). Data with high integrity have the confidence of data users (credibility) and are protected from corruption or falsification (computer and physical security), from disclosure to unauthorized parties (confidentiality), and from inappropriate political influence (scientific integrity).

Each of the dimensions in the framework should be considered when one is evaluating and communicating data quality. Nonetheless, some of these dimensions have traditionally been valued without being defined or communicated as elements of quality.[6] Most evaluations of data quality have focused largely on accuracy, defined as the closeness of an estimate to its true value. Although true values are generally unknown, for surveys, accuracy can be increased through higher sample sizes and efficient sampling, more complete lists for sampling (such as address or telephone lists), greater response rates, decreased measurement errors by using carefully tested questionnaires, and reductions in data-entry and data-processing errors.

The intended uses of the data may determine which dimensions of quality are most important. For more than 60 years, the National Health Interview Survey (NHIS) has prided itself on being a gold standard for data on health care access, health insurance, and disability, among other topics.[7] NHIS users are varied and range from decision-makers and journalists using published estimates to analysts conducting research with microdata. Therefore, for NHIS, the accuracy dimension remains one of the highest priorities.

Household-based interview surveys such as NHIS were particularly vulnerable to the impacts of COVID-19 on accuracy. The next sections of this article describe how NCHS responded to these threats and looked to new ways to collect timely and relevant data during a year (2020) when accuracy was harder to maintain.

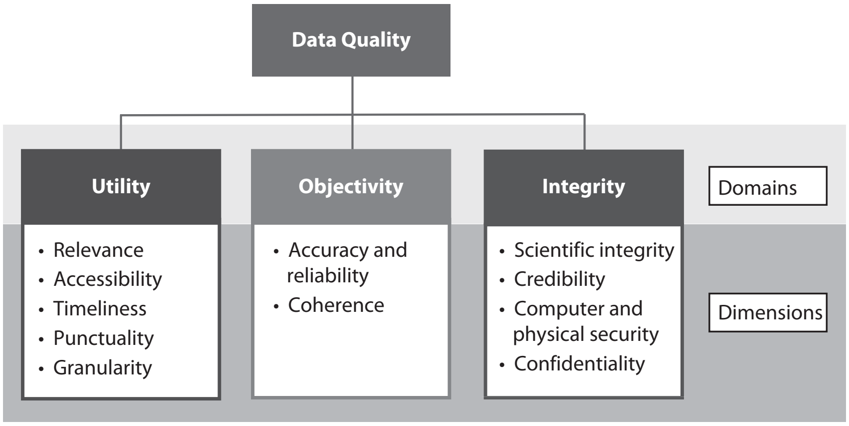

FIGURE 1— **The Federal Committee on Statistical Methodology Data Quality Framework**

NATIONAL HEALTH INTERVIEW SURVEY, APRIL–JUNE 2020

NHIS is the longest-running household-based health survey in the United States, fielded continuously since 1957. NHIS is a cross-sectional survey of a sample of the civilian noninstitutionalized population.[8] From each randomly selected household, 1 adult and 1 child (if any are present in the household) are selected for the interview. Commercial address lists are used as the main source of addresses for sampling, supplemented in selected geographic areas by field listers who visit those areas and log every address they find. Interviews are generally conducted in respondents' homes by Census Bureau field representatives, but follow-ups to complete interviews may be conducted over the telephone. Although some large national surveys also allow some respondents to complete interviews online or by mail, NHIS only uses in-person and telephone modes.

Despite the pandemic, NHIS never stopped collecting data. However, in the interest of staff and public safety, NHIS temporarily became only a telephone survey on March 19, 2020. Address listing by field listers also stopped. The commercial address list supplier provided telephone numbers for 60% of the sampled addresses. Field representatives used online searches and other techniques for the rest. Still, an increased risk of bias from coverage error remained because telephone numbers could not be found for some addresses. Accuracy may also be diminished because of lower response rates. Collecting data by telephone rather than in-person visit resulted in a reduction in the household response rate from 59% in January through March 2020 to 42% in April through June 2020.

TABLE 1— Comparisons of Select Sociodemographic Characteristics Between Quarter 1 and Quarter 2, 2020, Among Adults Aged 18 Years and Older: National Health Interview Survey, United States

Variable	Quarter 1, 2020, % (SE)	Quarter 2, 2020, % (SE)
Age group, y		
18–29	13.6 (0.41)	11.1* (0.47)
30–44	23.8 (0.52)	23.1 (0.72)
45–64	33.9 (0.59)	34.3 (0.67)
≥ 65	28.8 (0.78)	31.5* (0.84)
Male	46.2 (0.59)	45.5 (0.67)
Race and Hispanic origin		
Hispanic	14.4 (1.73)	11.3 (1.36)
Non-Hispanic White	66.7 (2.34)	71.9 (2.25)
Non-Hispanic Black	11.2 (0.76)	9.4* (0.65)
Non-Hispanic other	7.6 (1.01)	7.3 (1.05)
Educational attainment		
< high-school diploma	9.5 (0.48)	6.7* (0.46)
High-school diploma or GED	24.9 (0.71)	23.7 (0.87)
Some college	29.1 (0.72)	29.1 (0.83)
≥ bachelor's degree	36.5 (1.09)	40.5* (1.27)
Own or buying residence	65.1 (1.40)	73.1* (1.35)
Years at current residence		
< 1	13.0 (0.46)	8.5* (0.48)
1–3	21.6 (0.58)	20.0* (0.75)
4–10	24.8 (0.47)	24.8 (0.61)
11–20	19.2 (0.55)	22.2* (0.66)
> 20	21.4 (0.62)	24.5* (0.84)
Total family income, $		
< 35 000	26.0 (0.78)	20.5* (0.75)
35 000 to < 75 000	27.6 (0.71)	28.5 (0.79)
75 000 to < 100 000	11.3 (0.42)	12.9* (0.46)
≥ 100 000	26.6 (1.07)	29.2* (1.11)
Unknown	8.4 (0.48)	8.9 (0.49)

Note. GED = general equivalency diploma. Estimates are weighted by the initial household base weight, which represents the inverse of the probability of household selection.

Source. Reproduced from Dahlhamer et al.[9]

*$P < .10$ vs quarter 1 according to Dahlhamer et al.[9]

The resulting sample skewed toward older and more affluent households.[9] Adults aged 65 years and older, those with a 4-year college degree, and those with family incomes of $75 000 or more appear to be overrepresented in the responding sample from April through June 2020, when compared with the sample interviewed from January through March 2020 (Table 1). Adults interviewed in April through June were also more likely to reside in homes that were owned by a resident and were more likely to have lived at their current residence for 11 or more years. These findings are consistent with the expected coverage bias resulting from the exclusion of nontelephone households. They may have also occurred because efforts to identify telephone numbers associated with sampled addresses tend to be more difficult for renters and persons who have resided at their current address for only a short time. Furthermore, among those with telephones, nonresponse to telephone surveys is also historically higher for younger adults and those with less education.[10]

To reduce biases from coverage and nonresponse and differences that arise from sampling variability, NHIS weighting procedures have always included steps that calibrate the estimates to match US Census Bureau population estimates for age, sex, race, and ethnicity; educational attainment and subnational geographical controls (census division and metropolitan statistical area classification) were added with the 2019 data year.[11] For April through

June 2020, weights were also calibrated to population estimates of housing tenure. This addition reduced, but did not eliminate, bias in key estimates when compared with prepandemic data.[9] Calibration to housing tenure continued for the rest of the 2020 data year. Data users should note that measurement biases attributable to the change from in-person to telephone interviewing—described briefly in the next section—may still exist and cannot be eliminated.

NATIONAL HEALTH INTERVIEW SURVEY, JULY–DECEMBER 2020

In-person visits to sampled NHIS households resumed in selected areas in July and in all areas by September. For the remainder of the year, Census Bureau field management closed and reopened geographies for in-person interviewing as health conditions dictated, per Centers for Disease Control and Prevention and state guidelines. Safety protocols for in-person interviewing included wearing masks, social distancing whenever possible, conducting interviews outside, not entering respondents' homes, and not allowing respondents to touch Census Bureau equipment or materials.

In addition, NHIS cases were still attempted by telephone first. In-person visits were used only to follow up on nonresponse, to deliver recruitment materials, and to conduct interviews when telephone numbers were unknown. Figure 2 shows the percentage of interviews completed by in-person visit for each month of 2020, along with the associated response rates for the overall sample.

Higher response rates do not necessarily translate to more accurate estimates, but the return to some in-person visits likely improved this quality dimension. In-person interviewing has several measurement-related strengths relative to telephone interviewing.[12] In-person interviews have less item nonresponse (including "don't know") and generate more thoughtful and complete responses (e.g., to open-ended items). Interviewers have a greater opportunity to build rapport, which can lead to more open expression and fewer erroneous "socially desirable" responses. Respondent fatigue and impatience are less likely in face-to-face settings, especially for long interviews. (The median NHIS length was 54 minutes in 2020.) In-person interviewing is also better for cognitive- and hearing-impaired respondents, not only because it avoids poor telephone connections but also because it offers visual cues to the interviewer that respondents are having difficulty understanding the questions.

Nevertheless, telephone surveying remained the primary data collection mode in the latter half of 2020. Because of concerns about the accuracy and granularity of estimates from the available sample—reduced response rates result in lower numbers of completed interviews and reduced precision, especially for subgroup estimates—NCHS sought an alternative sampling frame with known coverage properties and nearly complete telephone contact information. Starting in August and continuing through December, nearly 20 000 adult respondents who completed the 2019 NHIS were selected to be recontacted by phone and asked to

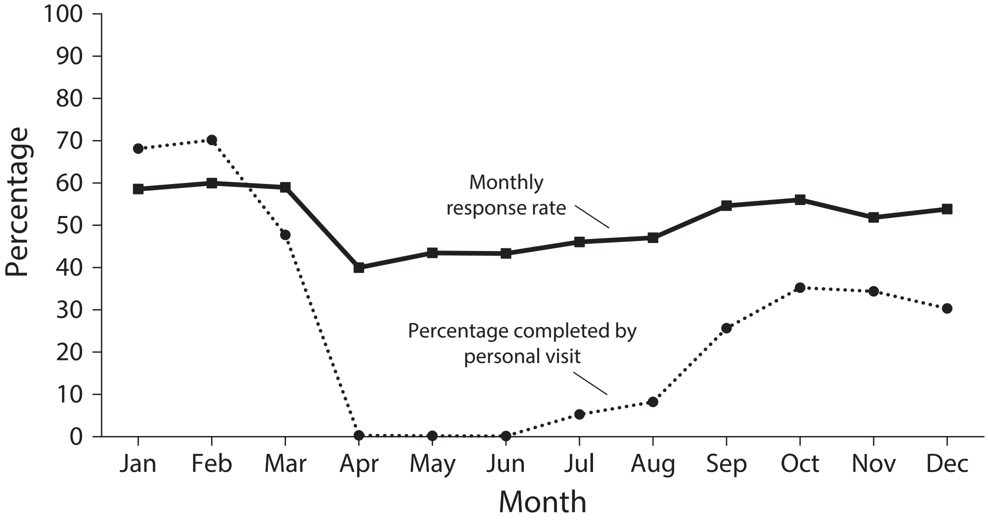

FIGURE 2— Household Response Rates and Percentage of Household Interviews Completed in Person, by Month: National Health Interview Survey, United States, 2020

participate again. Telephone numbers were available for 97% of these previously cooperative respondents, and detailed information about their health and health care in 2019 was available to permit careful examination of the impact of any nonresponse in 2020.

The completion rate for this follow-back survey was 55%. Response patterns were similar to the telephone-only sample from quarter 2. Educational attainment was the strongest predictor of successful recontact and reinterview; adults with less formal education were significantly less likely to participate. Younger adults and renters were also less likely to be reinterviewed. As for health and health care, adults reporting excellent or very good health in 2019 and adults with greater use of preventive health care (e.g., received a dental cleaning in the previous 12 months) were more likely to be reinterviewed. Each of these differences will be examined in detail in future reports. The impact of these response biases on survey estimates was reduced substantially through the inclusion of the 2019 survey responses in the nonresponse modeling and calibration stages of the weighting procedures. More information on any remaining biases (if known) will be made available when the data are publicly released.

In summary, NHIS fielded 4 designs in 2020: normal production in quarter 1, telephone-only in quarter 2, telephone first in quarters 3 and 4, and the follow-back of the 2019 respondents. All 4 designs used the same questionnaire, though the follow-back survey did not include a child interview. Across the 4 designs, approximately 31 600 adult interviews were completed, nearly the same as achieved in 2019. In 2020, about one quarter of the completed interviews were from quarter 1, one sixth from quarter 2, one quarter from the telephone-first sample in quarters 3 and 4, and one third from the follow-back. The telephone-first sample in quarters 3 and 4 had been reduced to provide the resources necessary to complete the follow-back survey. Ongoing challenges for NCHS include how to use weighting and estimation techniques to produce official 2020 estimates from these 4 disparate pieces, each with its own coverage and nonresponse issues.

The follow-back survey improves the relevance of NHIS. NCHS will publicly release follow-back data with a separate sampling weight to enable longitudinal analyses. Data users will be able to examine intraindividual changes in health, health care, and well-being from before and during the pandemic.

The relevance of NHIS for COVID-19–related data needs was also improved through new content. This content, added in July 2020, is available for both the production and follow-back respondents and continues on the 2021 NHIS questionnaire. Topics include doctor-diagnosed and testing-confirmed history of COVID-19 infection, immunosuppression, reduced access to care because of the pandemic, use of telemedicine, change in perceived social support, and the ability to maintain social distancing at work. New questions on vaccine receipt and reduced taste and smell sensitivity following COVID-19 infection were added for 2021. The 2020 data files were available publicly in fall 2021. This timeliness was the same as achieved with the 2019 data files.

NEW APPROACHES TO UNDERSTAND THE IMPACT OF COVID-19

For many data users, data availability within 1 year after the close of data collection is sufficient. But for policymakers and public health professionals who need real-time actionable information for decision-making, this timeline for processing the NHIS data and new content—not to mention the 2 to 3 months required for reprogramming and testing computerized survey questionnaires and the extended time needed for fielding interviewer-administered surveys—is too slow.

The COVID-19 pandemic re-emphasized the need for health and health care data for immediate decision-making while disrupting the legacy surveys traditionally providing such information. This demand from decision-makers and the public for current information opened the door for new data sources that could be developed and disseminated quickly. The relevance, timeliness, and accessibility dimensions of quality were favored relative to the need for gold-standard levels of accuracy. To meet this need for actionable COVID-19–related data, NCHS turned to 2 online data collection platforms: the HPS and RANDS.

HOUSEHOLD PULSE SURVEY

The HPS is a rapid-response survey, designed to be administered only online, that was developed by the US Census Bureau in collaboration with NCHS and 7 other federal agencies.[13] The goal was to take the "pulse" of the nation and ascertain the impact of the pandemic on individuals and households. Each agency was invited to include questions on the survey, and topics included employment status, capacity to telework, income loss, consumer spending, travel practices, food security, housing security, educational disruptions, and intentions to vaccinate. NCHS added questions on general health status, symptoms of generalized anxiety disorder and depressive disorders, health insurance coverage, and reduced access to health care because of the pandemic. Questions were later added on mental health care use and unmet needs. The mental health questions were selected and adapted from the 2019 NHIS questionnaire to permit comparisons with NHIS estimates from 2019.

The survey was launched with unprecedented speed for the federal statistical system. Planning for the HPS started March 23, 2020, and data collection began 1 month later with an emergency clearance from the Office of Management and Budget. Invitations to participate were sent by e-mail and text message. The sample was selected randomly from an extract of the Census Master Address File, to which mobile telephone numbers, e-mail addresses, or both were appended for 81% of addresses. The Master Address File is the file of all US housing units that is used for the decennial census. The Census Bureau was able to leverage this resource, along with existing contracts and a new software-as-service platform for rapid instrument development, to facilitate the rapid deployment of the HPS.

In the first phase of the survey, surveys were conducted online weekly for 12 straight weeks (the first "week" lasted 13 days: April 23–May 5). Over 90 days, 14 million households were invited to participate. Response rates averaged 3%, yielding about 90 000 completed surveys each week. In August 2020, the data collection periods were extended to 2 weeks to permit more reminders to be sent to nonrespondents; response rates increased to 9%. Response rates were lower in geographic areas with lower median incomes and home values.[14] Sampling weights were calibrated to national distributions of educational attainment, sex, age, race, and ethnicity. Because the data do not meet all of the Census Bureau's quality standards, they have been released with clear branding as experimental data products.

Coverage rates, response rates, and other traditional markers of accuracy may be less than ideal, but timeliness and relevance are unmatched compared with traditional household in-person surveys. The Census Bureau released data tables 8 days after the close of each data collection period. At the same time, NCHS updated online visualizations of trends in key health indicators.[15]

HPS trends have tracked in ways that may be expected given the impact of

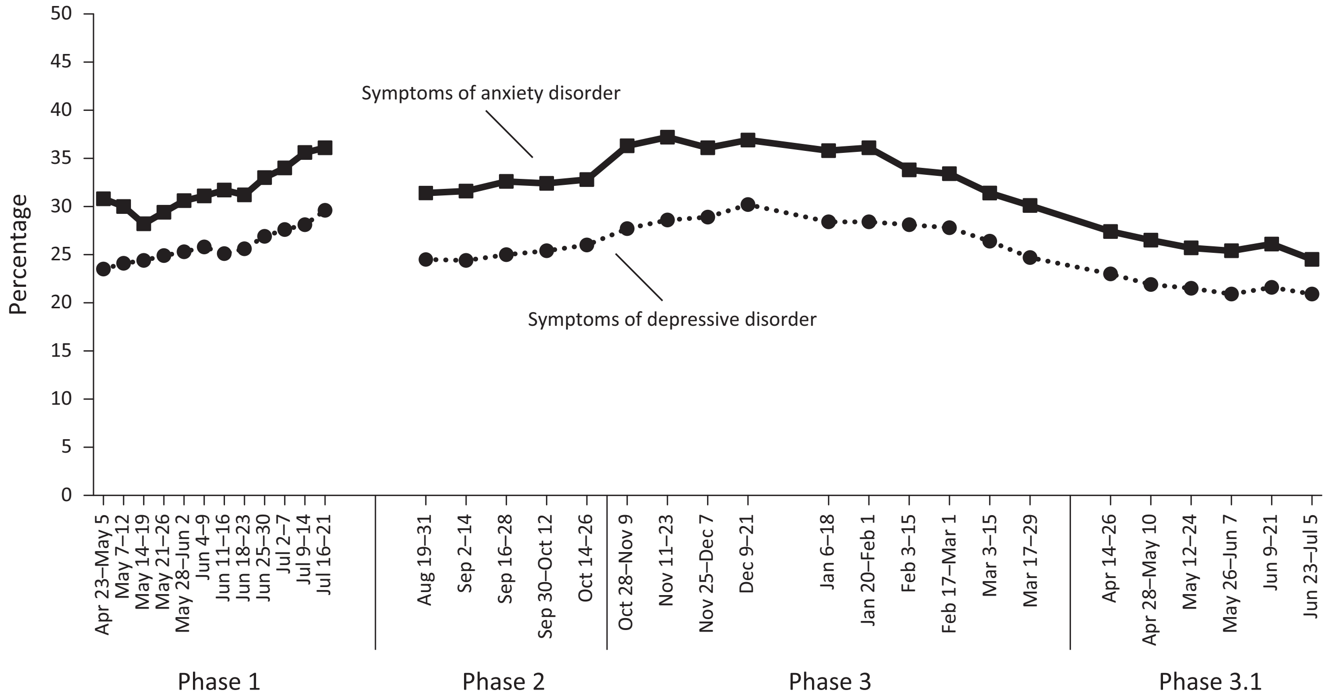

FIGURE 3— Percentage of Adults Aged 18 Years and Older With Symptoms of Anxiety or Depressive Disorders: Household Pulse Survey, United States, April 23, 2020–July 5, 2021

Note. Estimates were based on a modified version of the 2-item Patient Health Questionnaire (PHQ-2) and the 2-item Generalized Anxiety Disorder (GAD-2) scale, collecting information on symptoms over the last 7 days (rather than the typical 14 days). Data collection for phase 1 occurred from April 23, 2020–July 21, 2020; for phase 2 from August 19, 2020–October 26, 2020; for phase 3 from October 28, 2020–March 29, 2021; and for phase 3.1 from April 14, 2021–July 5, 2021. There was a break in data collection during phase 3 from December 22, 2020–January 5, 2021.

COVID-19 and other national events occurring during 2020. For example, the trends in symptoms of anxiety and depressive disorders from HPS (Figure 3) have been shown to be consistent with trends in the weekly number of reported COVID-19 cases from April to October 2020.[16,17] Similarly, HPS trends revealed a statistically significant increase in anxiety and depression symptoms among Black adults in the week following the violent death of George Floyd and the resulting protests about police conduct and racial inequity.[18] More recently, HPS data revealed a decline in the percentage of adults delaying medical care because of the pandemic, from 42% in June 2020 to 31% in October 2020,[19] and from 35% in December 2020 to 18% in May 2021.[20]

HPS data collection will continue through at least mid-October 2021. It is one of the best examples of cross-agency collaboration in recent history. HPS brought together expertise from across the federal statistical system to answer key questions about the pandemic that no one agency could have done on its own.[21]

NCHS RESEARCH AND DEVELOPMENT SURVEY

RANDS is a survey platform developed by NCHS for conducting methodological research using probability-sampled commercial survey panels.[22] These survey panels are designed to take advantage of the efficiencies in using online surveys, though other modes, such as telephone, can be used to improve data accuracy. Panel participants are recruited using statistical sampling and agree to participate in multiple surveys, typically in exchange for payment or prizes.

Since 2015, RANDS had been deployed for both questionnaire design research (e.g., detecting measurement error) and the development of innovative estimation methods (e.g., calibrating survey estimates). It had not, however, been used for dissemination of national estimates of health outcomes because of concerns that the estimates would be less accurate than those with traditional survey methods.

Traditionally, federal statistical agencies have avoided sample designs that rely on online data collection because of coverage and nonresponse concerns. There are no complete lists of e-mail addresses from which to draw a probability-based sample, not everybody has access to the Internet, and those who do not are different demographically from those who do.[23] Commercial probability-sampled survey panels improved upon these deficiencies by using telephone- or address-based recruitment of random samples and by offering Internet access or an alternative response mode to those who need it. Still, those who agree to participate in survey panels likely differ from those who do not, potentially reducing accuracy. Furthermore, as these platforms are relatively new, the accuracy of these data for key subpopulations and priority health outcomes is not as well-known as for legacy surveys such as NHIS.

Yet these platforms can be nimble and responsive, and they can collect and disseminate information quickly. The ability of RANDS to provide timely information on pandemic-related topics was demonstrated in June and August 2020.[24] RANDS used NORC's AmeriSpeak Panel to collect real-time, COVID-19–related data and disseminated findings under the name "RANDS During COVID-19." RANDS During COVID-19 surveys were completed with 6800 and 5981 panelists in June and August, respectively. Many panelists (5452) participated in both rounds. Cooperation rates were 78% and 69%; when combined with the recruitment rate to join the panel itself, response rates were 23% and 20%. Most (93%–94%) of the surveys were completed online, with the rest via telephone.

Health estimates that were approved for data release included loss of work because of illness with COVID-19, telemedicine access and use before and during the pandemic, and inability to get specific types of health care because of the pandemic. These topics were selected because they were aspects of the pandemic not being captured in detail in other government surveys. For example, as noted earlier, NHIS did not include questions on telemedicine until July 2020.

By contrast, RANDS estimates on these topics were first available in August 2020, about 1 month following data collection. The estimates were released in online tables accompanied by descriptive graphs so that the data could be readily used by decision-makers.[24] Like with HPS, RANDS During COVID-19 estimates were considered experimental. This is partly because the data collection and weighting approaches were new for NCHS, including an adjustment that calibrated the estimates to NHIS benchmarks for high cholesterol, diagnosed asthma, diagnosed hypertension, and diagnosed diabetes.[25] Research is ongoing to evaluate and improve the calibration methods and understand potential sources of measurement error.

LOOKING AHEAD

At some point, the impacts of COVID-19 on the economic, mental, and physical health of the US population will begin to recede; however, the renewed focus on the timeliness and relevance of federal health data for decision-making will not soon disappear. Even when NHIS can return to the proven survey operations that have made it a gold standard for accurate and reliable data collection, the demand is likely to continue for faster actionable data. Since 2001, NHIS has tried to meet this demand through the NHIS Early Release Program, which publishes preliminary quarterly and biannual estimates 5 to 6 months after the close of data collection.[26] For data collected during the first quarter of the year, those preliminary estimates come 9 to 12 months before final data files are publicly released. But are there ways to obtain estimates of key indicators even faster?

If so, approaches that take advantage of online data collection are likely to be part of the answer. Online data collection can be fast: HPS achieved about 90 000 responses on average each week, and estimates were available within days. Online data collection can also be nimble: questions on newly relevant topics can be added and fielded quickly with established commercial survey panels, as demonstrated by RANDS During COVID-19. However, without supplemental methods (such as telephone interviews) that increase costs and reduce timeliness, online data collection will not reach populations with limited Internet access or without technological devices.[23] Can data collected with these methods be sufficiently accurate for official statistics?

Model-based approaches may be the answer. Statistical models that combine the accuracy of gold-standard surveys with the timeliness and relevance of online data collection with commercial probability-sampled survey panels are promising. Propensity-score models and other approaches developed for nonprobability surveys can be used to develop improved sample weights.[25,27–29] Yet highly accurate estimates from online data collection are not essential. Trends may be reliable even if accuracy is subpar. More-complex models that combine the trends and associations available from timelier online data collections with the more accurate, yet older, baseline levels from gold-standard surveys may be useful for developing predictions or "nowcasted" estimates.

With such models, data collected online in parallel with NHIS could be used for advance estimates of key indicators from NHIS. There is precedence for such an approach in economics. Advance estimates of the gross domestic product are released 1 month after each calendar quarter, using the best available information but subject to change in the second and third estimates released later.[30] Earlier estimates incorporate more statistical modeling and have greater uncertainty than later estimates, but they are still considered useful as a gauge for informing users about the likely direction and magnitude of change in a key indicator of the health of the economy.

Online data collection with commercial survey panels will not replace NHIS or any other major NCHS surveys. Accuracy remains a critical marker of quality for federal data and is the most important quality dimension for many data users. But rather than limiting the use of online data collection with commercial survey panels to research and evaluation, NCHS is cautiously looking at how these panels can complement current data collection methods. Improving timeliness is a major focus, but increasing relevance and the scope of information, as well as the granularity of NCHS statistical products, is key as well.

NCHS will continue to rely on its current gold-standard collections as benchmarks to help judge the objectivity and utility of model-based estimates. The research will be done in a careful, deliberate, strategic, and transparent way. Data sources will be validated, assumptions reviewed, and model output checked. The accuracy of the resulting estimates will be carefully evaluated and, in the beginning, will be labeled experimental. Data users will need to assess the fitness of the estimates for their specific use.

Ultimately, NCHS will not impose unnecessary risks that might undermine trust in its statistics; after all, credibility of the data producer is an important dimension of quality. However, the optimal level of risk is not zero. NCHS will strive for a renewed balance between being cautious and releasing the right data at the right time for evidence-based policymaking needs, informed by its experiences with data collection and dissemination during the COVID-19 pandemic. AJPH

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CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

HUMAN PARTICIPANT PROTECTION

The surveys described are surveillance activities excluded from the regulatory requirements of 45 CFR 46.

REFERENCES

1. National Committee on Vital and Health Statistics. Shaping a health statistics vision for the 21st century. Washington, DC: US Department of Health and Human Services; 2002.
2. Office of Management and Budget. Statistical policy directive no. 1: fundamental responsibilities of federal statistical agencies and recognized statistical units. *Fed Regist.* 2014;79: 71609–71616.
3. Federal Committee on Statistical Methodology. A framework for data quality. FCSM 20-04. September 2020. Available at: https://nces.ed.gov/fcsm/pdf/FCSM.20.04_A_Framework_for_Data_Quality.pdf. Accessed February 12, 2021.
4. Information Quality Act, Pub L No. 106-554, § 515(a) (2000).
5. Federal Committee on Statistical Methodology. Measuring and reporting sources of error in surveys (Statistical Policy Working Paper 31). Washington, DC: US Office of Management and Budget; 2001.
6. Biemer PP. Total survey error: design, implementation, and evaluation. *Public Opin Q.* 2010;74(5): 817–848. https://doi.org/10.1093/poq/nfq058
7. Gentleman JF. The National Health Interview Survey: 50 years and going strong. *Chance.* 2008; 21(2):40–45. https://doi.org/10.1080/09332480.2008.10722902
8. National Center for Health Statistics. Survey description, National Health Interview Survey, 2019. September 2020. Available at: https://ftp.cdc.gov/pub/Health_Statistics/NCHS/Dataset_Documentation/NHIS/2019/srvydesc-508.pdf. Accessed February 12, 2021.
9. Dahlhamer JM, Bramlett MD, Maitland A, Blumberg SJ. Preliminary evaluation of nonresponse bias due to the COVID-19 pandemic on National Health Interview Survey estimates, April–June 2020. National Center for Health Statistics. February 2021. Available at: https://www.cdc.gov/nchs/data/nhis/earlyrelease/nonresponse202102-508.pdf. Accessed February 12, 2021.
10. Thornberry OT Jr. An experimental comparison of telephone and personal health interview surveys. *Vital Health Stat 2.* 1987;(106):1–4.
11. Bramlett MD, Dahlhamer JM, Bose J, Blumberg SJ. New procedures for nonresponse adjustments to the 2019 National Health Interview Survey sampling weights. National Center for Health Statistics. September 2020. Available at: https://ftp.cdc.gov/pub/Health_Statistics/NCHS/Dataset_Documentation/NHIS/2019/nonresponse-report-508.pdf. Accessed June 5, 2021.
12. Shuy RW. In-person versus telephone interviewing. In: Holstein J, Gubrium JF, eds. *Inside Interviewing: New Lenses, New Concerns*. Thousand Oaks, CA: Sage; 2003:174–193.
13. Fields JF, Hunter-Childs J, Tersine A, et al. Design and operation of the 2020 Household Pulse Survey, 2020. US Census Bureau. Available at: https://www2.census.gov/programs-surveys/demo/technical-documentation/hhp/2020_HPS_Background.pdf. Accessed February 12, 2021.
14. Peterson S, Toribio N. Nonresponse bias report for the 2020 Household Pulse Survey. US Census Bureau. March 24, 2021. Available at: https://www2.census.gov/programs-surveys/demo/technical-documentation/hhp/2020_HPS_NR_Bias_Report-final.pdf. Accessed April 5, 2021.
15. National Center for Health Statistics. COVID-19 data from NCHS: health care access and mental health. Available at: https://www.cdc.gov/nchs/covid19/health-care-access-and-mental-health.htm. Accessed February 12, 2021.
16. Vahratian A, Blumberg SJ, Terlizzi EP, Schiller JS. Symptoms of anxiety or depressive disorder and use of mental health care among adults during the COVID-19 pandemic—United States, August 2020–February 2021. *MMWR Morb Mortal Wkly Rep.* 2021;70(13):490–494. https://doi.org/10.15585/mmwr.mm7013e2
17. Sebenius I. Anxiety and depression are following a remarkably similar curve to Covid-19 cases. *Vox*. December 15, 2020. Available at: https://www.vox.com/22174464/covid-cases-anxiety-depression-mental-health. Accessed February 12, 2021.
18. Fowers A, Wan W. Depression and anxiety spiked among black Americans after George Floyd's death. *Washington Post*. June 12, 2020. Available at: https://www.washingtonpost.com/health/2020/06/12/mental-health-george-floyd-census. Accessed February 12, 2021.
19. Findling MG, Blendon RJ, Benson JM. Delayed care with harmful health consequences—reported experiences from national surveys during coronavirus disease 2019. *JAMA Health Forum*. 2020;1(12):e201463. https://doi.org/10.1001/jamahealthforum.2020.1463
20. National Center for Health Statistics. COVID-19 data from NCHS: reduced access to care. Available at: https://www.cdc.gov/nchs/covid19/pulse/reduced-access-to-care.htm. Accessed June 5, 2021.
21. Interagency Council on Statistical Policy. Statistical agency changes in response to the COVID-19 pandemic. January 15, 2021. Available at: https://www.bea.gov/system/files/2021-01/ICSP-COVID-19-Report_011521.pdf. Accessed February 12, 2021.
22. He Y, Cai B, Shin H-C, et al. The National Center for Health Statistics' 2015 and 2016 Research and Development Surveys. *Vital Health Stat 1*. 2020;(59):1–60.
23. Perrin A, Atske S. 7% of Americans don't use the internet. Who are they? Pew Research Center. April 2, 2021. Available at: https://pewrsr.ch/2GrhLUj. Accessed June 5, 2021.
24. National Center for Health Statistics. COVID-19 data from NCHS: health care access, telemedicine, and loss of work due to illness. Available at: https://www.cdc.gov/nchs/covid19/rands.htm. Accessed February 12, 2021.
25. Irimata KE, He Y, Cai B, Shin H-C, Parsons VL, Parker JD. Comparison of quarterly and yearly data for propensity score adjusted web survey estimates. *Surv Methods Insights Field*. 2020; epub ahead of print October 12, 2020. https://doi.org/10.13094/SMIF-2020-00018
26. National Center for Health Statistics. National Health Interview Survey Early Release Program. Available at: https://www.cdc.gov/nchs/nhis/releases.htm. Accessed February 12, 2021.
27. Lee S. Propensity score adjustment as a weighting scheme for volunteer panel web surveys. *J Off Stat.* 2006;22(2):329–349.
28. Lohr SL, Raghunathan TE. Combining survey data with other data sources. *Stat Sci.* 2017;32(2): 293–312. https://doi.org/10.1214/16-STS584
29. Schenker N, Raghunathan TE. Combining information from multiple surveys to enhance estimation of measures of health. *Stat Med.* 2007;26(8): 1802–1811. https://doi.org/10.1002/sim.2801
30. Bureau of Economic Analysis. Measuring the economy: a primer on GDP and the national income and product accounts. December 2015. Available at: https://www.bea.gov/sites/default/files/methodologies/nipa_primer.pdf. Accessed February 12, 2021.

Adapting Survey Data Collection to Respond to the COVID-19 Pandemic: Experiences From a Local Health Department

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See also Lau et al., p. 2085.

The New York City (NYC) Department of Health and Mental Hygiene ("Health Department") conducts routine surveys to describe the health of NYC residents. During the COVID-19 pandemic, the Health Department adjusted existing surveys and developed new ones to improve our understanding of the impact of the pandemic on physical health, mental health, and social determinants of health and to incorporate more explicit measures of racial inequities.

The longstanding Community Health Survey was adapted in 2020 to ask questions about COVID-19 and recruit respondents for a population-based severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) serosurvey. A new survey panel, Healthy NYC, was launched in June 2020 and is being used to collect data on COVID-19, mental health, and social determinants of health. In addition, 7 Health Opinion Polls were conducted from March 2020 through March 2021 to learn about COVID-19–related knowledge, attitudes, and opinions, including vaccine intentions.

We describe the contributions that survey data have made to the emergency response in NYC in ways that address COVID-19 and the profound inequities of the pandemic. (*Am J Public Health*. 2021;111(12): 2176–2185. https://doi.org/10.2105/AJPH.2021.306515)

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On March 16, 2020, Division of Epidemiology staff in the New York City (NYC) Department of Health and Mental Hygiene ("Health Department") who design and implement surveys left coffee cups on desks and sweaters on chairs and rapidly prepared to begin working from home because of the COVID-19 pandemic. Our immediate goal was to sustain survey operations for routine Health Department public health surveillance and add questions about COVID-19 to our annual survey of adults. As the pandemic exposed the various ways that systemic racism contributed to higher risk of COVID-19 illness and death in Black, Latino, and Indigenous communities,[1] the country also witnessed the killings of Breonna Taylor and George Floyd. Daily protests against racial inequity and police brutality swept the city, and racism was named nationwide as a public health issue.[2] The Health Department has taken steps during the COVID-19 pandemic to adjust existing surveys and develop new ones to improve our understanding of the impact of the pandemic on physical health, mental health, and social determinants of health and to incorporate more explicit measures of racial inequities.

NEW YORK CITY COMMUNITY HEALTH SURVEY

When the first COVID-19 case was detected in NYC on February 29, 2020,[3] the 2020 Community Health Survey (CHS) had been in the field for just over a month. The CHS is an annual multilingual surveillance survey of adults that measures health and risk behaviors.[4] This survey was telephone based from

2002 to 2020 and has been widely used to guide policy and programming,[5,6] inform the public about the health of NYC residents,[7,8] and answer research questions.[9] The CHS is used to measure health inequities by demographic characteristics[10] and by neighborhood[11] and to measure changes over time.[12] When the first COVID-19 case was detected in NYC, 2 immediate goals developed: (1) how to ensure continuity of survey operations and maintain data to inform trend analyses, and (2) how to adapt the CHS to inform the emergency response.

Adapting Operations

The primary hurdle to operating the CHS during the pandemic was the telephone interview process. Historically, a contracted vendor had conducted CHS interviews on landlines and later cell phones[13] in physical call centers. The COVID-19 pandemic made it impossible to safely continue call center operations because of the inability to socially distance in centers such as these.[14] The Health Department and its contractor worked together to revise protocols to allow interviewers to work from home by having access to equipment, connectivity, security, and a private space. By the third week of March 2020, virtual call centers were established. Once interviewers began working from home, the vendor and the Health Department continued their standard practice of monitoring telephone interviews to ensure data quality. The survey vendor calculated predictive margins[15] to compare responses to a selection of survey questions among respondents, controlling for the demographic characteristics of the respondent and whether the survey interview was conducted in a physical versus virtual call center.

On several key health indicators, but not all, calls made from the virtual versus physical call centers did not yield statistically different estimates.[16] Another indicator that the shift to virtual call centers was not detrimental was the survey response rates. At the beginning of data collection in early February 2020, CHS response rates were less than 8%. By April 14, they had risen to greater than 10%, where they remained through early August. By contrast, from April through August 2019, CHS response rates approached only 8% in May and never rose higher than 8% (Figure 1). The final 2020 response rate was 7.4%, very similar to the 7.2% response rate in 2019 when all interviews were conducted in physical call centers.

Adapting Questionnaire Content

The Health Department recognized during the early days of the pandemic that the CHS representative sample design could be used to collect COVID-19 burden of disease data. However, the survey needed to be adapted in 2 ways. First, the questionnaire was finalized in November 2019, but we needed to add COVID-19–related questions. We developed questions capturing respondent symptoms in the past 30 days that were consistent with COVID-19–like illness (CLI),[17] as well as questions about underlying conditions and health care–seeking behavior. Among households with children, we asked adult respondents about CLI symptoms of a randomly selected child aged 0 to 17 years in their household. On March 20, 2020, we initiated the CHS COVID-19 module. We adapted the COVID-19 module in subsequent months as knowledge emerged about COVID-19 symptoms, racial inequities in morbidity and mortality, and impacts of the pandemic on social and economic security.[18–20] For example, we added questions about loss of smell and taste, symptoms strongly associated with COVID-19,[21] broadened a question about experiencing discrimination in connection to COVID-19 from being asked only of respondents who had experienced symptoms to all respondents, and added a question about job loss owing to the pandemic.

Adapting Survey Weights

A second adaptation of the CHS was the creation of special survey weights. In a typical year of CHS data collection, 1 set of weights is created to enhance the representativeness of the data. For the COVID-19 questions, however, more sample weights were needed, including a weight of all respondents who completed the survey in a calendar month, a cumulative weight, and a weight to enable monthly estimates of people with new symptom onset for a given month. This last weight included respondents interviewed in a given month, as well as those interviewed for the subsequent 30 days, because the survey asked about symptoms within the past 30 days. Respondents were given greater weight for the proportion of their 30-day look-back period that occurred in the month of interest, in order to estimate monthly incidence of a new onset of symptoms.[17] Although this weighting approach could have introduced bias if the COVID-19 case rate changed from week to week, respondents who were interviewed later in any given month were unlikely to differ in other dimensions from

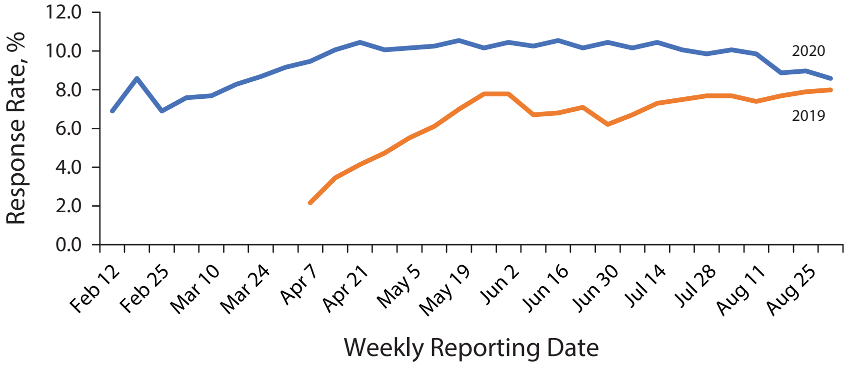

FIGURE 1— **Community Health Survey Response Rates: NYC, 2019 and 2020**

Note. NYC = New York City. We calculated response rates using the American Association for Public Opinion Research Response Rate #3 calculation for combined landline and cell phones, except in February 12–March 3, 2020, when only cell phones were dialed. In addition, the dates shown represent 2020 dates of reporting; 2019 dates were reported on slightly different days, almost always within 2 days of the 2020 dates. In 2019, data collection did not begin until March, and therefore data are not available for earlier months.

those interviewed earlier because the CHS was a random-digit dialing telephone survey.

HEALTHY NYC

Data collection for the 2020 CHS concluded on August 31, and we needed to find a different format for collecting COVID-19 data starting in September 2020. Before the COVID-19 pandemic, the Health Department had started to plan the creation of a probability-based panel of survey respondents that could facilitate Health Department survey research. Although panels have limitations, including possible panel attrition,[22] by drawing on an engaged group of panel members who have already agreed to participate in surveys, survey panels offer a timely and cost-effective option for public health surveillance, as they decrease recruitment costs and increase response rates.[23] In fall 2019, we started to investigate survey software programs to facilitate survey administration and panel maintenance and developed a sampling methodology. Most participants would be recruited through an address-based sample, which would be supplemented by participants in previous probability-based Health Department surveys who had agreed to be recontacted.

The pandemic posed an urgent need for the Health Department to establish the new Healthy NYC panel so that monthly COVID-19 data collection could continue. Healthy NYC would also enable more in-depth exploration of occupational risk factors, the mental health burden of COVID-19, and racial inequities in COVID-19 prevalence, testing, and morbidity.[24] A grant to build epidemiology and laboratory capacity from the Centers for Disease Control and Prevention helped support the launch of Healthy NYC.

We initially planned to conduct Healthy NYC surveys online, with paper surveys sent by mail to nonresponders. However, because staff were working from home, we did not have staff in the office to process questionnaires. Therefore, we created a virtual telephone call center for respondents who were unable or unwilling to use the Internet. We trained 25 Health Department staff to conduct surveys by telephone and enter data into an online data capture system. After recruitment efforts in June and September 2020, Healthy NYC had 9315 panelists by January 2021.

Healthy NYC was particularly suited to supporting the emergency response because the Health Department would fully manage and operate data collection, aside from using contracted survey software and incentive distribution. Moving most work in-house rather than using vendors enabled the Health Department to be nimble in survey administration. City government contracting processes start long before a project begins and do not allow much flexibility once they are in place. By moving away from vendors and contracts, we were able to quickly implement surveys and adapt them when the pandemic evolved.

Questionnaire Development

In August 2020, we conducted the first survey among Healthy NYC panelists, a COVID-19 survey that mirrored the COVID-19 module in the CHS. This survey was implemented concurrently with the last month of CHS 2020 data collection, which enabled us to compare the CHS-based and Healthy NYC–based estimates. The different survey modes and sampling frames between the 2 surveys produced similar estimates of CLI incidence, defined as CLI symptoms starting on August 1 or later (4.3% CHS; 5.7% Healthy NYC; $P > .05$). However, Healthy NYC yielded higher estimates of CLI prevalence than did CHS, where prevalence was defined as CLI symptoms during the past 30 days, irrespective of the date of symptom onset (10.8% CHS; 18.1% Healthy NYC;

$P < .05$).[25] It is possible that survey respondents felt more comfortable affirming symptoms of COVID-19 in the predominantly Web-based Healthy NYC than in the telephone-based CHS because of Web surveys raising fewer concerns about social desirability[26] or contact tracing.

In September, we continued to revise the COVID-19 questions to improve measurement of CLI. For example, we asked respondents about symptom onset in the last calendar month instead of the past 30 days to improve and simplify weighting and incidence calculations. We revised symptom questions to align with the updated interim case definition from the Council of State and Territorial Epidemiologists for CLI.[27] We removed questions about children living with survey respondents because of small sample sizes and to shorten the survey. As evidence emerged that some COVID-19 patients were experiencing prolonged symptoms after COVID-19 infection, we added questions to assess prevalence of "long COVID."[28]

The transition of COVID-19 data collection from CHS to Healthy NYC also enabled us to include questions to better capture inequities, social determinants of health, and mental health consequences of COVID-19. For example, early in the pandemic it was apparent that hospital workers and frontline essential workers were contracting COVID-19 at higher rates than was the general public.[29] We added questions to capture respondents' occupation and industry, as well as questions about the use of public transportation, ability to maintain distance from others at work, and interactions with patients in health care settings. These data will allow us to measure the association between employment risk factors and CLI or severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) seropositivity.

We also conducted a Healthy NYC survey focused on mental health that asked about respondents' emotions; symptoms of depression and anxiety; sources of stress, loneliness, and mental health care; and their children's mental health. This survey expanded on the CHS questions on mental health, which were limited to the Kessler 6 distress scale[30]; questions about having received medication or counseling; and questions about unmet mental health care need. In addition, building on a 2017 survey about social determinants of health that included questions about experiences of discrimination, social relationships, material hardship, and other topics,[31] we conducted a similar survey in 2020 with the new panel, adding questions about whether health care appointments were missed because of fear of the virus or lack of provider availability owing to the pandemic and social isolation in the context of the pandemic.

Implementing a Serosurvey

As the pandemic evolved, interest grew in measuring the proportion of the NYC population who may have ever had a SARS-CoV-2 infection. In June 2020, the Health Department began recruitment from the CHS for a population-based serosurvey to measure SARS-CoV-2 antibody prevalence among NYC adults. We contracted with a vendor to schedule appointments and send phlebotomists to participants' homes to collect blood specimens. Specimens were tested at the Health Department Public Health Laboratory. We aimed to recruit a minimum of 1000 participants for specimen collection from June through October; however, only 497 survey respondents consented to participate and completed the blood draw. By mid-June, recognizing that the response rate was lower than anticipated, we added a $30 gift card incentive. Before the incentive went into effect, 27.1% of CHS participants agreed to be contacted for the serosurvey; by the end of the CHS data collection period, 31.4% had agreed to be contacted. In addition, we developed a hybrid approach for determining whether respondents had SARS-CoV-2 antibodies: we used serosurvey data from those who provided blood and self-reported data from those who did not but provided a self-reported antibody test result.[32]

We conducted our second population-based SARS-CoV-2 serosurvey via Healthy NYC from November 2020 through February 2021. Participants were recruited from Healthy NYC respondents who answered the COVID-19 survey questions. Having already learned from the CHS that serosurvey recruitment was lower than expected, we included a question in the COVID-19 module of Healthy NYC surveys administered from August through October asking whether the respondent would be willing to be contacted during the upcoming year to participate in the serosurvey, so our sample would not be limited to respondents beginning in November. Of the 7629 people who were invited to take Healthy NYC surveys that included serosurvey recruitment, 1929 agreed to participate and 763 completed the blood draw. Although the respondents who had their blood drawn may be different from those who did not, we have mitigated possible bias by creating survey weights to adjust for differences between serosurvey participants and the NYC adult population and for differences between respondents and nonrespondents.

POLLING ABOUT COVID-19

In 2019, the Health Department launched a new Health Opinion Poll (HOP) to capture NYC residents' health-related knowledge, opinions, and attitudes. Five surveys had been conducted by the time the COVID-19 emergency began. Adult respondents were quota-sampled from nonprobability online panels through a vendor and weighted per American Community Survey 5-year estimates to match the NYC population on county, race/ethnicity, age, sex, and educational attainment. Recognizing the importance of opinion data as a complement to case-based surveillance and population surveys, we conducted 6 polls in 2020. These surveys assessed knowledge about COVID-19 transmission and prevention, awareness of information sources about COVID-19 and trust in those sources, adherence to social distancing and face-covering guidelines, opinions about NYC's efforts to contain the outbreak, concerns about contact tracing and quarantine guidelines, attitudes toward vaccination and testing, experiences of discrimination, and the impact of the pandemic on health care access, physical activity, mental health,[33] financial stress, household food security, and children's behavioral and emotional health.

These data have illustrated the inequities in New Yorkers' experiences throughout the pandemic. For example, in October 2020, anxiety was more commonly reported among respondents in higher poverty neighborhoods than in lower poverty neighborhoods, and financial stress was more common among Latino and Black respondents than among White respondents.[34] HOP data have been particularly essential to guiding the Health Department in its efforts to implement a COVID-19 vaccination campaign (Table 1).

In March 2021 HOP was conducted for the first time through the Healthy NYC panel. One methodological challenge that emerged as HOP data collection transitioned from a vendor's nonprobability online panels to the Health Department's probability-based panel was how to interpret changes in estimates over time. For example, in December 2020, using the nonprobability panels, we found that 55.3% of NYC adults intended to be vaccinated. In March 2021, using the Healthy NYC panel, we found that 81.6% of adults had already been or intended to be vaccinated.[35] Because of the difference in sampling frames between the December and March polls, it is difficult to know the extent to which this change over time is attributable to survey methodology versus a true attitudinal shift or vaccine availability. Future HOPs using Healthy NYC will allow us to examine trends over time.

HEALTH DEPARTMENT SURVEYS IN 2021

During the second year of the COVID-19 pandemic, the Health Department is continuing to collect survey data to support the emergency response. The CHS began data collection in March 2021, and it includes the COVID-19 module as well as recruitment for a third SARS-CoV-2 serosurvey. To account for the effect of vaccination, the third serosurvey asks whether respondents have been vaccinated, the number of doses they should have received, and the number and timing of doses they actually received. Another survey, NYC KIDS, is a biennial survey that was telephone based in 2017 and 2019 and collects data from a parent or guardian about children aged 1 to 13 years. The survey is being conducted in NYC on schedule in 2021 using new sampling frames and survey modes and includes questions on CLI symptoms and health care–seeking behavior, as well as questions about CLI in a randomly selected child aged 14 to 17 years among households that have a child in that age range. The high school and middle school Youth Risk Behavior Surveys, planned for fall 2021 and 2022, respectively, will also include questions capturing how the pandemic has affected youths.

In addition, a central effort of our surveillance surveys is to measure and describe pandemic-related inequities. The health inequities of the COVID-19 pandemic and its economic outcomes, combined with continued police violence toward Black and Latino NYC residents, have further exposed systemic racism in NYC.[34] In an effort to measure the public health crisis of racism,[2] social and economic insecurity, and mental health need, our surveys include questions that assess the mental health and socioeconomic impacts of the pandemic for children, adolescents, and adults. For example, our surveys ask about topics such as food and housing insecurity, financial stress, emergency childcare arrangements for essential workers, and technology access for students during remote learning.

Healthy NYC is fielding regular surveys measuring vaccine attitudes, access, and uptake, and the data are

TABLE 1— Description of COVID-19 Vaccine-Related Data Collected and How Data Have Been and Will Be Used to Inform the Health Department's COVID-19 Vaccine Rollout: NYC Health Opinion Poll; October and December 2020

Data Collected	How Data Have Been and Will Be Used
COVID-19 vaccine intentions (evaluated at multiple time points)	Evaluation over time of the impact of vaccine availability, vaccination campaigns, and promotional messages on vaccine acceptance Identification of groups that may benefit from tailored promotional messages
Reasons people are or are not getting COVID-19 vaccines	Creation of promotional messages to be used in a citywide vaccination campaign Development of community engagement strategies
Preferences for which populations should receive early limited doses of vaccine	Development of communication to explain prioritization decisions where they are not aligned with NYC residents' preferences Preparation for vaccine rollout Planning for gathering further public input about prioritization
Preferences for where to receive a COVID-19 vaccine	Informing decisions on vaccine allocation to vaccination sites during the distribution phase in which there is wide public availability
Trusted sources to increase comfort level in receiving a COVID-19 vaccine	Development of promotional messages and community-based partnerships Understanding of potential influence of Health Department messaging Communication to providers emphasizing their role in providing vaccine recommendations to increase uptake Identifying trusted messengers

Note. NYC = New York City.

being analyzed by race/ethnicity of respondents. Additionally, the Health Department has added more questions about racial and ethnic heritage or ancestry groups to improve our ability to provide data for specific groups. Healthy NYC, NYC KIDS, and CHS currently include questions about Asian, Black, and Latino heritage or ancestry, and the 2021 NYC KIDS and CHS surveys additionally include questions about Middle Eastern/North African and Native American heritage or ancestry. For the first time, the High School Youth Risk Behavior Survey planned for 2021 will include detailed Asian and Latino heritage or ancestry questions. These changes will provide more complete data to measure potential health and racial inequities associated with the COVID-19 pandemic.

COVID-19 has also reinforced the need to confront decades of distrust toward the government in communities of color, including how we build trust with survey participants. HOP data show that in December 2020, 56.6% of Asian/Pacific Islander, 33.2% of Black, 51.4% of Latino, and 50.5% of other or multiracial respondents planned to get the COVID-19 vaccine, compared with 72.5% of White respondents (Table 2),[35] a disparity likely rooted, in part, in medical mistrust.[36] By March 2021, the gap between race/ethnicity groups had attenuated, with 87.6% of Asian/Pacific Islander, 77.1% of Black, 77.5% of Latino, 74.1% of other or multiracial, and 86.6% of White respondents having received or planning to receive the vaccine.[35] The HOP also recorded racial/ethnic differences in willingness to share information on close contacts with contact tracers, concerns about racial discrimination during contact tracing, and concerns about protection from law enforcement and immigration officials during contact tracing (Table 2). To provide transparency and build trust among survey participants, we have continued to write survey recruitment materials with the goal of making respondents feel protected as research participants, focusing on our commitment to protecting privacy.

LIMITATIONS AND CONCLUSIONS

The NYC Health Department has updated and transformed our survey-based surveillance efforts to support the COVID-19 emergency efforts through surveys that cover the lifespan of New York City residents (Figure 2). This has included adapting existing surveys, developing new ones, and creating a unique panel of NYC residents to take periodic surveys. Combined, these efforts have provided important data on the burden of CLI in NYC and highlighted the racial and ethnic inequities and collateral consequences of the pandemic, ranging from economic stress to mental health. Although the COVID-19 public health emergency presented a large disruption, Health Department staff were able to sustain

TABLE 2— Indicators of Distrust in Contact Tracing and the COVID-19 Vaccine: NYC, 2020

Question	%	P
If you were diagnosed with COVID-19, would you share with a NYC contact tracer a list of people you have been in close contact with? (% responding "yes, all contacts")[a]		
Overall	81.0	
Race/ethnicity		
Asian/Pacific Islander	72.7	<.01
Black	78.7	.01
Latino/a	80.8	.03
Other/multiracial	66.1	.04
White (Ref)	87.3	
When it comes to contact tracing and receiving support services for people who are exposed to COVID-19, how concerned are you that you might be treated disrespectfully, receive lower quality services, or be discriminated against in another way based on your race/ethnicity? (% responding "very or somewhat concerned")[b]		
Overall	55.2	
Race/ethnicity		
Asian/Pacific Islander	73.6	<.01
Black	62.8	<.01
Latino/a	59.7	<.01
Other/multiracial	61.9	.02
White (Ref)	38.4	
If a NYC contact tracer reached out to you, how confident are you that your personal information would be protected from law enforcement and immigration officials? (% responding "Not confident at all")[b]		
Overall	18.2	
Race/ethnicity		
Asian/Pacific Islander	23.4	.03
Black	22.6	.02
Latino/a	16.5	.4
Other/multiracial	25.8	.23
White	13.9	Ref
When a coronavirus vaccine becomes available to you, will you get vaccinated? (% responding "yes")[35,a]		
Overall	55.3	
Race/ethnicity		
Asian/Pacific Islander	56.6	<.01
Black	33.2	<.01
Latino/a	51.4	<.01
Other/Multiracial	50.5	.03
White	72.5	Ref

Note. NYC = New York City. Race and ethnicity groups are mutually exclusive, so individuals who identify as Latino/a are in the Latino/a group, regardless of race selected. We used 2 sample z tests to test for differences between groups, testing the null hypothesis that the proportions are equal at a 95% confidence level.

[a] Data source: NYC Health Opinion Poll, December 2020, NYC Department of Health and Mental Hygiene.
[b] Data source: NYC Health Opinion Poll, October 2020, NYC Department of Health and Mental Hygiene.

survey operations while adapting practices to meet rapidly evolving safety standards and the need to flexibly adapt surveys in support of the Health Department's COVID-19 response.

Survey data have been particularly valuable in complementing traditional surveillance mechanisms during this emergency response for several reasons. First, administrative data measuring COVID-19 test results, emergency department and hospital visits, and deaths do not capture the percentage of the population who had symptoms of COVID-19 and did not seek

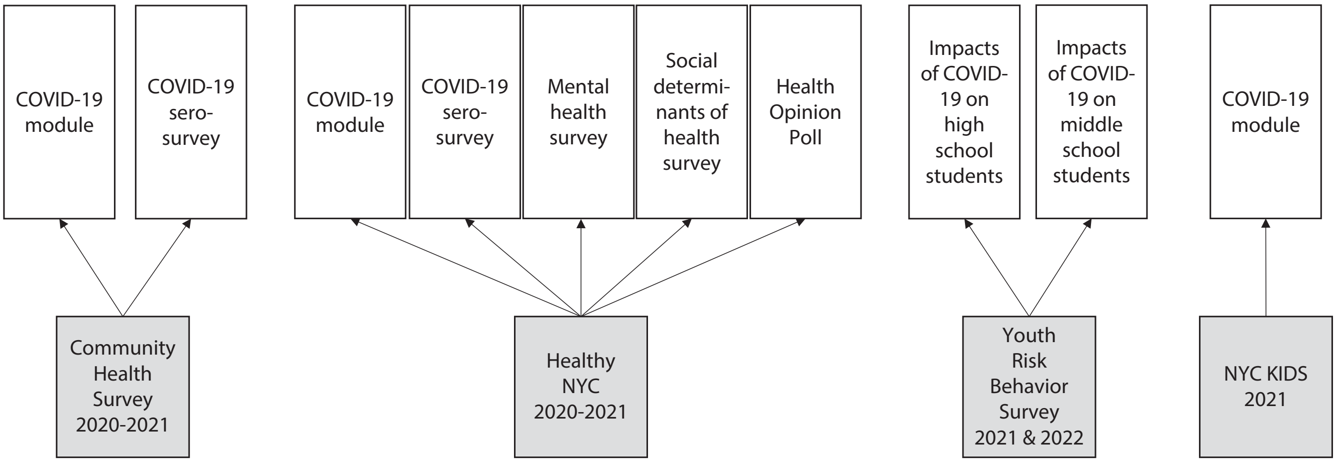

FIGURE 2— **Adapting and Adding to Health Department Surveys to Address the COVID-19 Pandemic: NYC, 2020–2022**

Note. NYC = New York City.

care or testing, which our COVID-19 surveys have been crucial in establishing.[17] Second, administrative data do not capture COVID-19–related experiences of discrimination, social and economic insecurity, and mental health, which our surveys were uniquely equipped to measure. Our survey data were especially helpful complements to administrative data because administrative data tend to have a great deal of missing race/ethnicity data,[37] unlike our surveys, which have the benefit of being self-reported and have low amounts of missing data in these fields. Finally, as our local government implemented a range of approaches to addressing the COVID-19 public health emergency, our surveys enabled policymakers to receive input from the public about their knowledge, attitudes, and opinions about the emergency and the public health interventions implemented to address it.

Our survey efforts have been limited by several factors. First, the speed at which the pandemic evolved and the inability to work with people in person have made it challenging to implement our typical approaches to questionnaire design. Under nonpandemic conditions, we conduct extensive cognitive testing of survey questions. During the pandemic, we have been more limited in our ability to conduct cognitive testing for the HOP surveys and have increased our reliance on expert review of questionnaires.

Second, the first 6 HOP surveys used nonprobability panels. These can have respondent bias, which we tried to mitigate through quota sampling and weighting. Beginning in March 2021, we implemented the HOP through our probabilistically sampled Healthy NYC panel.

Third, surveys cannot be limitless in length because of respondent fatigue, and therefore the added focus on COVID-19 in HOP came at the expense of questions about other topics.

Fourth, although we have continued routine surveillance data collection about non–COVID-19 health issues, given the disruptions that COVID-19 has caused in NYC, we will not know if any differences we see are attributable to actual changes over time or survey methodology features.

Finally, in the Healthy NYC panel, New Yorkers who were not accessible through the address-based sample frame because of circumstances such as homelessness, incarceration, or living outside New York City at the time that Healthy NYC recruitment invitations were sent did not have the opportunity to be included.

Surveys have played an important role in the Health Department's emergency response to COVID-19. By adapting to unexpected circumstances and modifying operations, the Health Department has seized this moment as an opportunity to collect COVID-19 symptom-based data and data on the social context of COVID-19 and its impact on people's well-being. Additionally, the societal dialogue on racism during the pandemic served as a further impetus to strengthen how we collect data on race/ethnicity and social determinants of health. The lessons we learned about how to be more nimble and flexible in data collection, and the new data collection systems we have established, will help the Health Department better respond to future public health emergencies and continue to address the unequal impacts of the pandemic.

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CONFLICTS OF INTEREST

There are no conflicts of interest to declare.

HUMAN PARTICIPANT PROTECTION

The New York City Health Department institutional review board reviewed all surveys. The Community Health Survey, NYC KIDS, Youth Risk Behavior Surveys, and surveys conducted via Healthy NYC were approved as human participant research. The serosurvey was considered to be public health surveillance. The Centers for Disease Control and Prevention (CDC) reviewed the serosurvey as well and determined that it was conducted consistent with applicable federal law and CDC policy. All surveys included an informed consent component.

REFERENCES

1. Egede LE, Walker RJ. Structural racism, social risk factors, and COVID-19—a dangerous convergence for Black Americans. *N Engl J Med*. 2020;383(12):e777. https://doi.org/10.1056/NEJMp2023616
2. American Public Health Association. Racism is a public health crisis. Available at: https://www.apha.org/topics-and-issues/health-equity/racism-and-health/racism-declarations. Accessed January 17, 2021.
3. Thompson CN, Baumgartner J, Pichardo C, et al. COVID-19 outbreak—New York City, February 29–June 1, 2020. *MMWR Morb Mortal Wkly Rep*. 2020;69(46):1725–1729. https://doi.org/10.15585/mmwr.mm6946a2
4. New York City Department of Health and Mental Hygiene. Community Health Survey methodology. Available at: https://www1.nyc.gov/site/doh/data/data-sets/community-health-survey-methodology.page. Accessed January 18, 2021.
5. Mettey A, Garcia A, Isaac L, Linos N, Barbot O, Bassett MT. Take care New York 2020: every neighborhood, every New Yorker, everyone's health counts. October 2015. Available at: https://www1.nyc.gov/assets/doh/downloads/pdf/tcny/tcny-2020.pdf. Accessed October 23, 2021.
6. City of New York. Mayor's management report. September 2020. Available at: https://www1.nyc.gov/assets/operations/downloads/pdf/mmr2020/2020_mmr.pdf. Accessed October 23, 2021.
7. Choden T, Gu Y, Huynh S, Hoenig J, Norman C. Serious psychological distress among New York City adults. New York City Department of Health and Mental Hygiene: Epi Data Brief. May 2018;(102). Available at: https://www1.nyc.gov/assets/doh/downloads/pdf/epi/databrief102.pdf. Accessed October 23, 2021.
8. Nieves C, Roberts C, Bedell J. Changes in accessibility and consumption of fruits and vegetables in New York City. New York City Department of Health and Mental Hygiene: Epi Data Brief. December 2016;(84). Available at: https://www1.nyc.gov/assets/doh/downloads/pdf/epi/databrief84.pdf. Accessed October 23, 2021.
9. Arasteh K. Prevalence of comorbidities and risks associated with COVID-19 among Black and Hispanic populations in New York City: an examination of the 2018 New York City Community Health Survey. *J Racial Ethn Health Disparities*. 2021;8(4):863–869. https://link.springer.com/article/10.1007%2Fs40615-020-00844-1
10. King L, Deng WQ. Health disparities among Asian New Yorkers. New York City Department of Health and Mental Hygiene: Epi Data Brief. March 2018;(100). Available at: https://www1.nyc.gov/assets/doh/downloads/pdf/epi/databrief100.pdf. Accessed October 23, 2021.
11. Weng O. Colorectal cancer prevention: timely colonoscopy screening among New Yorkers ages 50 and older. NYC Vital Signs. 2020;18(1). Available at: https://www1.nyc.gov/assets/doh/downloads/pdf/survey/colorectal-cancer-screening-2020.pdf. Accessed October 24, 2021.
12. Farley S, Dragan K, Hinterland K, Stalvey L. Secondhand smoke and smoke-free housing in New York City. NYC Vital Signs. 2018;17(1). Available at: https://www1.nyc.gov/assets/doh/downloads/pdf/survey/smoke-free-housing.pdf. Accessed October 24, 2021.
13. Corey C, Eisenhower D, Immerwahr S, Konty K, Norton JM, Sanderson M. Including New Yorkers who can be reached only by cell phone in the Community Health Survey: results from the 2008 Cell Phone Pilot Survey; May 2010. Available at: https://www1.nyc.gov/assets/doh/downloads/pdf/epi/epibrief-cellpilot.pdf. Accessed October 26, 2021.
14. Park S, Kim Y-M, Yi S, et al. Coronavirus disease outbreak in call center, South Korea. *Emerg Infect Dis*. 2020;26(8):1666–1670. https://doi.org/10.3201/eid2608.201274
15. Graubard BI, Korn EL. Predictive margins with survey data. *Biometrics*. 1999;55(2):652–659. https://doi.org/10.1111/j.0006-341X.1999.00652.x
16. Sokolowski J, Sanderson ML, Fernandez S, et al. New York City Community Health Survey (CHS) 2020 and COVID-19: response to the pandemic, obstacles overcome and impact on survey results. Paper presented at: American Association for Public Opinion Research 76th Annual Conference. Virtual; May 11–14, 2021.
17. Alroy KA, Crossa A, Dominianni C, et al. Population-based estimates of Coronavirus Disease 2019 (COVID-19)–like illness, COVID-19 illness, and rates of case ascertainment, hospitalizations, and deaths—non-institutionalized New York City residents, March–April 2020. *Clin Infect Dis*. 2021;73(9):1707–1710. https://doi.org/10.1093/cid/ciab038
18. Chokshi DA. From economic recovery to health resilience. *JAMA*. 2021;325(8):710–711. https://doi.org/10.1001/jama.2020.24936
19. Renelus BD, Khoury NC, Chandrasekaran K, et al. Racial disparities in COVID-19 hospitalization and in-hospital mortality at the height of the New York City pandemic. *J Racial Ethn Health Disparities*. 2021;8(5):1161–1167. https://doi.org/10.1007/s40615-020-00872-x
20. Clapp J, Calvo-Friedman A, Cameron S, et al. The COVID-19 shadow pandemic: meeting social needs for a city in lockdown. *Health Aff (Millwood)*. 2020;39(9):1592–1596. https://doi.org/10.1377/hlthaff.2020.00928
21. Dawson P, Rabold EM, Laws RL, et al. Loss of taste and smell as distinguishing symptoms of coronavirus disease 2019. *Clin Infect Dis*. 2021;72(4):682–685. https://doi.org/10.1093/cid/ciaa799
22. Pforr K, Schröder J. GESIS survey guidelines. Why panel surveys? Mannheim, Germany: GESIS – Leibniz Institute for the Social Sciences. 2016.

Available at: https://www.gesis.org/fileadmin/upload/SDMwiki/PforrSchr%c3%b6der_Why_Panel_Surveys.pdf. Accessed October 24, 2021. https://doi.org/10.15465/gesis-sg_en_008

23. Keeter S. Growing and improving Pew Research Center's American Trends Panel. Pew Research Center. February 27, 2019. Available at: https://www.pewresearch.org/methods/2019/02/27/growing-and-improving-pew-research-centers-american-trends-panel. Accessed October 24, 2021.
24. Tai DBG, Shah A, Doubeni CA, Sia IG, Wieland ML. The disproportionate impact of COVID-19 on racial and ethnic minorities in the United States. *Clin Infect Dis.* 2021;72(4):703–706. https://doi.org/10.1093/cid/ciaa815
25. Peebles K, Witt M, Sanderson M, et al. Population-based estimates of COVID-19 incidence in New York City: a comparison of two surveillance systems. Paper presented at: American Association for Public Opinion Research 76th Annual Conference. Virtual; May 11–14, 2021.
26. Cernat A, Couper MP, Ofstedal MB. Estimation of mode effects in the Health and Retirement Study using measurement models. *J Surv Stat Methodol.* 2016;4(4):501–524. https://doi.org/10.1093/jssam/smw021
27. Council of State and Territorial Epidemiologists. Update to the standardized surveillance case definition and national notification for 2019 novel coronavirus disease (COVID-19). Available at: https://cdn.ymaws.com/www.cste.org/resource/resmgr/ps/positionstatement2020/Interim-20-ID-02_COVID-19.pdf. Accessed October 27, 2021.
28. Centers for Disease Control and Prevention. Long-term effects of COVID-19. November 13, 2020. Available at: https://stacks.cdc.gov/view/cdc/97204. Accessed October 24, 2021.
29. Do DP, Frank R. Unequal burdens: assessing the determinants of elevated COVID-19 case and death rates in New York City's racial/ethnic minority neighbourhoods. *J Epidemiol Community Health.* 2020;75(4):321–326. https://doi.org/10.1136/jech-2020-215280
30. Kessler RC, Barker PR, Colpe LJ, et al. Screening for serious mental illness in the general population. *Arch Gen Psychiatry.* 2003;60(2):184–189. https://doi.org/10.1001/archpsyc.60.2.184
31. Bergeron G, Lundy De La Cruz N, Gould LH, Liu SY, Levanon Seligson A. Association between racial discrimination and health-related quality of life and the impact of social relationships. *Qual Life Res.* 2020;29(10):2793–2805. https://doi.org/10.1007/s11136-020-02525-2
32. Parrott JC, Maleki AN, Vassor VE, et al. Prevalence of SARS-CoV-2 antibodies in New York City adults, June–October 2020: a population-based survey. *J Infect Dis.* 2021;224(2):188–195. https://doi.org/10.1093/infdis/jiab296
33. Magas I, Norman C, Baxter A, Harrison M. Impact of COVID-19 on mental health in New York City. New York City Department of Health and Mental Hygiene. September 2020. Available at: https://www1.nyc.gov/assets/doh/downloads/pdf/covid/covid-19-mental-health-impacts-hop.pdf. Accessed October 24, 2021.
34. Dobosh K, Tiberio J, Dongchung TY, et al. Inequities in experiences of the COVID-19 pandemic, New York City. New York City Department of Health and Mental Hygiene: Epi Data Brief. May 2021;(123). Available at: https://www1.nyc.gov/assets/doh/downloads/pdf/epi/databrief123.pdf. Accessed October 24, 2021.
35. Peebles K, Deng WQ, Dongchung TY, et al. COVID-19 vaccination intentions, uptake, motivators, and barriers—New York City, October and December 2020 and March 2021. New York City Department of Health and Mental Hygiene: Epi Data Brief. May 2021;(124). Available at: https://www1.nyc.gov/assets/doh/downloads/pdf/epi/databrief124.pdf. Accessed October 24, 2021.
36. Bajaj SS, Stanford FC. Beyond Tuskegee—vaccine distrust and everyday racism. *N Engl J Med.* 2021;384(5):e12. https://doi.org/10.1056/NEJMpv2035827
37. Krieger N. ENOUGH: COVID-19, structural racism, police brutality, plutocracy, climate change—and time for health justice, democratic governance, and an equitable, sustainable future. *Am J Public Health.* 2020;110(11):1620–1623. https://doi.org/10.2105/AJPH.2020.305886

Comparing the COVID-19 Responses in Cuba and the United States

Mary Anne Powell, BS, BA, Paul C. Erwin, MD, DrPH, and Pedro Mas Bermejo, MD, PhD

The purpose of this analytic essay is to contrast the COVID-19 responses in Cuba and the United States, and to understand the differences in outcomes between the 2 nations.

With fundamental differences in health systems structure and organization, as well as in political philosophy and culture, it is not surprising that there are major differences in outcomes. The more coordinated, comprehensive response to COVID-19 in Cuba has resulted in significantly better outcomes compared with the United States. Through July 15, 2021, the US cumulative case rate is more than 4 times higher than Cuba's, while the death rate and excess death rate are both approximately 12 times higher in the United States. In addition to the large differences in cumulative case and death rates between United States and Cuba, the COVID-19 pandemic has unmasked serious underlying health inequities in the United States.

The vaccine rollout presents its own set of challenges for both countries, and future studies can examine the comparative successes to identify effective strategies for distribution and administration.
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The purpose of this essay is to contrast the COVID-19 responses in Cuba and the United States. The 2 nations present widely varying examples of responding to the pandemic through governmental actions, surveillance and mitigation, testing, and public messaging, and the respective outcomes demonstrate the overall effectiveness of each country's approach. Comparing the 2 will illuminate structural and organizational differences between the 2 health systems and how they have influenced COVID-19 outcomes.

PREPANDEMIC PROFILES

To better understand the influences and implications of each country's actions during the pandemic, a general understanding of their health systems' existing structure is required. The 1976 Cuban Constitution and the 1983 (Cuban) Public Health Law instituted the guiding principles for Cuba's health system. Notable among these core values are "health care is a right, available to all equally and free of charge; health care is the responsibility of the state; [and] health care activities are integrated with economic and social development."[1(p.e14)]

Although MINSAP (*Ministerio de Salud Pública* [Ministry of Public Health]) leads at the national level, it is community-level care that distinguishes the Cuban system. There are 11 128 *consultorios* (clinics) throughout the neighborhoods of Cuba, each staffed with a family doctor and nurse duo who often reside in the same community and are acutely familiar with the health status of the neighborhood and its residents. Family doctor and nurse teams are charged with health promotion, prevention, surveillance, rehabilitation, strengthening social cohesion, and other duties.[1,2] The country's nearly 500 polyclinics each oversee and support 20 to 40 of these *consultorios*.[1,2] Municipal hospitals occupy the rung above polyclinics and provide more specialized care, and, above them, provincial tertiary care hospitals perform research.[1] The Cuban health system was also designed without any delineation between public health and clinical care. Population health and medicine are inherently integrated at every level of the system, with sufficient allowance for local variance according to the unique needs of individuals and communities.[1]

The US public health system is built on the principle of decentralization—that is, the role of the federal government in matters of public health is second to that of state and local governments. While medical care in the United States may be available to some through Medicaid (primarily for low-income individuals) or Medicare (for persons aged ≥ 65 years), for many people, health insurance is obtained through an employer and, therefore, dependent on employment.[3] Across all forms of medical care, however, there are no guiding, agreed-upon values (e.g., affordability, accessibility, universality) to inform the systems that government or the private sector create, which has resulted in wide variability across the nation. Health coverage is not guaranteed, and 1 catastrophic health event could be the reason a person goes bankrupt. Thus, while the nation may be able to boast high-quality health care (for those who can access and afford it), the system remains rife with inequity and disparities.

In the sections that follow, the strengths and weaknesses of the 2 countries' health systems will be exposed through an examination of the surveillance and identification of cases, mitigation strategies (including isolation and quarantine), testing, vaccine development, and outcomes, including the unmasking of health inequities in the United States.

GOVERNMENT RESPONSES AND MITIGATION STRATEGIES

Cuba's response to COVID-19 began in January 2020, when the nation began surveilling arrivals at all ports of entry, and border and immigration officials received training on COVID-19 detection and response. In February, all personnel at hospitals and health care facilities were trained on COVID-19 prevention and treatment protocol. The first case of COVID-19 was detected in Cuba on March 11, 2020. Nine days later, Cuban President Díaz-Canel announced the first set of national measures aimed at combatting the spread of COVID-19.[4] These earliest measures addressed both health and economic concerns—they included stay-at-home orders, bans on large gatherings, and many facilities being closed, as well as provisions for financial protection for certain high-risk groups and individuals, including small businesses or those hospitalized with COVID-19 and unable to work.[4] In addition, outbound travel was limited to humanitarian efforts, and inbound travel was limited to Cuban residents who, upon arrival, were either hospitalized (if symptomatic) or ordered to quarantine at home (if asymptomatic).[4]

This practice changed with improved testing capacity, and health staff began to administer COVID-19 diagnostic tests (reverse transcriptase–polymerase chain reaction [RT-PCR]) to all arriving travelers in the airport, then hospitalizing the positive cases.[5] Schools at all levels were closed indefinitely on March 23, police presence on the streets increased, and every law enforcement station was equipped with a district attorney to facilitate charges against any violators of COVID-19 restrictions.[4] On April 1, the national mask mandate was instituted.[4] An important characteristic of government response and mitigation strategies employed in Cuba has been "intersectoral participation," with coordination across all high-level governmental units.[6]

The US COVID-19 response also began in January 2020, when the Centers for Disease Control and Prevention (CDC) established a 2019-nCoV Incident Management Structure (January 7),[7] and began screening for coronavirus at JFK International, San Francisco International, and Los Angeles International airports—the 3 US airports that receive the highest number of travelers from Wuhan, China. On January 21, the first case of COVID-19 was confirmed in Washington State, and, on January 31, the US Department of Health and Human Services secretary declared a US public health emergency.[8] The US government announced its first set of national coronavirus mitigation measures on March 13, 2020. President Trump upgraded the previous declaration to classify the COVID-19 pandemic a national emergency, a designation that opened billions of federal dollars to be allocated to relief. A travel ban also went into effect, barring non-Americans who had been to any of 26 specific countries in the previous 2 weeks from entering the United States.[8]

The federal government's main approach to combatting COVID-19 was frequently said to be to "flatten the curve," meaning to spread cases out over a longer period of time to avoid overwhelming the health system.[8] As such, initial government actions occurred quickly and included strict isolation and shutdown measures in many parts of the country; however, the United States hastily moved to less stringent measures upon seeing only slight improvement.[9] Implementation of stay-at-home orders, mask mandates, and other mitigation efforts were left to states' discretion because of the decentralized nature of the United States' public health system.[10] A federal mask mandate would have likely received pushback on its constitutionality, but state-to-state variability made the use of masks much less effective as interstate travel was still permitted.[11] On April 3, the CDC formally recommended the use of face coverings by the general public, and, by July 27, 31 states and the District of Columbia had issued statewide mask mandates.[11] Like many other COVID-19–related governmental efforts, the use of face masks became a politicized issue.[11]

SURVEILLANCE AND CASE DETECTION

A unique feature of the Cuban response to COVID-19 has been its nationwide screening effort, which was enabled by the country's strong primary health care system. Approximately 28 000 medical students volunteered to travel on foot in pairs to 80 to 100 homes and businesses every day, where they would ask how many individuals were present in the dwelling and if any had traveled, had respiratory symptoms, or had contact with a known COVID-19 case. Screening questionnaires were adapted to limit the likelihood of individuals hiding their symptoms and to promote early detection among high-risk populations.

The information was given to the *consultorio* family doctor, who passed it on to the coordinating polyclinic professor to be entered in a main database.[12] The family doctor then provided follow up to individuals reporting respiratory symptoms.[2] Existing data from the Continuous Assessment and Risk Evaluation—an annual assessment performed by family doctors to assess the general health of neighborhoods and residents—provided insight on higher-risk individuals who would require more attention. In addition to screening by medical students, these individuals with comorbidities also received regular follow up from family doctors.[12] Symptomatic individuals and those with suspected contact with a known COVID-19 case were tested and, if positive, moved to an isolation center.[12] Additional forms of ongoing surveillance include (1) monitoring all travelers arriving to Cuban ports, (2) testing suspected cases and the contacts of confirmed cases, and (3) postmortem testing on those who died with respiratory or diarrheal symptoms.[6]

Screening and surveillance in the United States have been relatively disjointed. In the initial weeks of the pandemic, testing was limited to symptomatic individuals with a travel history to China; only later was testing made available for asymptomatic individuals both with and without known exposure to COVID-19. As testing became more widely available, CDC offered guidelines to include testing at-risk groups (e.g., workers with face-to-face interactions, residents of congregate settings, teachers, and first responders), and when the test positivity rate exceeds 10.1%, random screening should occur at least twice a week and all close contacts of confirmed cases should be tested.[13] There was wide variety in how state and local governments and individual institutions and businesses implemented these recommendations.

ISOLATION, CONTACT TRACING, AND QUARANTINING

In Cuba, every confirmed case of COVID-19 is hospitalized.[14] After recovery, they are tested a second time and allowed to return home if negative. During the 15 days following their return home, those individuals are ordered to limit their movement out of the home and are provided follow-up from their local *consultorio*.[2,6] All confirmed COVID-19 cases also undergo contract tracing. In the early months of the pandemic, those contacts identified were referred for obligatory quarantine in 1 of Cuba's national isolation centers.[14] As outcomes have improved, however, isolation requirements for contacts have eased, and suspected contacts are now permitted to complete a 14-day quarantine at home, monitored by their family doctor.[14] Such broad, stringent isolation and contact-tracing efforts have been enabled by efficient horizontal and vertical data sharing. Robust communication about the status of cases and their contacts occurs throughout and across municipalities, provinces, and the nation.[2]

In the United States, state and local isolation and quarantine orders for the general population have followed from CDC recommendations, which suggest that all individuals with a positive test result or who receive an exposure notification isolate at home for at least 14 days. The CDC later amended the guidance for asymptomatic individuals with suspected exposure, who are currently recommended a 10-day quarantine without testing or a 7-day quarantine if testing negative 5 days after exposure.[13] These recommendations highlight the important consideration that testing and isolation orders go hand in hand: without being tested, asymptomatic, infected individuals are not made aware of the need to isolate.

It was estimated that between 100 000 and 300 000 tracers (numbers determined by population size) would be necessary to conduct effective contact tracing in the United States;

however, with or without the human resources, widespread community transmission of COVID-19 has made any chance of large-scale contact tracing of every case very unlikely until the spread begins to slow.[15] Some smaller-scale contact-tracing initiatives have been successful—for example those occurring on college campuses, often in tandem with local health departments.[15] Although there have been instances of successful isolation orders and contact tracing, broad efforts have been greatly hindered in the United States by restrictions related to freedom, privacy, and civil liberties.[15]

TESTING

The tests used to diagnose infection with SARS-CoV-2—the virus that causes COVID-19—fall into 2 categories: nucleic acid amplification tests (NAATs) and antigen tests. NAATs are more sensitive, but the cost per test is high, and processing times are long. Antigen tests are more likely to deliver a false negative, but they are less expensive and provide quick results. In addition to these 2 diagnostic tests, there are antibody tests that can be used to detect evidence of past SARS-CoV-2 infection.

At the onset of the pandemic, Cuba was not equipped with the expensive, specialized infrastructure or trained personnel needed to implement mass RT-PCR testing (NAAT).[14] To adapt and gradually build capacity, the nation prepared 7 diagnostic laboratories in regions across the country, and operated with the goal of a daily positivity rate below 10% of all tests.[16] By October 2020, Cuba had reached a total of 13 diagnostic laboratories and, by April 2021, a total of 27 diagnostic laboratories, with at least 1 in every province.[14] Although the process was slow-going in the early months, Cuban diagnostic facilities set the goal of performing high-volume testing to detect both symptomatic and asymptomatic cases.[17]

Testing in the United States has been more complex than in Cuba's experience. Like other COVID-19–related efforts, it has largely been defined by disorganization by, and mixed messages from, the US federal government.[18] The RT-PCR test developed by the CDC was the test used to detect the United States' first case of COVID-19 in January 2020. Laboratories around the country were developing tests of their own at this same time; however, all diagnostic tests were required to obtain US Food and Drug Administration (FDA) Emergency Use Authorization (EUA) before use. The CDC's test was the first to receive FDA approval, and shipments were sent to health departments in the early days of February. Only days later, they were found to be faulty.[18] Other tests were available and ready to use, but the FDA's EUA requirement placed a large bureaucratic barrier in the path, and it was not until February 29 that those tests (still without an EUA) were given the FDA's green light for use.[18]

The coordination did not improve from there. The United States suffered "inadequate and continued lack of testing" and "haphazard" administration of what tests were available (e.g., during the initial weeks of the outbreak, only symptomatic individuals with a travel history were tested, ignoring what was already known about community transmission in the United States).[9(p1790)] The failures in testing during the February–April timeframe in particular played a large role in the inability to contain the pandemic.[9]

Table 1 displays the number of daily new COVID-19 tests performed per 1000 people in Cuba and the United States at 4 time points. Both countries demonstrated a steady increase in testing capacity over time; however, as Pérez Riverol confirms, testing capacity is better quantified as the number of COVID-19 tests performed per confirmed case.[16] This metric considers the scope of the epidemic in a given area and better reflects whether the need for testing is being adequately met (Table 2).

MESSAGING

In the age of a proliferation of news and social media, health communication has become an essential step in combatting COVID-19. In Cuba, before COVID-19, state-owned television channels broadcast health education messages in place of commercials (as Americans know them). Strategic,

TABLE 1— Daily New COVID-19 Tests per 1000 People at 4 Time Points: Cuba and the United States, June 1, 2020–July 1, 2021

	Tests per 1000 People	
	Cuba	**United States**
June 1, 2020	0.12	1.33
October 1, 2020	0.67	3.70
March 15, 2021	1.75	2.86
July 1, 2021	3.18	1.90

Source. Roser et al.[19]

TABLE 2— Tests Performed per Confirmed Case of COVID-19 at 4 Time Points: Cuba and United States, June 1, 2020–July 1, 2021

	Tests per Confirmed Case	
	Cuba	United States
June 1, 2020	83.70	22.70
October 1, 2020	143.30	22.20
March 15, 2021	23.50	23.30
July 1, 2021	12.40	41.70

Source. Roser et al.[19]

informative communications related to COVID-19 began early in the pandemic, and health officials regularly provided "comprehensive stay-at-home messaging" that kept the public up to date and encouraged a collaborative spirit.[17(p16)] These messages were provided during daily briefings broadcasted throughout the country as part of an "intense media campaign," and they also included targeted information about people who were at most risk and the proper safety measures those individuals should take.[6(p48)]

To combat misinformation, Cuba's health network created the Web site *Infecciones por coronavirus*, which housed information from sources like the World Health Organization and Pan American Health Organization on the state of the pandemic and had a function allowing users to submit their questions to be answered by national experts.[20] *Juventud Técnica*—Cuba's only mass-circulation magazine focused on STEM (science, technology, engineering, and math) topics—initiated an effort to dismiss common rumors and debunk scientific misinformation. In addition to its fact-checking project, the publication also produced COVID-19–related infographics and materials with information from government agencies like MINSAP.[20]

COVID-19–related messaging in the United States was characterized by conflict, inconsistency, and blatant misinformation. Many believe the Trump administration is largely to blame for the way scientific information was cast aside in favor of more self-serving messages that downplayed the severity of the US epidemic. Former President Trump publicly and repeatedly undermined the authority and expertise of the CDC and other health agencies.[21] Under intense public scrutiny and facing criticism from the Trump administration, the CDC altered some of its previously published guidance despite objections from internal experts.[21] This and other inconsistencies sowed doubt and distrust of the agency, as evidenced by the 16-point drop in the public's trust in the CDC between April and September 2020.[10] In response to the public's growing uneasiness and concern about the safety of any vaccine put forward, 9 pharmaceutical companies released a statement in September 2020 affirming their loyalty to science over speed during the process of vaccine development.[21]

VACCINE DEVELOPMENT

Cuba's January 2020 national COVID-19 control plan ordered the formation of an "innovation committee" to begin development of a vaccine. The nation boasts one of the world's leading biotech industries, which comprises more than 30 research institutes and manufacturers and operates as the "state-owned conglomerate BioCubaFarma."[22(p10)] Because the industry is completely state-owned, -funded, and -operated, competition and the profit-driven actions of private companies have not been a factor in vaccine development.[23] Although the country has had to navigate difficulty obtaining certain raw materials because of the US embargo, BioCubaFarma's first vaccine candidate, SOBERANA01, was authorized by the Center for State Control of Medicines and Medical Devices to begin clinical trials in August 2020.[22] As of March 2021, 2 (SOBERANA02 and Abdala) of Cuba's 5 total vaccine candidates were in phase III clinical trials. Globally, a total of 21 other candidates had entered phase III trials by this time, and Cuba is the only Latin American country to have its own vaccine among that cohort.[23] Abdala was shown to be 92.28% effective against symptomatic illness, and, in July 2021, it was authorized for emergency use. By July 14, 10.2% of the Cuban population was fully vaccinated with 3 doses, and another 41.6% had received either 1 or 2 doses. Cuba projects that the entire population will be vaccinated by the end of 2021.[23] Cuban health authorities have been vocal about their intention to distribute vaccine doses internationally, especially to countries within the Global South, as domestic rollout continues.[22]

Multiple private companies have been involved in the process of developing a vaccine for use in the United States. The public–private partnership between those companies and the US government was first publicly announced by the Trump administration in May 2020. The effort was named Operation Warp Speed (OWS), and its initial goal was to have "substantial quantities" of a safe COVID-19 vaccine by January 2021.[24] Nearly $10 billion was allocated by Congress to OWS to fund efforts in development, manufacturing, and distribution. By October 2020, OWS had announced partnerships with 6 companies: Moderna, Pfizer–BioNTech, AstraZeneca, Johnson & Johnson, Novavax, and Sanofi/GSK.[24] In November 2020, both Pfizer and Moderna released promising results from phase III clinical trials. Days later, Pfizer became the first company to submit its vaccine candidate to the FDA for EUA, and in mid-December, the FDA granted EUAs for both the Pfizer and Moderna vaccines.[8] Moving the vaccine from initial development to injecting it into people's arms in less than 1 year was a monumental achievement. In February 2021, the 1-dose Johnson & Johnson vaccine also received EUA from the FDA.

As of July 15, 2021, 48% of the US population was fully vaccinated against COVID-19, with another 7.4% partly vaccinated.[19] The United States has not been without its fair share of distribution challenges. In the first few weeks of vaccine rollout, while CDC had provided guidance for prioritization, implementation at the state level was inconsistent and did not necessarily abide by CDC's recommendations. During the first several weeks of vaccine rollout, more vaccine doses were delivered (per capita) to Whites compared with people of color. The United States has also had major challenges in overcoming vaccine disinformation and vaccine hesitancy.

CASES, DEATHS, AND INEQUITIES

The COVID-19 pandemic has resulted in astoundingly different outcomes between the United States and Cuba, as shown in Table 3, which displays the cumulative numbers and rates of cases and deaths of both countries through July 15, 2021: the US cumulative case rate is more than 4 times higher than Cuba's, while the death rate and excess death rate are both approximately 12 times higher in the United States.

In addition to the large differences in cumulative case and death rates between United States and Cuba, the COVID-19 pandemic has unmasked underlying health inequities in the United States that, while understood in the public health community, were previously not in the public conscience. The immense contrast between COVID-19 outcomes in the United States and in Cuba and their correlation with certain organizational mechanisms of their health systems cannot be denied. In Cuba, mortality rates from COVID-19 and the number of confirmed cases has been balanced equally across socioeconomic strata. Provincial diagnostic facilities and neighborhood *consultorios* have meant that testing and therapeutics are equally accessible for residents of both urban and rural areas.[26] By contrast, racial/ethnic minority groups in the United States have COVID-19 mortality rates twice as high as that of White Americans. Also, low-income Americans have borne the brunt of the financial impacts of COVID-19 (e.g., unemployment, food insecurity) in addition to worse health outcomes. These disparities arise from structural shortcomings like inefficient health coverage systems, inadequate health care infrastructure, and misuse of existing resources.[3] Inequities have also been exposed in the areas of testing and vaccinations.

TABLE 3— Comparative Rates of COVID-19 Cases and Deaths: Cuba and United States, Through July 15, 2021

	Cuba	United States
Total population, no.	11 300 000	328 200 000
Cumulative cases, no.	263 086	33 980 000
Cumulative deaths,[a] no.	1 726	608 424
Cumulative excess deaths,[b] no.	2 553	933 982
Cases per 100 000 population	2 322	10 264
Deaths per 100 000 population	15.2	183.8
Excess deaths per 100 000 population	22.6	284.6

Source. Roser et al.[19]

[a] Reported deaths are the number of deaths officially reported as COVID-19.

[b] Excess deaths are the number of deaths estimated as attributed to COVID-19, including unreported deaths.[25]

CONCLUSION

Although Cuba and the United States differ from one another in numerous ways, their respective experiences—especially outcomes—signal clear failures in the United States. The more coordinated, comprehensive response to COVID-19 in Cuba has resulted in significantly better outcomes compared with the United States. Much of this difference can be attributed to the structure of the countries' health systems.

In Cuba, MINSAP has taken charge at every level: from provision of health services to preserving the system's universality and affordability even in the face of a global health crisis. In the United States, a decentralized structure has allowed for the diffusion of authority and accountability across multiple federal and state agencies, and no clear leader has emerged. Thus, it can be argued that the organization of the Cuban and US health systems was a primary determinant of their pandemic response because, respectively, they produced either consistency and clear direction, or disorganization and conflicting guidance.

In addition to structural differences, Cuba and the United States differ in their general trust of concentrated power. Pandemic response greatly relies on health protection measures and decisive leadership, which have been perceived as infringement on individual liberty by many Americans. In Cuba, the adoption of strict control measures and adherence to governmental guidance by most residents undoubtedly facilitated the successful COVID-19 response. It is questionable whether comparable actions would have been widely accepted by residents of the United States, but without a well-integrated health system, it is inconceivable that they could have been properly implemented—regardless of public opinion.

At the time of writing, the COVID-19 pandemic continues to evolve. In the United States, after a post-Thanksgiving (2020) to New Years' surge (2021), the 7-day rolling averages of new cases and deaths steadily trended downward through late March 2021, followed by another rise. By May 2021, numbers trended down, and then again creeped upward in the early days of July 2021. After months of relatively low case rates, Cuba experienced a surge in cases and deaths between January and March 2021, followed by a plateauing. In mid-June 2021, Cuba again saw a surge to an all-time high of nearly 7000 new cases in 1 day in mid-July. The increase is attributed to new, more contagious variants, the public's decreased risk perception because of months of low cases and the introduction of vaccines, and the ineffectiveness of renewed efforts to limit transmission through restricting movement of individuals. Between February and June 2021, the reproduction rate in Cuba and the United States remained at and below 1.0, respectively. By June 15, the reproduction rate began to rise in both countries, reaching 1.5 on July 10, 2021.[8] Neither country has moved beyond the pandemic, and further research may examine potential differences in the easing or tightening of COVID-19–related restrictions in Cuba and the United States and the subsequent effects. The vaccine rollout presents its own set of challenges for both countries, and future studies can examine the comparative successes to identify effective strategies for distribution and administration.

ADDENDUM

Data and policies described in this manuscript are accurate through July 15, 2021. Because of the time between the writing and publication of this article, we provide a more recent update on COVID-19 data in the Appendix (available as a supplement to the online version of this article at http://www.ajph.org).

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CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

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REFERENCES

1. Keck CW, Reed G. The curious case of Cuba. *Am J Public Health.* 2012;102(8):e13–e22. https://doi.org/10.2105/AJPH.2012.300822
2. Aguilar-Guerra TL, Reed G. Mobilizing primary health care: Cuba's powerful weapon against COVID-19. *MEDICC Rev.* 2020;22(2):53–57. https://doi.org/10.37757/MR2020.V22.N2.15
3. Butler S. Achieving an equitable national health system for America. Brookings. 2020. https://www.brookings.edu/research/achieving-an-equitable-national-health-system-for-america. Accessed May 19, 2021.
4. Cuba's COVID-19 strategy: main actions through April 23, 2020. *MEDICC Rev.* 2020;22(2):50–52. https://doi.org/10.37757/MR2020.V22.N2.14
5. Cuba's COVID-19 strategy: updated epidemic control and recovery measures through October 2020. *MEDICC Rev.* 2021;23(1). https://doi.org/10.37757/MR2020.V22.N3.3
6. Reed G. Stemming COVID-19 in Cuba: strengths, strategies, challenges Francisco Durán MD. National Director of Epidemiology, Ministry of Public Health, Cuba. *MEDICC Rev.* 2020;22(2):47–52. https://doi.org/10.37757/MR2020.V22.N2.13
7. Patel A, Jernigan DB. Initial public health response and interim clinical guidance for the 2019 novel coronavirus outbreak—United States, December 31, 2019–February 4, 2020. *Am J Transplant.* 2020;20(3):889–895. https://doi.org/10.1111/ajt.15805
8. *AJMC* Staff. A timeline of COVID-19 developments in 2020. *American Journal of Managed Care*. 2021. Available at: https://www.ajmc.com/view/a-timeline-of-covid19-developments-in-2020. Accessed May 14, 2021.

9. Bauchner H, Sharfstein J. A bold response to the COVID-19 pandemic: medical students, national service, and public health. *JAMA.* 2020;323(18):1790–1791. https://doi.org/10.1001/jama.2020.6166

10. Gostin LO. A 7-point action agenda to end the COVID-19 pandemic for President-elect Biden. *JAMA.* 2021;325(1):17–18. https://doi.org/10.1001/jama.2020.23848

11. Gostin LO, Cohen IG, Koplan JP. Universal masking in the United States: the role of mandates, health education, and the CDC. *JAMA.* 2020;324(9):837–838. https://doi.org/10.1001/jama.2020.15271

12. Gorry C. COVID-19 case detection: Cuba's active screening approach. *MEDICC Rev.* 2020;22(2):58–63. https://doi.org/10.37757/MR2020.V22.N2.16

13. Centers for Disease Control and Prevention. Overview of testing for SARS-CoV-2 (COVID-19). 2021. Available at: https://www.cdc.gov/coronavirus/2019-ncov/hcp/testing-overview.html. Accessed May 14, 2021.

14. Gail A. A PAHO perspective on COVID-19 in Cuba José Moya MD MPH PhD. *MEDICC Rev.* 2020;22(4):20–23. https://doi.org/10.37757/MR2020.V22.N4.12

15. Rubin R. Building an "army of disease detectives" to trace COVID-19 contacts. *JAMA.* 2020;323(23):2357–2360. https://doi.org/10.1001/jama.2020.8880

16. Pérez Riverol A. The Cuban strategy for combatting the COVID-19 pandemic. *MEDICC Rev.* 2020;22(3):64–68.

17. Coutin G, Gorry C. Early action, applied research & collaboration to combat COVID-19: María Guadalupe Guzmán MD PhD DSc. *MEDICC Rev.* 2020;22(4):16–19. https://doi.org/10.37757/MR2020.V22.N4.4

18. Maxmen A, Tollefson J. Two decades of pandemic war games failed to account for Donald Trump. *Nature.* 2020;584(7819):26–29. https://doi.org/10.1038/d41586-020-02277-6

19. Roser M, Ritchie H, Ortiz-Ospina E, Hasell J. Coronavirus pandemic (COVID-19). Our World in Data. 2020. Available at: https://ourworldindata.org/coronavirus. Accessed May 14, 2021.

20. Alonso-Galbán P, Alemany-Castilla C. Curbing misinformation and disinformation in the COVID-19 era: a view from Cuba. *MEDICC Rev.* 2020;22(2):45–46. https://doi.org/10.37757/MR2020.V22.N2.12

21. Gostin LO. Science, leadership, and public trust in the COVID-19 pandemic. *Milbank Quarterly Opinion.* New York, NY: Milbank Memorial Fund: September 28, 2020. https://doi.org/10.1599/mqop.2020.0928

22. Gorry C. SOBERANA, Cuba's COVID-19 Vaccine Candidates: Dagmar García-Rivera PhD. *MEDICC Rev.* 2020;22(4):10–15. https://doi.org/10.37757/MR2020.V22.N4.11

23. Yaffe H. Cuba Libre to be COVID-libre: five vaccines and counting… 2021. Available at: https://www.counterpunch.org/2021/03/30/cuba-libre-to-be-covid-libre-five-vaccines-and-counting. Accessed May 19, 2021.

24. Slaoui M, Hepburn M. Developing safe and effective COVID vaccines—Operation Warp Speed's strategy and approach. *N Engl J Med.* 2020;383(18):1701–1703. https://doi.org/10.1056/NEJMp2027405

25. Mas Bermejo P, Sánchez Valdés L, Somarriba López L, et al. Equity and the Cuban National Health System's response to COVID-19 [in Spanish]. *Pan Am J Public Health.* 2020;44:e138.

26. Institute for Health Metrics and Evaluation. COVID-19 projections. 2021. Available at: https://covid19.healthdata.org/global?view=cumulative-deaths&tab=trend. Accessed August 5, 2021.

Racial and Ethnic Disparities in COVID-19 Infection and Hospitalization in the Active Component US Military

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See also Lopez et al., p. 2089, and Galea and Vaughan, p. 2094.

Objectives. To assess COVID-19 disparities in the active component US military with an emphasis on race and ethnicity.

Methods. In this retrospective cohort study, we calculated the incidence of COVID-19 testing, infection, and hospitalization in the active component US military in calendar year 2020.

Results. Overall, 61.3 per 100 population per year were tested for COVID-19, 10.4% of tests were positive, and 1.1% of infected individuals were hospitalized. Non-Hispanic Blacks and Hispanics had a rate of testing for COVID-19 similar to that of Whites but had a higher risk of infection (adjusted risk ratio [ARR] = 1.25 and 1.26, respectively) and hospitalization (ARR = 1.28 and 1.21, respectively).

Conclusions. Although of lower magnitude than seen in civilian populations, racial and ethnic disparities in COVID-19 infection and hospitalizations exist in the US military despite universal eligibility for health care, similar rate of testing, and adjustment for comorbidities and other factors. Simply making health care coverage available may be insufficient to ensure health equity. Interventions to mitigate disparities in the US military should target the patient, provider, health care system, and society at large. (*Am J Public Health*. 2021;111(12):2194–2201. https://doi.org/10.2105/AJPH.2021.306527)

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Soon after the COVID-19 outbreak began in the United States, it became apparent that the pandemic was having a disproportionate effect on persons from Black, Indigenous, and other racial and ethnic groups.[1,2] Early data from the US Centers for Disease Control and Prevention (CDC) indicated that Black and Hispanic/Latino populations had at least 2.6 times the rate of COVID-19 cases and 4.6 times the rate of COVID-19 hospitalizations of non-Hispanic White nonpopulations.[3] A growing number of health care systems have reported racial and ethnic disparities in COVID-19 cases and related deaths, further demonstrating that the virus disproportionately affects persons from minority groups.[4–7]

The causes of health disparities related to COVID-19 and other conditions are complex, interrelated, and difficult to quantify. Contributing factors arise from all social–ecological levels of society, including individual, interpersonal, organizational, and community levels and include age, comorbidities, education, socioeconomic status, housing, household structure, geography, language proficiency, cultural background, bias, and stereotyping.[8] Access to care, complex in and of itself, also is a significant driver of health disparities. It includes eligibility for insurance and availability of care (the supply side of access) and acceptance of health recommendations and services (the demand side).[9] Trust plays an important role in the acceptance of health recommendations on individual and population levels, and research shows that Black persons report lower levels of trust of health care providers than White persons.[10] Previous studies have demonstrated lower uptake of influenza and COVID-19 vaccines among Black persons.[11,12]

Health care benefits are available to all military members, their families, and military retirees through the Military Health System (MHS). These benefits provide care to approximately 1.4 million active component (AC) service members and 9.5 million total beneficiaries.[13] Given the large racially and ethnically diverse population covered, the analysis of health outcomes in the MHS presents a unique opportunity to explore health equality. This is especially true because universal eligibility for health care in the MHS has been purported to eliminate health disparities in some areas, including outcomes following coronary artery bypass grafting and other surgical procedures,[14] cancer,[15] and initiation of treatment of mental health conditions.[16]

Our study objective was to assess factors associated with COVID-19 testing, infection, and hospitalization among AC service members, with special emphasis on assessing whether disparities exist by race and ethnicity. We hypothesized that COVID-19 outcomes in the US military would be similar among persons belonging to all racial and ethnic groups because of the provision of universal health care coverage.

METHODS

The Uniformed Services University institutional review board approved this study. The review board waived informed consent because this was a retrospective cohort study and we de-identified the patient data. We followed the Strengthening the Reporting of Observational Studies in Epidemiology reporting guideline for cohort studies.[17]

Population

This was a population-based, retrospective cohort study of the incidence of COVID-19 testing, infection, and hospitalization among all AC service members in service during calendar year 2020. The Armed Forces Health Surveillance Division (AFHSD) maintains the Defense Medical Surveillance System (DMSS), a continuously expanding relational database of military personnel and medical data.[18] For this analysis, we used DMSS to identify the study population, COVID-19 outcomes, and information on demographics and other variables.

Outcomes

AFHSD also maintains a master list of MHS beneficiaries, including AC service members, with reverse transcription-polymerase chain reaction (RT-PCR) or antigen test laboratory–confirmed COVID-19 infection. We updated this list daily, and it is composed of cases identified using RT-PCR and antigen tests for COVID-19 in Composite Health Care System Health Level 7–formatted and MHS Genesis laboratory data extracted by the Navy and Marine Corps Public Health Center, as well as medical event reports of RT-PCR laboratory–confirmed COVID-19 infection from the Disease Reporting System Internet. We derived testing and infection outcomes from this COVID-19 master list.

We considered patients to have been hospitalized if hospitalization was documented in the Disease Reporting System Internet (assessed via chart review for approximately 50% of COVID-19 cases tracked in the Disease Reporting System Internet) or if inpatient encounter data extracted from DMSS indicated a diagnosis of COVID-19–like illness in diagnosis code position 1 or 2 within 30 days of a COVID-19 infection. We empirically generated the 30-day window as the point past which very few additional hospitalizations occurred. Given the typical clinical course of COVID-19, hospitalizations past this window were likely attributable to other causes.

Exposure

We obtained self-reported race and ethnicity data from the DMSS records collected at the time of entry into military service and categorized this as non-Hispanic White, non-Hispanic Black, Hispanic, other, and unknown or missing.

Other Variables

We used the DMSS to obtain each service member's age (younger than 20 years, 5-year age groups 20–44 years, and 45 years or older), sex (male or female), service branch (Army, Navy, Air Force, Marines, Coast Guard), rank (enlisted or officer), education level (high school or less, some college, bachelor's or advanced degree, and other or unknown), marital status (single and never married, married, or other or unknown), military occupation (combat specific, motor transport, pilot or air crew, repair or engineering, communications or intelligence, health care, and other or unknown), and geographic region of assignment (Northeast, Midwest, South, West, overseas, and unknown or missing). We also used the DMSS to identify comorbidities from administrative records of inpatient and outpatient medical encounters, which include encounters from fixed military treatment facilities as well as outsourced care reimbursed by TRICARE (the health care program of the US Department of Defense [DoD] MHS). We considered an individual to have a comorbidity if they had an inpatient or outpatient encounter containing a diagnosis with an *International Classification* *of Diseases, 10th Revision* (Geneva, Switzerland: World Health Organization; 1992 [*ICD-10*]) code for that comorbidity in any diagnostic position between January 1, 2019 and December 31, 2020. The list of *ICD-10* codes, selected based on a review of the existing literature, can be found in Table A (available as a supplement to the online version of this article at http://www.ajph.org).

Statistical Analysis

We calculated adjusted rate ratios for COVID-19 testing using a negative binomial regression model, which we selected over a Poisson or zero-inflated model because it has the lowest Akaike's information criteria value. We censored person-time at risk at the date of the first COVID-19 test. We used an offset of the log of the follow-up time for each individual to account for different population sizes. For analyses of the risk of testing positive among those tested and the risk of being hospitalized among those infected, we calculated adjusted risk ratios (ARRs) using Poisson regression with robust variance estimation to avoid exaggeration of effect estimates because of violation of the rare disease assumption.[19] We adjusted all models for age, sex, race, service branch, rank, education level, marital status, military occupation, geographic region, and presence of any comorbidity using SAS version 9.4 (SAS Institute, Cary, NC). We selected these covariates a priori on the basis of being potential confounders.[20] We did not perform any analysis of effect modification, as we had no prespecified hypothesis for this.

RESULTS

The US active component military population used in this study is shown in Table 1 and is similar to previously published estimates.[21] There were 694 878 AC service members tested for COVID-19 in 2020, a rate of 61.3 per 100 person-years, of which 10.4% (n = 72 152) tested positive, and 1.1% (n = 846) were hospitalized (Table 1).

Those who self-reported as non-Hispanic Black or Hispanic had a similar but small and marginally statistically significant increase in testing compared with Whites (for Blacks, ARR = 1.01; 95% confidence interval [CI] = 1.00, 1.02; for Hispanics, ARR = 1.06; 95% CI = 1.04, 1.07), as seen in Table 2 and Table B (available as a supplement to the online version of this article at http://www.ajph.org). Among the population of those who were tested, non-Hispanic Blacks had 1.25 (95% CI = 1.22, 1.27) times the risk of testing positive for COVID-19 and Hispanics had 1.26 (95% CI = 1.24, 1.28) times the risk compared with non-Hispanic Whites after adjusting for covariates (Table 2; Table C, available as a supplement to the online version of this article at http://www.ajph.org). Similarly, all racial/ethnic groups demonstrated a higher risk of hospitalization for COVID-19 than did non-Hispanic Whites, with the highest risk found among those who reported "other" race/ethnicity (ARR = 1.39; 95% CI = 1.10, 1.75), followed by non-Hispanic Blacks (ARR = 1.28; 95% CI = 1.08, 1.53) and Hispanics (ARR = 1.21; 95% CI = 1.01, 1.45; Table 2; Table D, available as a supplement to the online version of this article at http://www.ajph.org).

We also found other health disparities by sex and rank (Tables B–D). Female service members had a modestly higher adjusted rate of testing than did males (ARR = 1.14; 95% CI = 1.13, 1.15), lower risk of infection (ARR = 0.94; 95% CI = 0.93, 0.96), and similar risk of hospitalization. Officers had a lower rate of testing than did enlisted ranks (ARR = 0.89; 95% CI = 0.88, 0.91), a similar risk of infection, and a lower risk of hospitalization (ARR = 0.69; 95% CI = 0.52, 0.91). Finally, although we did not see an association between the presence of any of the listed comorbidities and testing for or infection with COVID-19, the ARR for hospitalization among those with any comorbidity was elevated at 4.67 (95% CI = 3.99, 5.45).

DISCUSSION

By the end of calendar year 2020, 61.3 per 100 person-years of AC military service members had been tested for COVID-19, 10.4% of those tested positive, and 1.1% of those infected were hospitalized. Non-Hispanic Blacks and Hispanics had a similar rate of testing for COVID-19 as Whites, but they had a higher risk of infection (ARRs = 1.25 and 1.26, respectively) and hospitalization (ARRs = 1.28 and 1.21, respectively). Officer rank, a military correlate of higher socioeconomic status, was not associated with infection but was associated with a 31% lower adjusted risk of hospitalization. These associations persisted despite equal eligibility for health care; despite similar rate of testing; and after adjusting for comorbidities, occupation, and other factors associated with COVID-19. The presence of comorbidities was associated with a large increase in the risk of hospitalization.

This study builds on the emerging literature demonstrating the disproportionate impact of COVID-19 on persons having certain racial and ethnic characteristics. Race and ethnicity have been associated with infection and hospitalizations for COVID-19 in numerous populations, including US military

TABLE 1— Characteristics of Active Component US Military Service Members: 2020

	No. (%)
Total	1 361 399 (100.0)
Sex	
Male	1 128 236 (82.9)
Female	233 163 (17.1)
Age, y	
< 20	73 164 (5.4)
20–24	428 450 (31.5)
25–29	322 394 (23.7)
30–34	222 445 (16.3)
35–39	170 204 (12.5)
40–44	89 981 (6.6)
≥ 45	54 761 (4.0)
Race/ethnicity	
Non-Hispanic White	755 302 (55.5)
Non-Hispanic Black	215 414 (15.8)
Hispanic	230 987 (17.0)
Other	131 325 (9.6)
Unknown/missing	28 371 (2.1)
Service	
Army	473 296 (34.8)
Navy	335 391 (24.6)
Air Force	329 241 (24.2)
Marines	182 728 (13.4)
Coast Guard	40 743 (3.0)
Rank	
Enlisted	1 116 284 (82.0)
Officer	245 115 (18.0)
Education level	
High school or less	864 258 (63.5)
Some college	166 168 (12.2)
Bachelor's or advanced degree	306 116 (22.5)
Other/unknown	24 857 (1.8)
Marital status	
Single, never married	600 135 (44.1)
Married	693 161 (50.9)
Other/unknown	68 103 (5.0)
Military occupation	
Combat specific	180 668 (13.3)
Motor transport	43 879 (3.2)
Pilot/air crew	46 491 (3.4)
Repair/engineering	410 123 (30.1)
Communications/intelligence	292 532 (21.5)
Health care	115 471 (8.5)
Other/unknown	272 235 (20.0)

Continued

veterans.[4–6,22,23] As of July 2021, the CDC has reported a 2.8 times higher unadjusted rate of hospitalization for both Black persons and Hispanic persons, as compared with non-Hispanic White persons, but only a 1.1 and 1.9 times higher rate of infection, respectively.[24] However, associations between race/ethnicity and mechanical ventilation and deaths from COVID-19 have been inconsistent,[22,23] with 1 study actually showing better survival among Black and Hispanic populations.[25] We found a higher risk of both infection and hospitalization among Blacks and Hispanics, although these were of lesser magnitude than seen previously in civilian populations. This attenuation is likely to be attributable in part to the military's provision of universal eligibility for health care, resulting in increased access to care. The regional variation of infection and hospitalization seen in this study is generally consistent with that seen in the United States, although there has been heterogeneity among and in regions over time.[26] Racial and ethnic disparities also persisted over time, although they varied by region and became less pronounced over time in each region.

Associations of sex and age with COVID-19 in civilian populations were similar to those identified in this study.[6] The association of COVID-19 with chronic medical conditions was also similar to that found in previous studies,[4] although we found a significant association only with hospitalization and not with infection or testing.

Strengths and Limitations

A major strength of this study is the use of a large, well-characterized, and enumerated population with equal eligibility for health care and the ability to

TABLE 1— Continued

	No. (%)
Geographic region	
Northeast	43 358 (3.2)
Midwest	87 443 (6.4)
South	627 277 (46.1)
West	356 503 (26.2)
Overseas	148 890 (10.9)
Unknown/missing	97 928 (7.2)
Comorbidities	
Yes	458 138 (33.7)
No	903 261 (66.3)
COVID-19 outcomes	
Tested	694 878 (61.3)[a]
Infected	72 152 (10.4)[b]
Hospitalized	846 (1.1)[c]

[a] Per 100 person-years.
[b] Proportion of those tested.
[c] Proportion of those infected.

identify relevant health events, notably including testing for COVID-19.

The most important limitation is the possible misclassification of outcomes. There may have been cases of testing, infection, and hospitalization that we did not identify. In particular, asymptomatic or mildly symptomatic infections may have gone undiagnosed because of individuals not seeking medical care and because we initially limited testing to symptomatic cases. Because of universal eligibility for care in the MHS, we expected misclassification of outcomes to be nondifferential, and thus the associations seen in this study may be underestimates. Because of differences in the classification of ethnicity by service branch, we could not further differentiate the “other” race/ethnicity category into subcategories (e.g., Native Hawaiian/Pacific Islander or American Indian/Alaska Native).

Further, because operational deployment data were not available for the complete surveillance period at the time of the analysis, we may have misclassified geographic region, particularly for the overseas region, as that did not include deployments to Iraq or Afghanistan. The selection of individuals for testing may also have been biased by the DoD’s tiered testing strategy, which prioritized testing of critical national capabilities, engaged field forces, and forward deployed forces.[27] Differential access to surveillance testing likely resulted in some of the associations seen with testing, such as among health care personnel and pilots.

Because the military has different population characteristics, better preexisting health status, and universal health care coverage, the findings from this study may not be generalizable to civilian populations. Finally, the associations seen in this study may have changed over time because of the changing nature of the pandemic. However, including a time component in the models did not significantly change the associations observed (data not shown).

Public Health Implications

Health disparities related to race and ethnicity in the general US population have been attributed to differential access to health care, the presence of

TABLE 2— Adjusted Associations of Race and Ethnicity With Testing, Infection, and Hospitalization Among Active Component US Military Service Members: 2020

Race/Ethnicity	Testing, ARR[a] (95% CI)	Infection, ARR[a] (95% CI)	Hospitalization, ARR[a] (95% CI)
Non-Hispanic White	1 (Ref)	1 (Ref)	1 (Ref)
Non-Hispanic Black	1.01 (1.00, 1.02)	1.25 (1.22, 1.27)	1.28 (1.08, 1.53)
Hispanic	1.06 (1.04, 1.07)	1.26 (1.24, 1.28)	1.21 (1.01, 1.45)
Other	1.03 (1.01, 1.04)	1.00 (0.97, 1.02)	1.39 (1.10, 1.75)
Unknown	0.96 (0.94, 0.99)	1.04 (0.99, 1.11)	0.85 (0.47, 1.54)

Note. ARR = adjusted risk ratio; CI = confidence interval.

[a] Adjusted for the other variables in the table as well as age, sex, rank, comorbidities, service branch, geographic region, occupation, and marital status.

comorbidities, current work and living circumstances, and systemic racism and inequities in the underlying society.[7,8,28] This study shows that although they are attenuated compared with civilian populations, significant disparities in COVID-19 health events remain despite the same eligibility for care available in the DoD, similar work and living circumstances, and after adjusting for other important confounding variables such as age and comorbidities. Racial and ethnic health disparities have been identified for many conditions in the underlying US population, so it is not surprising to find that disparities exist in the US military. These disparities are objectionable in and of themselves, and they further pose a serious threat to the ability of the MHS to maintain a medically ready force, which is critical to national security.[13] The persistence of COVID-19–related health disparities among AC service members calls for deeper exploration and action aimed at improving care among non-Hispanic Black and Hispanic service members.

The military places special emphasis on equality and makes health care universally available through equal eligibility for care. Consistent with the notion that equal access to care ameliorates health disparities, this study demonstrated similar rates of testing among all racial and ethnic groups and reduced disparities in infection and hospitalization compared with civilian populations. The persistence of disparities in infection and hospitalization, however, suggests that the provision of universal health care does not necessarily result in equal access to care or the elimination of health disparities. There may be racially based differences in the perceived threat posed by the pandemic, although available evidence suggests that COVID-19 prevention behaviors do not differ among persons with different racial and ethnic characteristics and that thus individual behaviors do not explain COVID-19 disparities.[29] Persistent disparities are likely the result of subtle and complex social and societal mechanisms, such as distrust in the health care system, delays in care, and culturally inappropriate care.[7,8] Although these factors are believed to be largely mitigated in the DoD, this study suggests that the impact of these societal forces persists to some degree even in the military.

The CDC's COVID-19 Response Health Equity Strategy includes immediately available actions aimed at responding to COVID-19 disparities. The CDC's priority strategy 1 is to expand the evidence base by collecting and analyzing data relevant to health disparities, which is often lacking or of poor quality in both military and civilian populations.[30] Although the military collects race and ethnicity data on service members, these data are often unavailable for other beneficiaries, such as family members and retirees. Availability of these data would allow more robust identification of racial and ethnic factors related to COVID-19 and other conditions and assist with the development of interventions to promote health equity. The Uniformed Services Health Equity Collaboratory at the Uniformed Services University has recently been established to increase the evidence base, improve collaboration, and promote equity in the MHS.[31]

The US military can further optimize the health of service members and other MHS beneficiaries by ensuring equity in all aspects of COVID-19 care. In addition, the military can strive for early, frequent, transparent, and culturally and linguistically appropriate communication related to the pandemic. This has the potential to promote health literacy, engender trust, and improve adherence to and participation in recommended interventions, such as testing, nonpharmaceutical interventions, therapeutics, and vaccination.[7,8] It may also help identify and reduce delays in care, ensure culturally appropriate care, and increase trust in the MHS for all persons, but particularly those groups at greatest risk for health disparities. For the military to completely eliminate health disparities, the underlying societal causes of disparities must be addressed in both the military and the underlying US population from which the US military is drawn. Responses include structurally competent reforms and interventions aimed at eliminating the structural racism that drives many existing health inequities.[28]

The DoD's systematic efforts at promoting diversity, equity, and inclusion have historically been focused on employment and leadership opportunities but recently began to take a broader approach that includes the range of attributes, such as enhancing military performance.[32] The Uniformed Services Health Equity Collaboratory will continue to engage with civilian, military, and veteran communities to assess and address the role of structural racism and other factors that contribute to health disparities.

Conclusions

The COVID-19 pandemic disproportionately affects Black and Hispanic AC service members despite the same eligibility for health care as White service members. Addressing health disparities is important for designing effective interventions that control the pandemic, ensure military readiness, and achieve health equity. Additional interventions should be targeted at the patient, provider, health care system, and societal levels, including timely, accurate, and consistent public health education aimed at building trust, culturally appropriate care, community-based nonpharmaceutical interventions, and vaccination advocacy efforts.

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Note. The opinions and assertions expressed herein are those of the authors and do not necessarily reflect the official policy or position of the Department of Defense or the US government.

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CONTRIBUTORS

All authors contributed to conceptualizing the analysis, drafting the article, and reviewing the final draft.

CONFLICTS OF INTEREST

The authors report no conflicts of interest.

HUMAN PARTICIPANT PROTECTION

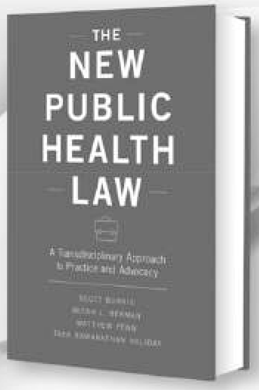
The Uniformed Services University’s institutional review board approved this research (protocol DBS.2020.167).

REFERENCES

1. Kendi IX. What the racial data show: the pandemic seems to be hitting people of color the hardest. April 6, 2020. Available at: https://www.theatlantic.com/ideas/archive/2020/04/coronavirus-exposing-our-racial-divides/609526. Accessed September 30, 2020.
2. Yancy CW. COVID-19 and African Americans. *JAMA*. 2020;323(19):1891–1892. https://doi.org/10.1001/jama.2020.6548
3. Centers for Disease Control and Prevention. Risk for COVID-19 infection, hospitalization, and death by race/ethnicity. August 13, 2021. Available at: https://www.cdc.gov/coronavirus/2019-ncov/covid-data/investigations-discovery/hospitalization-death-by-race-ethnicity.html. Accessed August 13, 2020.
4. Richardson S, Hirsch JS, Narasimhan M, et al. Presenting characteristics, comorbidities, and outcomes among 5700 patients hospitalized with COVID-19 in the New York City area. *JAMA*. 2020;323(20):2052–2059. https://doi.org/10.1001/jama.2020.6775
5. Price-Haywood EG, Burton J, Fort D, Seoane L. Hospitalization and mortality among Black patients and White patients with COVID-19. *N Engl J Med*. 2020;382(26):2534–2543. https://doi.org/10.1056/NEJMsa2011686
6. Hsu HE, Ashe EM, Silverstein M, et al. Race/ethnicity, underlying medical conditions, homelessness, and hospitalization status of adult patients with COVID-19 at an urban safety-net medical center—Boston, Massachusetts, 2020. *MMWR Morb Mortal Wkly Rep*. 2020;69(27):864–869. https://doi.org/10.15585/mmwr.mm6927a3
7. Webb Hooper M, Nápoles AM, Pérez-Stable EJ. COVID-19 and racial/ethnic disparities. *JAMA*. 2020;323(24):2466–2467. https://doi.org/10.1001/jama.2020.8598
8. Smedley BD, Stith AY, Nelson AR, eds.; Institute of Medicine, Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Washington, DC: National Academies Press; 2003.
9. Thiede M. Information and access to health care: is there a role for trust? *Soc Sci Med*. 2005;61(7):1452–1462. https://doi.org/10.1016/j.socscimed.2004.11.076
10. Halbert CH, Armstrong K, Gandy OH Jr, Shaker L. Racial differences in trust in health care providers. *Arch Intern Med*. 2006;166(8):896–901. https://doi.org/10.1001/archinte.166.8.896
11. Ojha RP, Stallings-Smith S, Flynn PM, Adderson EE, Offutt-Powell TN, Gaur AH. The impact of vaccine concerns on racial/ethnic disparities in influenza vaccine uptake among health care workers. *Am J Public Health*. 2015;105(9):e35–e41. https://doi.org/10.2105/AJPH.2015.302736
12. Lang MA, Stahlman S, Wells NY, et al. Disparities in COVID-19 vaccine initiation and completion among active component service members and health care personnel, 11 December 2020–12 March 2021. *MSMR*. 2021;28(4):2–9.
13. Tanielian T, Farmer C. The US military health system: promoting readiness and providing health care. *Health Aff (Millwood)*. 2019;38(8):1259–1267. https://doi.org/10.1377/hlthaff.2019.00239
14. Chaudhary MA, de Jager E, Bhulani N, et al. No racial disparities in surgical care quality observed after coronary artery bypass grafting in TRICARE patients. *Health Aff (Millwood)*. 2019;38(8):1307–1312. https://doi.org/10.1377/hlthaff.2019.00265
15. Gill AA, Enewold L, Zahm SH, et al. Colon cancer treatment: are there racial disparities in an equal-access healthcare system? *Dis Colon Rectum*. 2014;57(9):1059–1065. https://doi.org/10.1097/DCR.0000000000000177
16. Goldberg SB, Fortney JC, Chen JA, Young BA, Lehavot K, Simpson TL. Military service and military health care coverage are associated with reduced racial disparities in time to mental health treatment initiation. *Adm Policy Ment Health*. 2020;47(4):555–568. https://doi.org/10.1007/s10488-020-01017-2
17. von Elm E, Altman DG, Egger M, et al. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. *Ann Intern Med*. 2007;147(8):573–577. https://doi.org/10.7326/0003-4819-147-8-200710160-00010
18. Rubertone MV, Brundage JF. The Defense Medical Surveillance System and the Department of Defense serum repository: glimpses of the future of public health surveillance. *Am J Public Health*. 2002;92(12):1900–1904. https://doi.org/10.2105/AJPH.92.12.1900
19. Zou G. A modified Poisson regression approach to prospective studies with binary data. *Am J Epidemiol*. 2004;159(7):702–706. https://doi.org/10.1093/aje/kwh090
20. VanderWeele TJ. Principles of confounder selection. *Eur J Epidemiol*. 2019;34(3):211–219. https://doi.org/10.1007/s10654-019-00494-6
21. Department of Defense. 2019 Demographics: profile of the military community. Available at: https://download.militaryonesource.mil/12038/MOS/Reports/2019-demographics-report.pdf. Accessed May 15, 2021.
22. Ioannou GN, Locke E, Green P, et al. Risk factors for hospitalization, mechanical ventilation, or death among 10131 US veterans with SARS-CoV-2 infection. *JAMA Netw Open*. 2020;3(9):e2022310. https://doi.org/10.1001/jamanetworkopen.2020.22310
23. Muñoz-Price LS, Nattinger AB, Rivera F, et al. Racial disparities in incidence and outcomes among patients with COVID-19. *JAMA Netw Open*. 2020;3(9):e2021892. https://doi.org/10.1001/jamanetworkopen.2020.21892
24. Centers for Disease Control and Prevention. Risk for COVID-19 infection, hospitalization, and death by race/ethnicity. July 16, 2021. Available at: https://www.cdc.gov/coronavirus/2019-ncov/covid-data/investigations-discovery/hospitalization-death-by-race-ethnicity.html. Accessed July 22, 2021.
25. Kabarriti R, Brodin NP, Maron MI, et al. Association of race and ethnicity with comorbidities and survival among patients with COVID-19 at an urban medical center in New York. *JAMA Netw Open*. 2020;3(9):e2019795. https://doi.org/10.1001/jamanetworkopen.2020.19795
26. Centers for Disease Control and Prevention. Trends in racial and ethnic disparities in COVID-19 hospitalizations, by region—United States, March–December 2020. *MMWR Morb Mortal Wkly Rep*. 2021;70(15):560–565. https://doi.org/10.15585/mmwr.mm7015e2
27. Under Secretary of Defense for Personnel and Readiness. Force health protection guidance

(supplement 11)—Department of Defense guidance for coronavirus disease 2019 surveillance and screening with testing. June 11, 2020. Available at: https://media.defense.gov/2020/Jun/12/2002315485/-1/-1/1/DOD-Guidance-for-COVID-19-Surveillance-and-Screening-with-Testing.pdf. Accessed March 4, 2021.

28. Khazanchi R, Evans CT, Marcelin JR. Racism, not race, drives inequity across the COVID-19 continuum. *JAMA Netw Open.* 2020;3(9):e2019933. https://doi.org/10.1001/jamanetworkopen.2020.19933
29. Sauceda JA, Neilands TB, Lightfoot M, Saberi P. Findings from a probability-based survey of United States households about prevention measures based on race, ethnicity, and age in response to severe acute respiratory syndrome coronavirus 2. *J Infect Dis.* 2020;222(10):1607–1611. https://doi.org/10.1093/infdis/jiaa554
30. Laurencin CT, McClinton A. The COVID-19 pandemic: a call to action to identify and address racial and ethnic disparities. *J Racial Ethn Health Disparities.* 2020;7(3):398–402. https://doi.org/10.1007/s40615-020-00756-0
31. Uniformed Services University of the Health Sciences. Department of Preventive Medicine and Biostatistics. Available at: https://medschool.usuhs.edu/pmb. Accessed May 26, 2021.
32. Department of Defense Board on Diversity and Inclusion. Recommendations to improve racial and ethnic diversity and inclusion in the US military. Available at: https://media.defense.gov/2020/Dec/18/2002554852/-1/-1/0/dod-diversity-and-inclusion-final-board-report.pdf. Accessed April 28, 2021.



Defining Priorities for Action and Research on the Commercial Determinants of Health: A Conceptual Review

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In recent years, the concept of commercial determinants of health (CDoH) has attracted scholarly, public policy, and activist interest. To date, however, this new attention has failed to yield a clear and consistent definition, well-defined metrics for quantifying its impact, or coherent directions for research and intervention.

By tracing the origins of this concept over 2 centuries of interactions between market forces and public health action and research, we propose an expanded framework and definition of CDoH. This conceptualization enables public health professionals and researchers to more fully realize the potential of the CDoH concept to yield insights that can be used to improve global and national health and reduce the stark health inequities within and between nations. It also widens the utility of CDoH from its main current use to study noncommunicable diseases to other health conditions such as infectious diseases, mental health conditions, injuries, and exposure to environmental threats.

We suggest specific actions that public health professionals can take to transform the burgeoning interest in CDoH into meaningful improvements in health. (*Am J Public Health*. 2021;111(12):2202–2211. https://doi.org/10.2105/AJPH.2021.306491)

Amid an alarming rise in noncommunicable diseases worldwide in the early 21st century, public health scholars and activists proposed a unifying concept, the commercial determinants of health (CDoH), to explain the significant and growing influence of for-profit activities on human health. As the pace of economic globalization intensified and its geographical reach extended worldwide, evidence accumulated that CDoH were becoming an increasingly dominant force shaping global patterns of human and planetary health including health inequities within and between countries. We trace the origins of this concept and propose an expanded definition and framework for study and action on CDoH. By locating the concept of CDoH in its historical context and proposing a framework for research and action, we seek to ground the ideological, political, and economic debates about commercial influence in empirical evidence. We identify steps public health professionals can take to improve population health and reduce health inequities by tackling CDoH.

Although the term was new, the recognition that the economic and political arrangements that govern and sustain commerce also influence public health has been around for more than 200 years. In the last 2 decades, analyses have shown that the market-oriented global system has contributed to public health crises, from noncommunicable diseases (NCDs) to the COVID-19 pandemic, the global climate emergency, and "deaths of despair" from alcohol, drugs, changing work demands, and firearms.[1,2] While evidence on commercial influences on health most fully explores the role of the tobacco, alcohol, and ultra-processed food industries on the global rise of NCDs,[3] others have examined their role in infectious diseases such as HIV and COVID-19, depression and anxiety, iatrogenesis and limited access to health care, firearm injuries and deaths, physical inactivity, automobile crashes, and air pollution.[4,5]

Despite renewed interest in such influences, several obstacles complicate the use of the CDoH concept as a practical tool to address the public health challenges of the 21st century. Lacking are a shared comprehensive definition and clear metrics for quantifying the impact of CDoH. Reasons for the relative neglect include (1) inadequate funding for empirical research on the role of commercial influences; (2) limited synthesis of existing empirical studies and metrics to quantify exposures or assign fraction of disease attributable to CDoH across place, commodity, and industry; (3) dominance of reductionist biomedical and behavioral paradigms; and (4) intimidation of CDoH researchers by corporations.[6]

Ideological debates also block action. Some researchers and practitioners claim that adverse health effects of commercial influences are outweighed by their benefits, including economic growth and increases in longevity.[7] Others assert that voluntary public–private partnerships are the best way to resolve conflicts between public health and business goals and that public health professionals should focus on developing the skills to negotiate mutually acceptable compromises rather than impose stringent regulations that jeopardize beneficial economic growth.[8]

Proponents of greater attention to CDoH argue that commercial actors externalize the health burdens of their harmful practices, obscuring their costs, and claim that commercial influences contribute to widening national and international inequalities in health. Whatever positive role markets play, say these critics, they warrant heightened public health attention as fundamental drivers of global patterns of health and disease.

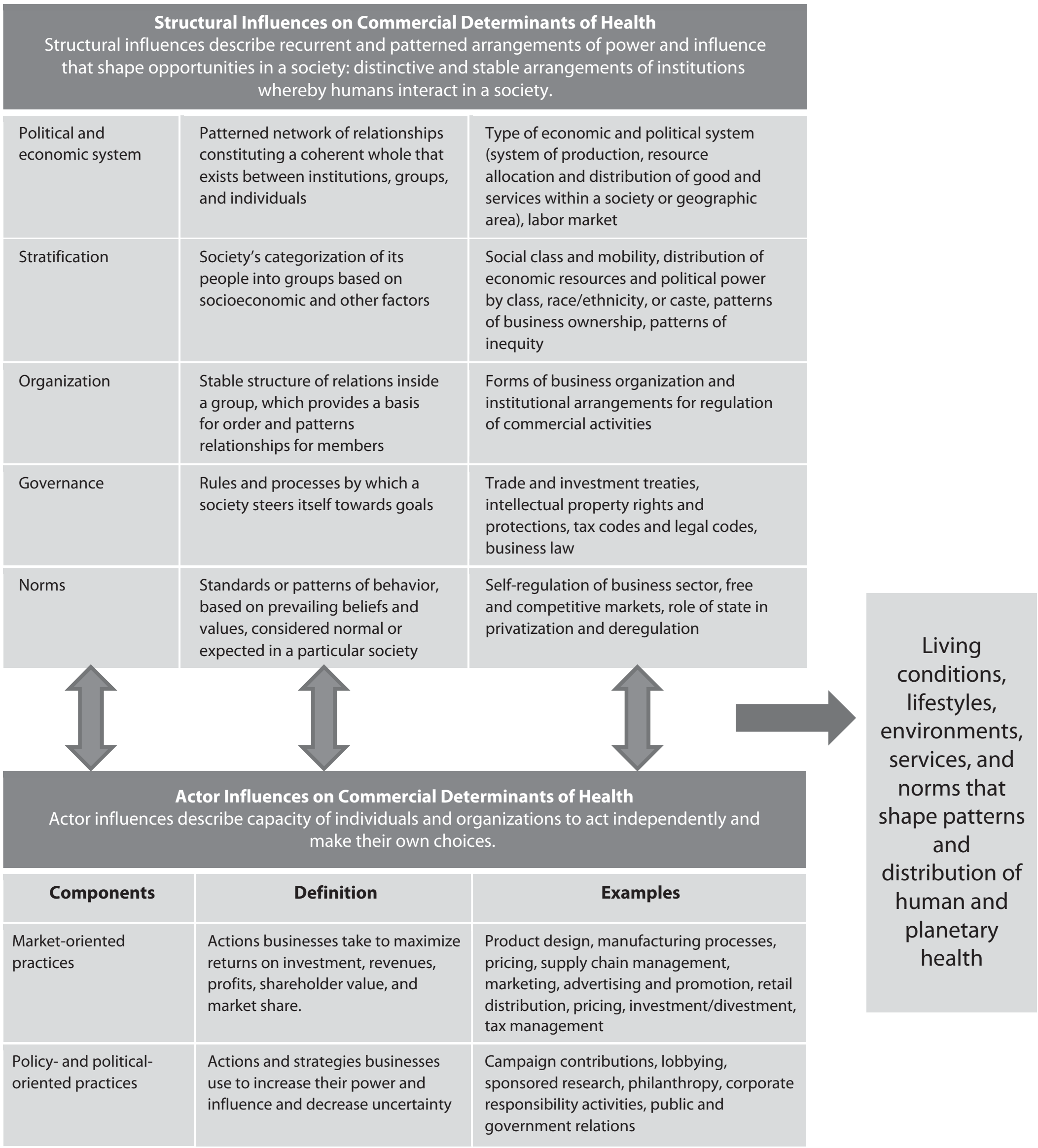
Recent scholarship on CDoH has focused on the role of commercial actors, especially the tobacco, alcohol, and food industries, in contributing to the burden of NCDs. In 2013, World Health Organization Director Margaret Chan summarized this perspective, noting, “Efforts to prevent noncommunicable diseases go against the business interests of powerful economic operators. In my view, this is one of the biggest challenges facing health promotion.”[9(p.i10)] While this emphasis has helped to make commercial interests who profit from health-harming products more accountable, in our view, the focus on NCDs and harmful products limits the potential of a CDoH framework to inform wider research and action. This includes other global health challenges such as mental health, occupational health, planetary health, and infectious diseases and their upstream drivers. To better harness the CDoH concept, we need a more systematic conceptual framework. Jabareen defines conceptual frameworks as “interlinked concepts that together provide a comprehensive understanding of a phenomenon” and argues that by grounding and linking concepts to their intellectual and social origins, scholars can deepen our understanding of the “real world.”[10(p51)]

To create such a framework for the study of CDoH, we reviewed existing reviews of the CDoH literature,[11–18] including our own work spanning business sectors, populations, and academic disciplines. Two meetings of all authors, and several additional meetings by the lead authors, were held in 2019 and 2020 to synthesize this work. Figure 1 synthesizes these multiple perspectives into a single framework that can inform future research and action. Based on this review, we propose an expanded definition of CDoH and then analyze future directions for research and action on commercial influences to improve population health and health equity. Finally, we describe why an empirically grounded science on CDoH may be a useful tool for addressing some of the greatest challenges facing human and planetary health today. We also foreshadow the practical, scientific, and political obstacles that such a framework might encounter and suggest strategies to overcome them.

COMMERCIAL ARRANGEMENTS AND INFLUENCES ON HEALTH

To enhance and sharpen the CDoH lens, we locate the concept within its historical roots. Markets and commercial actors have influenced human health since their inception. In the 17th and 18th centuries, corporations like the Dutch East India Company and then British East India Company set the stage for European imperialism and the rise of industrial capitalism. These early commercial, state-sponsored trading companies influenced health by shaping patterns of production and consumption at home and abroad, the health and well-being of workers in the imperial powers and their colonies, and government regulation.[19]

Over the next 2 centuries, industrial capitalism dramatically changed how markets operate, the living conditions of increasingly stratified populations, and, thus, patterns of health and



Structural Influences on Commercial Determinants of Health
Structural influences describe recurrent and patterned arrangements of power and influence that shape opportunities in a society: distinctive and stable arrangements of institutions whereby humans interact in a society.

Political and economic system	Patterned network of relationships constituting a coherent whole that exists between institutions, groups, and individuals	Type of economic and political system (system of production, resource allocation and distribution of good and services within a society or geographic area), labor market
Stratification	Society's categorization of its people into groups based on socioeconomic and other factors	Social class and mobility, distribution of economic resources and political power by class, race/ethnicity, or caste, patterns of business ownership, patterns of inequity
Organization	Stable structure of relations inside a group, which provides a basis for order and patterns relationships for members	Forms of business organization and institutional arrangements for regulation of commercial activities
Governance	Rules and processes by which a society steers itself towards goals	Trade and investment treaties, intellectual property rights and protections, tax codes and legal codes, business law
Norms	Standards or patterns of behavior, based on prevailing beliefs and values, considered normal or expected in a particular society	Self-regulation of business sector, free and competitive markets, role of state in privatization and deregulation

Actor Influences on Commercial Determinants of Health
Actor influences describe capacity of individuals and organizations to act independently and make their own choices.

Components	Definition	Examples
Market-oriented practices	Actions businesses take to maximize returns on investment, revenues, profits, shareholder value, and market share.	Product design, manufacturing processes, pricing, supply chain management, marketing, advertising and promotion, retail distribution, pricing, investment/divestment, tax management
Policy- and political-oriented practices	Actions and strategies businesses use to increase their power and influence and decrease uncertainty	Campaign contributions, lobbying, sponsored research, philanthropy, corporate responsibility activities, public and government relations

Living conditions, lifestyles, environments, services, and norms that shape patterns and distribution of human and planetary health

FIGURE 1— A Framework for the Study of Commercial Determinants of Health

disease.[20] In the last 50 years, contemporary forms of capitalism, dominated by transnational corporations, financial markets, and globalization—a transformation driven by neoliberal ideology—have shaped the pathways connecting commerce, population health, and health equity. The term neoliberalism describes the mix of deregulatory, privatizing, and austerity measures that assign previously public responsibilities to the private sector,[21] changes that public health scholars have described as pathways to ill health.[22]

The historical origins of the CDoH concept emerged from 3 principal developments. First, changes in political and economic structures modified capitalism in the last century. Second, strands of social science, public health, and medicine scholarship converged to document the impact of those changes. Third, social movements arose to challenge the prioritization of commercial over public interests. These included labor, environmental, civil rights, anticolonial, women's, Health for All, anticorporate, consumer protection, and corporate accountability movements.[23] These social mobilizations insisted that ordinary people had a role to play in demanding that businesses and governments make protecting public health a priority alongside promoting economic growth and profits.[24] These challenges to the established world order constitute the foundation for changing structures and practices that can, in turn, modify patterns of health and disease.[25] Some key ideas that emerged from the intersection of these influences are listed in Table A (available as a supplement to the online version of this article at http://www.ajph.org).

To summarize this history briefly, during the 18th and 19th centuries, industrialization by the imperial powers focused public health attention on new forms of business organization. These included changes in resource extraction and commodity production, manufacturing, and distribution, and large-scale human migration from rural to urban areas, often to live under unhealthy living conditions and poor sanitation. Over the next 100 years, as more workers were absorbed into mass production systems and factories became larger and more hazardous, occupational illnesses, injuries, and exposures became recognized as major causes of ill health.[26]

In Africa, Asia, and Latin America, imperialism evolved to exploit resources and workers to create a mercantile system of labor (including slavery and indentured labor) and traded commodities that increased harms to health and environments locally and globally.[27] Commercial exploitation of workers, indigenous peoples, and local environments in colonized parts of Asia, Africa, and Latin America continued during the 20th century, widening the health gaps between colonizing and colonized nations.[28] In the past 40 years, corporate globalization has transformed supply and value chains, trade and investment rules, intellectual property rights, and overall systems of production and consumption into truly global influences on population health and disease.

Beginning in the mid-19th century, in response to health concerns, workers, reformers, and the emerging public health profession mobilized to improve working conditions, urban water and sanitation, and housing within imperialist nations. In the 1830s and 1840s, the Sanitary Movement brought public attention to the deleterious consequences of industrialization,[29] and later labor movements forced governments to regulate occupational health and safety hazards.[30]

By the mid-20th century, reforms in industrial capitalism precipitated by the Great Depression and labor movements led to better protections for workers and stronger social safety-net programs in Europe and the United States. During the 1960s and 1970s, the civil rights, consumer protection, and environmental movements, and others campaigning for food justice, child safety, women's health, and tobacco control, led to a spate of new regulations.[31]

At the same time, industrialized countries increasingly relied on expanding personal consumption, at least by some groups, to drive economic growth.[32] The rise of NCDs that followed led public health researchers to focus attention on the link to consumption of unhealthy products such as alcohol, tobacco, and ultra-processed food.[3,33] In recent decades, as new evidence on the health consequences of air pollution, climate change, and other toxic exposures emerged, researchers explored broader commercial determinants of these outcomes.[13–15]

As well as increasing production and consumption of unhealthy products, commercial actors influence health and health inequities via other pathways. These include increased exposure to pollution, toxins, and social stressors; unsafe working conditions; and limiting access to life-saving health care, education, and public benefits.[4,11,17] The failure to make COVID-19 (and other) vaccines equitably available to poor nations and poor communities provides a stark illustration of industry opposition to manufacturing and distribution practices that reduce profits or market control.[34]

Attention to each of these expanding pathways of commercial influence on health determinants and outcomes was amplified by scientific and technological change. On the scientific front, biostatistics, social epidemiology, and social medicine, and the development of new technologies to make food, produce energy, and make medical care safer, helped to raise the bar for what business could be expected to do. At the same time, parts of the business community used paid consultants, patent law, trade treaties, and their political clout to distort science that they perceived to threaten their commercial interests, a process that tobacco, fossil fuel, food, and other industries have used to manufacture doubt about any scientific findings that jeopardize profits.[35]

In the past 50 years, large corporations have gained substantial political and economic power, creating asymmetries that make it difficult for public health and other actors to protect well-being and reduce health inequities.[16] For example, legislative changes in tax codes and tax enforcement enable corporations to shift or hide profits in ways that reduce government revenues to support health and other public services.[36]

It is also true, however, that social movements, governments, and civil society groups have challenged that power. These countervailing forces have won concessions from commercial actors such as new labor and environmental laws, consumer protection, and other measures that protect health against harmful commercial influences.[37] More recently, environmental justice and climate movements have demanded more rigorous public oversight of producers of pollutants and toxins with a special focus on exposures of vulnerable populations.[38] A chronology of the events summarized here can be found in Table A (available as a supplement to the online version of this article at http://www.ajph.org).

PROPOSED DEFINITION OF CDOH

A growing body of evidence, summarized in several recent reviews,[11–14] shows that CDoH, broadly defined as "factors that influence health which stem from the profit motive" by West and Marteau in 2013,[39(p686)] are shaping global patterns of health and disease.[40]

Lack of consensus on the definition and understanding of CDoH remains a major obstacle to overcoming this neglect. Scholars have proposed varied definitions of CDoH, summarized in a recent review,[14] and others have suggested models for considering the role of these determinants.[12–14] Informed by our review of the historical evolution of the term, and addressing some of the questions earlier definitions leave unresolved, we define the commercial determinants of health as the social, political, and economic structures, norms, rules, and practices by which business activities designed to generate profits and increase market share influence patterns of health, disease, injury, disability, and death within and across populations.

What is the rationale for this definition? First, it recognizes that CDoH can both promote and harm population health. This recognition may serve to engage a wider cross-section of researchers in developing a conceptual framework and applied research, and encourage policymakers, business leaders, and advocates to increase action to address CDoH.

Second, by focusing attention on both the social structures (including norms, rules, and legal frameworks) and practices that enable and sustain commerce, the definition gives researchers and advocates a fuller range of subjects for investigation and action. It also acknowledges that structural power, generally overlooked in past work on CDoH, is a key influence.[16,41] This broader perspective also acknowledges the ongoing debates about capitalism, not as a singular economic and political world order but characterized by multiple varieties, each with distinct characteristics and opportunities for health and diseases.[42] Indeed, the proposed definition invites researchers to specify the differing ways that CDoH shape well-being in the varieties of capitalism now operating around the world, including the state and authoritarian modes of capitalism in China, Russia, and other nations.[43]

Third, by identifying the scope of CDoH as investigating patterns of health attributable to market factors operating across populations and nations, the definition sets the stage for making health inequities a focus of research and action. This contrasts with the focus of the Global Burden of Disease study, which created a single measure of mortality and morbidity to compare countries and regions but did not emphasize documenting inequities among subpopulations.[44]

Fourth, by making the commercial-related activities and interactions of both state and market actors of interest, the definition extends study of CDoH beyond the corporation as only one, albeit dominant, form of economic organization. It includes all for-profit companies (privately owned, partnerships, cooperatives); trade associations; accounting, advertising, public relations, media, and communications firms; lobbyists; financial institutions; probusiness think tanks; and government entities, including state-owned businesses that seek profits and regulators dominated (or "captured") by businesses.[45] In this way, the definition encourages understanding of the full range of economic and political arrangements that shape commercial activities, from the local to global, as a complex system worthy of analysis.[17] It also encourages applying the CDoH lens to the operations, rules, and impact on health of the varieties of old and new markets and related regulatory regimes now operating around the world.[46]

Fifth, the definition expands the study of CDoH beyond "unhealthy products," notably alcohol, ultra-processed foods, and tobacco, the most studied industry,[3] to a much wider set of health-related goods and services, along with the markets and public and private actors that enable their production and consumption. Other industries that attract scrutiny through the CDoH lens included traditional and social media, extractive industries, pharmaceuticals, advertising, gaming, and entertainment sectors.

Finally, our definition sets the stage for further theoretical and empirical investigation of the extent to which

CDoH are a driver of other social determinants of health (i.e., a fundamental cause of global and national health inequities),[47] a subset of social determinants of health, or an alternative lens to examine social influences. Clarifying these relationships could strengthen the capacity of CDoH and social determinants of health frameworks to inform public health interventions.

PROMISE OF EXPANDED CONCEPT

Figure 1 seeks to inform the creation of a more integrated body of knowledge that can help to synthesize rapidly growing but, to date, often disjointed, bodies of work. It seeks to make these elements visible by identifying specific entities and processes that scholars of commercial influences and actors have investigated. We posit that political and economic structures shape, and are shaped by, the formulation and creation of business rules and practices, which, in turn, create the exposures and living conditions that influence health determinants and outcomes.

Ultimately, the promise of a definition, conceptualization, and framework to study CDoH is improved evidence to guide more effective interventions to minimize intersecting threats to human and planetary well-being. For each threat, we need to better understand how commercial influences play an important role in shaping why these problems are occurring, which populations are most affected, and the prevalence and distribution of the health consequences of these threats. For these reasons, CDoH warrant fuller investigation in public health.

Our definition of CDoH and Figure 1 call attention to the critical role of power in shaping the impact of commercial influences. Structural and systemic forces have over the past 50 years allocated new political and economic power to corporations and their allies. These organizations and their leaders have used this power to select market and nonmarket strategies intended to increase revenues and profit often at the cost of unintended harms to health. The decisions of tobacco, unhealthy food, and alcohol producers to shift their marketing from more regulated high-income countries to less regulated low- and middle-income ones illustrate this process.[48]

For the most part, in the past 2 decades, while new discoveries have benefited many individuals, they have less frequently contributed to meaningful improvements in population health and have often exacerbated rather than reduced inequities in health.[49] One reason for the disappointing health impact of new discoveries is that commercial actors have used their power to shape patent laws, trade treaties, and disinformation campaigns that ensure that science and technology are deployed in ways that protect profit maximization, even if such uses harm health.

CDOH INFORMED PRACTICE

We conclude that there are several ways to deliver on the potential for CDoH to effectively frame a more impactful area of inquiry and action focused on improving population health and health equity.[50]

First, researchers need to identify focused research questions and appropriate methodologies to answer them. Suggestions are listed in Box 1. Some researchers have proposed research agendas for studying CDoH,[51] but to guide implementation of such agendas, investigators will have to set priorities, share resources, and, as Hastings puts it, develop a "boldness of purpose" that matches the vigor with which business groups pursue their agenda.[52] Among the key tasks are mapping the variability of CDoH practices, pathways, and impact across business sectors, nations, time periods, and populations. For example, how do the practices of the tobacco industry, the best studied of harmful commodity producers, differ from and resemble those of the food, alcohol, and pharmaceutical sectors? Of key importance, researchers need to assess what portion of the glaring inequities in health within and between nations can be attributed to various CDoH. Such evidence can guide the translation of growing but mostly separate bodies of evidence into cohesive practice and policy.

Second, CDoH researchers and public health officials should identify metrics that can be used to quantify and monitor CDoH and their impact on health (Box 1). To further advance research on CDoH, scholars can use the framework in Figure 1 to identify and begin to measure a broader range of specific variables across the domains, investigate the interactions among them, and then analyze the mechanisms by which they shape health outcomes. Researchers can also identify common and differing drivers, and the specific and intersecting pathways by which CDoH influence human and planetary health through production, consumption, and environmental routes. Clarifying the specific routes by which CDoH get "embodied" in states of health and the burden of disease imposed by each will help to select priorities for intervention.

Third, to advance the science and practice of CDoH-informed public

BOX 1— Key Research and Policy Questions on Commercial Determinants of Health (CDoH)

Questions on	
Methodologies	What are the strengths and weaknesses of methodologies such as systems thinking, a holistic approach that seeks to understand how systems interact to influence each other and outcomes; health impact assessment, which seeks to judge the potential health effects of changes in policy or organizational practices; social impact assessment, a process of identifying and managing the social impacts of industrial projects; and the development of indices and scales to measure various components of CDoH? How can practice-based evidence and implementation science contribute to a deeper understanding of modifying harmful CDoH?
Priorities	What specific commercial determinants impose the largest attributable burden of disease? What business sectors impose the largest burden of disease? Which contribute most to health inequities? How do CDoH influence health in low- and middle-income countries as compared to high-income countries? Which are most possible to modify in short and middle run?
Metrics	What are the strengths and weaknesses of such metrics as those used in the Global Burden of Disease study, the Corporate Permeation Index, or corporate health impact assessments? What other metrics exist or could be developed to compare the impact of commercial influences across populations, nations, and business sectors?
Education and workforce development	What are the skills and competencies that public health professionals and researchers need to tackle commercial determinants? (See also Box 2.) What disciplines need to contribute to a science of CDoH? How do commercial actors influence education of public health and other professionals? What strategies (e.g., litigation, regulation, public mobilization) are most effective in reducing which specific harmful influences?
Role of science	How do commercial actors influence the questions researchers ask, their methods of communicating findings, and the public discussion of evidence on harms and benefits?
Change strategies	How effective and under what circumstances are voluntary public–private partnerships effective in mitigating harmful commercial influences? What role can social movements and civil society groups play in reducing harm from commercial influences? What are the advantages and disadvantages of addressing commercial actors and influences at local, regional, national, and global levels? What role should international organizations such as the World Health Organization and World Bank play in addressing CDoH? What regulatory approaches are most effective in addressing commercial influences across industries, populations, levels of economic development, and governance regimes?

health will require new inclusive approaches to research, education, and advocacy as well as new forms of intersectoral and interdisciplinary collaboration and dialogue. These approaches should incorporate bodies of knowledge from public health, history, political economy, law, and other disciplines, as well as social movement theory and practice. Schools of public health can identify and ensure that their graduates master the competencies needed to limit harmful commercial influences and ensure that students acquire the requisite skills and knowledge, with some suggestions shown in Box 2.

Fourth, to develop a body of practice-based evidence, public health and other professionals, along with policymakers, can evaluate the effectiveness and feasibility of strategies and interventions to reduce the harmful impact of CDoH and to enhance positive effects through the co-creation of evidence-informed and practice-based bodies of knowledge. They can also assess and strengthen the capacity of their organizations to monitor and regulate CDoH. Some scholars and advocates have warned that when business interests play a growing role in bodies such as the World Health Organization, the World Trade Organization, and national governments, these commercial actors can distort democratic governance and public accountability, reducing opportunities for protecting public health.[53]

Fifth, public health organizations, professionals, and training institutions can act to protect science from industry and political interference. Commercial actors appropriate new science for their private interest rather than public benefit, propagate doubt about scientific evidence that jeopardizes profitability, and hide or obfuscate their own sponsored research that contradicts their claims. By denormalizing such practices through institutional policies, laws, and social norms, the public health community can reassert the value of basing public policy on evidence.

Finally, and perhaps most importantly, together with civil society organizations, social movements, and others,

BOX 2— Proposed Commercial Determinants of Health (CDoH) Competencies for Public Health Professionals and Researchers

Graduates of schools of public health should be able to

1. **Define CDoH and discuss its history and evolving conceptions of its meaning, importance, and relationship to other determinants (e.g., biological and behavioral) and public health frameworks such as social determinants of health.**
2. **Apply CDoH frameworks to the analysis of public health practice, research, and policy analysis to be able to develop research studies and interventions that contribute to effective strategies for minimizing the harms and maximizing the benefits of CDoH.**
3. **Assess marketing practices and corporate political activity among major health-harming industries such as tobacco, alcohol, food and beverage, pharmaceuticals, social media, fossil fuels, and others.**
4. **Identify key sources of evidence and data on the distribution, impact, and pathways by which CDoH influence health and assess the strengths and limitations of these sources.**
5. **Assess the strengths and weakness of various supply-side and demand-side government policy solutions and intergovernmental agreements to reduce noncommunicable and other diseases.**
6. **Assess the various strategies, tactics, countermarketing, and campaigns by advocacy groups and coalitions to address the harms of CDoH and help reduce noncommunicable diseases and other adverse outcomes.**
7. **Evaluate the impact of strategies designed to reduce the harms and enhance the benefits of CDoH and communicate the findings clearly to various constituencies.**
8. **Make the case for public health practice and research that address CDoH as fundamental determinants of health and health equity.**

those seeking to reduce the harmful health influences of commercial actors must explore and propose alternatives to the paradigms and social, political, and economic models that pose the current system as inevitable and immutable.[2] To expedite collaboration and knowledge exchange, researchers and advocates can strengthen and expand international and interdisciplinary networks and open dialogues with others seeking to modify commercial structures and practices. To date, public health researchers have not achieved consensus regarding whether any interactions with corporate leaders are warranted, given the extensive evidence that businesses use such interactions to co-opt, distract, or confuse public discourse. The empirical evidence on public health and corporate partnerships suggests limited benefits and significant potential adverse effects.[54] At a minimum, the current power asymmetry between public health and corporations would need to be better balanced before equitable partnerships could be considered.

Researchers and policymakers who use CDoH frameworks differ in their views on the inevitability, mutability, and necessity of replacing contemporary forms of corporate-dominated capitalism with other political and economic systems. But most agree that improving public health and health equity will require significant changes in the structures, norms, rules, and practices that now sustain business activities. Furthermore, most agree that the neoliberal argument, that the invisible hands of free markets are self-regulating mechanisms that will ultimately best balance supply and demand and produce what people want and need, does not describe the world in the early 21st century. CDoH can provide a framework for researchers and practitioners with varying political and ideological stances to overcome unproductive and polarizing conflicts that "gridlock" action, making it possible to advance empirical investigations and test interventions designed to reduce harmful commercial influences on health.

For the past 2 centuries, public health progress has depended on alliances among social reformers, health professionals, researchers, and social movements. To craft such relationships to take on CDoH will require new skills, organizational forms, and forums for developing and testing strategies. Applying these lessons to the 21st century has the potential to strengthen public health's capacity to tackle CDoH as one of the fundamental causes of the world's most serious health, social, and environmental problems. AJPH

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REFERENCES

1. Case A, Deaton A. *Deaths of Despair and the Future of Capitalism.* Princeton, NJ: Princeton University Press; 2021. https://doi.org/10.2307/j.ctv161f3f8
2. Freudenberg N. *At What Cost Modern Capitalism and the Future of Health.* New York, NY: Oxford University Press; 2021.
3. Stuckler D, McKee M, Ebrahim S, Basu S. Manufacturing epidemics: the role of global producers in increased consumption of unhealthy commodities including processed foods, alcohol, and tobacco. *PLoS Med.* 2012;9(6):e1001235. https://doi.org/10.1371/journal.pmed.1001235
4. Maani N, Van Schalkwyk MC, Petticrew M, Galea S. The commercial determinants of three contemporary national crises: how corporate practices intersect with the COVID-19 pandemic, economic downturn, and racial inequity. *Milbank Q.* 2021;99(2):503–518. https://doi.org/10.1111/1468-0009.12510
5. Parra DC, de Sá TH, Monteiro CA, Freudenberg N. Automobile, construction and entertainment business sector influences on sedentary lifestyles. *Health Promot Int.* 2018;33(2):239–249.
6. Infante PF, Melnick R, Vainio H, Huff J. Commentary: IARC Monographs Program and public health under siege by corporate interests. *Am J Ind Med.* 2018;61(4):277–281. https://doi.org/10.1002/ajim.22811
7. Pritchett L, Summers LH. *Wealthier Is Healthier.* Washington, DC: World Bank Publications; 1993.
8. Reich MR. *Public–Private Partnerships for Public Health*. Cambridge, MA: Harvard University Press; 2002:1–18.
9. Opening address by Dr Margaret Chan, Director-General, World Health Organization. *Health Promot Int.* 2014;29(suppl 1):i9–i10. https://doi.org/10.1093/heapro/dau037
10. Jabareen Y. Building a conceptual framework: philosophy, definitions, and procedure. *Int J Qual Methods.* 2009;8(4):49–62. https://doi.org/10.1177/160940690900800406
11. Maani N, Collin J, Friel S, et al. Bringing the commercial determinants of health out of the shadows: a review of how the commercial determinants are represented in conceptual frameworks. *Eur J Public Health.* 2020;30(4):660–664. https://doi.org/10.1093/eurpub/ckz197
12. Mialon M, Vandevijvere S, Carriedo-Lutzenkirchen A, et al. Mechanisms for addressing and managing the influence of corporations on public health policy, research and practice: a scoping review. *BMJ Open.* 2020;10(7):e034082. https://doi.org/10.1136/bmjopen-2019-034082
13. Lima JM, Galea S. Corporate practices and health: a framework and mechanisms. *Global Health.* 2018;14(1):1–2. https://doi.org/10.1186/s12992-018-0336-y
14. de Lacy-Vawdon C, Livingstone C. Defining the commercial determinants of health: a systematic review. *BMC Public Health.* 2020;20(1):1022. https://doi.org/10.1186/s12889-020-09126-1
15. McKee M, Stuckler D. Revisiting the corporate and commercial determinants of health. *Am J Public Health.* 2018;108(9):1167–1170. https://doi.org/10.2105/AJPH.2018.304510
16. Wood B, Baker P, Sacks G. Conceptualising the commercial determinants of health using a power lens: a review and synthesis of existing frameworks. *Int J Health Policy Manag.* 2021; epub ahead of print. https://doi.org/10.34172/ijhpm.2021.05
17. Knai C, Petticrew M, Mays N, et al. Systems thinking as a framework for analyzing commercial determinants of health. *Milbank Q.* 2018;96(3):472–498. https://doi.org/10.1111/1468-0009.12339
18. Buse K, Tanaka S, Hawkes S. Healthy people and healthy profits? Elaborating a conceptual framework for governing the commercial determinants of non-communicable diseases and identifying options for reducing risk exposure. *Global Health.* 2017;13(1):34. https://doi.org/10.1186/s12992-017-0255-3
19. Robins N. *The Corporation That Changed the World.* London, England: Pluto Press; 2012.
20. Steckel RH, Floud R, eds. *Health and Welfare During Industrialization.* Chicago, IL: University of Chicago Press; 1997. https://doi.org/10.7208/chicago/9780226771595.001.0001
21. Harvey D. *A Brief History of Neoliberalism.* New York, NY: Oxford University Press; 2005. https://doi.org/10.1093/oso/9780199283262.001.0001
22. Rushton S, Williams OD. Frames, paradigms and power: global health policy-making under neoliberalism. *Glob Soc.* 2012;26(2):147–167. https://doi.org/10.1080/13600826.2012.656266
23. Musolino C, Baum F, Freeman T, Labonté R, Bodini C, Sanders D. Global health activists' lessons on building social movements for Health for All. *Int J Equity Health.* 2020;19(1):116. https://doi.org/10.1186/s12939-020-01232-1
24. Brown TM, Fee E. Social movements in health. *Annu Rev Public Health.* 2014;35(1):385–398. https://doi.org/10.1146/annurev-publhealth-031912-114356
25. Grinin L. Evolution of world order. In: Grinin LE, Korotayev AV, eds. *Evolution and Big History.* Volgograd, Russia: Uchitel Publishing House; 2016:75–95.
26. Weindling P, ed. *The Social History of Occupational Health.* Beckhenham, England: Croom Helm; 1985.
27. Bashford A. *Imperial Hygiene: A Critical History of Colonialism, Nationalism and Public Health.* London, England: Palgrave Macmillan; 2003.
28. Pratik C. *Medicine & Empire: 1600–1960.* Basingstoke, UK: Palgrave Macmillan; 2014.
29. Chadwick E. *General Report on the Sanitary Condition of the Labouring Population of Great Britain.* London, England: Clowes; 1842.
30. Rosen G. *A History of Public Health.* New York, NY: M.D. Publications; 1958.
31. Cohen L. *A Consumers' Republic: The Politics of Mass Consumption in Postwar America.* New York, NY: Vintage Books; 2008.
32. Shammas C. Standard of living, consumption, and political economy over the past 500 years. In: Trentmann F, ed. *The Oxford Handbook of the History of Consumption.* Oxford, UK: Oxford University Press; 2012: 211–226.
33. *Global Action Plan for the Prevention and Control of Noncommunicable Diseases 2013–2020.* Geneva, Switzerland: World Health Organization; 2013.
34. Sell SK. What COVID-19 reveals about twenty-first century capitalism: adversity and opportunity. *Development (Rome)*. 2020;(63):150–156. https://doi.org/10.1057/s41301-020-00263-z
35. Michaels D. *Doubt Is Their Product: How Industry's Assault on Science Threatens Your Health.* New York, NY: Oxford University Press; 2008.
36. Wiist WH. Public health and corporate avoidance of US federal income tax. *World Med Health Policy.* 2018;10(3):272–300. https://doi.org/10.1002/wmh3.274
37. Friel S. Redressing the corporate cultivation of consumption: releasing the weapons of the structurally weak. *Int J Health Policy Manag.* 2020; epub ahead of print. https://doi.org/10.34172/ijhpm.2020.205
38. Bullard RD. From civil rights to Black Lives Matter. In: Mascarenhas M, ed. *Lessons in Environmental Justice. From Civil Rights to Black Lives Matter.* Thousand Oaks, CA: Sage Publishers; 2020:2–18.
39. West R, Marteau T. Commentary on Casswell (2013): the commercial determinants of health. *Addiction.* 2013;108(4):686–687. https://doi.org/10.1111/add.12118

40. Moodie R, Stuckler D, Monteiro C, et al., Lancet NCD Action Group. Profits and pandemics: prevention of harmful effects of tobacco, alcohol, and ultra-processed food and drink industries. *Lancet.* 2013;381(9867):670–679. https://doi.org/10.1016/S0140-6736(12)62089-3
41. Lacy-Nichols J, Marten R. Power and the commercial determinants of health: ideas for a research agenda. *BMJ Glob Health.* 2021;6(2):e003850. https://doi.org/10.1136/bmjgh-2020-003850
42. Hall PA. Varieties of capitalism. In: Scott RA, Buchmann MC, eds. *Emerging Trends in the Social and Behavioral Sciences: An Interdisciplinary, Searchable, and Linkable Resource.* Hoboken, NJ: John Wiley and Sons; 2015:1–5.
43. Dolfsma W, Grosman A. State capitalism revisited: a review of emergent forms and developments. *J Econ Issues.* 2019;53(2):579–586. https://doi.org/10.1080/00213624.2019.1606653
44. Mathers C. Global Burden of Disease—an overview. In: Cockerham W, ed. *International Encyclopedia of Public Health.* 2nd ed. Amsterdam, the Netherlands: Elsevier; 2017. https://doi.org/10.1016/B978-0-12-803678-5.00175-2
45. Mindell JS, Reynolds L, Cohen DL, McKee M. All in this together: the corporate capture of public health. *BMJ.* 2012;345:e8082. https://doi.org/10.1136/bmj.e8082
46. Roth AE. Marketplaces, markets, and market design. *Am Econ Rev.* 2018;108(7):1609–1658. https://doi.org/10.1257/aer.108.7.1609
47. Clouston SA, Link BG. A retrospective on fundamental cause theory: state of the literature and goals for the future. *Annu Rev Sociol.* 2021;47:131–156. https://doi.org/10.1146/annurev-soc-090320-094912
48. Moodie R, Stuckler D, Monteiro C, et al., Lancet NCD Action Group. Profits and pandemics: prevention of harmful effects of tobacco, alcohol, and ultra-processed food and drink industries. *Lancet.* 2013;381(9867):670–679. https://doi.org/10.1016/S0140-6736(12)62089-3
49. Weiss D, Rydland HT, Øversveen E, Jensen MR, Solhaug S, Krokstad S. Innovative technologies and social inequalities in health: a scoping review of the literature. *PLoS One.* 2018;13(4):e0195447. https://doi.org/10.1371/journal.pone.0195447
50. Buse K, Tanaka S, Hawkes S. Healthy people and healthy profits? Elaborating a conceptual framework for governing the commercial determinants of non-communicable diseases and identifying options for reducing risk exposure. *Global Health.* 2017;13(1):34. https://doi.org/10.1186/s12992-017-0255-3
51. Paichadze N, Werbick M, Ndebele P, Bari I, Hyder AA. Commercial determinants of health: a proposed research agenda. *Int J Public Health.* 2020;65(7):1147–1149. https://doi.org/10.1007/s00038-020-01445-9
52. Hastings G. Why corporate power is a public health priority. *BMJ.* 2012;345:e5124. https://doi.org/10.1136/bmj.e5124.
53. Lee K, Smith J. The role of the business sector in global health politics. In: *The Oxford Handbook of Global Health Politics*. New York, NY: Oxford University Press; 2020: 385–408.
54. Kostyak L, Shaw DM, Elger B, Annaheim B. A means of improving public health in low- and middle-income countries? Benefits and challenges of international public–private partnerships. *Public Health.* 2017;149:120–129. https://doi.org/10.1016/j.puhe.2017.03.005

Using Point-in-Time Homeless Counts to Monitor Mortality Trends Among People Experiencing Homelessness in Los Angeles County, California, 2015–2019

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See also Galea and Vaughan, p. 2094.

Objectives. To report trends in mortality rates, mortality rate ratios (MRRs), and causes of death among people experiencing homelessness (PEH) in Los Angeles County, California, by using annual point-in-time homeless counts and to compare findings to published longitudinal cohort studies of homeless mortality.

Methods. We enumerated homeless deaths and determined causes by using 2015–2019 medical examiner–coroner data matched to death certificate data. We estimated midyear homeless population denominators by averaging consecutive January point-in-time homeless counts. We used annual demographic surveys of PEH to estimate age- and gender-adjusted MRRs. We identified comparison studies through a literature review.

Results. Mortality rates increased from 2015 to 2019. Drug overdose was the leading cause of death. Mortality was higher among White than among Black and Latino PEH. Compared with the general population, MRRs ranged from 2.8 (95% confidence interval [CI] = 2.7, 3.0) for all causes to 35.1 (95% CI = 31.9, 38.4) for drug overdose. Crude mortality rates and all-cause MRRs from comparison cohort studies were similar to those in the current study.

Conclusions. These methods can be adapted by other urban jurisdictions seeking to better understand and reduce mortality in their homeless populations. (*Am J Public Health*. 2021;111(12):2212–2222. https://doi.org/10.2105/AJPH.2021.306502)

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Public health strategies for reducing mortality in the general population are guided by trends in mortality rates that use midyear census estimates as proxies for person-years of exposure to mortality risk. Tracking mortality prevention efforts for people experiencing homelessness (PEH) is more challenging because PEH are not well-represented in census data.[1] Nevertheless, the need for these efforts is urgent, as evidenced by a growing number of cohort studies finding that mortality rates among PEH are considerably higher than those among the general public.[2–19] These studies of PEH served by specific shelter or health care systems tracked deaths over time to derive homeless mortality rates using person-years of observation as denominators. Standardized mortality ratios or mortality rate ratios (MRRs) were then estimated to compare homeless mortality with general population mortality. However, these studies are of limited use to local officials seeking data to guide homeless mortality reduction strategies in their communities because they were conducted over different time periods in different jurisdictions.

Rather than relying on census data, local officials can leverage federally mandated census-like estimates of homeless populations, called point-in-time (PIT) counts, for monitoring mortality rates among PEH. In 2007, the US Department of Housing and Urban Development began requiring local homeless services authorities, called continuums of care (CoCs), to conduct biannual counts of sheltered and unsheltered PEH in their jurisdictions as a condition of funding. These PIT counts occur during the last 10 days of January. According to a recent US Government Accountability Office study, there is considerable variability in the quality of PIT count data across the 397 CoCs in the United States, although quality is highest among CoCs in large urban areas.[20]

The current study estimated mortality rates and MRRs among PEH in Los Angeles (LA) County, California, which has the largest unsheltered population in the United States. The LA County CoC PIT count methodology is particularly strong as it includes (1) a canvassing of all census tracts (i.e., a complete census) for the unsheltered count and (2) a demographic survey in a stratified random sample of census tracts to produce gender, age-group, and racial/ethnic estimates for unsheltered PEH with specified sampling errors.[21] Thus, the LA County CoC PIT count provides a good test case from which to assess the potential utility of PIT-count data for calculating PEH mortality rates. To make this assessment, we compared the results of a PIT count–based methodology in LA County with those of longitudinal cohort studies from other jurisdictions. We examined methodological strengths, limitations, and differences of each approach.

Specifically, we used LA County CoC PIT count data and medical examiner–-coroner (MEC) data matched to death certificate data to (1) estimate all-cause and cause-specific mortality trends among PEH in LA County from 2015 to 2019, (2) compare age-adjusted mortality trends among gender and racial/ethnic subgroups of PEH from 2017 to 2019, and (3) compare all-cause and cause-specific PEH mortality rates with corresponding rates in the general LA County population for the combined years of 2017 to 2019. We assumed that the average of 2 consecutive January PIT counts approximates person-years of exposure to homelessness for the index year and can thus serve as a reasonable denominator for an annual homeless mortality rate. To explore this assumption, we compared the mortality rates and MRRs from the current study to those reported in previously published cohort studies.

METHODS

Because California death certificates do not systematically document homelessness, this study's primary source of data on homeless deaths was the LA County MEC. State law requires the MEC to investigate all violent, sudden, unusual, or unattended deaths. Before this study was conducted, LA County had begun to use MEC data to produce informal counts of homeless deaths. We augmented the subset of 2015–2019 MEC case records coded as homeless through systematic text-based searches of relevant data fields to identify misclassified records. All records with emergency shelter or transitional housing addresses were coded as homeless. Cases with homeless key words (i.e., homeless, transient, shelter, lives in van, lives in car, lives in vehicle, no fixed abode, no known residence, tent, encampment, indigent, skid row, and vagrant) in descriptive fields were independently reviewed by 2 analysts using Department of Housing and Urban Development homelessness criteria, and those cases meeting criteria were also coded as homeless.

To identify homeless deaths not investigated by the MEC, we also searched all 2015–2019 LA County death certificates for addresses suggesting homelessness, including homeless key words, emergency shelter or transitional housing addresses, and location descriptions consistent with instructions for local registrars on how to code addresses for homeless decedents. As an additional check on the completeness of MEC data as a source for homeless deaths—particularly those occurring in hospitals—we compared the proportion of MEC homeless deaths that occurred in hospitals to the proportion of all MEC investigated deaths and all LA County deaths in hospitals.

We obtained LA County mortality data for 2017–2019 MRRs from the Los Angeles County Department of Public Health. Data from 2018 to 2019 did not include out-of-state deaths among LA County residents.

Population Denominators

We used the averages of 2 consecutive January PIT homeless counts to estimate midyear homeless population denominators for annual rate calculations. The LA County CoC PIT count is conducted by the LA Homeless Services Authority in collaboration with researchers at the University of Southern California.[21] The unsheltered count consists of an enumeration in all 2163 LA County CoC census tracts using trained volunteers and special outreach teams assigned to hard-to-reach places. The sheltered count is an enumeration of all individuals living in emergency shelters and transitional housing in the LA County CoC, including those receiving vouchers for hotels or motels provided by emergency shelters. Three cities within LA County—Pasadena, Glendale, and Long Beach—which together comprised an average of 4% of the county homeless population from 2015 to 2020, have their own CoCs and PIT counts, and are the only portions of LA County not served by the LA County CoC. We used the sums of all 4 CoC PIT counts to estimate the countywide PEH population.

We obtained estimates of the gender, racial/ethnic, and age-group characteristics of unsheltered PEH from demographic surveys conducted in stratified random samples of census tracts.[21] In January 2020, for example, 6368 surveys were completed across 505 selected census tracts. Numbers of surveys and tracts were similar across years. Demographic estimates of sheltered PEH came from the LA County CoC's Homeless Management Information System. To estimate the demographic characteristics of PEH countywide, we assumed that the demographics of PEH in the 3 smaller CoCs were the same as those in the LA County CoC, which appears to be reasonable based on PIT count reports from Long Beach and Pasadena.[22,23] We used the averages of 2 consecutive years of demographic data to approximate midyear demographic estimates for 2017 to 2019. We obtained demographic data for the 2017–2019 LA County population from Hedderson Demographic Services.

Causes of Death

MEC records were matched to death certificate data to capture *International Classification of Diseases, Tenth Revision*[24] cause-of-death codes only available from death certificates; 98% of MEC records were successfully matched. This matching also allowed for homeless deaths investigated by the MEC to be distinguished from those identified solely from death certificate addresses.

Mortality Rate Ratios

We used MRRs to compare directly standardized rates. The standard population was the 2010 US census population for LA County. First, we compared all-cause mortality rates among racial/ethnic and gender subgroups of PEH, by year, for 2017 to 2019. We calculated MRRs by dividing the directly standardized rate for each PEH subgroup by that of the reference subgroup. The direct standardization in these analyses was based on age only. The age groupings used (< 18, 18–24, 25–54, 55–61, and ≥ 62 years) were dictated by LA Homeless Services Authority's age-group reporting conventions. Second, we compared all-cause and cause-specific mortality rates among PEH with those among the general LA County population for the combined years of 2017 through 2019. We calculated MRRs by dividing the directly standardized rates for PEH by those for the LA County population. The direct standardization in these analyses was based on age and gender. We calculated 95% confidence intervals (CIs) for all rates and MRRs by using SAS version 9.4 and SAS/STAT version 14.3 (SAS Institute, Cary NC). We used conservative CIs for rates; only log-normal CIs were available for MRRs.

Comparisons With Previous Cohort Studies

We conducted a review of published studies of homeless mortality to identify findings that could be compared with those of the current study. Primary inclusion criteria included prospective or retrospective cohort studies that reported mortality rates as numbers of deaths during the study period divided by person years of observation, and MMRs or standardized mortality ratios (SMRs) comparing mortality in a homeless population to mortality in a general population. We excluded studies that focused exclusively on hospitalized PEH, veterans, or other age-, gender-, or disease-related subgroups of PEH.

RESULTS

The PIT population of PEH increased by 50% from January 2015 to January 2020, from 44 359 to 66 436 (Table 1). In January 2020, 72% of PEH were unsheltered, 38% (95% CI = 31.8%, 45.1%) were chronically homeless; 67% (95% CI = 64.2%, 70.1%) were male; and approximately 77% were younger than 55 years. African Americans comprised 34% (95% CI = 27.1%, 40.5%) of the homeless population, compared with 9% of the general population. Latinos comprised 36% (95% CI = 29.8%, 42.2%) of the homeless population compared with 49% of the general population. Whites were proportionately represented among PEH.

Mortality Trends

Of 4988 homeless deaths identified, 235 (5%) were identified solely from death certificate data. Of 4753 MEC-investigated homeless deaths identified, 1517 (32%) occurred in hospitals. By comparison, 36% of all 2015–2019 MEC deaths and 41% of all 2017–2019 LA County deaths occurred in hospitals.

From 2015 to 2019, deaths among PEH increased from 741 to 1267, and the crude mortality rate increased by

TABLE 1— Size and Characteristics of Homeless Population: Los Angeles County, California, 2015–2020

Characteristics	2015[a] (n = 44 359), %	2016[a] (n = 46 874), %	2017 (n = 55 048), % (95% CI)[b]	2018 (n = 52 765), % (95% CI)[b]	2019 (n = 58 936), % (95% CI)[b]	2020 (n = 66 436), % (95% CI)[b]
Gender[c]						
Male	66	66	68 (65, 70)	68 (66, 70)	68 (65, 71)	67 (64, 70)
Female	33	33	32 (27, 37)	31 (27, 35)	31 (26, 37)	32 (28, 37)
Age, y						
< 18	10	8	9 (8,10)	9 (8, 11)	9 (4, 14)	12 (7, 16)
18–24	8	8	6 (0, 22)	6 (0, 14)	6 (0, 23)	7 (0, 18)
25–54	57	60	61 (59, 63)	59 (57, 62)	61 (56, 65)	58 (54, 62)
55–61	17	16	16 (9, 23)	16 (9, 22)	15 (2, 28)	14 (3, 24)
≥ 62	8	9	8 (0, 17)	10 (1, 18)	9 (0, 24)	10 (0, 23)
Race/ethnicity[d]						
Non-Hispanic Black	39	39	40 (30, 50)	36 (30, 41)	33 (24, 42)	34 (27, 40)
Hispanic/Latino	27	27	35 (25, 45)	35 (29, 41)	36 (27, 45)	36 (30, 42)
Non-Hispanic White	25	26	20 (3, 37)	25 (18, 32)	25 (14, 35)	25 (17, 34)
Shelter status[e]						
Unsheltered	70	75	73	75	75	72
Sheltered	30	25	27	25	25	28
Chronically homeless	34	31	31 (24, 38)	27 (22, 31)	28 (17, 38)	38 (32, 45)

Note. CI = confidence interval. Totals were based on a countywide census enumeration. Percentages and CIs were estimated from a sample survey of the Los Angeles County continuum of care (CoC), which comprised an average of 96% of people experiencing homelessness (PEH) in Los Angeles County from 2015 to 2020.[21] Age and racial/ethnic characteristics of PEH in the smaller CoCs were similar to those in the Los Angeles CoC.[22,23]

[a] 95% CIs were not available for 2015 and 2016 demographic estimates. These estimates were based on sample surveys similar to those for the 2017-to-2020 point-in-time counts but were conducted by a different group of university-based researchers that was not accessible to the University of Southern California researchers who conducted the more recent surveys.

[b] CI minima were set to zero if they were less than or equal to zero.

[c] Male and female genders include those who identified as transgender and identified their gender as male or female. Those who identified as gender nonconforming are not reported because their numbers were small and statistically unstable.

[d] Those identifying with other racial/ethnic groups were not reported because their numbers were small and statistically unstable.

[e] Percentages of sheltered and unsheltered PEH are from the Los Angeles CoC and have no CIs because they are based on full census enumerations.

24%, from 1624 to 2021 per 100 000 (Table 2). Mortality rates increased more among females (34%) than among males (22%). Rates increased only slightly among those aged 25 to 54 years but increased substantially among all other age groups. Blacks experienced a 40% increase in mortality over this period, versus more modest increases among Whites and Latinos of 10% and 16%, respectively.

The top 5 causes of death were drug overdose, coronary heart disease, traffic injury, homicide, and suicide. These 5 causes accounted for almost two thirds of all deaths. Crude mortality rates from all causes except homicide increased from 2015 to 2019. Drug overdose death rates increased precipitously from 2016 to 2019, surpassing coronary heart disease as the leading cause of death in 2017.

Mortality Rate Ratios

From 2017 to 2019, despite a decrease in the age-adjusted mortality rate among White PEH (2600 per 100 000 vs 2237 per 100 000) and an increase in the age-adjusted mortality rate among Black PEH (1136 per 100 000 vs 1321 per 100 000), the MRRs for Black versus White PEH remained significantly less than 1 (0.44 [95% CI = 0.36, 0.52], 0.51 [95% CI = 0.43, 0.60], and 0.59 [95% CI = 0.50, 0.69], respectively; Table 3). Findings for Latino versus White PEH were similar. However, by 2019, the MRR was no longer significantly different from 1 (0.58 [95% CI = 0.49, 0.69], 0.77 [95% CI = 0.66, 0.90], and 0.88 [95% CI = 0.76, 1.02], respectively). Age-adjusted MRRs

TABLE 2— Number of Deaths and Crude Rates per 100 000 Among People Experiencing Homelessness: Los Angeles County, California, 2015–2019

	2015 (n = 45 617[a]), No. of Deaths (Crude Rate)	2016 (n = 50 961[a]), No. of Deaths (Crude Rate)	2017 (n = 53 907[a]), No. of Deaths (Crude Rate)	2018 (n = 55 851[a]), No. of Deaths (Crude Rate)	2019 (n = 62 686[a]), No. of Deaths (Crude Rate)	% Change 2015–2019
All deaths	741 (1624)	871 (1709)	995 (1846)	1114 (1995)	1267 (2021)	24
Gender						
Male	601 (1992)	720 (2109)	803 (2207)	884 (2362)	1023 (2436)	22
Female	135 (895)	146 (895)	188 (1125)	219 (1265)	236 (1195)	34
Age, y						
18–24	14 (399)	24 (678)	20 (618)	28 (836)	29 (712)	78
25–54	393 (1475)	422 (1371)	491 (1518)	570 (1701)	573 (1536)	4
55–61	167 (2239)	193 (2397)	238 (2759)	259 (2992)	319 (3510)	57
≥ 62	160 (4176)	225 (5319)	241 (4967)	244 (4599)	336 (5642)	35
Race/ethnicity						
White	301 (2593)	340 (2907)	369 (3042)	406 (2908)	447 (2852)	10
Black	186 (1048)	220 (1090)	253 (1252)	258 (1359)	307 (1462)	40
Latino	218 (1773)	268 (1696)	324 (1717)	388 (1957)	463 (2052)	16
Cause of death						
Overdose	149 (327)	153 (300)	246 (456)	273 (489)	346 (552)	69
CHD	141 (309)	208 (408)	194 (360)	227 (406)	255 (407)	32
Transportation-related injuries	54 (118)	70 (137)	92 (171)	102 (183)	103 (164)	39
Homicide	54 (118)	65 (128)	60 (111)	78 (140)	73 (116)	−2
Suicide	36 (79)	36 (71)	51 (95)	57 (102)	58 (93)	18

Note. CHD = coronary heart disease.

[a] These are the averages of the index year and subsequent year populations, which are the midyear estimates used to calculate mortality rates. The percent change in the total homeless population from 2015 to 2019 was 37%.

of male versus female PEH were significantly greater than 1, but decreased from 2017 to 2019 (1.50 [95% CI = 1.24,1.80], 1.51 [95% CI = 1.27, 1.79], and 1.41 [95% CI = 1.19, 1.67], respectively). Gender differences in drug overdose mortality rates were considerably smaller than for all causes and were not statistically significant in 2018 and 2019 (1.29 [95% CI = 0.95, 1.76] and 1.25 [95% CI = 0.93, 1.69], respectively; not shown). For the combined years of 2017 through 2019, PEH experienced an almost 3-fold greater risk of mortality than the general LA County population (2.8; 95% CI = 2.7, 3.0; Table 4). MRRs were markedly higher for drug overdose (35.0; 95% CI = 31.9, 38.4), traffic injury (15.3; 95% CI = 13.0, 18.0), homicide (14.3; 95% CI = 12.1, 17.0), and suicide (7.7; 95% CI = 6.4, 9.3).

Comparisons With Cohort Studies

Nine cohort studies met inclusion criteria for comparisons with the current study (Table 4): 5 from the United States,[2–4,11,17] 1 from Canada,[7] and 3 from Europe.[5,8,9] All US studies were conducted in northeastern cities. All but 3 studies used homeless shelter registries to identify cohorts. The 3 studies from Boston, Massachusetts,[3,11,17] used client encounter data from Boston Health Care for the Homeless. Cohort follow-up periods ranged from 3 to 11 years and the total number of deaths recorded ranged from 67 to 3280. All but 1 study[9] reported crude mortality rates per person-years of observation, and all but 1[8] reported these rates by gender, age group, or race/ethnicity. Six studies used direct standardization of rates and reported MRRs comparing PEH mortality to general population mortality.[2,3,7–9,11] Three used indirect standardization and reported SMRs for comparisons with a general population.[4,5,17]

TABLE 3— Age-Adjusted Mortality Rates and Morality Rate Ratios Among Subgroups of People Experiencing Homelessness: Los Angeles County, California, 2017–2019

Characteristic[a]	2017 No. of Deaths	2017 Age-Adjusted Mortality Rate per 100 000 (95% CI)[b]	2017 MRR (95% CI)[c]	2018 No. of Deaths	2018 Age-Adjusted Mortality Rate per 100 000 (95% CI)[b]	2018 MRR (95% CI)[c]	2019 No. of Deaths	2019 Age-Adjusted Mortality Rate per 100 000 (95% CI)[b]	2019 MRR (95% CI)[c]
Race/ethnicity									
White	369	2600 (2306, 3036)	1 (Ref)	406	2318 (2072, 2680)	1 (Ref)	447	2237 (2014, 2542)	1 (Ref)
Latino	324	1506 (1327, 1709)	0.58 (0.49, 0.69)	388	1782 (1587, 2001)	0.77 (0.66, 0.90)	463	1970 (1772, 2189)	0.88 (0.76,1.02)
Black	253	1136 (988, 1305)	0.44 (0.36, 0.52)	258	1174 (1026, 1343)	0.51 (0.43, 0.60)	307	1321 (1169, 1489)	0.59 (0.50, 0.69)
Gender									
Female	188	1209 (1016, 1435)	1 (Ref)	219	1246 (1062 ,1461)	1 (Ref)	236	1401 (1194, 1640)	1 (Ref)
Male	803	1809 (1673, 1965)	1.50 (1.24, 1.80)	884	1881 (1750, 2030)	1.51 (1.27, 1.79)	1023	1977 (1849, 2119)	1.41 (1.19,1.67)

Note. CI = confidence interval; MRR = mortality rate ratio.

[a] Race/ethnicity and gender data were available for 100% of homeless deaths. Age data for age adjustments were missing for less than 1% of deaths for the race/ethnicity and gender analyses.

[b] CIs for rates, rounded to integer values, are computed to be conservative and are based on a γ distribution.

[c] CIs for MRRs, rounded to 2 decimal places, are based on a lognormal distribution.

We found an overall crude mortality rate of 1964 per 100 000 (Table 4). The average among 7 cohort studies reporting comparable rates was 1939 per 100 000. Although 3 studies reported gender-specific rates only by age group or race/ethnicity,[2,3,11] gender-specific rates in the current study fell in the middle of the range reported across the cohort studies (males: 2332 current vs 1772–4618; females: 1179 current vs 196–2588; Table 4).

None of the selected cohort studies reported an overall MRR adjusted for age and gender as did the current study. However, Hibbs et al.[2] reported an age-adjusted overall MRR of 3.5, and Morrison[8] reported an age-, gender-, and morbidity-adjusted overall MRR of 1.6. Nordentoft and Wandall-Holm[5] reported an age- and gender-adjusted overall SMR of 3.8, and Roncarati et al.,[17] in their study of unsheltered PEH, reported an age-adjusted SMR of 9.8.

In the current study, the age-adjusted MRR for female PEH was significantly lower than that for males (2.6; 95% CI = 2.3, 2.8 vs 3.1; 95% CI = 2.9, 3.2). Only 2 cohort studies reported significant gender difference in MRRs—both reporting higher rates for females.[4,5]

Much like the 6 studies reporting SMRs or MRRs for circulatory system or heart disease,[3,7–9,11,17] the current study found the MRR for coronary heart disease to be only slightly higher than that for all causes (3.6; 95% CI = 3.2, 4.1). However, while previously reported MRRs or SMRs for drug-related deaths were 1.5 to 5 times greater than those for all causes (Table A, available as a supplement to the online version of this article at http://www.ajph.org),[7,8,11,17] the current study reported an MRR for drug

TABLE 4— Comparison of Current Study to Selected Cohort Studies of Homeless Mortality

Study: Location; Period; Population	No. of Deaths	Category–Subgroup: Crude Mortality Rate Per 100 000[a]; MRR or SMR (95% CI)[b]	Adjustment Factor(s)	Comparison Population
Current: Los Angeles County; 2017–2019; all sheltered and unsheltered PEH (PIT count)	3376	Total: 1964; 2.8 (2.7, 3.0)	Age and gender	Los Angeles County general population
		Gender–male: 2332; 3.1 (2.9, 3.2); female: 1179; 2.6 (2.3, 2.8)	Age	
		Age–18–24 y: 737; 11.1 (8.8, 14.0); 25–54 y: 15 971; 8.4 (7.9, 8.8); 55–61 y: 3196; 4.6 (4.2, 5.0); ≥ 62 y: 5220; 1.5 (1.4, 1.7)	Gender	
		Cause of death–drug overdose: 506; 35.0 (31.9, 38.4); coronary heart disease: 396; 3.6 (3.2, 4.1); traffic injury: 174; 15.3 (13.0, 18.0); homicide: 124; 14.3 (12.1, 17.0); suicide: 97; 7.7 (6.4, 9.3)	Age and gender	
Barrow et al.[4]: New York City; 1987–1994; representative sample of single adult shelter residents	161	Total: NR; NR	NR	New York City general population
		Gender–male: 1765; 2.2 (1.9, 2.6); female: 1458; 3.7 (2.6, 5.2)	Age	
Baggett et al.[11]: Boston, MA; 2003–2008; adults with an in-person encounter with Boston Health Care for the Homeless	1302	Total: 1440; NR	NR	Massachusetts general population
		Gender by age–male 25–44 y: 950; 8.6 (7.4, 9.9); male 45–64 y: 2338; 4.5 (4.1, 4.9); male 65–84 y: 4051; 1.1 (0.1, 1.4); female 25–44 y: 586; 9.6 (7.4, 12.4); female 45–64 y: 1469; 4.5 (3.6, 5.6); female 65–84 y: 2353; 1.1 (0.1, 1.8)	Race	
Roncarati et al.[17]: Boston; 2000–2009; unsheltered adults with an in-person encounter with Boston Health Care for the Homeless	134	Total: 3713; 9.8 (8.2, 11.5)	Age	Massachusetts general population
		Gender–male: 4618; NR; female: 1592; NR	NR	
Nordentoft and Wandall-Holm[5]: Copenhagen, Denmark; 1991–2002; residents of 2 hostels for homeless people	141	Total: 2544; 3.8 (3.5, 4.1)	Age and gender	General population of Copenhagen
		Gender–male: 2537; 2.8 (2.6, 3.1); female: 2588; 5.6 (4.3, 6.9)	Age	
Hwang et al.[7]: Canada; 1991–2001; residents of shelters, rooming houses, and hotels aged ≥ 25 y who could be linked to tax records	3280	Total: 2315; NR	NR	Representative sample of general population of Canada
		Gender–male: 2467; 2.0 (1.9, 2.1); female: 1260; 1.8 (1.7, 1.9)	Age	
Morrison[8]: Glasgow, Scotland; 2000–2005; adults with encounters	457	Total: 1414; 1.6 (1.3, 1.9)	Age, gender, and morbidity	Age- and gender-matched random sample of nonhomeless Glasgow population

Continued

TABLE 4— Continued

Study: Location; Period; Population	No. of Deaths	Category–Subgroup: Crude Mortality Rate Per 100 000[a]; MRR or SMR (95% CI)[b]	Adjustment Factor(s)	Comparison Population
with the homeless service system				
Hibbs et al.[2]: Philadelphia, PA; 1985–1987; sheltered and unsheltered PEH registered with at least 1 of 2 local homeless service agencies	67	Total: 1035; 3.5 (2.8, 4.5)	Age	General population of Philadelphia
		Race by gender–White male: 1742; 4.9 (2.8, 8.6); non-White male: 772; 1.6 (1.0, 2.5); White female: 1174; 4.5 (1.9, 10.8); non-White female: 888; 2.2 (1.3, 3.6)	Age	
Beijer et al.[9]: Stockholm, Sweden; 1995–2005; adults with registered stays at homeless shelters	421	Total: 2856; 2.8 (2.5, 3.1)	NR	General population of Stockholm
		Gender–male: 3270; 3.1 (2.8, 3.5); female: 2469; 2.5 (1.9, 3.1)	Age	
Hwang et al.[3]: Boston; 1988–1993; adults with an in-person encounter with Boston Health Care for the Homeless	606	Total: 1114; NR	NR	General population of Boston
		Gender by age–male 18–24 y: 534; 5.9 (2.1, 17.0); male 25–44 y: 1218; 3 (2.6, 3.5); male 45–64 y: 2170; 1.6 (1.3, 1.8); female 18–24 y: 196; 11.8 (4.2, 33.1); female 25–44 y: 490; 3.9 (2.8, 5.5); female 45–64 y: 1004; 1.5 (1.0, 2.2)	Race	

Note. MRR = mortality rate ratio; NR = not reported; PEH = people experiencing homelessness; PIT = point in time; SMR = standardized mortality ratio.

[a] Beijer et al.[9] reported age-adjusted rates only. All other studies reported crude rates. Except for the current study, all studies reported rates per person-years of observation.

[b] Barrow et al.,[4] Roncarati et al.,[17] and Nordentoft and Wandall-Holm[5] reported SMRs. All other studies reported MRRs.

overdose that was 12 times greater than the all-cause MRR.

DISCUSSION

To our knowledge, this is the first published study of homeless mortality rates and MRRs for LA County. While studies in other jurisdictions have relied on cohort designs to determine mortality rates per person-years of observation, this one used annual PIT counts to approximate person-years of homelessness much like census data are used as denominators in studies of general population mortality. We are aware of only 2 other studies that used PIT-like counts to calculate homeless mortality rates.[25,26]

The comparisons in Table 4 help to demonstrate the similarity of our findings with those of previous cohort studies. They also point to interesting differences. For example, the only study of unsheltered PEH[17] reported the highest overall SMR of 9.8 compared with the general population. Because about three quarters of LA County's homeless population are unsheltered, it is notable that the overall MRR for LA County was closer to those reported in studies of sheltered PEH. This may be attributable to differences between LA County and other study locations in the demographic characteristics of PEH or in the environmental conditions they face. This study's finding of a lower MRR for females than males may be attributable to differences in the circumstances of female PEH in LA County compared with other locations, although the lack of gender differences in drug overdose mortality points to the particular need for substance use interventions targeting female PEH.

Like Hibbs et al., Baggett et al., and Roncarati et al.,[2,11,17] in our current study, we found that mortality rates among White PEH were significantly higher than those among Black PEH. The authors of the previous studies suggest that Black PEH may have fewer comorbidities when they become homeless because their homelessness is more closely linked to adverse socioeconomic circumstances rooted in systemic racism and discrimination. By contrast, White individuals may experience years of accumulated mental, behavioral, and physical comorbidities before they become homeless. Thus, both the disproportionate representation of Blacks among PEH and lower mortality rates among Black versus White PEH are likely explained by systemic racism and discrimination.

Limitations

A limitation of this study is that we may not have identified all deaths among PEH during the study period because we assumed that the MEC investigates nearly all homeless deaths. We were able to identify a small number of non-MEC deaths from searches of death certificate address fields, but these may contain outdated or next-of-kin addresses and are, thus, not always reliable indicators of homelessness. While a sizable proportion of MEC-investigated deaths occurred in hospitals, the hospital proportions of all MEC and all LA County deaths were greater. Thus, we may have missed an unknown number of PEH who died in hospitals of natural causes without MEC involvement.

Another limitation is that an annual PIT count may not be an accurate approximation of person-years of exposure to homelessness. A PIT count will underestimate the number of people who have experienced homelessness for any portion of the year, but most of the latter—particularly in Los Angeles County, where only about a third of PEH are chronically homeless—do not contribute a full person year of exposure to homelessness. A more salient concern is whether a PIT count approximates the number of PEH on an average day of the year—the assumption inherent in general population mortality statistics using midyear population denominators. Having a federally supported process for conducting annual PIT counts allows for this concern to be addressed empirically. The lack of volatility in the LA County CoC PIT count from year to year provides some reassurance that the average of 2 consecutive annual counts is a reasonable estimate of the average number of PEH on any given day during the index year.

Finally, it is important to note that methodological differences between this study and previous cohort studies may have contributed to some differences in the findings. In the current study, all deaths occurred while the decedent was experiencing homelessness, and the denominator for mortality rates is expressed as person-years of homelessness. Deaths in previous studies occurred among cohorts of PEH who may or may not have been homeless when they died. Denominators in these studies are expressed as person-years of observation. Thus, if the risk of dying from particular causes of death is elevated during periods of homelessness but decreases during periods of stable housing, the current study would likely find higher mortality rates from these causes because of the study design. The 3 causes of homeless deaths with the highest MRRs compared with the general LA County population align with this logic. Homicide is easier to perpetrate against someone lacking the protection of a home. People living on the street are more exposed to potentially lethal road traffic than those who are housed. Someone who is severely addicted to drugs may lose his or her housing as a result of their addiction, in which case an overdose death may be associated with an inability to regain housing.

This same methodological difference may explain why, unlike previous studies,[11–13,17,19] the current study did not identify cancer among the top causes of death among PEH. Unlike coronary heart disease—a leading cause of natural death among LA County PEH—cancer is more likely to go unreported as a cause of death if it is not diagnosed before death. Those who die while experiencing homelessness may be less likely to receive the full autopsy necessary to identify undiagnosed cancer (Jonathan Lucas, medical examiner; e-mail communication; March 24, 2021). By contrast, members of study cohorts defined by their registered use of shelter and homeless health care systems may have better access to diagnostic services and, once diagnosed with cancer, may be more able to access permanent supportive housing.

Public Health Implications

This study has demonstrated the feasibility of monitoring homeless mortality to inform local prevention strategies using (1) federally mandated homeless counts and accompanying demographic surveys to estimate population size and demographic composition and (2) linked coroner and death certificate data to enumerate deaths and identify causes. It has also demonstrated the general consistency of findings with those of previous studies of homeless mortality that used longitudinal cohort designs. The results of the analyses described here informed the organization of a cross-department homeless mortality prevention initiative in LA County. Priority strategies of the initiative include improvement and expansion of substance use disorder treatment services for PEH, expansion of interim housing options for PEH in substance use disorder treatment, and prioritization of permanent housing placement for those completing substance use disorder treatment, among others. The LA County Department of Public Health now produces an annual homeless mortality report to inform this ongoing initiative. The methods described in this study can be applied in other US urban jurisdictions seeking to better understand mortality trends and reduce preventable deaths in their homeless populations. AJPH

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CONTRIBUTORS

W. Nicholas conceptualized the study design, oversaw the analyses, and led the writing of the article. L. Greenwell led the analyses and contributed to the writing and editing of the article. B. Henwood contributed to the writing and editing of the article. P. Simon provided input on the study design and analyses and contributed to the writing and editing of the article.

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CONFLICTS OF INTEREST

The authors have no conflicts of interest to disclose.

HUMAN PARTICIPANT PROTECTION

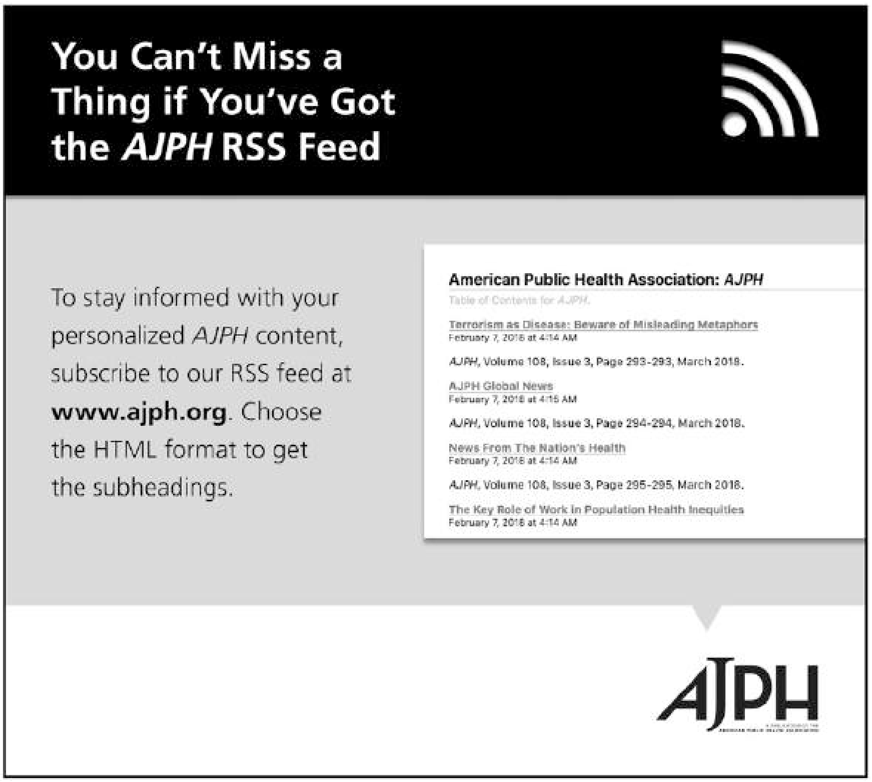
This study was conducted in accordance with the statutory duties of the Los Angeles County Department of Public Health and was deemed research of an exempt type by the department's institutional review board.

REFERENCES

1. Kearns B. Down for the count: overcoming the Census Bureau's neglect of the homeless. National Coalition for the Homeless. 2013:31. Available at: http://nationalhomeless.org/wp-content/uploads/2013/01/DownfortheCount_CensusReport.pdf. Accessed July 21, 2021.
2. Hibbs JR, Benner L, Klugman L, et al. Mortality in a cohort of homeless adults in Philadelphia. *N Engl J Med*. 1994;331(5):304–309. https://doi.org/10.1056/NEJM199408043310506
3. Hwang SW, Orav EJ, O'Connell JJ, Lebow JM, Brennan TA. Causes of death in homeless adults in Boston. *Ann Intern Med*. 1997;126(8):625–628. https://doi.org/10.7326/0003-4819-126-8-199704150-00007
4. Barrow SM, Herman DB, Córdova P, Struening EL. Mortality among homeless shelter residents in New York City. *Am J Public Health*. 1999;89(4):529–534. https://doi.org/10.2105/AJPH.89.4.529
5. Nordentoft M, Wandall-Holm N. 10 year follow up study of mortality among users of hostels for homeless people in Copenhagen. *BMJ*. 2003;327(7406):81. https://doi.org/10.1136/bmj.327.7406.81
6. Cheung AM, Hwang SW. Risk of death among homeless women: a cohort study and review of the literature. *CMAJ*. 2004;170(8):1243–1247. https://doi.org/10.1503/cmaj.1031167
7. Hwang SW, Wilkins R, Tjepkema M, O'Campo PJ, Dunn JR. Mortality among residents of shelters, rooming houses, and hotels in Canada: 11 year follow-up study. *BMJ*. 2009;339:b4036. https://doi.org/10.1136/bmj.b4036
8. Morrison DS. Homelessness as an independent risk factor for mortality: results from a retrospective cohort study. *Int J Epidemiol*. 2009;38(3):877–883. https://doi.org/10.1093/ije/dyp160
9. Beijer U, Andreasson S, Agren G, Fugelstad A. Mortality and causes of death among homeless women and men in Stockholm. *Scand J Public Health*. 2011;39(2):121–127. https://doi.org/10.1177/1403494810393554
10. Nielsen SF, Hjorthøj CR, Erlangsen A, Nordentoft M. Psychiatric disorders and mortality among people in homeless shelters in Denmark: a nationwide register-based cohort study. *Lancet*. 2011;377(9784):2205–2214. https://doi.org/10.1016/S0140-6736(11)60747-2
11. Baggett TP, Hwang SW, O'Connell JJ, et al. Mortality among homeless adults in Boston: shifts in causes of death over a 15-year period. *JAMA Intern Med*. 2013;173(3):189–195. https://doi.org/10.1001/jamainternmed.2013.1604
12. Baggett TP, Chang Y, Porneala BC, Bharel M, Singer DE, Rigotti NA. Disparities in cancer incidence, stage, and mortality at Boston Health Care for the Homeless program. *Am J Prev Med*. 2015;49(5):694–702. https://doi.org/10.1016/j.amepre.2015.03.038
13. Baggett TP, Chang Y, Singer DE, et al. Tobacco-, alcohol-, and drug-attributable deaths and their contribution to mortality disparities in a cohort of homeless adults in Boston. *Am J Public Health*. 2015;105(6):1189–1197. https://doi.org/10.2105/AJPH.2014.302248
14. Auerswald CL, Lin JS, Parriott A. Six-year mortality in a street-recruited cohort of homeless youth in San Francisco, California. *PeerJ*. 2016;4(e1909):1–13. https://doi.org/10.7717/peerj.1909
15. Aldridge RW, Story A, Hwang SW, et al. Morbidity and mortality in homeless individuals, prisoners, sex workers, and individuals with substance use disorders in high-income countries: a systematic review and meta-analysis. *Lancet*. 2018;391(10117):241–250. https://doi.org/10.1016/S0140-6736(17)31869-X
16. Stenius-Ayoade A, Haaramo P, Kautiainen H, Gissler M, Wahlbeck K, Eriksson JG. Mortality and causes of death among homeless in Finland: a 10-year follow-up study. *J Epidemiol Community Health*. 2017;71(9):841–848. https://doi.org/10.1136/jech-2017-209166
17. Roncarati JS, Baggett TP, O'Connell JJ, et al. Mortality among unsheltered homeless adults in Boston, Massachusetts, 2000–2009. *JAMA Intern Med*. 2018;178(9):1242–1248. https://doi.org/10.1001/jamainternmed.2018.2924
18. Schinka JA, Leventhal KC, Lapcevic WA, Casey R. Mortality and cause of death in younger homeless veterans. *Public Health Rep*. 2018;133(2):177–181. doi:https://doi.org/10.1177/0033354918755709
19. Aldridge RW, Menezes D, Lewer D, et al. Causes of death among homeless people: a population-based cross-sectional study of linked hospitalisation and mortality data in England. *Wellcome Open Res*. 2019;4:49. https://doi.org/10.12688/wellcomeopenres.15151.1
20. US Government Accountability Office. Homelessness: better HUD oversight of data collection

could improve estimates of homeless population. GAO-20-433. 2020. Available at: https://www.gao.gov/products/GAO-20-433. Accessed February 3, 2021.

21. Henwood B, Kaileh L, Wilson N, et al. USC 2020 homeless count methodology report. Los Angeles Homeless Services Authority. 2020. Available at: https://www.lahsa.org/documents?id=4658-usc-2020-homeless-count-methodology-report. Accessed February 3, 2021.
22. City of Long Beach. 2020 Long Beach point-in-time count statistic summary. Available at: http://www.longbeach.gov/globalassets/health/homeless-services-divsion/homeless-count/clb-homeless-count-infographic-06-16. Accessed July 21, 2021.
23. City of Pasadena. Pasadena homeless count 2020. Available at: https://pasadenapartnership.org/wp-content/uploads/2020/06/Pasadena-Homeless-Count_2020-FINAL.pdf. Accessed July 21, 2021.
24. *International Classification of Diseases, Tenth Revision*. Geneva, Switzerland: World Health Organization; 1992.
25. Ivers J-H, Zgaga L, O'Donoghue-Hynes B, Heary A, Gallwey B, Barry J. Five-year standardised mortality ratios in a cohort of homeless people in Dublin [erratum in *BMJ Open.* 2019;9(6):e023010corr1]. *BMJ Open.* 2019;9(1):e023010. https://doi.org/10.1136/bmjopen-2018-023010
26. Kibel M, Pierzchalski J, Gorfinkel L, et al. Standardized mortality ratios between street-connected young people and the general age-equivalent population in an urban setting in Kenya from 2010 to 2015. *Glob Health Action.* 2020;13(1):1802097. https://doi.org/10.1080/16549716.2020.1802097



Portion Sizes of Ultra-Processed Foods in the United States, 2002 to 2021

Lisa R. Young, PhD, RDN, and Marion Nestle, PhD, MPH

See also Monteiro and Cannon, p. 2091.

Objectives. To assess the US food industry's response to calls from public health authorities to reduce portion sizes by comparing current with past sizes of selected examples of single-serve ultra-processed packaged and fast foods.

Methods. We obtained manufacturers' information about current portion sizes and compared it with sizes when first introduced and in 2002.

Results. Few companies in our sample reduced portion sizes since 2002; all still sold portions of ultra-processed foods in up to 5-times-larger sizes than when first introduced.

Conclusions. Policies and practices focused on reducing portion size could help discourage the consumption of excessive amounts of ultra-processed foods. (*Am J Public Health*. 2021;111(12):2223–2226. https://doi.org/10.2105/AJPH.2021.306513)

The rising prevalence of obesity is a major public health concern.[1] As of 2018, nearly 74% of US adults were considered overweight or obese and at higher risk for diet-influenced chronic diseases.[2] Socioeconomic factors associated with weight gain—poverty, inadequate education, racial and gender discrimination, unemployment, and lack of health care—are also associated with frequent consumption of inexpensive, high-calorie, ultra-processed foods in large amounts.[3] Reducing consumption of such foods could be a useful strategy to improve public health.

Large portions provide more calories than small portions, but it is difficult to recognize how much the sizes of packaged and fast foods have increased since the early 1980s. We previously demonstrated parallel increases in portion sizes, calorie intake, and the prevalence of overweight and obesity.[4,5] By 2002, many single-serve portions had enlarged 2- to 5-fold since they were introduced.[6] Large portions have effects beyond calories; they encourage people to eat more[7] and to underestimate how much they are eating.[8]

The 2020–2025 Dietary Guidelines for Americans advise individuals to "pay attention to portion sizes" particularly for foods that are not "nutrient dense" (i.e., ultra-processed foods).[2(p25)] Researchers also called on the food industry to sell foods in more reasonable portion sizes.[7] In 2003, we reported increases in portion sizes of selected packaged and fast-food products.[6] Here, we report our more recent assessment of this selection.

METHODS

In 2021, we examined the sizes of specific ultra-processed food items sold as single servings that we have tracked since 2002: packaged products (candy bars, soda, and beer) and fast foods (hamburgers, french fries, and fountain soda). We selected this product sample from among those that are major contributors of calories in US diets,[9] ranked highest in sales,[4,5] associated in observational studies with weight gain and poor health,[10] and marketed as single servings. We obtained portion-size information from package labels and from company Web sites, as described previously.[4,6] We compared current portions with their sizes when first introduced and measured again in 2002.

RESULTS

As shown in Table 1, food companies are still selling chocolate bars, bottled and canned soda and beer, hamburgers, french fries, and fountain sodas in larger portions than when first introduced. While some companies have reduced their portions by small amounts, most continue to sell the larger sizes; we observed little change from sizes offered in 2002.

At first introduction, most companies offered products in just 1 size; that size is smaller than or equal to the smallest size currently available. For example, the original size of a Coca-Cola bottle was 6.5 ounces; today it comes in 6 sizes marketed as single servings; these range from 7.5 ounces to 24 ounces, 4 of which have been introduced since 2002.

Since 2002, McDonald's has reduced the sizes of its french fries and eliminated its "supersize" french fries and soda, but still offers quart-sized sodas and double burgers. While McDonald's and Burger King decreased the size of their largest portion of french fries, they increased the sizes of their smallest portions. While Burger King reduced the sizes of it's hamburger sandwiches, since 2002 they added a triple Whopper.

Although we did not observe consistent differences between portion-size trends in packaged products and fast foods, we note that some packaged food companies have increased the number of sizes offered, some of them smaller but some larger than those offered in 2002. Packaged food companies and fast-food chains still sell products up to 5 times larger than when first introduced.

DISCUSSION

Despite pleas from public health authorities to sell foods in smaller sizes, our observations indicate that marketplace portions of our selected examples of popular ultra-processed packaged and fast foods remain considerably larger than when first introduced and with little change since 2002.

Even where manufacturers reduced the size of some products, they compensated by introducing larger options. In 2020, for example, McDonald's introduced a Double Big Mac with 4 patties

TABLE 1— Portion Sizes of Selected Foods and Beverages When First Introduced Compared With Sizes in 2002 and 2021: United States

Food or Beverage (Year Introduced)	Original Size[a]	Size, 2002, oz or fl oz	Size, 2021, oz or fl oz
Packaged products			
Chocolate bar, milk chocolate			
Hershey's milk chocolate bar (1908)	0.6	1.6	1.6
		2.6	2.6
		4.0	3.5
		7.0	4.4
		8.0	7.0
Nestlé Crunch (1938)	1.6	1.6	1.6
		2.8	2.8
		5.0	4.4
Soda, commercially packaged			
Coca-Cola, bottle (1916)	6.5	8.0	8.0
		20.0	8.5
			12.0
			16.9
			20.0
			24.0
Coca-Cola, can (1960)	12.0	12.0	7.5
			12.0
			16.0
Beer			
Budweiser, can (1936)	12.0	8.0	8.0
		12.0	12.0
		16.0	16.0
		24.0	25.0
Budweiser, bottle (1976)	7.0	7.0	7.0
		12.0	12.0
		22.0	14.0
		40.0	16.0
			22.0
			32.0
			40.0
Fast-food products			
Hamburger, beef only[b]			
McDonald's (1955)	1.6	1.6	1.6
		3.2	3.2
		4.0	4.0
		8.0	8.0
Hamburger sandwich[c]			
Burger King, sandwich (1954)	3.9	4.4 (Hamburger)	3.5 (Hamburger)

Continued

TABLE 1— Continued

Food or Beverage (Year Introduced)	Original Size[a]	Size, 2002, oz or fl oz	Size, 2021, oz or fl oz
		6.0 (Whopper Jr.)	4.7 (Whopper Jr.)
		6.1 (Double hamburger)	4.8 (Double hamburger)
		9.9 (Whopper)	9.5 (Whopper)
		12.6 (Double Whopper)	12.5 (Double Whopper)
			15.5 (Triple Whopper)
French fries			
Burger King (1954)	2.6	2.6 (Small)	3.1 (Value)
		4.1 (Medium)	4.5 (Small)
		5.7 (Large)	5.4 (Medium)
		6.9 (King)	6.1 (Large)
McDonald's (1955)	2.4	2.4 (Small)	1.3 (Kid)
		5.3 (Medium)	2.6 (Small)
		6.3 (Large)	3.9 (Medium)
		7.1 (Supersize)	5.9 (Large)
Soda, poured from fountain			
Burger King (1954)	12.0	12.0 (Kiddie)	16.0 (Value)
	16.0	16.0 (Small)	20.0 (Small)
		22.0 (Medium)	29.0 (Medium)
		32.0 (Large)	38.0 (Large)
		42.0 (King)	
McDonald's (1955)	7.0	12.0 (Child)	12.0 (Extra small)
		16.0 (Small)	16.0 (Small)
		21.0 (Medium)	21.0 (Medium)
		32.0 (Large)	30.0 (Large)
		42.0 (Supersize)	

Note. Information obtained from manufacturers. Sizes are stated in ounces (oz) for solid foods such as chocolate bars, french fries, hamburger beef, and sandwiches, and in fluid ounces (fl oz) for beverages such as beer and soda. Manufacturers are the following: Anheuser-Busch Inc (St Louis, MO); Burger King Corporation (Miami, FL); The Coca-Cola Company (Atlanta, GA); Ferrera Candy Co (Chicago, IL); Hershey Foods Corporation (Hershey, PA); McDonald's Corporation (Oakbrook, IL); and Nestlé USA (Arlington, VA).

[a] When introduced, these products came only in the size options indicated.
[b] Precooked beef.
[c] Includes cooked beef, bun, vegetable, and condiment. Does not include cheese or mayonnaise.

(containing more than 700 calories). Burger King now markets a Triple Stacker King sandwich with more than three quarters of a pound of beef (nearly 1400 calories). Most recently, some companies used their newly introduced larger portions to boost sales and gain customers. The pizza chain Papa John's introduced an Epic Stuffed Crust pizza with 360 calories per slice compared with a regular slice, which contains 220 calories. The Red Lobster restaurant chain introduced the Codzilla, a large fried fish sandwich containing 830 calories.

The packaged soft drink industry has added smaller-size sodas to their offerings while simultaneously introducing new larger sizes. But it often prices the small sizes higher than larger sizes. On Amazon's Web site, for example, the 8.0-ounce Coca-Cola bottles cost 3 times as much per ounce as the 16.0-ounce bottles.

In Europe, the sizes of many fast-food portions are smaller than those in the United States. A large fountain Coca-Cola from Burger King in the United Kingdom contains 262 calories whereas the US large has 510 calories. But US companies have no incentive to reduce portion sizes, especially as consumers in the United States are now conditioned to expect large portions.

Current US policies support the production of larger portions through subsidies of basic ingredients that promote overproduction and low prices. Food in the United States is relatively inexpensive compared with the costs of manufacturing and service, and larger portions can generate additional revenue for little cost. To consumers, large portions may appear as a bargain, but they contain more calories and encourage overeating.[10] It is time for more focused action to encourage the food industry to restore portion sizes to more reasonable amounts.

Since our findings in 2002, some health departments have implemented education initiatives focused on portion control. New York City launched a campaign, Cut Your Portion, Cut Your Risk, and Los Angeles County launched the Choose Less, Weigh Less, Portion Size Matters campaign. Because education is rarely enough to change behavior, New York City's Board of Health attempted in 2012 to limit the size of sugary beverages to 16 ounces. The measure failed when the beverage industry and other opposing groups sued the city, and courts ruled in their favor. Portion caps, however, might still be legally viable under some circumstances[11] and could be useful. One study compared the effects of serving smaller and larger portions; people served smaller portions chose to eat less at subsequent meals, suggesting that offering smaller portions can help normalize perceptions of how much food constitutes a reasonable amount.[12]

Ideally, government, food industry, and educators would collaborate to develop consistent messages to educate the public about the relationship between portion sizes, calorie intake, and weight gain. But our data indicate that voluntary approaches to portion-size reduction are unlikely to be effective on their own. We think it is time to also consider caps and other legislatively mandated national policy options to require the food industry to make smaller food portions more available, convenient, and inexpensive:

- offer consumers price incentives for smaller portions of ultra-processed foods,
- discontinue the largest sizes of ultra-processed packaged foods and fast-food portions, and
- restrict marketing of large portions of ultra-processed foods, especially those targeted to children and minorities.

While these suggested policies are likely to face substantial political and, perhaps, legal obstacles, we believe they could help foster more healthful choices. Policymakers and health professionals should consider such portion-size actions as key efforts to improve nutritional health in the United States.

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CONTRIBUTORS

L. R. Young designed the study; collected, analyzed, and interpreted the data; and drafted and revised the article. M. Nestle contributed to the study's intellectual content, editorial content, and article revision.

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The authors declare no conflict of interest.

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REFERENCES

1. Hales CM, Carroll MD, Fryar CD, Ogden CL. Prevalence of obesity and severe obesity among adults: United States, 2017–2018. NCHS Data Brief, no 360. Hyattsville, MD: National Center for Health Statistics; 2020.
2. US Department of Agriculture, US Department of Health and Human Services. *Dietary Guidelines for Americans, 2020–2025*. 9th ed. December 2020. Available at: https://dietaryguidelines.gov. Accessed January 5, 2021.
3. Baraldi LG, Martinez Steele E, Canella DS, Monteiro CA. Consumption of ultra-processed foods and associated sociodemographic factors in the USA between 2007 and 2012: evidence from a nationally representative cross-sectional study. *BMJ Open*. 2018;8(3):e020574. https://doi.org/10.1136/bmjopen-2017-020574
4. Young LR, Nestle M. The contribution of increasing portion sizes to the obesity epidemic. *Am J Public Health*. 2002;92(2):246–249. https://doi.org/10.2105/AJPH.92.2.246
5. Young LR, Nestle M. Reducing portion sizes to prevent obesity: a call to action. *Am J Prev Med*. 2012;43(5):565–568. https://doi.org/10.1016/j.amepre.2012.07.024
6. Young LR, Nestle M. Expanding portion sizes in the US marketplace: implications for nutrition counseling. *J Am Diet Assoc*. 2003;103(2):231–234. https://doi.org/10.1053/jada.2003.50027
7. Hollands GJ, Shemilt I, Marteau TM, et al. Portion, package or tableware size for changing selection and consumption of food, alcohol and tobacco. *Cochrane Database Syst Rev*. 2015;(9):CD011045. https://doi.org/10.1002/14651858.CD011045.pub2
8. Block JP, Condon S, Kleinman K, et al. Consumers' estimation of calorie content at fast food restaurants: cross sectional observational study. *BMJ*. 2013;346:f2907. https://doi.org/10.1136/bmj.f2907
9. Huth PJ, Fulgoni VL, Keast DR, Park K, Auestad N. Major food sources of calories, added sugars, and saturated fat and their contribution to essential nutrient intakes in the U.S. diet: data from the National Health and Nutrition Examination Survey (2003–2006). *Nutr J*. 2013;12(1):116. https://doi.org/10.1186/1475-2891-12-116
10. Hall KD, Ayuketah A, Brychta R, et al. Ultra-processed diets cause excess calorie intake and weight gain: an inpatient randomized controlled trial of ad libitum food intake [errata in *Cell Metab*. 2019;30(1):226 and *Cell Metab*. 2020;32(4):690]. *Cell Metab*. 2019;30(1):67–77.e3. https://doi.org/10.1016/j.cmet.2019.05.008
11. Roberto CA, Pomeranz JL. Public health and legal arguments in favor of a policy to cap the portion sizes of sugar-sweetened beverages. *Am J Public Health*. 2015;105(11):2183–2190. https://doi.org/10.2105/AJPH.2015.302862
12. Robinson E, Kersbergen I. Portion size and later food intake: evidence of the normalizing effect of reducing food portion size. *Am J Clin Nutr*. 2018;107(4):640–646. https://doi.org/10.1093/ajcn/nqy013

Effects of Government-Implemented Cash Plus Model on Violence Experiences and Perpetration Among Adolescents in Tanzania, 2018–2019

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See also Galea and Vaughan, p. 2094.

Objectives. To examine the impacts of a government-implemented cash plus program on violence experiences and perpetration among Tanzanian adolescents.

Methods. We used data from a cluster randomized controlled trial (n = 130 communities) conducted in the Mbeya and Iringa regions of Tanzania to isolate impacts of the "plus" components of the cash plus intervention. The panel sample comprised 904 adolescents aged 14 to 19 years living in households receiving a government cash transfer. We estimated intent-to-treat impacts on violence experiences, violence perpetration, and pathways of impact.

Results. The plus intervention reduced female participants' experiences of sexual violence by 5 percentage points and male participants' perpetration of physical violence by 6 percentage points. There were no intervention impacts on emotional violence, physical violence, or help seeking. Examining pathways, we found positive impacts on self-esteem and participation in livestock tending and, among female participants, a positive impact on sexual debut delays and a negative effect on school attendance.

Conclusions. By addressing poverty and multidimensional vulnerability, integrated social protection can reduce violence.

Public Health Implications. There is high potential for scale-up and sustainability, and this program reaches some of the most vulnerable and marginalized adolescents. (*Am J Public Health*. 2021;111(12): 2227–2238. https://doi.org/10.2105/AJPH.2021.306509)

One billion children experience violence annually,[1] and adverse effects include increased risk of injury, mental health problems, early pregnancy, sexual risk taking, and noncommunicable diseases.[2–4] Violence experiences and witnessing of violence in childhood increase the risk of experiencing and perpetrating violence in adulthood.[5,6]

A consortium of international agencies developed INSPIRE, a set of strategies to reduce violence against children (VAC); strategies include income and economic strengthening (such as cash transfers) and life and social skills training.[7]

Poverty is a structural driver of violence, and there are several pathways through which economic-strengthening programs such as "cash plus," defined as a combination of cash transfers with additional complementary support or linkages to services,[8] may reduce the risk of childhood violence. "Cash plus" may also imact food security, financial empowerment and bargaining power, changes in time use activities (including schooling, labor, and domestic chores), caregiving behaviors, psychosocial wellbeing, child marriage, and time spent in high-risk settings.[9,10]

More evidence is still needed on VAC reduction interventions involving men and boys and around economic empowerment.[3,11,12] A review of noncontributory social safety net programs, including cash transfers, found that social safety nets can contribute to VAC reduction.[10] More recently, studies from Mali and Zimbabwe have demonstrated that household-targeted cash plus programs reduced violence experienced by children and youths.[13,14]

Violence impacts have also been examined in bundled interventions targeted to adolescents comprising components related to economic strengthening, life skills, and strengthening health capabilities, but the evidence is mixed. Interventions in sub-Saharan Africa show reductions in forced sex in Uganda (Livelihood Empowerment for Adolescents), physical or sexual violence in Zimbabwe (Shaping the Health of Adolescents in Zimbabwe) and Kenya (Adolescent Girls Initiative), and reduced participation in transactional sex in Zambia (Adolescent Girls Empowerment Program).[15–18] Nevertheless, in Zambia, the Adolescent Girls Empowerment Program found no impacts on physical violence, intimate partner violence, or "unwanted sex," and an intervention implemented in Kampala, Uganda, found that providing girls with a savings account but no other life skills training increased the risk of unwanted sexual touching and harassment.[15,19] When replicated in Tanzania, the Livelihood Empowerment for Adolescents intervention failed to demonstrate protective impacts,[20] while another intervention in Liberia (Girl Empower) did not lead to reductions in violence.[21]

The aforementioned interventions were implemented by nongovernmental organizations, and, thus, evidence is needed on government-implemented programs, which have greater potential for sustainability and scale-up. Recent studies have called for additional research of at-scale programs to prevent violence within households, as well as programs tailored to reach adolescent girls.[22,23] We examined impacts of the "plus" components from a government-run, multisectoral cash plus intervention on male and female adolescents' experiences and perpetration of violence.

METHODS

We used data from a longitudinal cluster randomized controlled trial (n = 130 communities), which was implemented by United Nations Children's Fund (UNICEF) Office of Research–Innocenti, University at Buffalo, and EDI Global, in collaboration with Tanzania Social Action Fund (TASAF), Tanzania Commission for AIDS, and UNICEF Tanzania.

Participants

The cash plus intervention was piloted in 4 districts and targeted adolescents aged 14 to 19 years living in households participating in the Government of the Republic of Tanzania's flagship social protection program, the Productive Social Safety Net (PSSN). The PSSN reaches 1 million households nationally, providing a cash transfer every other month, livelihoods enhancement, and public works.[24] Cash transfer payments were variable depending on school enrollment and health-related coresponsibilities, but these averaged US $7.10 per month (maximum US $21.70 per month), equivalent to approximately 16% of household consumption.[24,25] All study households (intervention and control arms) had been enrolled in the PSSN since 2015 and received cash transfers. The intervention that was randomized was the "plus" components targeted to adolescents. We used a sample size calculation to determine the number of clusters required (Appendix A, available as a supplement to the online version of this article at http://www.ajph.org).

Randomization

Random assignment of 130 villages into study arms (65 intervention and 65 control) was conducted in July 2017, after completion of the baseline surveys, and was stratified by TASAF administrative areas (program administrative areas, corresponding to Mafinga and Mufindi districts in Iringa, and Rungwe and Busokelo districts in Mbeya) and village size (large vs small villages).

Procedures

The "Ujana Salama" Cash Plus Model for Safe Transitions to a Healthy and Productive Adulthood intervention followed a capabilities approach[26,27] to strengthen youth productive, human, and health assets (Conceptual Framework in Appendix B, available as a supplement to the online version of this article at http://www.ajph.org). Guiding principles included government ownership, implementation within the PSSN livelihoods enhancement strategy and existing government frameworks, linkages with other government services, and age- and gender-sensitive livelihoods interventions.

The intervention comprised (1) face-to-face livelihoods and life skills training delivered 2 hours per week over 12 weeks (January–May 2018); (2) mentoring (occurring biweekly and then monthly between July 2018 and March 2019) and a productive grant (totaling US $80 disbursed in up to 2 payments between March and June 2019), conditional on having attended trainings and developing an approved educational or business plan; and (3) facilitated linkages to adolescent-friendly HIV and sexual and reproductive health services in government health facilities (July 2018–March 2019; Appendix C, available as a supplement to the online version of this article at http://www.ajph.org).

The training included sessions on livelihoods, sexual and reproductive health, and HIV prevention and treatment, including a bundle of high-impact behavior change communication approaches and peer support groups (topics summarized in Appendix C). During mentoring, adolescents were provided with linkages to training and apprenticeship activities, input on business plans, peer education, and linkages to health facilities (Activities in Appendix D, available as a supplement to the online version of this article at http://www.ajph.org). Two mentors (1 male, 1 female) were selected per village. Addressing supply of health services, UNICEF worked with the Ministry of Health, Community Development, Gender, Elderly, and Children to perform a training in July 2019 with staff at government primary health care facilities in treatment villages to strengthen adolescent-friendly services.

We used TASAF administrative data on PSSN enrollment (in 2015) to identify households that would have adolescents aged 14 to 19 years in 2017. We approached all of these households and aimed to interview all eligible youths (including new youths not registered in the household in 2015; Appendix F, available as a supplement to the online version of this article at http://www.ajph.org). Three rounds of data were collected: baseline (April–June 2017), round 2 (May–July 2018), and round 3 (June–August 2019). We used a split sample approach for modules on violence victimization and perpetration for male and female participants based on best practices guidance, in which male participants answered the violence module in one community and female participants in another, to protect confidentiality of participants and reduce the chance that a perpetrator–-victim pair would both be interviewed.[28] We provided anonymized referral information to respondents containing contact numbers for district social welfare officers.[29]

Interviews were conducted in Swahili with same-sex enumerators in private settings and data were entered into SurveyBe version 5.10.210 (EDI Global Limited, Gerrards Cross, UK) software via tablets.

Measures

The primary outcomes were experienced violence (emotional, physical, sexual), help-seeking related to violence, and perpetration of physical and emotional violence in the past 12 months. We assessed these by using an adapted version of questionnaire items used in the World Health Organization (WHO) Multi-country Study on Women's Health and Domestic Violence,[30] which draws on the Conflict Tactics Scale.[31] We adapted these items to include any perpetrator (not just intimate partners) for the current study. Binary violence indicators for emotional, physical, and sexual violence were created from multiple items per violence type (Appendix E, available as a supplement to the online version of this article at http://www.ajph.org). At baseline, because of an error in a data-entry skip pattern, sexual violence questions were only asked of individuals who reported ever having had sex. In subsequent rounds, sexual violence questions were asked to all individuals selected for the violence module.

Respondents experiencing any type of violence were then asked whether they had ever tried to seek help or tell anyone about the violence. In line with existing literature,[32,33] we further categorized help seeking into formal and informal sources (Appendix E).

We added questions on violence perpetration at round 3. Binary perpetration indicators were created separately for 12-month emotional and physical violence based on items summarized in Appendix D.

Intermediate pathways examined included age at first sexual intercourse, entry into marriage or cohabitation, engaging in an age-disparate sexual relationship, self-perceived stress, self-efficacy, self-esteem, school attendance, and time use (Appendix E). Age-disparate sexual relationship was defined as having a sexual partner 5 or more years older, in line with previous studies.[34] Self-perceived stress was measured using the Enhanced Life Distress Inventory, which measures distress across multiple areas of social life and functioning[35] and results in an overall scale ranging from 0 to 39 and 3 subscales (economic and health-related well-being, risk and security, relationships). We measured self-efficacy by using a locus-of-control index[36,37] and self-esteem by using 2 items from Rosenberg's self-esteem scale.[38] For time use, we examined participation in 5 types of economic activities performed in the past 7 days (farm work, livestock herding, fishing, nonagricultural business, paid work outside the household) and household chores performed in the previous day (collecting water; collecting firewood or other fuel materials; collecting nuts or other tree fruits; taking care of children, cooking, or cleaning; and taking care of the elderly or sick household members). Activities were not mutually exclusive, and multitasking was reported as separate activities. An additional pathway examined elsewhere was gender-equitable attitudes.[39]

Statistical Analysis

As policymakers are interested in understanding population impacts, we used intention-to-treat analyses to examine impacts of the program, including all clusters and adolescents, irrespective of program uptake (uptake was 48.5% among those eligible),[40] among participants who were interviewed at all 3 rounds. We calculated intervention effects with data separately at each follow-up round by using ordinary least squares for continuous outcomes and linear probability models for binary outcomes. For continuous and binary outcomes, we reported b coefficients. We adjusted the regression models for age, sex, and stratum (district and village size), and we adjusted standard errors for clustering and heteroskedasticity by using the VCE (robust) command in Stata version 16 (StataCorp LP, College Station, TX). We further calculated average-treatment-on-the-treated estimates by using 2-stage least squares regressions with linear probability models, in which we predicted program take up in the first-stage regressions and treatment impacts on the treated in the second stage.

We tested program impacts on potential pathways of impact at rounds 2 and 3, and then tested pathway impacts by gender at round 3 only. We describe perpetrators of violence descriptively only, given low proportions in the categories of perpetrators and limited power to estimate program impacts.

RESULTS

Out of 3599 adolescents found eligible at baseline, a total of 2458 completed interviews (68%). Among this baseline evaluation sample (n = 2458), approximately half (n = 1165) were interviewed for the violence questions, and, among these, 988 and 1033 were followed up at rounds 2 and 3, respectively, representing the panel samples (Appendix F). Among the panel sample interviewed at all 3 rounds (n = 904), no adolescents had missing values for variables of interest. The average age of the sample at baseline was 16 years, 47.4% of the sample were female, and 57% were attending school (Table 1). All background characteristics were balanced at baseline between study arms.

Outcomes

At baseline, 35%, 27%, and 1% of adolescents reported having experienced emotional, physical, and sexual violence, respectively (Table 1). Physical and sexual violence outcomes were balanced at baseline in the pooled (male and female participants) sample, while emotional violence was not (39% of the treatment group vs 31% of controls had experienced emotional violence). Among those who had experienced physical or emotional violence (n = 404), 31.7% reported seeking help or disclosing to someone (8.4% to formal sources vs 24.5% to informal sources). Examining indicators by gender, we found evidence for baseline balance for all characteristics and outcomes, except farm work for the household excluding livestock among female participants and experience of physical violence and informal reporting of violence among male participants (Appendix G, available as a supplement to the online version of this article at http://www.ajph.org). By round 3, experiences of violence among the control (treatment) group were 33% (29%) for emotional violence, 13% (11.1%) for physical violence, and 6% (2%) for sexual violence (Table 2).

Intervention Impacts

By round 3, treatment adolescents had a 3-percentage-point reduction of experiencing sexual violence as a result of the intervention (b = −0.03; 95% confidence interval [CI] = −0.06, −0.00; Table 2). The intervention had no impact on emotional or physical violence experiences in the pooled sample, nor on help seeking (formal or informal sources). When examining impacts separately by gender, we saw that the sexual violence impacts were driven by the female sample, who experienced a 5-percentage-point reduction in sexual violence (b = −0.05; 95% CI = −0.10, −0.00; Table 3) as a result of the program (there were no impacts on this indicator among male participants, who reported low rates of sexual violence; Table 3). Impacts at round 2 are presented in Appendix H (available as a supplement to the online version of this article at http://www.ajph.org).

In the pooled sample we found no impacts on emotional and physical violence perpetration. However, when we examined male and female participants separately, we found that male participants were less likely to report physical violence perpetration as a result of the intervention (b = −0.06; 95% CI = −0.10, −0.02; Table 3). There were no impacts on emotional violence

TABLE 1— Sample Characteristics at Baseline by Treatment Status: Tanzania Adolescent Cash Plus Study, 2017, Iringa and Mbeya Regions of Tanzania

Variables	Full Sample (n = 904), Mean ±SD or No. (%)	Cash Plus (Intervention; n = 440), Mean ±SD or No. (%)	Cash Only (Control; n = 464), Mean ±SD or No. (%)
General characteristics			
Female	429 (47)	204 (46)	225 (48)
Age, y	16.0 ±1.6	15.9 ±1.5	16.0 ±1.6
Age of household head, y	58.7 ±16.4	58.8 ±16.3	58.5 ±16.5
Female-headed household	603 (67)	288 (65)	315 (68)
Mufindi or Mafinga districts	475 (53)	239 (54)	236 (51)
Primary outcomes			
Experiences of violence			
Emotional	318 (35)	136 (31)	182 (39)
Physical	247 (27)	109 (25)	138 (30)
Sexual[a]	8 (1)	4 (1)	4 (1)
Help seeking for emotional or physical violence (n = 402)			
Any	128 (32)	50 (28)	78 (35)
Formal	34 (8)	14 (8)	20 (9)
Informal	99 (25)	35 (20)	64 (28)
Intermediate pathway outcomes			
Age at first sexual intercourse (n = 137), y	15.9 ±1.8	15.8 ±1.7	15.9 ±2.0
Age-disparate sex (female participants only; n = 68)	18 (26)	6 (19)	12 (33)
Locus of control index	3.2 ±0.5	3.3 ±0.5	3.2 ±0.5
Self-esteem index	3.9 ±0.8	4.0 ±0.8	3.9 ±0.8
ELDI (0–39)	3.3 ±4.7	3.3 ±4.7	3.3 ±4.6
ELDI economic and health-related well-being subscale	2.7 ±3.5	2.6 ±3.5	2.8 ±3.5
ELDI risk subscale	0.3 ±1.0	0.3 ±1.0	0.2 ±0.9
ELDI relations subscale	0.3 ±1.2	0.4 ±1.3	0.3 ±1.1
Currently attending school	512 (57)	254 (58)	258 (56)
Has a spouse or cohabitating partner	1 (0)	0 (0)	1 (0)
Time use indicators (% participating)			
Any economic activities	709 (78)	347 (79)	362 (78)
Paid work outside the household	121 (13)	52 (12)	69 (15)
Farm work for the household, excluding livestock	598 (66)	298 (68)	300 (65)
Livestock herding for the household	433 (48)	213 (48)	220 (47)
Fishing for the household	14 (2)	7 (2)	7 (2)
Household business	41 (5)	16 (4)	25 (5)
Any chores	811 (90)	404 (92)	407 (88)
Collecting water	607 (67)	316 (72)	291 (63)
Collecting firewood	358 (40)	193 (44)	165 (36)
Collecting nuts and other tree fruits	120 (13)	63 (14)	57 (12)

Continued

TABLE 1— Continued

Variables	Full Sample (n = 904), Mean ±SD or No. (%)	Cash Plus (Intervention; n = 440), Mean ±SD or No. (%)	Cash Only (Control; n = 464), Mean ±SD or No. (%)
Taking care of children, cooking, or cleaning	661 (73)	327 (74)	334 (72)
Taking care of elderly or sick	211 (23)	109 (25)	102 (22)

Note. ELDI = Enhanced Life Distress Inventory. Economic activities included those conducted in the previous week, and time-use activities have a reference period of the previous day.

[a] The sexual violence indicator included in this table differs from those used in impacts analyses in Tables 2 and 3 because of a skip pattern error at baseline, whereby only adolescents who reported having had sexual intercourse were asked questions about sexual violence. In subsequent waves, all youths in the violence module were asked questions about sexual violence, which may include other forced sexual acts.

TABLE 2— Intervention Effects (Intent-to-Treat) on Violence at Round 3: Tanzania Adolescent Cash Plus Study, 2019, Iringa and Mbeya Regions of Tanzania

Variables	Cash Plus, No. (%)	Cash Only, No. (%)	b (95% CI)
Experienced	440	464	
Emotional violence	126 (29)	155 (33)	−0.05 (−0.11, 0.02)
Physical violence	49 (11)	58 (13)	−0.01 (−0.06, 0.03)
Sexual violence	10 (2)	26 (6)	−0.03 (−0.06, 0.00)
Emotional, physical, or sexual violence	148 (34)	181 (39)	−0.05 (−0.12, 0.02)
Sought help	148	181	
Any	61 (41)	76 (42)	−0.02 (−0.13, 0.10)
Formal	11 (7)	11 (6)	0.02 (−0.03, 0.07)
Informal	54 (36)	65 (36)	0.00 (−0.11, 0.11)
Perpetrated	440	464	
Emotional violence	19 (4)	28 (6)	−0.02 (−0.05, 0.02)
Physical violence	16 (4)	30 (6)	−0.03 (−0.06, 0.00)

Note. CI = confidence interval. Linear probability models, male and female participants. Models controlled for age, gender, and stratum (district and village size); only coefficients on treatment indicator are shown. Standard errors are clustered at the community level.

perpetration among male participants nor on either outcome among female participants.

There were no impacts on help seeking among either gender (Table 3).

Pathways Analyses

We found positive impacts on participation in livestock herding for the household (b = 0.09; 95% CI = 0.02, 0.17; Table 4) and self-esteem (b = 0.19; 95% CI = 0.08, 0.29). There were no intervention impacts on self-perceived stress, self-efficacy (locus of control), marriage or cohabitation, school attendance, or age-disparate relationships. When we examined pathway impacts separately by gender (Appendix I, available as a supplement to the online version of this article at http://www.ajph.org), we saw that changes in livestock herding were driven by female participants (b = 0.14; 95% CI = 0.03, 0.24), while we observed increases in self-esteem for both female (b = 0.19; 95% CI = 0.05, 0.33) and male participants (b = 0.29; 95% CI = 0.05, 0.36). In addition, among female participants, we found a protective impact on delaying age at first sexual intercourse (b = −0.55; 95% CI = −1.02, −0.09) and a negative impact on school attendance (b = −0.10; 95% CI = −0.19, 0.00). This delay in sexual debut translates to approximately half a year (0.55 × 12 = 6.6 months).

Robustness Check

Difference-in-differences models confirmed findings from the single-difference models with respect to null impacts on emotional and physical violence (Appendix J, available as a

TABLE 3— Intervention Effects (Intent-to-Treat) on Violence at Round 3: Tanzania Adolescent Cash Plus Study, 2019, Iringa and Mbeya Regions of Tanzania

Variables	Cash Plus, No. (%)	Cash Only, No. (%)	b (95% CI)
Male participants			
Experienced	236	239	
Emotional violence	58 (25)	77 (32)	−0.07 (−0.16, 0.01)
Physical violence	23 (10)	30 (13)	−0.01 (−0.07, 0.05)
Sexual violence	5 (2)	11 (5)	−0.03 (−0.07, 0.01)
Sought help	65	90	
Any	24 (37)	34 (38)	0.00 (−0.17, 0.16)
Formal	6 (9)	7 (8)	0.01 (−0.07, 0.09)
Informal	21 (32)	26 (29)	0.05 (−0.10, 0.20)
Perpetrated	236	239	
Emotional violence	10 (4)	13 (5)	−0.01 (−0.05, 0.03)
Physical violence	5 (2)	20 (8)	−0.06 (−0.10, −0.02)
Female participants			
Experienced	204	225	
Emotional violence	68 (33)	78 (35)	−0.01 (−0.11, 0.09)
Physical violence	26 (13)	28 (12)	0.00 (−0.06, 0.06)
Sexual violence	5 (2)	15 (7)	−0.05 (−0.10, 0.00)
Sought help	83	91	
Any	37 (45)	42 (46)	−0.05 (−0.20, 0.10)
Formal	5 (6)	4 (4)	0.02 (−0.06, 0.10)
Informal	33 (40)	39 (43)	−0.06 (−0.21, 0.10)
Perpetrated	204	225	
Emotional violence	9 (4)	15 (7)	−0.02 (−0.08, 0.03)
Physical violence	11 (5)	10 (4)	0.01 (−0.03, 0.06)

Note. CI = confidence interval. Linear probability models, by gender. Models controlled for age, gender, and stratum (district and village size); only coefficients on treatment indicator are shown. Standard errors are clustered at the community level.

supplement to the online version of this article at http://www.ajph.org).

Average-Treatment-on-the-Treated Analyses

Average-treatment-on-the-treated estimates were in the same direction and maintained the same significance levels but were generally 2 to 3 times larger in magnitude as compared with intention-to-treat estimates (Appendices K, L, and M, available as supplements to the online version of this article at http://www.ajph.org). We found impacts on the economic and health-related well-being stress Enhanced Life Distress Inventory subscale to be statistically significant (b = −1.40; 95% CI = −2.65, −0.14) in the average-treatment-on-the-treated models, but not in intention-to-treat models.

Perpetrators

Among those who reported emotional or physical violence at baseline (n = 402), the most common perpetrators were peers (45%) and family members (41%), followed by partner or spouse (27%), and then authorities (21%; Appendix M). Other perpetrators were reported by only 3% of respondents. Subsequently, at round 3, those reporting physical or emotional violence (n = 316) reported the most common perpetrators as peers (44%), partner or spouse (34%), and family members (25%; Appendix N, available as a supplement to the online version of this article at http://www.ajph.org).

DISCUSSION

We examined the effects of a government-implemented cash plus program targeted to adolescents and found that the intervention reduced

TABLE 4— Intervention Effects on Intermediate Pathway Indicators at Round 3: Tanzania Adolescent Cash Plus Study, 2019, Iringa and Mbeya Regions of Tanzania

Variables	Cash Plus (n = 440), Mean ±SD or No. (%)	Cash Only (n = 464), Mean ±SD or No. (%)	b (95% CI)
Age at first sexual intercourse, y			−0.27 (−0.61, 0.08)
Mean ±SD	16.9 ±1.4	17.2 ±1.8	
Total no.	151	161	
Age-disparate sex (female participants only)			−0.10 (−0.23, 0.03)
No. (%)	23 (30)	34 (40)	
Total no.	77	85	
Locus of control index	3.3 ±0.5	3.3 ±0.5	0.03 (−0.04, 0.10)
Self-esteem index	3.9 ±0.8	3.8 ±0.8	0.19 (0.08, 0.29)
ELDI (0–39)	3.5 ±4.9	4.1 ±5.3	−0.61 (−1.42, 0.21)
ELDI economic and health-related well-being subscale	2.8 ±3.5	3.4 ±4.0	−0.59 (−1.12, −0.06)
ELDI risk subscale	0.3 ±1.2	0.3 ±1.0	−0.01 (−0.19, 0.17)
ELDI relations subscale	0.4 ±1.2	0.4 ±1.4	0.00 (−0.24, 0.23)
Currently attending school	152 (35)	174 (38)	−0.04 (−0.10, 0.03)
Has a spouse or cohabiting partner	30 (7)	25 (5)	0.02 (−0.01, 0.05)
Time use	440	464	
Any economic activities	359 (82)	376 (81)	0.01 (−0.05, 0.06)
Paid work outside the household	108 (25)	106 (23)	0.02 (−0.04, 0.07)
Farm work for the household	265 (60)	261 (56)	0.04 (−0.03, 0.11)
Livestock herding for the household	260 (59)	232 (50)	0.09 (0.02, 0.17)
Fishing for the household	9 (2)	9 (2)	0.00 (−0.02, 0.02)
Household business	69 (16)	68 (15)	0.01 (−0.04, 0.07)
Any chores	393 (89)	412 (89)	0.01 (−0.04, 0.05)
Collecting water	325 (74)	339 (73)	0.01 (−0.06, 0.08)
Collecting firewood	148 (34)	122 (26)	0.07 (−0.01, 0.14)
Collecting nuts and other tree fruits	36 (8)	23 (5)	0.03 (0.00, 0.07)
Taking care of children, cooking, or cleaning	303 (69)	327 (70)	−0.01 (−0.08, 0.06)
Taking care of elderly or sick	81 (18)	83 (18)	0.01 (−0.05, 0.06)

Note. CI = confidence interval; ELDI = Enhanced Life Distress Inventory. Ordinary least squares and linear probability models (intent-to-treat estimates). Standard errors are clustered at the community level. Economic activities included those conducted in the previous week, and time use activities had a reference period of the previous day. Models controlled for age, gender, and stratum (district and village size); only coefficients on treatment indicator are shown.

experience of sexual violence among female participants and perpetration of physical violence among male participants.

With respect to pathways, we found that the program increased self-esteem and led to changes in time use—namely, participation in livestock herding among female participants. We also found that the program delayed age at sexual debut by half a year and reduced school attendance among female participants. We found no impacts on other pathways. By delaying the window of exposure to sexual relationships, this may have prevented intimate partner sexual violence. Increases in self-esteem may have led to reduced sexual violence via improved assertiveness, communication, and interpersonal skills learned in the trainings. Previous research has found that a lack of these skills may contribute to sexual violence risk in southern Africa.[41] This may, in part, explain why we found protective effects for sexual violence but no other forms of violence. Moreover, previous evidence demonstrates a link between low self-esteem and increased risk of both experiencing and perpetrating dating violence among adolescents,[42] and given positive impacts on self-esteem in our study, this is a potential pathway for the observed reductions in violence experiences and perpetration.

In a context with limited formal employment opportunities, when older female participants were presented with the opportunity to start a business, they may have opted to do so, possibly explaining negative school attendance impacts. Changes in school attendance could have affected exposure to environments where adolescents are at risk for violence, but our data do not allow us to make more detailed conclusions about this pathway. Although we did not ask about perpetrators of sexual violence because of the sensitive nature of this information, peers and authority figures were common perpetrators of emotional and physical violence. These findings are supported by a global meta-analysis that found that student peers are the second-most-common perpetrators of VAC.[22]

The observed impact on livestock herding is likely a result of the training around business planning and starting a business, and some participants invested in small livestock with the aim of selling them for a profit. Some program mentors were agriculture extension workers, which may have also influenced choices. Another study from this sample found that engaging in paid work outside the household was associated with increased risk of experiencing sexual violence and emotional violence, while livestock herding was associated with increased risk of experiencing emotional and physical violence perpetrated by family members (T. P., written communication, July 15, 2020). Thus, more participation in livestock herding induced by the intervention may be protective against sexual violence when resulting from a substitution from paid labor outside the household. However, we found no simultaneous decreases in the latter.

The intervention led to an increase in equitable gender attitudes (including around violence) among male participants, examined elsewhere.[39] This pathway may partly explain decreases in physical violence perpetration, as attitudes about sex, gender, normative behaviors, and hostile masculinity are learned in adolescence,[41,43] and, thus, this is a key window to model equitable gender norms and healthy relationships.[44] These findings may have implications for reducing future violence perpetration.

Our findings are consistent with those from an intervention in Uganda[16] but are in contrast with studies from Uganda, Zambia, and Liberia that did not find protective effects against violence.[15,19,21] These mixed findings underscore that context matters in violence-reduction interventions, as do program design and implementation. Among the cited studies, there is variation in program components, implementing agencies, and dosage of exposure to components. It is difficult to make conclusions about which combinations are most effective in reducing VAC because few studies have tested different combinations of components, and there have been limited examples of the same program being implemented in multiple contexts. In our own study, we were unable to distinguish impacts of the individual intervention components because we could not vary program components across villages.

Studies that have evaluated impacts of cash transfers (in contrast with our study, which only evaluated the “plus” components in cash plus) have found positive impacts on school attendance,[45,46] reductions in intimate partner violence among adolescents,[34] and reductions in other violence-related outcomes among children and adolescents.[10] These studies are not in contrast with our findings, because the interventions studied were different (cash transfers vs “plus” components). Other studies examining effects of cash plus programs have found that these reduced violence against adolescents and youths,[14] as well as harsh discipline or corporal punishment among young children.[13,47,48]

Limitations

Generalizability of the results to all adolescents in Tanzania is limited. In addition, the productive grant was disbursed shortly before round 3, and, thus, full impacts of the intervention may not have fully materialized. During round 3 fieldwork, households experienced a delay in PSSN payments for the first time, and this may have mitigated impacts of the cash plus program. Underreporting of violence is not expected to be correlated with treatment status and therefore should not bias impact estimates. Perpetration of physical and emotional violence was not assessed at baseline so we could not assess balance between intervention arms before program roll-out. Our study design did not allow us to disentangle effects of the different program components, and, thus, we could not conclude which components may have contributed more to violence reduction. Finally, it is possible that our subanalyses were subject to type II errors, as power is reduced as sample sizes are reduced, and ability to make conclusions about heterogeneous treatment effects is limited.

A key factor in the successful implementation of this intervention was multisectoral coordination, including at the district level, where staff were based and activities were implemented. While most program components were administered through PSSN structures, health facilities strengthening was carried out by Ministry of Health, Community Development, Gender, Elderly, and Children, with technical support from UNICEF.

Conclusions

Multisectoral approaches are increasingly advocated to address the drivers of violence. Our study showed that a government-run, multisectoral cash plus intervention reduced violence experiences and perpetration. The broad potential reach of similar scalable interventions has implications for VAC reduction at the population level. AJPH

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CONTRIBUTORS

T. Palermo conceptualized the article. T. Palermo, L. Prencipe, and L. Kajula were responsible for the research design. T. Palermo and L. Prencipe led the statistical analysis. All authors interpreted findings and contributed to writing the article and approved the final version. Members of the evaluation team further contributed to study design and data collection.

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CONFLICTS OF INTEREST

The authors have no competing financial and nonfinancial interests to declare.

HUMAN PARTICIPANT PROTECTION

Ethics approval for the study was granted by the National Institute for Medical Research (NIMR/HQ/R.8a/Vol.IX/2784) and the Tanzania Commission for Science and Technology. Informed assent and parental consent were obtained for all unmarried adolescents aged 14 to 17 years, and written informed consent was obtained directly for those aged 18 and 19 years and married adolescents aged 15 to 17 years. There were no married adolescents younger than 15 years, which was the legal age of marriage in Tanzania for girls. The study was retrospectively registered with the Pan African Clinical Trial Registry as PACTR201804003008116.

REFERENCES

1. Hillis S, Mercy J, Amobi A, Kress H. Global prevalence of past-year violence against children: a systematic review and minimum estimates. *Pediatrics.* 2016;137(3):e20154079. https://doi.org/10.1542/peds.2015-4079
2. Ellsberg M, Jansen HAFM, Heise L, Watts CH, Garcia-Moreno C, WHO Multi-country Study on Women's Health and Domestic Violence Against Women Study Team. Intimate partner violence and women's physical and mental health in the WHO Multi-country Study on Women's Health and Domestic Violence: an observational study. *Lancet.* 2008;371(9619):1165–1172. https://doi.org/10.1016/S0140-6736(08)60522-X
3. Hillis SD, Mercy JA, Saul JR. The enduring impact of violence against children. *Psychol Health Med.* 2017;22(4):393–405. https://doi.org/10.1080/13548506.2016.1153679
4. Chiang LF, Chen J, Gladden MR, et al. HIV and childhood sexual violence: implications for sexual risk behaviors and HIV testing in Tanzania. *AIDS Educ Prev.* 2015;27(5):474–487. https://doi.org/10.1521/aeap.2015.27.5.474
5. Abramsky T, Watts CH, Garcia-Moreno C, et al. What factors are associated with recent intimate partner violence? Findings from the WHO Multi-country Study on Women's Health and Domestic Violence. *BMC Public Health.* 2011;11(1):109. https://doi.org/10.1186/1471-2458-11-109

6. Fulu E, Jewkes R, Roselli T, Garcia-Moreno C; UN Multi-country Cross-sectional Study on Men and Violence research team. Prevalence of and factors associated with male perpetration of intimate partner violence: findings from the UN Multi-country Cross-Sectional Study on Men and Violence in Asia and the Pacific. *Lancet Glob Health.* 2013;1(4):e187–e207. https://doi.org/10.1016/S2214-109X(13)70074-3
7. INSPIRE: seven strategies for ending violence against children. Geneva, Switzerland: World Health Organization; 2016.
8. Roelen K, Devereux S, Abdulai AG, Martorano B, Palermo T, Ragno LP. How to make "cash plus" work: linking cash transfers to services and sectors. Florence, Italy: UNICEF Office of Research; 2017.
9. Buller AM, Peterman A, Ranganathan M, Bleile S, Hidrobo M, Heise L. A mixed-method review of cash transfers and intimate partner violence in low-and middle-income countries. *World Bank Res Obs.* 2018;33(2):218–258. https://doi.org/10.1093/wbro/lky002
10. Peterman A, Neijhoft AN, Cook S, Palermo TM. Understanding the linkages between social safety nets and childhood violence: a review of the evidence from low- and middle-income countries. *Health Policy Plan.* 2017;32(7):1049–1071. https://doi.org/10.1093/heapol/czx033
11. Ellsberg M, Arango DJ, Morton M, et al. Prevention of violence against women and girls: what does the evidence say? *Lancet.* 2015;385(9977):1555–1566. https://doi.org/10.1016/S0140-6736(14)61703-7
12. Gibbs A, Willan S, Misselhorn A, Mangoma J. Combined structural interventions for gender equality and livelihood security: a critical review of the evidence from southern and eastern Africa and the implications for young people. *J Int AIDS Soc.* 2012;15(3 suppl 1):1–10. https://doi.org/10.7448/IAS.15.3.17362
13. Heath R, Hidrobo M, Roy S. Cash transfers, polygamy, and intimate partner violence: experimental evidence from Mali. *J Dev Econ.* 2020;143:102410. https://doi.org/10.1016/j.jdeveco.2019.102410
14. Chakrabarti A, Handa S, Angeles G, Seidenfeld D. A cash plus program reduces youth exposure to physical violence in Zimbabwe. *World Dev.* 2020;134:105037. https://doi.org/10.1016/j.worlddev.2020.105037
15. Austrian K, Hewett PC, Soler-Hampejsek E, Bozzani F, Behrman JR, Digitale J. Adolescent Girls Empowerment Programme: research and evaluation mid-term technical report. Nairobi, Kenya: Population Council; 2016. https://doi.org/10.31899/pgy9.1005
16. Bandiera O, Buehren N, Burgess R, et al. Women's empowerment in action: evidence from a randomized control trial in Africa. *Am Econ J.* 2020;12(1):210–259. https://doi.org/10.1257/app.20170416
17. Dunbar MS, Dufour MSK, Lambdin B, Mudekunye-Mahaka I, Nhamo D, Padian NS. The SHAZ! Project: results from a pilot randomized trial of a structural intervention to prevent HIV among adolescent women in Zimbabwe. *PLoS One.* 2014;9(11):e113621. https://doi.org/10.1371/journal.pone.0113621
18. Austrian K, Soler-Hampejsek E, Mumah J, et al. Adolescent Girls Initiative–Kenya: midline results report. Nairobi, Kenya: Population Council; 2018. https://doi.org/10.31899/pgy14.1026
19. Austrian K, Muthengi E. Can economic assets increase girls' risk of sexual harassment? Evaluation results from a social, health and economic asset-building intervention for vulnerable adolescent girls in Uganda. *Child Youth Serv Rev.* 2014;47(2):168–175. https://doi.org/10.1016/j.childyouth.2014.08.012
20. Buehren N, Goldstein M, Gulesci S, Sulaiman M, Yam V. Evaluation of an adolescent development program for girls in Tanzania. Washington, DC: World Bank; 2017. https://doi.org/10.1596/1813-9450-7961
21. Özler B, Hallman K, Guimond MF, Kelvin EA, Rogers M, Karnley E. Girl Empower—a gender transformative mentoring and cash transfer intervention to promote adolescent wellbeing: impact findings from a cluster-randomized controlled trial in Liberia. *SSM Popul Health.* 2019;10:100527. https://doi.org/10.1016/j.ssmph.2019.100527
22. Devries K, Knight L, Petzold M, et al. Who perpetrates violence against children? A systematic analysis of age-specific and sex-specific data. *BMJ Paediatr Open.* 2018;2(1):e000180. https://doi.org/10.1136/bmjpo-2017-000180
23. Stöckl H, March L, Pallitto C, Garcia-Moreno C, WHO Multi-country Study Team. Intimate partner violence among adolescents and young women: prevalence and associated factors in nine countries: a cross-sectional study. *BMC Public Health.* 2014;14(1):751. https://doi.org/10.1186/1471-2458-14-751
24. Rosas N, Zaldivar S, Granata J, et al. Evaluating Tanzania's Productive Social Safety Net: findings from the midline survey. Washington, DC: World Bank and Tanzania Social Action Fund; 2019.
25. Tanzania PSSN Youth Study Evaluation Team. Tanzania Youth Study of the Productive Social Safety Net (PSSN) impact evaluation: endline report. Florence, Italy: UNICEF Office of Research–Innocenti; 2018.
26. Gender and adolescence: why understanding adolescent capabilities, change strategies and contexts matters. London, England: GAGE Consortium, Overseas Development Institute; 2017.
27. Sen A. Human rights and capabilities. *J Hum Dev.* 2005;6(2):151–166. https://doi.org/10.1080/14649880500120491
28. Tanzania UNICEF, US Centers for Disease Control and Prevention, Muhimbili University of Health and Allied Sciences. Violence against children in Tanzania: findings from a national survey, 2009. Summary report on the prevalence of sexual, physical and emotional violence, context of sexual violence, and health and behavioural consequences of violence experienced in childhood. Dar es Salaam, Tanzania: UNICEF Tanzania; 2011.
29. *Researching Violence Against Women: Practical Guidelines for Researchers and Activists.* Geneva, Switzerland: World Health Organization; 2005.
30. Garcia-Moreno C, Jansen HAFM, Ellsberg M, Heise L, Watts CH, WHO Multi-country Study on Women's Health and Domestic Violence Against Women Study Team. Prevalence of intimate partner violence: findings from the WHO Multi-country Study on Women's Health and Domestic Violence. *Lancet.* 2006;368(9543):1260–1269. https://doi.org/10.1016/S0140-6736(06)69523-8
31. Straus MA, Hamby SL, Boney-McCoy S, Sugarman DB. The revised Conflict Tactics Scales (CTS2) development and preliminary psychometric data. *J Fam Issues.* 1996;17(3):283–316. https://doi.org/10.1177/019251396017003001
32. Palermo T, Bleck J, Peterman A. Tip of the iceberg: reporting and gender-based violence in developing countries. *Am J Epidemiol.* 2014;179(5):602–612. https://doi.org/10.1093/aje/kwt295
33. Pereira A, Peterman A, Neijhoft AN, et al. Disclosure, reporting and help seeking among child survivors of violence: a cross-country analysis. *BMC Public Health.* 2020;20(1):1051. https://doi.org/10.1186/s12889-020-09069-7
34. Pettifor A, MacPhail C, Hughes JP, et al. The effect of a conditional cash transfer on HIV incidence in young women in rural South Africa (HPTN 068): a phase 3, randomised controlled trial. *Lancet Glob Health.* 2016;4(12):e978–e988. https://doi.org/10.1016/S2214-109X(16)30253-4
35. Palermo T, Hall BJ, Cirillo C, Tanzania PSSN Youth Study Evaluation Team, Tanzania Adolescent Cash Plus Study Team, and Ghana LEAP 1000 Evaluation Team in Acknowledgement. Enhanced Life Distress Inventory: development and validation in two African countries. *Br J Health Psychol.* 2020;25(3):728–753. https://doi.org/10.1111/bjhp.12448
36. Levenson H. Differentiating among internality, powerful others, and chance. In: Lefcourt HM. *Research With the Locus of Control Construct.* New York, NY: Academic Press; 1981:15–63. https://doi.org/10.1016/B978-0-12-443201-7.50006-3
37. Laajaj R, Macours K. Measuring skills in developing countries. Washington, DC: The World Bank; 2017. https://doi.org/10.1596/1813-9450-8000
38. Rosenberg M. *Society and the Adolescent Self-Image.* Princeton, NJ: Princeton University Press; 1965. https://doi.org/10.1515/9781400876136
39. Chzhen Y, Prencipe L, Eetaama F, Luchemba P, Lukongo TM, Palermo T. Impacts of a cash plus intervention on gender attitudes among Tanzanian adolescents. *J Adolesc Health.* 2021;68(5):899–905. https://doi.org/10.1016/j.jadohealth.2020.07.025
40. Tanzania Cash Plus Evaluation Team. A cash plus model for safe transitions to a healthy and productive adulthood: round 3 report. Florence, Italy: UNICEF Office of Research–Innocenti: 2021.
41. Petersen I, Bhana A, McKay M. Sexual violence and youth in South Africa: the need for community-based prevention interventions. *Child Abuse Negl.* 2005;29(11):1233–1248. https://doi.org/10.1016/j.chiabu.2005.02.012
42. Pflieger JC, Vazsonyi AT. Parenting processes and dating violence: the mediating role of self-esteem in low-and high-SES adolescents. *J Adolesc.* 2006;29(4):495–512. https://doi.org/10.1016/j.adolescence.2005.10.002
43. Levant RF, Brooks GR. *Men and Sex: New Psychological Perspectives.* New York, NY: John Wiley & Sons Inc; 1997.
44. John N, Stoebenau K, Ritter S, Edmeades J, Balvin N. Gender socialization during adolescence in

low- and middle-income countries: conceptualization, influences and outcomes. Innocenti Discussion Papers. Florence, Italy: UNICEF Office of Research; 2017.

45. Baird S, Ferreira FHG, Özler B, Woolcock M. Conditional, unconditional and everything in between: a systematic review of the effects of cash transfer programmes on schooling outcomes. *J Dev Effect.* 2014;6(1):1–43. https://doi.org/10.1080/19439342.2014.890362
46. De Hoop J, Gichane MW, Groppo V, Zuilkowski SS, on behalf of the Productive Social Safety Net Youth Evaluation Team. Cash transfers, public works and child activities: mixed methods evidence from the United Republic of Tanzania. Working Paper Series (WP-2020-03). Florence, Italy: UNICEF Office of Research–Innocenti; 2020.
47. Roelen K, Saha A. Pathways to stronger futures? The role of social protection in reducing psychological risk factors for child development in Haiti. *World Dev.* 2021;142:105423. https://doi.org/10.1016/j.worlddev.2021.105423
48. Roy S, Hidrobo M, Hoddinott J, Ahmed A. Transfers, behavior change communication, and intimate partner violence: postprogram evidence from rural Bangladesh. *Rev Econ Stat.* 2019;101(5):865–877. https://doi.org/10.1162/rest_a_00791

Prevalence and Predictors of Home Health Care Workers' General, Physical, and Mental Health: Findings From the 2014–2018 Behavioral Risk Factor Surveillance System

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See also Galea and Vaughan, p. 2094.

Objectives. To determine the prevalence and predictors of US home health care workers' (HHWs') self-reported general, physical, and mental health.

Methods. Using the 2014–2018 Behavioral Risk Factor Surveillance System, we analyzed the characteristics and health of 2987 HHWs (weighted n = 659 000) compared with 2 similar low-wage worker groups (health care aides and health care support workers, not working in the home). We conducted multivariable logistic regression to determine which characteristics predicted HHWs' health.

Results. Overall, 26.6% of HHWs had fair or poor general health, 14.1% had poor physical health, and 20.9% had poor mental health; the prevalence of each outcome was significantly higher than that of the comparison groups. Among HHWs, certain factors, such as low household income, an inability to see a doctor because of cost, and a history of depression, were associated with all 3 aspects of suboptimal health.

Conclusions. HHWs had worse general, physical, and mental health compared with low-wage workers not in home health.

Public Health Implications. Increased attention to the health of HHWs by public health experts and policymakers is warranted. In addition, targeted interventions appropriate to their specific health needs may be required. (*Am J Public Health*. 2021;111(12):2239–2250. https://doi.org/10.2105/AJPH.2021.306512)

Home health care workers (HHWs) are one of the fastest growing workforces in the health care industry. There are currently more than 2 million in the United States, and the field is expected to grow by 38% by 2024.[1] Largely employed by home care agencies, they provide hands-on care to older adults and those with chronic conditions and disabilities in the home. This includes providing assistance with personal care and medically oriented care, and offering emotional support.[2,3] Unlike doctors or nurses, HHWs are with patients in their home on a daily or near-daily basis, giving them a unique vantage point from which to observe, support, and advise patients.

Despite their integral role in patient care, HHWs are an underserved group of health care professionals. Mostly women and minorities, they are poorly compensated and have limited opportunities for career advancement.[4,5] In addition, their own health and safety have not been prioritized.[6–8] This is problematic as this workforce faces unique physical and mental challenges. Although they provide direct patient care like other frontline health care workers, HHWs differ in that they deliver hands-on, manual care alone to patients in their homes, which are not often optimally equipped for the delivery of care. Studies have shown that HHWs are commonly injured on the job, often lack health insurance, and frequently work multiple jobs to make ends meet, which may create stress and limit their ability to prioritize their own health.[9–12] Indeed, a study found HHWs to have a high burden of clinical comorbidities and adverse health behaviors, compared with both nurses and non–health care clerical workers.[13] In addition, recent studies of HHWs and their experiences caring for patients during the COVID-19 pandemic suggest that they endure high levels of physical, emotional, and financial strain.[8,14] Yet, to our knowledge, how these specific vulnerabilities influence HHWs' overall health status has not been investigated. A better understanding of their health, and the factors that influence it, is needed to better support HHWs' well-being and to ensure their ability to provide hands-on care in the future.

Herein, we used data from the Centers for Disease Control and Prevention's (CDC's) Behavioral Risk Factor Surveillance System (BRFSS) to determine the prevalence and predictors of HHWs' general, physical, and mental health

METHODS

Administered by the CDC and state (and some local) health departments, the BRFSS is a cross-sectional telephone survey designed to collect data about US residents regarding their health, health behaviors, and use of preventive services.[15] The survey is administered by trained interviewers via landline and cellular phones to the US noninstitutionalized adult population (≥ 18 years) from all 50 states, the District of Columbia, and 3 US territories. A multistage design and random-digit dialing are used to obtain representative samples of noninstitutionalized adults. The survey questionnaire assesses the prevalence of medical conditions, health behaviors, and preventive health practices. All data are self-reported.[16]

Starting in 2013, the BRFSS survey included a module sponsored by the National Institute for Occupational Safety and Health to elicit the industry and occupation of participants who are employed for wages, self-employed, or out of work for less than 1 year. Participants were asked, "What kind of work do you do?" followed by, "What kind of business or industry do you work in?" For this study, we coded responses with the 2010 US Census Bureau industry and occupation codes.[17] States and localities can elect to include this module each year; during 2014 to 2018, 38 states included the module at least once, while 17 included the module each year.

Study Population

We included all employed or self-employed noninstitutionalized adults aged 18 years or older who completed the industry and occupation module between 2014 and 2018. Our main population of interest was HHWs, which included employees from 2 occupational groups who worked in home health (e.g., in the patient home): (1) nursing, psychiatric, and home health aides and (2) personal care aides. To contextualize our findings on HHWs, we also included 2 comparison worker groups in our analyses: (1) nursing, psychiatric, and home health aides not working in the home (hereafter referred to as "health care aides (HCAs) not working in the home" and (2) health care support workers (HSWs) not working in the home (hereafter referred to as "HSWs not working in the home"). The specific types of occupations that comprise these groups are further detailed in Table A (available as a supplement to the online version of this article at http://www.ajph.org). We selected the HCA group as the first comparison group because, although they have similar demographic characteristics and the same job as HHWs, they do not provide care in the home. We selected the HSW group as a second comparison group because, while they also have similar demographic characteristics to HHWs and HCAs, they have different jobs and do not provide care in the home.

Self-Reported General, Physical, and Mental Health

In the BRFSS, general health status was assessed with, "Would you say that in general your health is excellent, very good, good, fair, or poor?" Following the methodology of previous studies, we dichotomized responses to (1) fair or poor versus (2) good, very good, or excellent general health.[12] Physical health status was assessed with, "Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?" Similar to previous studies, we defined participants who reported 14 or more days of not good physical health as having poor physical health. Mental health status was assessed with "Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?" Similarly, we defined participants who reported 14 or more days of not good mental health as having poor mental health.

All 3 questions have been shown to have good construct validity and reasonably good criterion validity with respect to the Medical Outcomes Study Short-Form 36 in healthy and disabled populations.[18,19] In addition, the unhealthy days measures have been validated in previous studies. Finally, the 14-day cutpoint for physical and mental health has been previously shown to be clinically meaningful.[20]

Study Variables

Similar to other studies of health status and quality of life, we used the Andersen's Behavioral Model to guide variable selection;[21] this model has been used to explain how factors relate to health status and outcomes.[22] In this model, variables are grouped into predisposing, need, and enabling variables. Predisposing variables are social and cultural characteristics (e.g., education); need variables are conditions that require medical treatment and health behaviors that have an impact on health (e.g., chronic conditions); and enabling variables are related to the logistical aspects of getting care including financing care (e.g., income or insurance). As such, we included data on sociodemographic characteristics including age (18–34 years, 35–54 years, or ≥ 55 years), gender (women or men), race/ethnicity (non-Hispanic White, non-Hispanic Black, non-Hispanic other, or Hispanic), education (< high school, high-school graduate, some college or technical school, or ≥ college graduate), household income (< $20 000, $20 000–$34 999, or ≥ $35 000), marital status (married, never married, divorced, separated, or widowed), covered by a health insurance plan (yes or no), and homeowner status (rent or other arrangement vs own).

We included data on participants' health behaviors as follows: smoking status (current vs former vs never), alcohol use in the past 30 days (yes or no), binge drinking (yes or no), any leisure-time physical activity or exercise in the past month (yes or no), and hours of sleep per day (inadequate vs adequate, with less than 7 hours being inadequate). We included data on clinical comorbidities, which were obtained as self-report of a physician's diagnosis of heart disease (history of heart disease or myocardial infarction), stroke, hypertension, high cholesterol, diabetes, arthritis, cancer, chronic obstructive pulmonary disease (COPD), and asthma. Obesity was defined by body mass index of 30 or higher calculated from self-reported height and weight. We included data on participants' health care access and utilization by assessing whether they had (yes or no) a personal doctor or health care provider, a routine doctor visit in the past year, inability to see a doctor because of cost in the past year, a dental visit in the last year, received the flu shot in the past year, and ever received the pneumonia shot.

Data Analysis

First, we calculated descriptive statistics of all variables, including frequencies and proportions with 95% confidence intervals (CIs), for each worker group; we weighted all estimates to provide population-based estimates. We then used the Rao–Scott χ^2 test to determine differences between HHWs and comparison worker groups. Next, we estimated the prevalence of health status (general, physical, and mental health) among HHWs by their characteristics. We used the Rao–Scott χ^2 test to determine associations between each characteristic and health status domain. Finally, we used multivariable logistic regression with backward stepwise elimination method in multiple stages to determine the subset of characteristics that best predicted each health status (general, physical, and mental health) among HHWs. In the first stage, we started with all sociodemographic variables and kept those significant at an α of 0.1; in the second and third stages, we added health behavior and health care access variables significant at an α of 0.1; in the final stage, we added clinical comorbidities and retained all characteristics significant at an α of 0.05. We estimated adjusted odds ratios (ORs) along with 95% CIs.

We conducted all analyses with SAS version 9.4 (SAS Institute Inc, Cary, NC) survey procedures and SAS-callable SUDAAN version 11.0.1 (RTI International, Research Triangle Park, NC) to account for the complex survey sampling design. To handle missing data, we used pairwise deletion—that is, participants with missing information on a particular characteristic or outcome were only excluded from analyses involving that characteristic or outcome.

RESULTS

During the period of 2014 to 2018, 2987 participants were identified as HHWs (weighted n = 659 000), 4861 were identified as HCAs not working in the home (weighted n = 983 000), and 9305 were identified as HSWs not working in the home (weighted n = 1 967 000).

Home Health Care Workers vs Other Worker Groups

One in 4 HHWs was aged 55 years or older, 90.6% were women, 29.3% were non-Hispanic Black, 18.8% were Hispanic, and 54.8% had a high-school education or less (Table 1). Compared with both HCAs and HSWs, HHWs were older, more often women, had lower household income, had lower educational attainment, and were less likely to be covered by a health insurance plan. Compared with HSWs (but not HCAs), HHWs were less likely to be non-Hispanic White and less often married. HHWs were less likely than both comparison groups to report consuming alcoholic beverages in the past 30 days, although they were more likely to be current smokers.

Although 76.6% of HHWs had a personal doctor, 31.5% reported they could not see a doctor because of cost, compared with 21.6% and 19.0% among HCAs and HSWs, respectively. Compared with both comparison groups, HHWs were less likely to have had a flu shot (or spray) or a dentist visit in the past year. Compared with both HCAs and HSWs, HHWs had significantly higher prevalence of clinical conditions including stroke, diabetes, arthritis, COPD, asthma, hypertension, and high cholesterol. Compared with HSWs (but not HCWs), HHWs had higher prevalence of obesity, depression, and cancer.

Overall, 26.6% of HHWs rated their health as fair or poor, compared with 14.6% of HCAs and 11.5% of HSWs (Table 1). With respect to physical health, 14.1% of HHWs reported poor physical health, compared with 7.5% of HCAs and 6.6% of HSWs. With respect to mental health, 20.9% of HHWs reported poor mental health, compared with 14.5% of HCAs and 13.3% of HSWs.

Predictors of General Health

Among HHWs, the following characteristics were associated with reporting fair or poor general health: lower educational attainment; lower household income; renting a home; lacking health insurance; current smoking; being obese; having a history of depression, diabetes, arthritis, or hypertension; being unable to see a doctor because of cost; and not visiting a dentist in the past year (Table 2).

In a fully adjusted model, Hispanic ethnicity (OR = 3.43; 95% CI = 1.81, 6.50; ref: non-Hispanic White), lower household income (OR = 1.82; 95% CI = 1.07, 3.10), having access to a doctor limited by cost (OR = 3.33; 95% CI = 1.94, 5.72), obesity (OR = 1.92; 95% CI = 1.17, 3.17), depression (OR = 2.25; 95% CI = 1.27, 3.98), arthritis (OR = 3.06; 95% CI = 1.80, 5.19), and COPD (OR = 2.71; 95% CI = 1.49, 4.92) were independently associated with higher odds of self-rated fair or poor general health (Table 3).

Predictors of Physical Health

HHWs who were older; women; had lower household income; had no leisure-time physical activity; had inadequate sleep; had a history of heart disease, depression, diabetes, arthritis, cancer, COPD, or hypertension; and were unable to see a doctor because of cost were more likely to have poor physical health (Table 2).

In a fully adjusted model, increased age (OR = 2.71 [95% CI = 1.34, 5.47] for those aged 35 to 54 years and 5.05 [95% CI = 2.09, 12.19] for those aged 55 years or older; ref: those aged 18 to 34 years), lower household income (OR = 4.01; 95% CI = 2.23, 7.21), no leisure-time physical activity (OR = 2.68; 95% CI = 1.51, 4.75), being unable to access a doctor because of cost (OR = 1.80; 95% CI = 1.02, 3.19), and a history of depression (OR = 2.19; 95% CI = 1.29, 3.73) were independently associated with higher odds of poor physical health (Table 3).

Predictors of Mental Health

HHWs who were younger; were women; had lower household income; consumed alcoholic drinks in the past 30 days; had inadequate sleep; had a history of depression, arthritis, COPD, or asthma; and were unable to access a doctor because of cost were more likely to have poor mental health (Table 2).

In a fully adjusted model, older age (OR = 0.28; 95% CI = 0.14, 0.55 for those aged 55 years and older; ref = those aged 18–34 years) was associated with lower odds of poor mental health; by contrast, lower household income (OR = 2.29; 95% CI = 1.33, 3.96), having access to a doctor limited by cost (OR = 4.04; 95% CI = 2.27, 7.18), history of COPD (OR = 2.41; 95% CI = 1.11, 5.22), history of arthritis (OR = 2.25; 95% CI = 1.26, 4.02), and history of depression (OR = 4.49; 95% CI = 2.60, 7.76) were independently associated with higher odds of poor mental health (Table 3).

DISCUSSION

Using population-representative data from 38 states in the United States from the 2014–2018 BRFSS, we found that 1 out of 4 HHWs rated their general health as fair or poor, 1 in 7

TABLE 1— Characteristics of Home Health Care Workers (HHWs) Compared With Other Workers: Behavioral Risk Factor Surveillance System, United States, 2014–2018

Characteristic	HHWs,[a] Weighted % (95% CI)	HCAs Not Working in Home Health[b]		HSWs Not Working in Home Health[c]	
		Weighted % (95% CI)	P[d]	Weighted % (95% CI)	P[d]
Sociodemographics					
Age, y			.002		<.001
18–34	34.1 (27.3, 41.4)	43.5 (40.2, 46.8)		44.0 (41.5, 46.5)	
35–54	40.4 (34.8, 46.2)	40.1 (36.6, 43.6)		40.7 (38.3, 43.2)	
≥55	25.5 (21.5, 29.9)	16.4 (14.5, 18.6)		15.3 (13.9, 16.8)	
Women	90.6 (87.9, 93.0)	85.5 (82.5, 88.2)	.007	86.4 (84.6, 88.2)	.011
Race/ethnicity			.19		.036
Non-Hispanic White	44.9 (38.4, 51.4)	47.6 (44.2, 51.0)		53.6 (51.1, 56.1)	
Non-Hispanic Black	29.3 (24.4, 34.6)	32.0 (29.0, 35.2)		22.7 (20.8, 24.7)	
Non-Hispanic other	6.9 (4.3, 10.5)	6.9 (5.1, 9.1)		6.8 (5.5, 8.2)	
Hispanic	18.8 (15.0, 23.3)	13.5 (11.0, 16.3)		16.9 (14.6, 19.4)	
Not married	65.4 (61.0, 69.6)	62.8 (59.3, 66.1)	.34	57.2 (54.7, 59.6)	.001
Education			<.001		<.001
<high school	23.2 (16.0, 31.7)	10.2 (8.0, 12.9)		6.3 (5.1, 7.8)	
High-school graduate	31.6 (26.9, 36.6)	35.4 (32.3, 38.6)		27.1 (25.0, 29.2)	
Some college or technical school	33.9 (29.0, 39.0)	42.4 (39.1, 45.9)		50.8 (48.4, 53.3)	
≥college graduate	11.3 (8.0, 15.4)	11.9 (10.0, 14.0)		15.8 (14.2, 17.5)	
Household income, $			<.001		<.001
<20 000	41.7 (36.7, 46.8)	20.6 (17.8, 23.7)		14.6 (12.9, 16.5)	
20 000–34 999	33.3 (28.9, 37.9)	40.5 (36.9, 44.3)		35.0 (32.5, 37.6)	
≥35 000	25.0 (20.9, 29.6)	38.8 (35.5, 42.3)		50.3 (47.7, 53.0)	
Does not own home	59.7 (54.0, 65.2)	53.0 (49.6, 56.4)	.04	46.7 (44.2, 49.2)	<.001
Not covered by health plan	23.5 (16.4, 31.9)	13.7 (11.4, 16.2)	.003	11.8 (10.3, 13.5)	<.001
Health behaviors					
Smoking status			.06		.003
Current smoker	26.0 (19.1, 34.1)	21.5 (19.0, 24.1)		18.7 (17.0, 20.6)	
Former smoker	17.5 (13.9, 21.6)	13.9 (11.9, 16.1)		16.1 (14.6, 17.8)	
Never smoked	56.5 (49.7, 63.0)	64.6 (61.6, 67.6)		65.1 (62.8, 67.3)	
Alcohol use					
Any alcoholic beverages in past 30 d	38.8 (33.1, 44.6)	49.1 (45.6, 52.6)	.002	54.3 (51.8, 56.9)	<.001
Binge drinking	10.1 (7.6, 13.1)	15.9 (13.5, 18.6)	.002	17.1 (15.2, 19.1)	<.001
No leisure-time physical activity	29.4 (24.6, 34.5)	28.4 (25.3, 31.7)	.76	25.2 (23.1, 27.5)	.12
Inadequate sleep per day[e]	45.9 (39.1, 52.8)	49.4 (45.2, 53.5)	.37	44.1 (41.2, 47.1)	.64
Health care access and utilization					
No personal doctor	23.4 (16.4, 31.7)	21.2 (18.5, 24.2)	.58	19.9 (17.9, 22.0)	.34
No routine check up within 1 y	22.1 (18.2, 26.4)	25.8 (23.0, 28.8)	.14	27.9 (25.7, 30.3)	.015
Access to doctor limited by cost	31.5 (24.4, 39.3)	21.6 (18.8, 24.5)	.005	19.0 (17.0, 21.2)	<.001
No dentist visit within 1 y[e]	48.0 (41.0, 55.2)	37.4 (33.5, 41.4)	.006	30.9 (28.4, 33.6)	<.001
No adult flu shot (or spray) in past 12 mo	63.3 (57.6, 68.8)	48.8 (45.2, 52.3)	<.001	54.0 (51.5, 56.6)	.003
No pneumonia shot ever	70.7 (64.6, 76.3)	72.2 (68.8, 75.4)	.66	76.0 (73.7, 78.1)	.08

Continued

TABLE 1— Continued

	HHWs,[a] Weighted % (95% CI)	HCAs Not Working in Home Health[b]		HSWs Not Working in Home Health[c]	
Characteristic		**Weighted % (95% CI)**	***P*[d]**	**Weighted % (95% CI)**	***P*[d]**
Clinical comorbidities					
Heart disease	3.9 (2.2, 6.3)	2.8 (1.8, 4.1)	.29	2.0 (1.5, 2.7)	.022
Stroke	3.2 (1.7, 5.4)	1.2 (0.8, 1.7)	.002	1.0 (0.7, 1.4)	< .001
Obesity	46.5 (39.7, 53.4)	39.8 (36.4, 43.3)	.07	36.9 (34.4, 39.4)	.005
Depression	27.0 (22.2, 32.3)	22.9 (19.9, 26.2)	.16	22.0 (20.0, 24.2)	.06
Diabetes	12.0 (8.5, 16.2)	7.5 (5.9, 9.4)	.018	6.3 (5.3, 7.5)	< .001
Arthritis	24.6 (20.3, 29.3)	18.1 (16.0, 20.4)	.007	16.0 (14.5, 17.5)	< .001
Cancer	5.1 (3.8, 6.7)	3.6 (2.6, 4.9)	.11	3.4 (2.8, 4.2)	.029
COPD	6.8 (4.8, 9.4)	4.3 (3.1, 5.8)	.041	3.6 (2.8, 4.5)	.001
Asthma	14.6 (11.2,18.6)	8.9 (7.4,10.6)	.002	10.5 (9.1,12.0)	.021
Hypertension[f]	30.8 (25.3, 36.7)	22.6 (18.7, 27.0)	.019	20.2 (17.5, 23.2)	< .001
High cholesterol[f]	38.4 (30.5, 46.9)	24.2 (19.7, 29.1)	.001	22.8 (19.4, 26.5)	< .001
Self-reported health status					
General health fair or poor	26.6 (19.6, 34.7)	14.6 (12.5, 16.9)	< .001	11.5 (10.1, 13.1)	< .001
≥ 14 days physical health not good	14.1 (10.3, 18.5)	7.5 (6.2, 9.1)	< .001	6.6 (5.6, 7.6)	< .001
≥ 14 days mental health not good	20.9 (16.2, 26.1)	14.5 (12.2, 17.0)	.012	13.3 (11.7, 15.0)	< .001

Note. CI = confidence interval; COPD = chronic obstructive pulmonary disease; HCA = health care aide; HSW = health care support worker.

[a] 2010 Census occupation = 3600 or 4610, and 2010 Census industry = 8170. No. (weighted no.) = 2987 (659 000).

[b] HCAs not working in home health; defined as nursing, psychiatric, and home health aides not working in home setting; 2010 Census occupation = 3600, and 2010 Census industry not 8170. No. (weighted no.) = 4861 (983 000).

[c] HSWs excluding home health industry; 2010 Census occupation = 3600–3655, and 2010 Census industry not 8170. No. (weighted no.) = 9305 (1 967 000).

[d] Rao–Scott χ^2 test of differences in characteristic distribution in home care workers and each comparison group.

[e] Only data from 2014, 2016, and 2018 available.

[f] Only data from 2015 and 2017 available.

reported poor physical health, and 1 in 5 reported poor mental health. Each of these prevalences was significantly higher compared with those of HCAs and HSWs, which is striking, because both comparison worker groups are frontline, low-wage workers with similar health care responsibilities and job functions. We also note that these groups differed meaningfully by demographic factors, certain health behaviors, health care access, and clinical comorbidities, which may contribute to the differences we found in the self-rated health status of each group. In addition, we found that, among HHWs, certain factors, such as low household income, an inability to see a doctor because of cost, and a history of depression, were associated with all 3 aspects of suboptimal health. Taken together, our findings suggest that increased attention to the health of HHWs is urgently needed and targeted interventions appropriate to their specific health needs may be required.

To date, only a few studies have characterized the health of HHWs at a statewide or national level, and these studies have generally found that HHWs have higher burdens of chronic conditions than other low-wage frontline health care workers not providing care in the home. For example, Silver et al. found that home health aides fared worse than nursing home aides and hospital aides with respect to health behaviors (less exercise, more smoking) and burden of chronic conditions.[13] Similarly, Howard and Marcum found that HHWs in Washington State were more likely to be overweight, smoke, have serious mental illness, and have more arthritis and diabetes compared with non–home-based health care providers.[23]

Our study confirms and expands this body of literature in a few key ways. First, we also found that HHWs' burden of chronic conditions is high, with nearly half of HHWs in our study having

TABLE 2— Weighted Prevalence of Suboptimal General, Physical, and Mental Health by Home Health Care Workers' Characteristics: Behavioral Risk Factor Surveillance System, United States, 2014–2018

	Fair or Poor Health		≥ 14 Days Physical Health Not Good		≥ 14 Days Mental Health Not Good	
	Weighted % (95% CI)	*P*[a]	Weighted % (95% CI)	*P*[a]	Weighted % (95% CI)	*P*[a]
Demographics						
Age, y		.75		.004		.049
18–34	29.7 (13.1, 51.5)[b]		6.6 (3.7, 10.7)		25.9 (16.4, 37.5)	
35–54	26.2 (18.8, 34.6)		16.8 (10.4, 25.0)		22.3 (14.7, 31.6)	
≥ 55	23.2 (17.7, 29.4)		19.9 (12.2, 29.7)		11.8 (7.9, 16.7)	
Gender		.06		.001		.028
Men	16.1 (8.4, 27.0)		4.7 (1.9, 9.4)[b]		12.0 (6.7, 19.4)	
Women	27.7 (20.0, 36.4)		15.1 (11.0, 20.0)		21.8 (16.7, 27.6)	
Race/ethnicity		.50		.42		.31
Non-Hispanic White	25.6 (12.3, 43.4)		11.2 (7.6, 15.9)		18.4 (12.7, 25.4)	
Non-Hispanic Black	23.7 (15.5, 33.6)		13.2 (6.9, 22.3)		25.4 (15.3, 37.7)	
Non-Hispanic other	18.8 (8.4, 34.1)[b]		[c]		11.3 (5.0, 21.2)[b]	
Hispanic	35.0 (24.1, 47.3)		19.7 (10.0, 33.0)		23.2 (13.0, 36.2)	
Marital status		.12		.92		.15
Married	19.2 (13.2, 26.4)		15.1 (8.9, 23.4)		17.5 (11.2, 25.4)	
Not married	25.9 (20.7, 31.7)		14.7 (10.2, 20.3)		24.5 (18.5, 31.2)	
Education		< .001		.34		.18
< high school	51.4 (30.3, 72.1)		20.8 (10.1, 35.6)		31.9 (16.6, 50.7)	
High-school graduate	18.7 (13.9, 24.3)		13.6 (7.6, 21.8)		17.7 (11.4, 25.5)	
Some college or technical school	19.2 (14.1, 25.3)		9.8 (6.5, 14.1)		16.9 (12.2, 22.4)	
≥ college graduate	20.8 (6.2, 44.3)[b]		[c]		19.9 (5.6, 43.7)[b]	
Household income, $		.030		< .001		.005
< 20 000	32.6 (25.1, 40.9)		25.3 (16.6, 35.7)		30.8 (22.2, 40.5)	
20 000–34 999	19.6 (13.9, 26.5)		7.3 (5.0, 10.1)		13.1 (9.1, 18.0)	
≥ 35 000	18.2 (8.7, 31.6)[b]		8.6 (4.8, 13.9)		19.1 (9.3, 32.9)	
Housing status		.049		.70		.09
Own home	19.6 (13.6, 26.9)		15.1 (9.5, 22.4)		16.1 (10.3, 23.5)	
Does not own home (rents home or other arrangement)	31.2 (20.5, 43.6)		13.5 (8.8, 19.7)		24.4 (17.6, 32.3)	
Not covered by health plan		.001		.28		.89
Yes	46.3 (24.8, 69.0)		18.9 (8.0, 34.9)[b]		21.5 (10.0, 37.7)[b]	
No	20.6 (16.6, 25.0)		12.5 (9.2, 16.6)		20.6 (15.9, 25.9)	
Health behaviors						
Smoking status		.051		.44		.30
Current smoker	39.0 (18.6, 62.7)[b]		15.4 (8.5, 24.8)		26.5 (15.5, 40.2)	
Former smoker	30.4 (18.9, 44.0)		19.0 (11.6, 28.5)		24.7 (13.3, 39.3)	
Never smoked	20.4 (15.4, 26.2)		12.4 (7.2, 19.6)		17.6 (11.9, 24.6)	
Any alcoholic beverages in past 30 d		.77		.87		.025
Yes	26.0 (19.0, 34.0)		14.9 (9.3, 22.1)		27.3 (19.3, 36.5)	
No	27.9 (17.2, 40.9)		14.2 (9.1, 20.7)		16.5 (11.3, 23.0)	
Binge drinking		.63		.89		.40
No	27.5 (19.4, 36.8)		14.3 (10.1, 19.3)		20.3 (15.2, 26.3)	

Continued

TABLE 2— Continued

	Fair or Poor Health		≥ 14 Days Physical Health Not Good		≥ 14 Days Mental Health Not Good	
	Weighted % (95% CI)	P^a	**Weighted % (95% CI)**	P^a	**Weighted % (95% CI)**	P^a
Yes	23.9 (13.2, 37.8)		15.1 (6.2, 28.8)[b]		25.4 (15.0, 38.3)	
Any leisure-time physical activity		.66		<.001		.09
Yes	25.9 (16.3, 37.4)		9.5 (6.1, 13.8)		18.5 (13.4, 24.5)	
No	28.9 (20.9, 37.9)		26.3 (17.4, 36.9)		27.4 (18.1, 38.5)	
Inadequate sleep[d]		.56		<.001		<.001
Yes	29.3 (21.4, 38.2)		23.7 (15.3, 34.0)		31.2 (21.9, 41.7)	
No	24.6 (12.8, 39.9)		6.8 (4.4, 10.0)		11.2 (7.6, 15.7)	
Health care access and utilization						
No personal doctor		.07		.66		.63
Yes	40.1 (18.0, 65.6)		12.3 (4.8, 24.6)[b]		18.6 (9.1, 32.0)	
No	22.6 (18.1, 27.6)		14.7 (10.6, 19.5)		21.7 (16.6, 27.4)	
No routine check-up within 1 y		.85		.68		.63
Yes	25.6 (17.9, 34.7)		15.6 (8.1, 26.2)		22.9 (14.9, 32.5)	
No	26.8 (18.1, 37.1)		13.7 (9.5, 18.8)		20.4 (15.0, 26.8)	
Access to doctor limited by cost		<.001		.041		<.001
Yes	48.5 (31.6, 65.7)		21.0 (11.6, 33.5)		38.0 (23.8, 53.9)	
No	16.6 (13.5, 20.1)		10.9 (7.5, 15.2)		13.1 (10.1, 16.5)	
Adult flu shot (or spray) in past 12 mo		.08		.68		.28
Yes	20.6 (15.5, 26.5)		13.3 (7.8, 20.7)		17.7 (11.9, 24.8)	
No	30.4 (19.6, 43.1)		15.1 (9.9, 21.6)		22.8 (16.1, 30.8)	
Pneumonia shot ever		.97		.72		.09
Yes	27.4 (18.1, 38.3)		15.4 (8.0, 25.7)		28.5 (17.6, 41.6)	
No	27.0 (16.6, 39.7)		13.7 (8.9, 19.8)		18.5 (13.2, 24.9)	
No dentist visit within 1 y[d]		.019		.22		.87
Yes	34.7 (21.6, 49.7)		17.4 (9.7, 27.8)		20.9 (13.7, 29.8)	
No	19.4 (13.6, 26.4)		11.7 (7.4, 17.3)		20.0 (12.8, 29.1)	
Clinical comorbidities						
Heart disease		.80		.04		.84
Yes	28.7 (12.7, 49.8)[b]		32.5 (12.0, 59.4)[b]		19.4 (7.2, 38.2)[b]	
No	26.3 (18.9, 34.7)		13.4 (9.6, 17.9)		21.0 (16.2, 26.4)	
Stroke		.41		.66		.59
Yes	36.2 (14.4, 63.1)[b]		17.4 (5.0, 38.7)[b]		16.3 (4.4, 37.2)[b]	
No	26.3 (19.0, 34.7)		14.0 (10.2, 18.6)		21.0 (16.3, 26.5)	
Obesity		<.001		.20		.63
Yes	37.9 (24.5, 52.9)		11.9 (7.9, 17.0)		22.4 (14.3, 32.3)	
No	18.3 (13.3, 24.2)		16.7 (10.6, 24.5)		19.8 (14.1, 26.6)	
Depression		.024		<.001		<.001
Yes	39.5 (29.2, 50.5)		26.6 (17.2, 38.0)		49.2 (38.7, 59.7)	
No	21.8 (12.9, 33.2)		9.5 (6.2, 13.7)		10.5 (7.1, 14.8)	
Diabetes		.025		<.001		.08
Yes	44.8 (28.5, 61.9)		34.9 (18.1, 55.1)		33.3 (16.6, 53.8)	
No	24.3 (16.4, 33.6)		11.2 (8.0, 15.0)		19.2 (14.6, 24.4)	

Continued

TABLE 2— Continued

	Fair or Poor Health		≥ 14 Days Physical Health Not Good		≥ 14 Days Mental Health Not Good	
	Weighted % (95% CI)	P[a]	Weighted % (95% CI)	P[a]	Weighted % (95% CI)	P[a]
Arthritis		.01		.002		< .001
Yes	41.4 (31.7, 51.6)		24.3 (16.4, 33.6)		38.0 (27.5, 49.5)	
No	21.5 (12.7, 32.7)		10.6 (6.6, 15.9)		15.4 (11.1, 20.5)	
Cancer		.16		.008		.76
Yes	36.7 (24.3, 50.5)		30.4 (16.0, 48.3)		22.7 (12.0, 36.8)	
No	26.1 (18.7, 34.7)		13.3 (9.5, 17.9)		20.8 (15.9, 26.3)	
COPD		.63		.005		.002
Yes	30.0 (18.2, 44.1)		30.2 (16.8, 46.6)		42.0 (26.0, 59.3)	
No	26.4 (18.9, 35.1)		12.9 (9.1, 17.6)		19.3 (14.6, 24.9)	
Current asthma		.36		.06		< .001
Yes	32.1 (21.7, 44.0)		22.4 (12.8, 34.8)		39.8 (26.0, 54.9)	
No	25.5 (17.4, 35.1)		12.7 (8.7, 17.6)		17.6 (13.1, 23.0)	
Hypertension[e]		< .001		.047		.13
Yes	36.7 (27.2, 47.1)		15.3 (8.5, 24.6)		21.2 (13.5, 30.7)	
No	13.3 (8.4, 19.7)		8.3 (5.5, 12.0)		14.3 (9.8, 19.9)	
High cholesterol[e]		.12		.20		.81
Yes	26.4 (15.9, 39.3)		13.2 (6.5, 23.1)		15.3 (7.9, 25.8)	
No	16.7 (10.9, 24.1)		8.3 (5.4, 12.2)		14.1 (9.3, 20.1)	

Note. CI = confidence interval; COPD = chronic obstructive pulmonary disease.

[a] Rao–Scott χ^2 test of association between each characteristic and each outcome.
[b] Estimates with relative standard error (RSE) of > 30% to ≤ 50% and should be interpreted with caution.
[c] Estimates with RSE > 50% were suppressed because of low precision.
[d] Only data from 2014, 2016, and 2018 available.
[e] Only data from 2015 and 2017 available.

a history of obesity, one third with hypertension and hyperlipemia, and a quarter with arthritis. Second, like other studies, we found that HHWs, who were mostly women and racial/ethnic minorities, had lower household incomes and were less likely to have health insurance compared with both HCAs and HSWs. And, despite their chronic disease burden, more than a third of HHWs were unable to see a doctor because of cost, a prevalence that was significantly greater than that of HCAs and HSWs. These findings highlight not only the financial vulnerability of this workforce compared with other similar workforces but also the occupational health disparities that likely contribute to suboptimal health status we observed. Third, we found that nearly two thirds of HHWs did not receive the flu shot (or spray) in the past year. While there are several potential reasons for this (e.g., decentralized workforce, lack of paid time off) the finding suggests that HHWs and their employers may be an important target for current and future vaccination campaigns. Finally, some factors like low household income, an inability to see a doctor because of cost, and a history of depression were associated with higher odds of fair or poor general health, and poor physical and mental health, whereas other characteristics, like having a history of obesity, was only associated with higher odds of poor general health.

The reason HHWs had suboptimal health in general, and relative to other frontline low-wage health care workers, is likely multifactorial. Confirming national trends, we found that HHWs experienced even greater financial disadvantages than similar low-wage health care workers providing care outside of the home, including having low incomes and inadequate health insurance.[7,24] These circumstances may not only predispose HHWs to developing medical conditions but also may limit

TABLE 3— Final Models for the Associations Between Home Health Care Workers' Characteristics and Suboptimal General, Physical, and Mental Health: Behavioral Risk Factor Surveillance System, United States, 2014–2018

Characteristic	AOR (95% CI)
Fair or poor general health[a]	
Race/ethnicity	
Non-Hispanic White (Ref)	1
Non-Hispanic Black	1.24 (0.58, 2.17)
Non-Hispanic other	1.56 (0.62, 3.95)
Hispanic	3.43 (1.81, 6.50)
Household income < $20 000	1.82 (1.07, 3.10)
Access to doctor limited by cost	3.33 (1.94, 5.72)
Obesity	1.92 (1.17. 3.17)
Depression	2.25 (1.27, 3.98)
Arthritis	3.06 (1.80, 5.19)
COPD	2.71 (1.49, 4.92)
Poor physical health[a,b]	
Age group, y	
18–34 (Ref)	1
35–54	2.71 (1.34, 5.47)
≥ 55	5.05 (2.09, 12.19)
Household income < $20 000	4.01 (2.23, 7.21)
Access to doctor limited by cost	1.80 (1.02, 3.19)
No leisure-time physical activity	2.68 (1.51, 4.75)
Depression	2.19 (1.29, 3.73)
Poor mental health[a,c]	
Age group, y	
18–34 (Ref)	1
35–54	0.55 (0.29, 1.04)
≥ 55	0.28 (0.14, 0.55)
Household income < $20 000	2.29 (1.33, 3.96)
Access to doctor limited by cost	4.04 (2.27, 7.18)
COPD	2.41 (1.11, 5.22)
Arthritis	2.25 (1.26, 4.02)
Depression	4.49 (2.60, 7.76)

Note. AOR = adjusted odds ratio; CI = confidence interval; COPD = chronic obstructive pulmonary disease. Final model was derived from backward stepwise model selection in 4 stages that sequentially added variables from the following: stage 1: sociodemographics (age, gender, race/ethnicity, marital status, household income, housing), stage 2: health behaviors (smoking, alcohol, leisure-time physical activity), stage 3: health care access and utilization (insurance status, personal doctor, routine doctor visit, access to doctor limited by cost), and stage 4: clinical comorbidities (stroke, heart disease, obesity, depression, diabetes, arthritis, cancer, COPD, asthma). Dentist visit, hypertension, and high cholesterol were not included because they were not available in all 5 years.

[a] Fair or poor general health report complete case n = 2354/2987; poor physical health report complete case n = 2476/2987; poor mental health report complete case n = 2534/2987.

[b] Poor physical health defined as self-report of ≥ 14 days in the past month with physical health not good.

[c] Poor mental health defined as self-report of ≥ 14 days in the past month with mental health not good.

their ability to adequately manage them. Although we were unable to quantify condition severity and duration, it is likely that a lack of access to regular medical care, as well as insufficient funds, contribute to worse health.[21,25] In addition, aspects of the job are also likely to contribute to worse overall health. HHWs are known for working multiple jobs and having erratic hours and shifts.[24] Unlike the comparison groups who work in hospitals, clinics, or nursing homes,[25] HHWs often care for their patients in isolation, with less access to standardized equipment (e.g., ramps, elevators, bed lifts), and without shift breaks, which may negatively affect their physical and mental health.[26–29] All of these factors may contribute to poor self-care, which, in turn, can worsen chronic conditions and negatively affect physical and mental health.

Public Health Implications

A conceptual framework by Zarska et al. elucidates how various factors, including policies that govern HHWs' employment, as well as the working conditions in which they provide care, influence workers' health.[30] This framework and our findings highlight the need for higher minimum wages across states, as well as paid sick days and overtime pay.[31]

Unfortunately, median hourly wages for HHWs have remained stagnant over the past decade, and substandard wages combined with lack of affordable health insurance impede HHWs' access to health care. Although we were unable to examine organization-level factors in this study (e.g., training, workplace practices), our findings suggest the need for programs that address both physical and mental health hazards experienced by HHWs. Current research on interventions ranges from equipping the home environment to reduce physical occupational hazards to mobile health applications that encourage HHWs and their patients (dyads) to engage in physical activity.[32–34] Other possibilities include instituting screening programs at the state or agency level to detect adverse health conditions or programs that incentivize HHWs to carry out healthy behaviors. Collectively, these initiatives might improve the ability of HHWs to adequately address their existing medical conditions by engaging in preventive and self-care.

Strengths and Limitations

This study had several strengths. BRFSS is a large health survey administered by trained interviewers and uses standardized weighting methodology across states and years. The data allowed for the assessment of health conditions, behaviors, and status of HHWs and the comparison with other frontline health care worker groups, which have been understudied in the literature. We also note several limitations. First, all data in the BRFSS were self-reported and are therefore subject to recall and social desirability biases. Future studies are needed that can objectively quantify the duration and severity of HHWs' clinical comorbidities, in addition to adjudicating their health outcomes. Second, the industry and occupation module was optionally administered by states, with different states participating each year; thus, the findings are not nationally representative. Because the data are cross-sectional, we cannot make causal inferences on the basis of the results. Lastly, recent studies have shown that COVID-19 has exacerbated many of the underlying vulnerabilities of this workforce.[8,14] Future studies are needed to understand how working during COVID-19 affected specific aspects of HHWs' health.

Conclusions

As the population ages, and as people with disabilities and chronic diseases want to remain at home, the demand for HHWs will continue to grow. Yet, the health of this workforce is suboptimal, which limits their own well-being as well as their ability to meet the needs of their patients. Using data from the BRFSS, we found that HHWs had significantly worse general, physical, and mental health compared with other similar low-wage health care workers not working in the home setting. Increased attention to the health status of HHWs by public health experts and policymakers is warranted. In addition, targeted policies and programs appropriate to their specific health needs may be required.

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CONTRIBUTORS

M. R. Sterling, J. Li, and S. R. Silver jointly conceptualized the study. J. Li led the data analysis. M. R. Sterling, J. Li, J. Cho, J. B. Ringel, and S. R. Silver jointly interpreted the data. M. R. Sterling led the writing of the article. J. Li, J. Cho, J. B. Ringel, and S. R. Silver jointly provided critical feedback on the article draft. M. R. Sterling and S. R. Silver provided overall supervision.

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CONFLICTS OF INTEREST

None of the authors have any conflicts of interest.

HUMAN PARTICIPANT PROTECTION

BRFSS was approved as exempt research including human participants by the Centers for Disease Control and Prevention institutional review board (protocol 2968), and data were collected with Office of Management and Budget approval (control number 0920-1061).

REFERENCES

1. PHI. US home care workers: key facts (2019). Available at: https://phinational.org/resource/u-s-home-care-workers-key-facts-2019. Accessed May 21, 2020.
2. Reckrey JM, Tsui EK, Morrison RS, et al. Beyond functional support: the range of health-related tasks performed in the home by paid caregivers in New York. *Health Aff (Millwood).* 2019;38(6):927–933. https://doi.org/10.1377/hlthaff.2019.00004
3. Sterling MR, Shaw AL. Sharing the care—a patient and her caregivers. *JAMA Intern Med.* 2019;179(12):1617–1618. https://doi.org/10.1001/jamainternmed.2019.4231

4. Bercovitz A, Moss A, Sengupta M, Park-Lee EY, Jones A, Harris-Kojetin LD. An overview of home health aides: United States, 2007. *Natl Health Stat Report.* 2011;(34):1–31.
5. Stone R, Wilhelm J, Bishop CE, Bryant NS, Hermer L, Squillace MR. Predictors of intent to leave the job among home health workers: analysis of the National Home Health Aide Survey. *Gerontologist.* 2017;57(5):890–899. https://doi.org/10.1093/geront/gnw075
6. Shotwell JL, Wool E, Kozikowski A, et al. "We just get paid for 12 hours a day, but we work 24": home health aide restrictions and work related stress. *BMC Health Serv Res.* 2019;19(1):907. https://doi.org/10.1186/s12913-019-4664-2
7. PHI. Caring for the future: the power and potential of America's direct care workforce. Available at: https://phinational.org/resource/caring-for-the-future-the-power-and-potential-of-americas-direct-care-workforce. Accessed January 18, 2021.
8. Sterling MR, Tseng E, Poon A, et al. Experiences of home health care workers in New York City during the coronavirus disease 2019 pandemic: a qualitative analysis. *JAMA Intern Med.* 2020;180(11):1453–1459. https://doi.org/10.1001/jamainternmed.2020.3930
9. McCaughey D, McGhan G, Kim J, Brannon D, Leroy H, Jablonski R. Workforce implications of injury among home health workers: evidence from the National Home Health Aide Survey. *Gerontologist.* 2012;52(4):493–505. https://doi.org/10.1093/geront/gnr133
10. Hewko SJ, Cooper SL, Huynh H, et al. Invisible no more: a scoping review of the health care aide workforce literature. *BMC Nurs.* 2015;14(1):38. https://doi.org/10.1186/s12912-015-0090-x
11. Muramatsu N, Sokas RK, Lukyanova VV, Zanoni J. Perceived stress and health among home care aides: caring for older clients in a Medicaid-funded home care program. *J Health Care Poor Underserved.* 2019;30(2):721–738. https://doi.org/10.1353/hpu.2019.0052
12. Shockey TM, Zack M, Sussell A. Health-related quality of life among US workers: variability across occupation groups. *Am J Public Health.* 2017;107(8):1316–1323. https://doi.org/10.2105/AJPH.2017.303840
13. Silver S, Boiano J, Li J. Patient care aides: differences in healthcare coverage, health-related behaviors, and health outcomes in a low-wage workforce by healthcare setting. *Am J Ind Med.* 2020;63(1):60–73. https://doi.org/10.1002/ajim.23053
14. Bandini J, Rollison J, Feistel K, Whitaker L, Bialas A, Etchegaray J. Home care aide safety concerns and job challenges during the COVID-19 pandemic. *New Solut.* 2021;31(1):20–29. https://doi.org/10.1177/1048291120987845
15. Centers for Disease Control and Prevention. About BRFSS. Available at: http://www.cdc.gov/brfss/annual_data/annual_2015.html. Accessed March 1, 2020.
16. Centers for Disease Control and Prevention. BRFSS survey data and documentation. Available at: https://www.cdc.gov/brfss/data_documentation/index.htm. Accessed March 1, 2020.
17. National Institute for Occupational Safety and Health. Industry and occupation coding: about the NIOSH Industry & Occupation Computerized Coding System (NIOCCS). Available at: https://csams.cdc.gov/nioccs/Default.aspx. Accessed June 10, 2020.
18. Odom EC, Fang J, Zack M, Moore L, Loustalot F. Associations between cardiovascular health and health-related quality of life, Behavioral Risk Factor Surveillance System, 2013. *Prev Chronic Dis.* 2016;13:E99. https://doi.org/10.5888/pcd13.160073
19. Ford ES, Mokdad AH, Li C, et al. Gender differences in coronary heart disease and health-related quality of life: findings from 10 states from the 2004 Behavioral Risk Factor Surveillance System. *J Womens Health (Larchmt).* 2008;17(5):757–768. https://doi.org/10.1089/jwh.2007.0468
20. Dwyer-Lindgren L, Mackenbach JP, Van Lenthe FJ, Mokdad AH. Self-reported general health, physical distress, mental distress, and activity limitation by US county, 1995–2012. *Popul Health Metr.* 2017;15(1):16. https://doi.org/10.1186/s12963-017-0133-5
21. Andersen RM. Revisiting the behavioral model and access to medical care: does it matter? *J Health Soc Behav.* 1995;36(1):1–10. https://doi.org/10.2307/2137284
22. Babitsch B, Gohl D, von Lengerke T. Re-revisiting Andersen's Behavioral Model of Health Services Use: a systematic review of studies from 1998–2011. *Psychosoc Med.* 2012;9:Doc11. https://doi.org/10.3205/psm000089
23. Howard N, Marcum J. Comparison of BRFSS data between home-based care providers and health care support workers in clinical environments in Washington State [erratum in *Workplace Health Saf.* 2020;68(5):251–252. *Workplace Health Saf.* 2020;68(2):92–102. https://doi.org/10.1177/2165079919857448
24. Scales K. It's time to care: a detailed profile of America's direct care workforce. Available at: https://phinational.org/resource/its-time-to-care-a-detailed-profile-of-americas-direct-care-workforce. Accessed June 10, 2020.
25. Ayanian JZ, Weissman JS, Schneider EC, Ginsburg JA, Zaslavsky AM. Unmet health needs of uninsured adults in the United States. *JAMA.* 2000;284(16):2061–2069. https://doi.org/10.1001/jama.284.16.2061
26. Faucett J, Kang T, Newcomer R. Personal service assistance: musculoskeletal disorders and injuries in consumer-directed home care. *Am J Ind Med.* 2013;56(4):454–468. https://doi.org/10.1002/ajim.22133
27. Galinsky T, Waters T, Malit B. Overexertion injuries in home health care workers and the need for ergonomics. *Home Health Care Serv Q.* 2001;20(3):57–73. https://doi.org/10.1300/J027v20n03_04
28. Franzosa E, Tsui EK, Baron S. "Who's caring for us?": understanding and addressing the effects of emotional labor on home health aides' well-being. *Gerontologist.* 2019;59(6):1055–1064. https://doi.org/10.1093/geront/gny099
29. Spetz J, Stone RI, Chapman SA, Bryant N. Home and community-based workforce for patients with serious illness requires support to meet growing needs. *Health Aff (Millwood).* 2019;38(6):902–909. https://doi.org/10.1377/hlthaff.2019.00021
30. Zarska A, Avgar AC, Sterling MR. Relationship between working conditions, worker outcomes, and patient care: a theoretical model for frontline health care workers. *Am J Med Qual.* 2021; epub ahead of print July 21, 2021. https://doi.org/10.1097/01.JMQ.0000735508.08292.73
31. Landers S, Madigan E, Leff B, et al. The future of home health care: a strategic framework for optimizing value. *Home Health Care Manag Pract.* 2016;28(4):262–278. https://doi.org/10.1177/1084822316666368
32. Bien E, Smith R. The unique occupational environment of the home healthcare worker. NIOSH Science Blog. Available at: https://blogs.cdc.gov/niosh-science-blog/2020/09/29/hhcws. Accessed March 8, 2021.
33. Sun C, Buchholz B, Quinn M, Punnett L, Galligan C, Gore R. Ergonomic evaluation of slide boards used by home care aides to assist client transfers. *Ergonomics.* 2018;61(7):913–922. https://doi.org/10.1080/00140139.2017.1420826
34. Danilovich MK, Diaz L, Saberbein G, Healey WE, Huber G, Corcos DM. Design and development of a mobile exercise application for home care aides and older adult Medicaid home and community-based clients. *Home Health Care Serv Q.* 2017;36(3-4):196–210. https://doi.org/10.1080/01621424.2017.1381869