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*Public Health Reports* is the official journal of the Office of the US Surgeon General and the US Public Health Service and has been published since 1878. It is published bimonthly, plus supplemental issues, through an official agreement with the Association of Schools and Programs of Public Health. The journal is peer-reviewed and publishes original research and commentaries in the areas of public health practice and methodology, original research, public health law, and public health schools and teaching. Issues contain regular commentaries by the US Surgeon General and executives of the US Department of Health and Human Services and the Office of the Assistant Secretary for Health.

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**Public Health Reports** (ISSN 0033-3549) (J829) is published bimonthly—in January/February, March/April, May/June, July/August, September/October, and November/December—by SAGE Publishing, 2455 Teller Road, Thousand Oaks, CA 91320, on behalf of the Association of Schools and Programs of Public Health, 1900 M St. NW, Ste. 710, Washington, DC 20036. Periodicals postage paid at Thousand Oaks, California, and at additional mailing offices. POSTMASTER: Send address changes to Public Health Reports, c/o SAGE Publishing, 2455 Teller Road, Thousand Oaks, CA 91320.

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# Advancing Housing and Health: Promoting Smoking Cessation in Permanent Supportive Housing

Public Health Reports  
2020, Vol. 135(4) 415-419  
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DOI: 10.1177/0033354920922374  
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**Maya Vijayaraghavan, MD, MAS<sup>1</sup> ; and Brian A. King, PhD, MPH<sup>2</sup>**

## Keywords

permanent supportive housing, smoking cessation, smoke-free policies

Cigarette smoking and homelessness are interconnected public health problems that contribute to health disparities. Smoking is common among persons with disabilities, mental health, and/or substance use disorders, as well as those living below the federal poverty level. These are the same populations living in permanent supportive housing, which is subsidized housing with closely linked or on-site voluntary social and/or medical services for formerly homeless adults. Among persons residing in permanent supportive housing, cigarette smoking not only presents an opportunity cost (ie, something that detracts from an essential need), threatening housing stability, but also leads to adverse health outcomes. Smoking cessation could improve health outcomes and free up funds to enhance housing stability. Smoke-free policies and cessation services, 2 evidence-based approaches, could provide the support needed for permanent supportive housing residents to quit smoking. However, such policies are uncommon in permanent supportive housing, in part because of concerns that they may increase evictions. We describe barriers to and opportunities for increasing access to comprehensive smoke-free policies and smoking cessation services in permanent supportive housing. By facilitating the implementation of such policies, permanent supportive housing could empower residents to engage in smoking cessation while avoiding unintended consequences.

## Relationship Among Homelessness, Housing, and Smoking

In 2017, an estimated 376 086 persons lived in permanent supportive housing,<sup>1</sup> which is subsidized housing with closely linked voluntary medical and/or social services for formerly homeless adults and families.<sup>2</sup> Permanent supportive housing residents are typically persons who have experienced long-term homelessness; who may live with disabilities, mental illness, and/or substance use disorders; and who cycle in and out of various acute care services,

including hospital emergency departments, inpatient hospital stays, psychiatric hospitals, jails, and prisons.<sup>2</sup> Permanent supportive housing is an evidence-based solution to ending chronic homelessness, not only helping to increase housing stability and health but also reducing costs related to the use of acute care services.<sup>2</sup> In some permanent supportive housing, residents are required to pay rent, which can amount to up to 30% of their income if they have an income, with the remainder covered by federal subsidies.<sup>2,3</sup> The US Department of Housing and Urban Development (HUD) is one of the primary sources of funding for permanent supportive housing programs.<sup>2,3</sup> Most permanent supportive housing uses a “housing first” approach, which provides housing without preconditions of abstinence from alcohol or substance use or a requirement to engage in case management services.<sup>2,3</sup>

Cigarette smoking and homelessness are interconnected public health risk factors that contribute to and exacerbate health disparities.<sup>4,5</sup> Compared with the general population, the prevalence of cigarette smoking is markedly higher among many of the same populations that commonly live in permanent supportive housing, including persons with physical disabilities, mental illness, and substance use disorders and persons who live below the federal poverty level.<sup>6,7</sup> In 2017, approximately 70% of persons experiencing current

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homelessness and about half of formerly homeless residents living in permanent supportive housing currently smoked cigarettes.<sup>5,8</sup> Moreover, heart disease and cancer, which are major smoking-attributable health outcomes,<sup>4</sup> are the leading causes of disability and death among homeless adults aged ≥45.<sup>9,10</sup> The risk of smoking-attributable health outcomes increases with age, and more than 40% of homeless persons entering permanent supportive housing are aged >50.<sup>1</sup> Furthermore, mortality among permanent supportive housing residents is double that of the general population,<sup>11</sup> and smoking-related diseases contribute to more than 60% of the all-cause mortality among formerly homeless persons.<sup>11</sup>

In addition to causing substantial morbidity and mortality, smoking exacerbates poverty and housing instability. Among homeless adults, tobacco-related expenditures amount to 30% of monthly income,<sup>12,13</sup> an amount equivalent to the rent required to stay in permanent supportive housing. Smokers who are homeless and have a higher level of nicotine dependence are more likely than smokers who are homeless and have lower levels of nicotine dependence to have subsistence challenges, such as finding shelter, food, clothing, or somewhere to wash themselves.<sup>13</sup> Among permanent supportive housing residents who smoke, tobacco-related expenditures amount to about 11% of residents' monthly income (range, 6%-26%).<sup>14,15</sup> These smoking-related expenditures could interfere with residents' ability to pay living expenses, including rent, which can place them at risk for eviction. In a mixed-methods study that included a survey of 23 permanent supportive housing sites in the San Francisco Bay Area, 17 sites did not offer on-site cessation services or discuss the effect of smoking on housing stability.<sup>16</sup> Service staff members at these sites reported rent evasion and the resulting threat of eviction as some of the most common reasons for case management interventions in permanent supportive housing.<sup>16</sup> Despite the potential effect of smoking on financial and/or housing instability, service staff members in these sites rarely engaged in discussion on the potential for smoking cessation to help alleviate the health or financial burden caused by smoking.<sup>16</sup>

### **Smoking Cessation in Permanent Supportive Housing: The Benefits of Smoke-Free Policies**

Smoking cessation could play an important role in improving population-level health among persons living in permanent supportive housing by not only reducing smoking-attributable morbidity and mortality but also by freeing up funds to enhance housing stability and reduce food insecurity. Permanent supportive housing could provide an effective venue for smoking cessation because it offers a supportive environment for behavior change for permanent supportive housing residents.

Smoke-free policies are an evidence-based approach that could be the primary lever for supporting smoking cessation among permanent supportive housing residents<sup>1</sup> and, in turn, increase their well-being. Research indicates that smoke-free policies are effective not only in reducing secondhand smoke exposure but also in promoting cessation among current smokers and preventing relapse among former smokers.<sup>17,18</sup> This evidence informed HUD's decision to adopt a smoke-free policy in public housing in July 2018.<sup>19</sup> However, the existing policy does not apply to permanent supportive housing, and most permanent supportive housing providers restrict smoking in indoor shared areas (eg, hallways) but permit smoking in living areas.<sup>16</sup> Therefore, permanent supportive housing residents are susceptible to secondhand smoke exposure and its associated risks, as well as an environment that continues to normalize smoking.

### **Challenges and Opportunities for Smoke-Free Policies in Permanent Supportive Housing**

Discussions about the adoption of smoke-free policies in permanent supportive housing must include a consideration of strategies to avoid unintended consequences (Table).<sup>16</sup> First, a no-smoking policy may appear to contradict the housing-first approach of permanent supportive housing if it poses additional barriers to housing chronically homeless persons or has the unintended consequence of increasing the number of unsheltered homeless persons. Second, such policies should not lead to increasing eviction rates, which would contradict the primary goal of permanent supportive housing (ie, to keep persons successfully housed). Third, residents with disabilities, cognitive impairment, or severe mental illness may have difficulty complying with a smoke-free policy. Fourth, consequences for policy violations should be carefully considered, because eviction is neither an ethical nor an acceptable outcome for persons with a history of long-standing homelessness. Fifth, unlike public housing in which HUD oversees policy implementation, permanent supportive housing is operated by nonprofit housing providers, and policy implementation is left to their discretion. Therefore, the lack of a common regulatory authority could limit adoption of a uniform smoke-free policy. Sixth, the lack of culturally and linguistically appropriate cessation programs that could be integrated in permanent supportive housing in combination with smoke-free policies is another important barrier.

Despite these challenges, permanent supportive housing could play an integral role in promoting smoking cessation and reducing tobacco-related disease and death among formerly homeless adults residing in permanent supportive housing (Table). To facilitate an environment in which smoke-free policies are strongly supported by residents and unintended consequences are minimized, certain actions can be taken to promote smoke-free norms. For example, permanent supportive

**Table.** Barriers and opportunities to adopting smoke-free policies and cessation services in permanent supportive housing

Barriers	Opportunities
Smoke-free policies are not feasible in permanent supportive housing.	<b>Smoke-Free Policy Implementation</b> Supporting a ground-up approach of voluntary smoke-free home adoption can pave a pathway for a building-wide smoke-free policy.
Persons with disabilities might be unable to adhere to the policy.	Identify and provide reasonable accommodations to help persons with disabilities adhere to smoke-free policies.
Evictions will increase as a result of nonadherence to the policy.	Designing repercussions to violations that do not include evictions is essential, including providing access to cessation resources to increase adherence.
High levels of nicotine dependence will pose a barrier to policy adherence.	Provide cessation medications to minimize withdrawal symptoms.
Tobacco screening and brief cessation services are not offered in permanent supportive housing.	<b>Access to Cessation Services</b> Train service staff members to obtain information on smoking status of residents and provide brief cessation counseling upon residents' entry into housing.
Medications for cessation are not offered in permanent supportive housing.	Provide on-site access to medications for cessation either through on-site medical clinics or by contracting with county medical services.
Missed opportunities for smoking cessation counseling.	Use case management encounters to draw parallels between smoking and difficulty paying rent, having financial hardship, and/or experiencing food insecurity.
Culturally and linguistically appropriate cessation counseling is unavailable.	Train service staff members on how to incorporate permanent supportive housing residents' lived experiences (eg, mental health and/or substance use) into cessation counseling.

housing residents who report smoking indoors could be empowered through a “ground-up approach,” whereby they are educated on and encouraged to voluntarily adopt smoke-free home rules (ie, voluntary no-smoking rules in indoor living areas) and engage in cessation services. Permanent supportive housing sites that are considering becoming smoke-free could initiate policy implementation using a ground-up approach by encouraging voluntary adoption of smoke-free homes, followed by a top-down approach in which a building-wide smoke-free policy is implemented. This implementation process could ensure resident support for the policy while minimizing subsequent violations and punitive repercussions to violations. This process could also lead to a social norm effect of other residents in a building voluntarily adopting smoke-free homes. Providing “reasonable accommodations,” such as housing residents with disabilities on the ground floor and close to exits, may also facilitate policy adherence.

To mitigate the concerns that a smoke-free policy in permanent supportive housing may lead to an increased eviction rate or may lead persons to decline permanent supportive housing because of the policy, permanent supportive housing providers could use methods to enforce policies in a way that encourages policy adherence and minimizes punitive consequences. HUD’s public housing experience could provide important lessons for permanent supportive housing providers that are

interested in becoming smoke-free. For example, public housing authorities provide residents who have not complied with the policy with several verbal and/or written warnings about the violations, along with resources for cessation.<sup>19</sup> As a result, housing providers have not reported a rise in eviction rates related to the smoke-free policy.<sup>20</sup> Such strategies have also been adopted by permanent supportive housing providers that have become smoke-free, without any evidence of eviction.<sup>8,16</sup> As the field evolves, new studies will likely describe other strategies and solutions to implementing and enforcing these policies in permanent supportive housing while minimizing unintended consequences.

Moreover, the academic community can play an important role in disseminating evidence on the benefits of smoke-free policies and successful implementation strategies to permanent supportive housing providers. For example, activities such as writing policy briefs, giving webinars, or facilitating local symposia can help in translating evidence into practice and policy. Academic conferences focused on tobacco control interventions can be broadly tailored to audiences that provide services to these populations, including the option to gain continuing medical education credits to maintain licensing requirements. Such incentives could increase stakeholder commitment to promote knowledge about smoking and implement interventions to increase delivery of smoking cessation care to

permanent supportive housing residents. The academic community can play a role in helping to evaluate the effect of these policies on the behaviors of permanent supportive housing residents, such as engaging with smoke-free rules and cessation services and smoking cessation. In addition, the academic community can evaluate delivery and receipt of smoking cessation interventions in permanent supportive housing sites.

## Importance of Cessation Resources

For policies to be successfully implemented in permanent supportive housing, it is critical that they be accompanied by efforts to increase access to and use of proven cessation interventions. Many persons who live in permanent supportive housing are interested in quitting smoking but may face barriers to smoking cessation, such as lack of access to smoking cessation services.<sup>14</sup> Behavioral counseling and pharmacotherapy are proven smoking cessation interventions, and the likelihood of success is higher when these interventions are combined rather than used individually.<sup>4,21</sup> These engagement strategies could be reinforced when persons enter permanent supportive housing, including screening for tobacco use and providing brief interventions for smoking cessation. Case managers can integrate cessation counseling into discussions of rent evasion, food insecurity, or financial hardship. To have these nuanced discussions, service staff members in these sites could benefit from additional training on how to integrate the lived experiences (eg, experiences of chronic homelessness, challenges with mental health and/or substance use disorders) of permanent supportive housing residents into smoking cessation counseling.

It is also important for cessation services to be culturally and linguistically tailored to the needs of permanent supportive housing residents who belong to racial/ethnic minority groups and/or have limited English proficiency. Bilingual case managers or substance use counselors working in permanent supportive housing programs can be trained to provide culturally relevant cessation counseling. Permanent supportive housing programs can also use the lay health worker or peer support models to provide cessation outreach to their residents.<sup>22</sup> A lay health worker or peer shares the same race/ethnicity, language, and cultural background of the target population and, although he or she is not a health professional, has received training in communicating health-related messages to the target population. These models could help improve access to culturally relevant cessation care.

Furthermore, on-site access to medications for cessation could facilitate smoking cessation among permanent supportive housing residents and minimize withdrawal symptoms that might hinder adherence to a smoke-free policy. Although some permanent supportive housing offers an integrated care model with on-site primary care and behavioral health services, most contract with county departments of public health or community health clinics to deliver these services. This integrated

model of care, whether delivered by the housing organization's or the county's service staff members, offers a useful infrastructure for permanent supportive housing to provide cessation services, including Medicaid-covered pharmacotherapy.

## Conclusion

For housing to fulfill its promise as the foundation for good health,<sup>23,24</sup> an environment that is supportive of smoking cessation is essential. Smoking places an enormous health and financial toll on persons experiencing homelessness, and permanent supportive housing is an untapped opportunity to reduce the burden of tobacco use on this already vulnerable population. Implementing comprehensive smoke-free policies in coordination with evidence-based smoking cessation services in permanent supportive housing that help residents quit can improve health outcomes and well-being for this underserved population. In addition, permanent supportive housing providers can serve an important role in facilitating the implementation of such policies in a manner that empowers permanent supportive housing residents and avoids unintended consequences.

## Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the Tobacco Related Disease Research Program grant 25IP-0015. The findings and conclusions in this article are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

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# Need to Amplify Health Security? Fuse Academia and Practice

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Public Health Reports  
2020, Vol. 135(4) 420-423  
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DOI: 10.1177/0033354920935075  
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## Keywords

public health practice, pandemic, preparedness, security, financing, academic public health, academic health departments

In December 2007, we traveled to Springfield, Illinois, to engage more than 150 physicians, state and local public health officials, university officials, judges, and attorneys in a scenario exercise to prepare for a future influenza pandemic. The event was organized by the Association of State and Territorial Health Officials and the Centers for Disease Control and Prevention (CDC). It was just one of the numerous workshops and stakeholder meetings on pandemic influenza that we would facilitate and/or participate in both domestically and internationally that year as part of the University of North Carolina Center for Public Health Preparedness (UNC CPHP).

A primary mission of centers such as the UNC CPHP, which opened in 2003, was to link university faculty members and public health practitioners by bringing academic rigor to state and local health departments, adding qualified state and local public health professionals to the faculty, and influencing scholarly research and its translation to real-world action. These partnerships provided students a window into health security, thereby inspiring them to devote their careers to threats such as COVID-19 through government service.<sup>1</sup> The UNC CPHP was one of a network of 27 Centers for Public Health Preparedness that grew from the events after 9/11, when health emerged as a national security concern.<sup>2</sup> Consequently, substantial federal investment in domestic health security transformed and modernized public health, especially after passage of the Pandemic and All-Hazards Preparedness Act in 2006 mandated research to improve federal, state, local, and tribal public health preparedness and response systems.<sup>2,3</sup>

It would have been in the country's best interest to continue programs such as the UNC CPHP, which, among other activities, established robust systems for outbreak detection and control, as well as provided continuing education opportunities for people who are the foundation of the local response to the COVID-19 pandemic (eg, epidemiologists, infection-control practitioners, public health nurses, disease intervention specialists/contact tracers). However, beginning

in the mid-2000s, investments in preparedness slowly deteriorated, and the CDC-funded program for the Centers for Public Health Preparedness and their corresponding outgrowths of 9 Preparedness and Emergency Response Research Centers (in 2008) and 14 Preparedness and Emergency Response Learning Centers (in 2010) has mostly ended,<sup>4,5</sup> despite recommendations by an external scientific review to continue these programs.<sup>6,7</sup> Likewise, in 2010, the UNC CPHP evolved into the UNC Preparedness and Emergency Response Learning Center and was subsequently closed in 2016.

This waning federal investment in health security—including divestment in formalized linkages between local and academic public health—may have contributed to delays or mishandling of the COVID-19 crisis. An October 2019 report by the US Department of Health and Human Services was only the most recent of several reports highlighting that the government was underfunded and unprepared for a pandemic.<sup>8</sup> Compounding this issue is that the workforce of public health professionals at the state and local level shrunk by more than 50 000 workers from 2008 to 2016.<sup>9</sup> In addition, a national survey in 2017 found that 22% of the public health workforce was planning to retire by 2023 and another 24% were considering leaving their organizations by 2018—a figure up 41% since 2014.<sup>10</sup> These factors have direct implications for the domestic response to the COVID-19 crisis. For example, at the peak of the COVID-19

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epidemic in Wuhan, China, 18 000 people had been mobilized locally to trace contacts in Wuhan alone.<sup>11</sup> In comparison, in the United States, only about 2000 people had been trained to safely conduct this work<sup>12</sup> before the COVID-19 pandemic (ie, disease intervention specialists<sup>13</sup> or contact tracers). Thus, without a robust and well-trained cadre of public health preparedness professionals ready to act in the early days of the US epidemic, we found ourselves outnumbered and outmaneuvered by COVID-19.

The structural relationships between academia and practice that were so robust in the early 2000s have diminished substantially, with several key consequences. The first is that insufficient planning and waning expertise in health security via a shrinking public health workforce have not been met with an adequate influx of graduates from schools and programs of public health. A 2015 survey revealed that only 39% of schools or programs of public health had a formal (written) agreement with a governmental public health agency,<sup>14</sup> and only about half of local health departments had a formal relationship with an academic institution.<sup>15</sup> Public health students today may have few avenues to explore health security through real-world experience, including meaningful, practice-based internships. It is therefore not surprising that they are increasingly likely to work at a for-profit company after graduation.<sup>16</sup> At the doctoral level, fewer than 1 in 5 graduates go on to work for government.<sup>17</sup> Exacerbating this trend is that most faculty members at a given institution may have little or no experience in the practice of applied public health. Today's student interested in health security must rely on a loose network of faculty and practice leaders who maintain research collaborations. By contrast, clinical medicine clearly does not have this problem, with its thriving system of teaching hospitals as a primary venue for the clinical education and training of medical students. Unfortunately, its counterpart system to train public health first responders is almost nonexistent in 2020.

A second consequence of the diminished structural relationship between academia and practice is that a lack of formalized partnerships has impeded the ability of schools and programs of public health to quickly backstop local and state health departments in a crisis. For example, such "surge" support might have been operationalized as early as January 2020, after the first case reports of COVID-19, by reinforcing working professionals with hundreds if not thousands of eager faculty and student volunteers, plugging in to fill key gaps in surveillance systems, informatics, data analysis, modeling, data collection, survey and questionnaire design, and health communications. Such support would also have had the benefit of infusing public health with innovative tools from academic public health (eg, machine learning, behavioral science). These bridges would be further strengthened by preexisting workforce development efforts<sup>18</sup> (eg, certificates in field epidemiology,<sup>19</sup> interactive case studies,<sup>20</sup> courses in disaster management<sup>21</sup> and communicable disease nursing,<sup>22</sup> technical assistance for

pandemic influenza training,<sup>23</sup> tabletop exercises,<sup>24</sup> ethics discussions,<sup>25</sup> crisis communication trainings, and the fiscal reinforcement of programs to create student surge capacity<sup>26</sup> for emergencies [eg, Team-Epi Aid<sup>27</sup> at UNC, which closed in 2016; Cal Student Assistance for Public Health at the University of California, Berkeley; or the Student Epidemic Action Leaders<sup>28</sup> at the University of Washington, among others]).

Instead, some academic centers of public health may find themselves underutilized and struggling to harness the collective expertise and energy of their institutions to support frontline public health workers in response to the COVID-19 pandemic.<sup>5,29,30</sup> This assertion, of course, is not to minimize the outstanding contributions of individual faculty members to research on severe acute respiratory syndrome (SARS-CoV-2), the development of COVID-19 resources by academic centers, and the growth of online education necessitated by the shift to remote learning. However, public health professionals like us lament the loss of the vision we had more than a decade ago for academic schools and programs of public health to prepare a diverse and thriving workforce for the most unprecedented public health event of our lives. Organizations such as the Council on Linkages Between Academia and Public Health Practice and the Public Health Accreditation Board attempt to fill this gap by fostering collaborations between academia and public health practice and encouraging the development of a sufficient number of qualified public health workers. However, relying on the volunteer efforts of *individual* faculty and government public health officials is unsustainable; without dedicated funding for infrastructure, formalized relationships, data sharing and privacy agreements, mentorship, and leadership commitments (via academic health departments, centers, and/or deans of public health practice), it will be challenging to rebuild robust partnerships and scaffold long-term relationships.

More than 13 years ago, we had a vision for how we would respond to the pandemic of today. Structural linkages between academic schools and programs of public health and the local, state, and federal public health practice community would expose students to public health practice, thereby opening new career opportunities in health security; fostering academic research with practical, policy-relevant public health benefits; bringing technical expertise to local governments; and being readily scalable for response to urgent public health threats. We now have an opportunity to determine our nation's future response to a major health security threat, and perhaps the best place to look for a playbook lies in the past.

### Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The authors declared no financial support with respect to the research, authorship, and/or publication of this article.

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# From Global Thinking to Local Action: The Planetary Diet as Chronic Disease Prevention

Public Health Reports  
2020, Vol. 135(4) 424-427  
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DOI: 10.1177/0033354920935070  
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## Keywords

planetary diet, chronic disease, prevention, food system, climate change

In this Anthropocene age, the detrimental effects of our industrial actions are increasingly visible on the planet's ecosystems, natural resources, and general health, as well as on the health of its inhabitants. Malnutrition is a major cause of premature mortality globally.<sup>1</sup> Our efforts to feed ourselves and to put food on our plates have imposed unsustainable practices on humans and the planet. Food, therefore, is at the center of one of our biggest environmental and public health challenges. More than 40% of adults in the United States are obese.<sup>2</sup> Obesity and various dietary risk factors lead to chronic diseases, and these diseases are associated with mortality, disability, and ever-increasing health care costs. As noted in the Global Burden of Diseases, Injuries and Risk Factors Study (GBD), in 2017, eleven million deaths were caused by 15 dietary risk factors globally. Moreover, the same dietary risk factors were also responsible for 255 million disability-adjusted life years.<sup>3</sup>

These deaths and disabilities likely could have been avoided had an optimal, nutritious diet been available. What is often overlooked in discussing the obesity epidemic, however, is the inextricable links among food, health, and the environment. Food production is responsible for about 30% of all greenhouse gas emissions and 70% of all freshwater use.<sup>4</sup> As we approach the limits of the carrying capacity of the environment we depend upon, food security will soon become a more pressing issue, both in the United States and globally.<sup>5</sup>

How to feed a planetary population that is predicted to comprise 10 billion persons by 2050 in a sustainable way that also ensures food security for future generations is, therefore, a pertinent question. This question was answered and quantified by the EAT-Lancet Commission on Food, Planet, Health (hereinafter, the Commission).<sup>4,6</sup> The Commission presents a planetary diet that can serve as a reference for a global diet that will be both sustainable and capable of preventing dietary-related chronic diseases and mortality. To generate a change in dietary-based morbidity and mortality, key goals from the report must be met. Red meat and sugar consumption, for example, must

be reduced by approximately 50%, and the intake of fruit, vegetables, legumes, nuts, and pulses must increase significantly, by more than 100% in most places. Regions throughout the world differ in how they define a healthy reference diet, but decreasing the consumption of red meat and sugar and increasing the intake of fruit and vegetables are common denominators. Given the correlations among higher red meat consumption, ill health effects, and increased mortality from noncommunicable diseases, these changes align with current public health recommendations for a healthy diet in the United States.<sup>7</sup> Similarly, given the soaring rates of type 2 diabetes and the ensuing risk of cardiovascular disease, decreased sugar consumption is also a priority.<sup>8,9</sup> The Commission pleads that a radical shift in the global food system and in patterns of consumption is needed to reduce premature mortality and the diet-related disease burden. The need to address changes in the food system is increasingly urgent and has become an important priority for many multilateral, global agendas.<sup>10,11</sup>

This plea for food system change must become a major public health priority. The public health community should be at the forefront of advocating for a shift in the food system and should demand an important role in making it happen. The reasons for change are obvious: changing our diets and improving the manner in which our food is produced can substantially and dramatically affect our efforts to combat obesity and prevent many chronic diseases. Moving toward an increasingly plant-based diet via the planetary diet and other flexitarian diets can reduce global mortality rates by as much as 23%.<sup>4,12</sup> The

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potential for such an effect on human mortality is enormous and more than justifies including it as part of the public health agenda. The added bonus is that adopting the planetary diet as a means of preventing obesity and chronic disease will also combat climate change as an important byproduct.<sup>4</sup>

Given the futility of current efforts to prevent obesity and tackle the growing obesity epidemic, it is time to try a new approach.<sup>13</sup> For years, diet-related diseases such as obesity and other chronic diseases have been treated as problems largely related to personal choice and behavior within the control of each person. It has become clear, however, that these diseases also stem from systemic issues that are rooted in our industrial food systems and structural barriers to an optimal diet (eg, lack of access to affordable and healthy food). As Professor William Dietz terms it, we are experiencing a global “syndemic,” a synergy of the 3 pandemics of obesity, undernutrition, and climate change.<sup>14</sup> In the United States, where nearly 1 in 7 households with children is food insecure,<sup>15</sup> it is tempting to conclude that food insecurity and obesity are unrelated. However, findings from a study of participants in the Supplemental Nutrition Assistance Program in the United States revealed that the 2 conditions are strongly correlated.<sup>16</sup>

The cheapest calories available for low-income families are in processed foods, which serve as dietary risk factors for increased morbidity and mortality from chronic diseases.<sup>17</sup> When structural factors such as residential segregation create “food deserts,” where the components of a healthy diet are difficult to access, food insecurity becomes an inevitable consequence.<sup>14</sup> Characterizing these problems as the result of the poor, misinformed choices that people make about their diet fails to address the structural processes that limit individual choice. It is also a form of “blaming the victim” that diverts our attention from the need to address food insecurity as a structural problem. What is needed is a change in the way that the issue of chronic diseases and food choices is addressed. This is a crisis. We must claim responsibility for the solution, and we must act now.

To exemplify how the public health community can act now, we can look at another defining public health epidemic, or pandemic: the fight against HIV/AIDS. When the public health community came together and claimed responsibility for the HIV/AIDS epidemic, the public health community worked across fields of expertise and acknowledged the need for combined efforts: behavioral interventions; structural interventions that affect laws and policy makers; and community interventions, where community leaders were engaged before they took responsibility for engaging their groups.<sup>18</sup> In that fight, as in the fight against the obesity epidemic, it was also necessary to combat the stigma of the disease before efficient treatment and prevention could take place.

Certainly, the challenges of food system change and chronic disease prevention differ from the challenges of infectious disease prevention. Complex issues such as structural and political barriers, international trade agreements and local subsidies, and the noncommunicable and chronic aspect of the diseases at

hand (eg, diabetes, cardiovascular disease) require multiple targets for immediate action. Although we have not seen the “AIDS-free generation” yet, the way the epidemic eventually was confronted by the public health community shows that we can achieve great progress with the right motivation, with a multipronged approach, and with a good dose of urgency.<sup>19</sup>

If we, as members of the public health community, agree that the solution to the epidemics of obesity and chronic diseases is to respond to the global call for a shift in the food system, the EAT-Lancet report gives us a platform to gather the public health community around a common cause: improved chronic disease prevention through the planetary diet. Critics may argue that this global call is not generalizable to local contexts. However, we must take this global call and act locally in accordance with guidelines of the EAT-Lancet report. These guidelines can be adapted to conform to the circumstances and needs of each nation, city, health care facility, and home. For example, cities can facilitate green spaces and urban gardens, provide funding for research, and minimize their food waste. Nationally, policy makers can help facilitate policies that improve not just the quantity but also the quality of food that is available. They can create policies that moderate food-price volatility and that increase food security.

Aligning national dietary recommendations with the planetary diet is another concrete local point of action, as Canada has shown in its national dietary recommendations.<sup>20</sup> These recommendations are in line with the EAT-Lancet report. Similarly, health care professionals can provide their patients with dietary recommendations that promote plant-based proteins and discourage sugar intake. Researchers can aid in improving the quality of metrics and data, such as was done by the GBD study,<sup>3</sup> which will further support evidence-based policies that improve the food system.

Other local recommendations can be developed for actors, such as farmers, who are directly involved with food production. For example, for farmers, an incentive to grow what is natural in their local environment while cultivating insect-friendly crops in 10% of their crop space could be vital.<sup>4</sup> Growing crops in their natural habitats would, in turn, maintain biodiversity and promote the sustainability of the food system, while also enhancing future food security nationally. Speeding up change implies speeding up adaptation to a local version of the planetary diet that focuses on the demand side as well. The local adaptation implies a consumer shift toward increased plant-based food, something all of us can advocate for, with public health officials at the forefront.

Control of such adaptation is at the level of governance. Ultimately, we require better governance of the global food system, with a correction to the asymmetry of the food system power of today, partly through new policy and partly by realigning agricultural subsidies.<sup>14</sup> Although this process is complicated and can take years or decades, the public health community can play an important role. If we view this challenge as a population-level challenge that we confront in the

face of an epidemic, we might succeed in getting buy-in from the general public.

As public health workers, we have a moral obligation to promote health equity for all and to reduce the social and health disparities of populations that are most affected by these disparities, regardless of political beliefs. In the United States, nevertheless, one difficulty with reports such as the EAT-Lancet report is that these reports can be interpreted as politicizing the issue to control the food industry and turn agricultural practices in a certain direction. Regardless of political standing and beliefs, the EAT-Lancet report and its accompanying research<sup>12</sup> have the potential to guide efforts to confront the obesity epidemic and to prevent chronic diseases. In the landscape of chronic diseases, risk factors are shifting; we are moving from 1 or 2 diseases to clusters of multiple chronic diseases. There is no silver bullet for dealing with this shift, and we are challenged to develop a multipronged approach to confront it. Yet a sweeping shift in diet might be the closest and most efficient tool we have.

Simply put: the food system of today is making our population and our planet sick. In matters of sickness and health, we, the public health community, must have a voice, and a loud one at that. As Goethe once wrote, "Knowing is not enough; we must apply. Willing is not enough; we must do." It is time for public health to claim responsibility for sustainable food production to promote chronic disease prevention. It is time for action.

### Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The authors declared no financial support with respect to the research, authorship, and/or publication of this article.

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# Lessons Learned From an Intensive Writing Training Course for Applied Epidemiologists

Public Health Reports  
2020, Vol. 135(4) 428-434  
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DOI: 10.1177/0033354920932659  
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## Abstract

Although writing is a valued public health competency, authors face a multitude of barriers (eg, lack of time, lack of mentorship, lack of appropriate instruction) to publication. Few writing courses for applied public health professionals have been documented. In 2017 and 2018, the Council of State and Territorial Epidemiologists and the Centers for Disease Control and Prevention partnered to implement a *Morbidity and Mortality Weekly Report* Intensive Writing Training course to improve the quality of submissions from applied epidemiologists working at health departments. The course included 3 webinars, expert mentorship from experienced authors, and a 2-day in-person session. As of April 2020, 39 epidemiologists had participated in the course. Twenty-four (62%) of the 39 epidemiologists had submitted manuscripts, 17 (71%) of which were published. The program's evaluation demonstrates the value of mentorship and peer feedback during the publishing process, the importance of case study exercises, and the need to address structural challenges (eg, competing work responsibilities or supervisor support) in the work environment.

## Keywords

workforce development, epidemiology, writing training, public health

One of the public health professional competencies is communicating public health content through writing.<sup>1</sup> Writing is practiced in school and continues in academic positions with an emphasis on publishing research. Writing may improve through practice and mentorship, but applied epidemiology positions often do not emphasize writing for professional audiences. Professional writing is not part of job descriptions for applied epidemiology positions; government staffing, outside of pure research settings, rarely includes time or funds to publish findings; and mentors for writing are not often available. Thus, applied epidemiologists have few opportunities or encouragement for continuing education or practice to improve professional writing skills.

Literature on professional writing programs is robust. Writing across the curriculum,<sup>2</sup> distance learning,<sup>3</sup> collaborative writing applications,<sup>4</sup> and online writing centers<sup>5</sup> have been described, some extensively. Most of these strategies are being applied in academic settings rather than on the job, and few strategies have been applied in the health field.<sup>2-5</sup> A systematic review of health-related journals from 1990 to 2013 found 12 studies on writing for publication.<sup>6</sup> These studies focused primarily on strategies to build writing skills.<sup>7-18</sup> Such

studies were evaluated primarily on the basis of increased publication output, often an increase from none to one, with little information about the publications' quality or the value of the educational components. These findings suggest that studies evaluating writing trainings are scarce and of low quality, limiting knowledge on the effectiveness of existing programs.<sup>6</sup> None of these studies focused on applied epidemiologists. None addressed structural barriers for public health professionals, such as limited resources, absence of supervisor support, or the fact that writing for publication is rarely included in job descriptions or in legislative or contractual funding language.<sup>19-24</sup> Although written communication skills are required

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for entry-level epidemiologists,<sup>25</sup> such skills are used more for internal reports than for disseminating information through published literature.<sup>7,26</sup>

In response to the need to improve writing skills among applied epidemiologists, in October 2016, the Council of State and Territorial Epidemiologists (CSTE) and the Centers for Disease Control and Prevention (CDC) partnered to develop a *Morbidity and Mortality Weekly Report (MMWR)* Intensive Writing Training course to improve the quality of submissions by applied epidemiologists. CSTE offered the course in 2017 and 2018. Demand for the program was high: 78 applications were submitted in 2017 for 21 spots (cohort 1), and 57 applications were submitted in 2018 for 18 spots (cohort 2). Despite interest in the program, the course was not continued after 2018 because of a lack of funding. In this case study, we share lessons learned from the training, evaluation, and monitoring of the participants. These lessons can inform best practices for future writing courses and resource allocation to support writing activities among applied public health professionals.

## Intensive Writing Training Course

### Participant Recruitment and Selection

In February and December 2017, CSTE advertised the training course to state, territorial, local, and tribal epidemiologists who were CSTE members and to the National Association of County and City Health Officials epidemiology workgroup via email announcements and social media. Eligibility required that applicants (1) had never published in *MMWR* as a first or senior author; (2) had published <5 professional articles as a first or senior author; (3) were employed at a state, territorial, local, or tribal agency; and (4) had supervisory and agency support to participate in the course. Applicants were required to describe their interest in the course, outline their proposed manuscript, and provide a letter of support from their agency. CSTE notified selected participants of acceptance to the course, which included webinars, an in-person session, and the assignment of an expert mentor who provided one-on-one guidance to complement the support the participants received at their agency. CSTE invited applicants who were not selected to participate in publicly available webinars.

### Training Approach

Participants viewed 3 required educational webinars about the writing process and submission requirements specific to *MMWR* in advance of attending a 2-day in-person session in Atlanta, Georgia (May 10-11, 2017, and April 10-11, 2018). *MMWR* staff members developed and taught the webinar content. The 3 webinars<sup>27</sup> were publicly available and promoted by CSTE and CDC. Before the in-person session, participants worked with their mentors to develop a first draft of

their manuscript. Based on lessons learned from cohort 1, in which participants did not bring a complete draft manuscript to the in-person session, cohort 2 participants were expected to have a complete draft manuscript to discuss at the in-person session.

The in-person session included group feedback meetings, in which preassigned groups of participants met to provide feedback on each other's drafts and share writing experiences; dedicated one-on-one time with expert mentors; a case study, in which participants were able to view and work through an example of a submitted manuscript with edits; and additional presentations on topics such as creating a promotion plan for the publication, working with the press, and understanding the legal implications of publishing their data. All participants set goals and identified sources of motivation and accountability to support continued progress on their manuscript after completing the course. After the in-person session, participants continued to work with their expert mentors, who established periodic telephone appointments to track progress, review the latest versions of the manuscripts, and respond to questions about the manuscript or the writing process in general. This formal mentorship concluded 6 months after the in-person session.

## Methods

### Evaluation and Analysis

The evaluation included 3 approaches to assess the participants: (1) webinar evaluations, completed immediately after each of the 3 webinars; (2) session evaluation, completed within 1 month of the in-person session; and (3) periodic check-in emails, commencing 2 months after the in-person session.

The webinar and training evaluations measured participants' level of confidence in their knowledge, skills, and abilities linked to the course's learning objectives, by using 5-point Likert scales (not at all confident to very confident and not effective to extremely effective). The in-person session evaluation also collected qualitative data through 3 open-ended questions:

1. How will you use the information learned in the training?
2. In what ways could the training be improved?
3. Do you have any additional comments on the overall training?

CSTE continued to follow participants' progress by email, requesting updates on participants' manuscript progress. As of April 2020, CSTE had collected email updates from cohort 1 seven times during the 33-month follow-up and from cohort 2 seven times during the 21-month follow-up. Monitoring of participants' progress is ongoing until

participants receive a manuscript determination or indicate discontinued efforts.

CSTE analyzed all quantitative data from the webinar evaluations and in-person session evaluations by using Qualtrics and Microsoft Excel. Two people (J.A., M.P.) coded the qualitative data thematically. The coders discussed and resolved any differences by recoding to a single theme.

## Outcomes

A total of 39 epidemiologists completed the course: 21 participants in cohort 1 (2017) and 18 participants in cohort 2 (2018). Thirty-seven of the 39 participants evaluated the in-person session, for a response rate of 94.9%. All participants in both cohorts reported that they would recommend the course to others, and 35 (95%) participants said the course was useful to their work (Table). All participants reported that they would submit a manuscript to *MMWR* by the end of the year after the course was completed. Most participants in both cohorts rated the group feedback session ( $n = 32/35$ , 91%) and the case study ( $n = 32/35$ , 91%) as extremely effective or very effective, followed by the reflection and action planning activities ( $n = 27/35$ , 77%), and the small-group discussions ( $n = 26/35$ , 74%) (Figure 1).

Participant confidence in their knowledge, skills, and abilities related to the course's learning objectives increased after completing the course (Figure 2). Participants recommended program improvements of completing a manuscript draft before the in-person session, reserving more time with expert mentors, and enhancing the group feedback component by reviewing their peers' drafts in advance.

Manuscript progress among participants varied greatly. As of April 2020, 24 of 39 (62%) participants had submitted their manuscripts for publication. Of the 24 manuscripts submitted, 17 were accepted, 4 were rejected, 2 were under review, and 1 had been withdrawn. Of the 15 remaining manuscripts, 7 were complete drafts and 8 were incomplete.

Qualitative data from the evaluation and check-in emails resulted in 3 themes related to the course: writing, communication, and experiential learning.

### Writing

Participants noted changes in their writing abilities, such as learning to write more clearly and succinctly. Many participants also reported that the writing skills they developed during the course facilitated their manuscript development and submission.

### Communication

Communication emerged as a theme in several ways. Participants highlighted communicating and networking with one another, communicating within their agency, and communicating their findings to the public. Participants

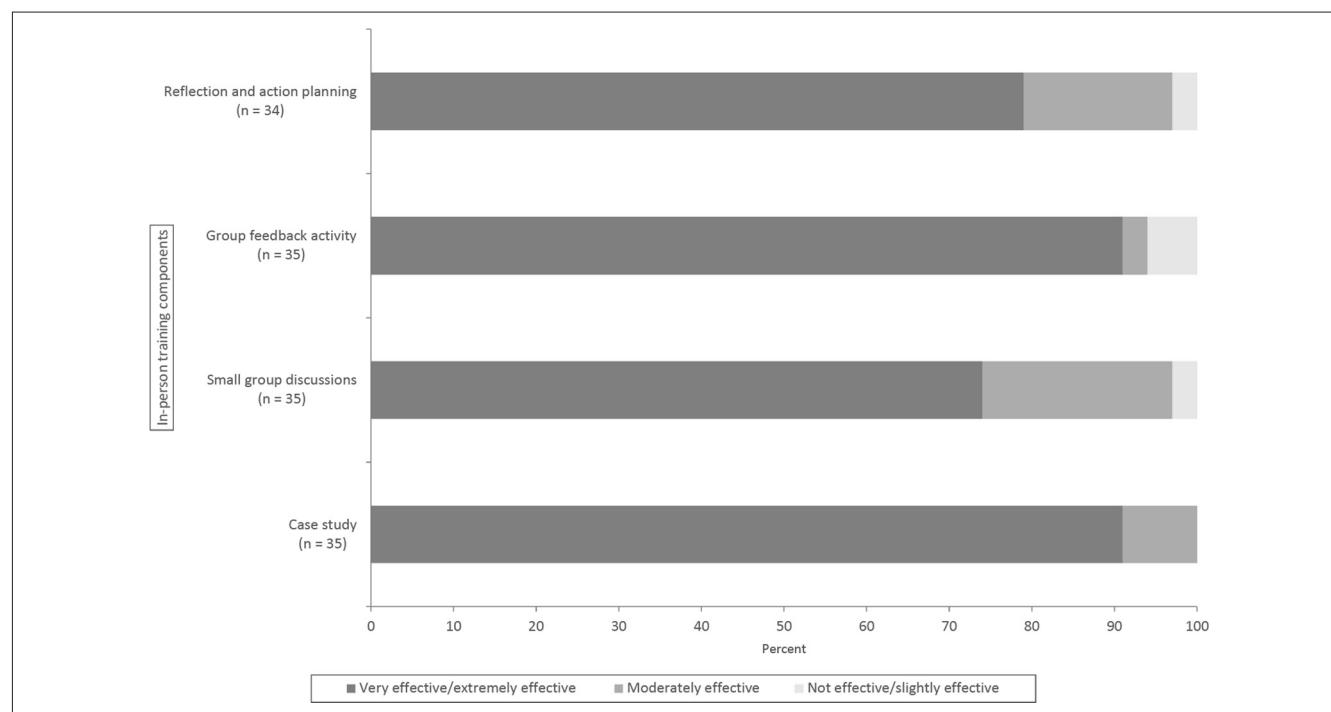
**Table.** Participant evaluation of the Council of State and Territorial Epidemiologists/Centers for Disease Control and Prevention *MMWR* Intensive Writing Training course, 2017-2018<sup>a</sup>

Evaluation Statement	Responses No. (%) (n = 37)
<b>Overall Training Evaluation</b>	
I would recommend the training to others	
Agree/strongly agree	37 (100)
Neutral	0
Strongly disagree/disagree	0
The training content was useful to my work	
Agree/strongly agree	35 (95)
Neutral	2 (5)
Strongly disagree/disagree	0
<b>Mentor Evaluation</b>	
I used my mentor for the development of an <i>MMWR</i> submission	
Agree/strongly agree	33 (89)
Neutral	2 (5)
Strongly disagree/disagree	2 (5)
I value my mentor's opinion	
Agree/strongly agree	35 (95)
Neutral	2 (5)
Strongly disagree/disagree	0
I had adequate time with my mentor	
Agree/strongly agree	28 (76)
Neutral	6 (14)
Strongly disagree/disagree	4 (10)
My mentor was engaged and involved in my work	
Agree/strongly agree	32 (86)
Neutral	2 (5)
Strongly disagree/disagree	3 (8)

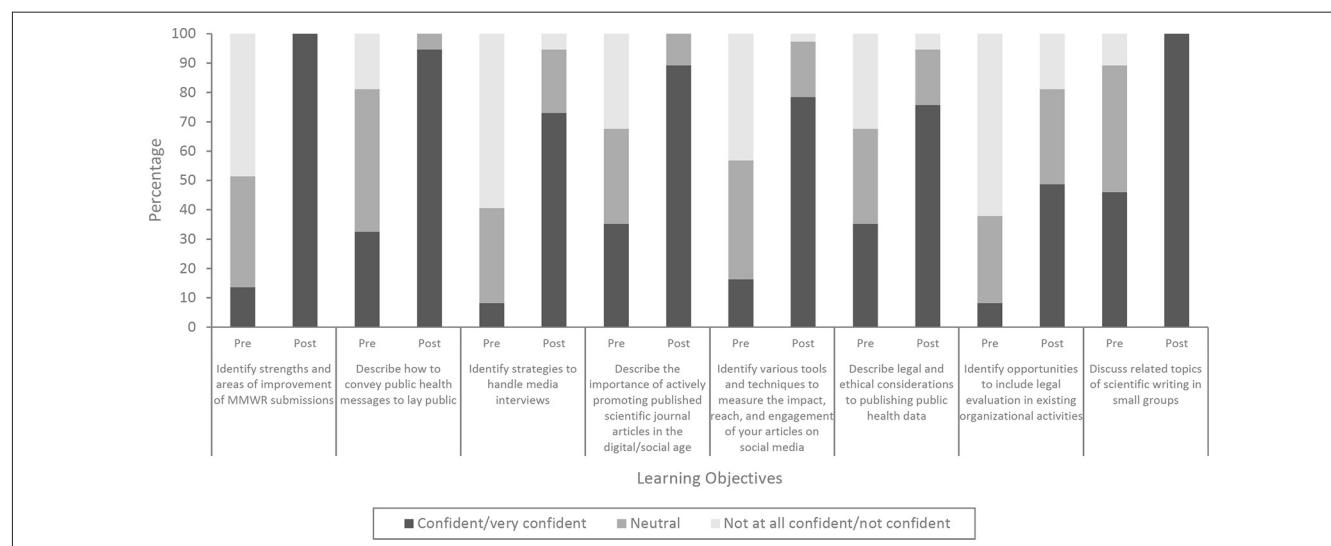
Abbreviation: *MMWR*, Morbidity and Mortality Weekly Report.

<sup>a</sup>The Intensive Writing Training course provided on-the-job scientific writing instruction and mentorship for selected applied epidemiologists working on a manuscript. The course was offered in 2017 and 2018. Each course included 3 webinars, expert mentorship from experienced authors, and a 2-day in-person session.

noted the value of connecting with peers at other agencies to expand their support network. They felt the course was valuable to their professional development. Participants also mentioned their intention to share their newly acquired knowledge and skills with colleagues at their agency. In addition, participants suggested a desire to encourage and advocate for a culture of publication at their agency. Lastly, participants reported that they learned strategies for communicating to the public, such as how to communicate with news outlets or promote their message using social media.



**Figure 1.** Participant-reported value of in-person training components in the Council of State and Territorial Epidemiologists/Centers for Disease Control and Prevention *Morbidity and Mortality Weekly Report* (MMWR) Intensive Writing Training course for applied epidemiologists, 2017-2018. The Intensive Writing Training course provided on-the-job scientific writing instruction and mentorship for selected applied epidemiologists working on a manuscript. The course was offered in 2017 and 2018. Each course included 3 webinars, expert mentorship from experienced authors, and a 2-day in-person session.



**Figure 2.** Participant confidence pre- and post-training, by learning objective, in the Council of State and Territorial Epidemiologists/Centers for Disease Control and Prevention *Morbidity and Mortality Weekly Report* (MMWR) Intensive Writing Training course for applied epidemiologists (n = 37), 2017-2018. The Intensive Writing Training course provided on-the-job scientific writing instruction and mentorship for selected applied epidemiologists working on a manuscript. The course was offered in 2017 and 2018. Each course included 3 webinars, expert mentorship from experienced authors, and a 2-day in-person session.

### Experiential Exercises

The most valued training components were experiential learning opportunities. Both the group feedback sessions, in which participants worked together to edit and improve manuscript drafts, and the case study, in which participants viewed and worked through a sample manuscript submission with reviewer edits, were viewed by participants as helpful to the manuscript development process.

Qualitative data from the check-in emails revealed the common barriers and facilitators to publication that participants experienced as they sought publication during the months after course completion.

**Barriers to publication.** Participants noted several barriers that prevented them from publishing their manuscripts within their intended time frame. First, a lack of data halted efforts early in the process. Second, for participants who did have access to data, competing priorities (eg, data requests, grants, or urgent field investigations) and changes to job responsibilities were common barriers. Lastly, after overcoming these barriers and completing their manuscript, many participants felt the process took so long that their data and manuscript were no longer relevant.

**Facilitators to publication.** The expert mentors' technical expertise and their roles as monitors of participants' progress were important facilitators of the writing process. Although participants' competing demands were a challenge, working with a mentor helped participants set deadlines and prioritize manuscript efforts. Participants also noted check-in emails as an accountability prompt.

### Lessons Learned

This writing course demonstrated the merits of mentoring novice authors on successful steps for publishing an article in *MMWR*. We summarize the lessons learned from implementing 2 cohorts of the CDC/CSTE *MMWR* Intensive Writing Training course.

Both quantitative and qualitative evaluation data demonstrate the value and appreciation of mentorship, including expert mentorship and the informal peer-to-peer mentorship among participants. Although mentorship was valued by participants, serving as a mentor in addition to normal job responsibilities can limit the availability and engagement of the mentor to support the participant's progress. Future courses should assess mentor availability and workload, in addition to their subject matter expertise, to assure accessibility for the participants.

The in-person group feedback activity allowed participants to discuss their own manuscripts and writing experiences. The communal discussion provided insight into the writing and submission process and helped participants manage their own expectations. Although plenty of time was dedicated to the

group feedback sessions, CSTE suggests a useful improvement would be to require participants to share their draft manuscript with their groups in advance of meeting to better use the time for critique and discussion rather than reading the drafts. In addition, fostering continued discussion among the groups after the in-person feedback sessions through telephone calls or virtual meetings should be considered as a beneficial source of mentorship and accountability.

Participants indicated that the case study exercise was a useful component and improved participant confidence to identify strengths and areas of improvement of *MMWR* submissions. The review and critique of sample manuscripts fostered discussion of strategies for clear, concise writing and the formatting requirements of *MMWR*. The ability to view submitted manuscripts with feedback is a low-cost activity that should be considered in future writing courses.

The goal-oriented approach harnessed the participants' intention to complete and submit a manuscript. Regular communication with expert mentors helped participants set deadlines for progress. The group discussed anticipated challenges and strategies for success and identified sources of motivation to further support participants. At the conclusion of the in-person session, each participant created an action plan outlining next steps for manuscript progress. After the course, the monitoring email check-ins were an opportunity to hold participants accountable and share strategies to mitigate barriers to progress. The supportive goal-oriented course approach paired with periodic accountability reminders provided a structure for progress.

Although the expert mentorship helped participants develop and finalize their manuscripts, the mentorship appeared to be more beneficial for cohort 2, when participants had a preexisting manuscript draft to share and discuss, than for cohort 1, when participants did not have a draft ready to share and discuss. Some participants needed additional support early in the writing process to develop and recognize the central hypothesis and public health implications of their work. Working through the 3 suggested "sidebar boxes" of the *MMWR* (What is already known? What is added by this report? What are the implications for public health practice?) was a useful first task for participants to organize their thoughts and establish a context for the work to be described.

Participants had approximately 6 months to work with their expert mentors, which was insufficient for most participants to receive mentorship through to submission. Participants experienced the challenge of competing priorities, which slow analytic and writing progress, and favored a longer mentorship period until the manuscript is submitted. It takes time to move manuscripts through the review process required by each author's organization, often leading to months-long delays for manuscripts with authors from multiple organizations. To effectively use and

engage mentorship as part of the program, consideration should be given to the lengthy interval between manuscript conception and submission.

Other lessons learned related to the structural realities of the work environment. Although participants intended to submit their manuscripts by the end of the year, most did not. This delay may have indicated insufficient motivation and commitment to the process of submitting a manuscript. One stipulation in the process of selecting participants for each cohort was an assurance that the participants' supervisors would support them by approving time for them to write, participate in conference calls, and attend the in-person session. Even when participants felt supported by their supervisors, work responsibilities such as data requests, grants, and outbreaks were competing priorities that affected manuscript progress and program participation. The attempt to mitigate these structural barriers by formalizing supervisor support was insufficient, suggesting that future courses should incorporate new ways to address these challenges.

Writing trainings for applied public health professionals should consider using peer or expert mentorship or both, reviewing edited materials, and integrating components of accountability and goal setting. The mentoring relationships prove most useful when implemented after a first draft is attempted. Activities such as group feedback and case studies allow for real-time feedback and discussion of successful writing strategies that ultimately foster improved skills for quality writing. Lastly, courses for applied public health professionals must incorporate innovative ways to target the structural barriers to writing for publication.

### Acknowledgments

CSTE values the partnership with CDC to provide this course. The authors thank Charlotte Kent, who was instrumental in the creation and delivery of the *MMWR* Intensive Writing Training course.

### Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This project was supported in part by CDC cooperative agreement #5U38OT000143.

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# Addressing COVID-19 Among People Experiencing Homelessness: Description, Adaptation, and Early Findings of a Multiagency Response in Boston

Public Health Reports  
2020, Vol. 135(4) 435-441  
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## Abstract

People experiencing homelessness are at high risk for coronavirus disease 2019 (COVID-19). In March 2020, Boston Health Care for the Homeless Program, in partnership with city and state public health agencies, municipal leaders, and homeless service providers, developed and implemented a citywide COVID-19 care model for this vulnerable population. Components included symptom screening at shelter front doors, expedited testing at pop-up sites, isolation and management venues for symptomatic people under investigation and for people with confirmed disease, quarantine venues for asymptomatic exposed people, and contact investigation and tracing. Real-time disease surveillance efforts in a large shelter outbreak of COVID-19 during the third week of operations illustrated the need for several adaptations to the care model to better respond to the local epidemiology of illness among people experiencing homelessness. Symptom screening was de-emphasized given the high number of asymptomatic or minimally symptomatic infections discovered during mass testing; contact tracing and quarantining were phased out under the assumption of universal exposure among the sheltered population; and isolation and management venues were rapidly expanded to accommodate a surge in people with newly diagnosed COVID-19. During the first 6 weeks of operation, 429 of 1297 (33.1%) tested people were positive for COVID-19; of these, 395 people were experiencing homelessness at the time of testing, representing about 10% of the homeless adult population in Boston. Universal testing, as resources permit, is a focal point of ongoing efforts to mitigate the effect of COVID-19 on this vulnerable group of people.

## Keywords

homelessness, COVID-19, emerging infectious diseases, public health practice, community health

On any given day, about 568 000 people are homeless in the United States.<sup>1</sup> The high transmissibility of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) infection, coupled with its variable and often subtle clinical presentation, makes homeless shelters and encampments especially susceptible to large outbreaks of coronavirus disease 2019 (COVID-19) among people with an already high likelihood of chronic heart<sup>2</sup> and lung<sup>3</sup> disease and accelerated aging.<sup>4</sup> Early reports demonstrate the potential for widespread infection in this vulnerable population.<sup>5-7</sup>

Before the first known case of COVID-19 was identified in a homeless person, Boston Health Care for the Homeless Program (BHCHP)—a nonprofit, federally qualified health center serving more than 11 000 currently and formerly

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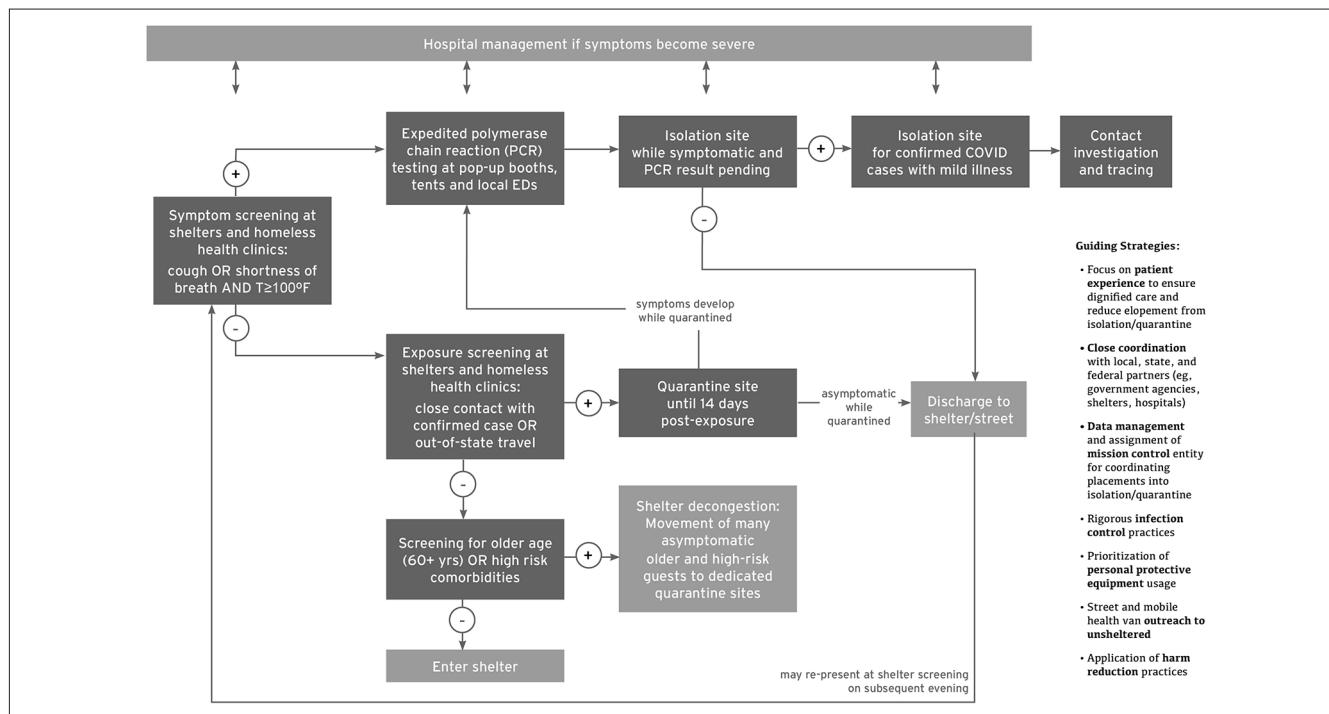
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**Figure 1.** COVID-19 response model for people experiencing homelessness in Boston, 2020. Abbreviations: COVID-19, coronavirus disease 2019; ED, emergency department; T, temperature.

homeless people annually<sup>8</sup>—partnered with city and state public health agencies, municipal leaders, and homeless service providers to proactively develop a comprehensive response model for homeless and marginally housed people in Boston. In this case study, we describe the initial model of care, as well as adaptations, early outcomes, and lessons learned during the first 6 weeks of deploying this model.

## Methods

The initial COVID-19 care model (Figure 1) consisted of multiple interrelated components deployed across various venues, many of which were newly constructed or repurposed for COVID care (Table).

### Front-Door Symptom Screening

Staff members at local shelters and BHCHP clinical sites implemented front-door screening for cough or shortness of breath. If shelter guests reported either symptom, then clinical personnel measured their body temperature and triaged people with readings  $\geq 100^{\circ}\text{F}$  for expedited SARS-CoV-2 polymerase chain reaction (PCR) testing at local emergency departments or pop-up testing sites in areas of high homeless service density (Figure 2). For the pop-up sites, the Massachusetts Department of Public Health provided testing supplies and processed all specimens in the state public health laboratory.

### Isolation and Management Venues

To prevent viral spread while awaiting PCR results, BHCHP partnered with the City of Boston and a local construction company to rapidly build 2 tents: 1 tent for isolation of symptomatic patients with suspected COVID-19 and 1 tent for quarantine of COVID-exposed asymptomatic people. These tents, which were deployed in <1 week from conception to implementation, incorporated rigorous infection control elements. For the isolation tent, the guiding principle was that patients awaiting test results should not mix. Heavy vinyl panels partitioned the tent into 16 pods measuring approximately 52 sq ft (Figure 3), each with dedicated equipment for measuring vital signs and a portable toilet outside. The isolation tent incorporated negative pressure airflow, and staff members wore full personal protective equipment (PPE) consisting of an N95 respirator, face shield, gown, and gloves. Surface decontamination occurred at least every 4 hours. Patients with positive PCR test results were either hospitalized or transferred to a 17-bed homeless-specific COVID-19 care unit in a partitioned-off wing of BHCHP's 104-bed medical respite program. More beds were eventually added to this inventory.

### Exposure Screening, Contact Tracing, and Quarantine

The second tent (Figure 4) was intended for quarantine of people who were asymptomatic but had been exposed to

**Table.** Components of the original and adapted COVID-19 response model for people experiencing homelessness in Boston, 2020

Venue Type	Original Model (first 3 weeks)	Adapted Model (week 4 and later)
Pop-up COVID-19 testing sites	<ul style="list-style-type: none"> <li>Format: booth or portable tent</li> <li>Staffing: 1 health care provider, 1 nonclinical staff member</li> <li>PPE: N95 respirator, face shield, gown, gloves</li> </ul>	Format, staffing, and PPE unchanged
Isolation site for symptomatic people while COVID-19 test is pending	<ul style="list-style-type: none"> <li>Format: constructed 16-bed tent with internal partitions, negative airflow, bed-specific portable toilets</li> <li>Staffing: 2 health care providers, 2 nurses, 2 nonclinical staff members</li> <li>PPE: N95 respirator, face shield, gown, gloves</li> </ul>	<ul style="list-style-type: none"> <li>Format: expanded to 36 beds by repurposing quarantine tent</li> <li>Staffing and PPE unchanged</li> </ul>
Isolation sites for management of people with confirmed COVID-19	<p>Site I:</p> <ul style="list-style-type: none"> <li>Format: 17-bed unit in brick-and-mortar medical respite facility</li> <li>Staffing: 1 health care provider, 2 nurses</li> <li>PPE: N95 respirator, face shield, gown, gloves</li> </ul>	<ul style="list-style-type: none"> <li>Format: expanded to 52 beds</li> <li>Staffing: 4 health care providers, 4 nurses</li> <li>PPE unchanged</li> </ul>
Quarantine site for COVID-exposed people without symptoms	<ul style="list-style-type: none"> <li>Format: constructed 18-bed tent with internal partitions, shared toilets</li> <li>Staffing: 1 health care provider, 1 nurse, 2 nonclinical staff members</li> <li>PPE: surgical mask and gloves; N95 respirator for aerosolizing procedures only</li> </ul>	<p>Site 2:</p> <ul style="list-style-type: none"> <li>Format: 84 beds in reopened decommissioned health care facility</li> <li>Staffing: 1 health care provider, 2 nurses, 1 nonclinical staff member per 40-44 beds</li> <li>PPE: N95 respirator, face shield, gown, gloves</li> </ul> <p>Site 3:</p> <ul style="list-style-type: none"> <li>Format: 120 beds in reopened segment of decommissioned hospital</li> <li>Staffing: 2 nurses, 3 nonclinical staff members per 60 beds; 1 health care provider per 120 beds</li> <li>PPE: N95 respirator, face shield, gown, gloves</li> </ul> <p>Site 4:</p> <ul style="list-style-type: none"> <li>Format: 500-bed field hospital in Boston Convention and Exhibition Center</li> <li>Staffing: 1 health care provider, 1 nurse, 1 medical assistant, and 1 nonclinical staff member per 50 beds; behavioral health clinician available for crisis consultation</li> <li>PPE: N95 respirator, face shield, gown, gloves</li> </ul> <ul style="list-style-type: none"> <li>Format: repurposed as second isolation tent for symptomatic people with pending COVID-19 tests</li> <li>Staffing and PPE: changed to reflect isolation tent standards</li> </ul>

Abbreviations: COVID-19, coronavirus disease 2019; PPE, personal protective equipment.

<sup>a</sup>Data source: Boston Health Care for the Homeless Program.

COVID-19, ascertained by 2 methods. First, shelter and clinic staff members deployed front-door exposure screening along with the symptom screening described previously to identify people reporting either (1) contact with someone known to have COVID-19 or (2) travel outside the state within the past 14 days. Second, BHCHP personnel conducted contact investigations of homeless people in Boston with confirmed COVID-19, and these contact investigations helped to identify people who may not have been aware of their exposure. Exposed people remained in the quarantine tent for 14 days after the estimated date of exposure. The quarantine tent had the same structure and layout as the

isolation tent, but quarantine tent staff members used a lower level of PPE consisting of a surgical mask and gloves. People in the quarantine tent who developed symptoms were tested and isolated according to the algorithm previously described.

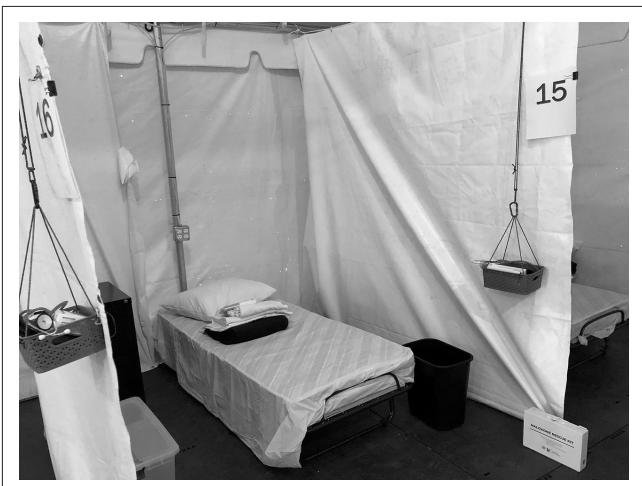
### ***Shelter-Based Infection Control***

Concurrent efforts deployed by area shelters included emphasis on disinfection (eg, frequent cleaning, supporting hand and respiratory hygiene, ensuring adequate ventilation); environmental controls (eg, bed distancing, staggered showering schedules, staggered meals); and administrative



**Figure 2.** Pop-up booth for severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) testing in Boston, Massachusetts. Photo taken March 20, 2020.

controls (eg, ensuring clearly communicated sick-leave policies for staff members, reducing unnecessary assembly of staff members and guests). Ultimately, many shelters used a decongestion strategy to relocate people at highest risk for COVID-19 complications to vacated university dormitories.



**Figure 3.** Isolation tent pods for people with pending severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) tests in Boston, Massachusetts. Photo taken March 21, 2020.



**Figure 4.** Quarantine tent for asymptomatic people with coronavirus disease 2019 (COVID-19) exposure in Boston, Massachusetts. The tent was later repurposed for isolation of symptomatic people with pending severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) tests. Photo taken April 19, 2020.

### Real-Time Surveillance

From the outset, BHCHP developed a COVID-19 surveillance strategy that incorporated data from multiple sources. BHCHP's preexisting electronic health record spanning all clinical sites proved useful for tracking patients across various components of its COVID care model. BHCHP leadership established lines of communication with area hospitals to identify homeless people with COVID-19 or COVID-like illness in need of alternate care arrangements or post-discharge follow-up. Data analysts in the BHCHP Institute for Research, Quality, and Policy in Homeless Health Care cross-checked COVID-19 cases identified through testing at BHCHP or area hospitals with the Boston Homeless Management Information System, enabling a determination of the timing and location of recent shelter stays and the identification of shelters with rapid upticks in infections or high levels of sustained disease activity. A case tracking database served as a centralized repository of all known SARS-CoV-2 tests and results among people experiencing homelessness in Boston, allowing a real-time assessment of the scale and trajectory of COVID-19 in this population.

### Command Structure and Organizational Dynamics

BHCHP established a command center early in the response to oversee the multiple components described previously. The command center was composed of senior leaders at BHCHP who met daily to design and implement programming specific to the crisis, enabling a centralized approach to decision-making and rapid deployment of resources when and where needed. In addition, a mission control team

consisting of BHCHP nurses and case managers handled incoming patient referrals for isolation and quarantine, coordinated daily admissions to various care sites based on staffing and bed availability, facilitated transportation of patients from one venue to another, and coordinated care and discharge planning with area health care facilities for patients with confirmed or suspected COVID-19.

Staffing needs related to the COVID-19 response, combined with a general de-emphasis of in-person nonurgent aspects of health care (eg, routine health maintenance visits), required major shifts in other aspects of BHCHP operations. Under typical circumstances, BHCHP operates more than 40 clinics at shelters, day programs, and other community venues throughout greater Boston. Many of these clinic sites temporarily halted or cut back services to deploy staff members and resources for the COVID response. Where possible, clinics shifted to a telehealth approach for delivering medical, psychiatric, and addiction-oriented care that did not require in-person evaluation. The shift to telehealth was facilitated by regulatory waivers allowing reimbursement for such services from Medicaid and other payers. Early in the pandemic, BHCHP shifted nonclinical employees to remote work arrangements and limited meeting sizes in its facilities. As the situation evolved, many staff members were redeployed in other capacities to support COVID-related operations.

Transparent communication was emphasized early on. BHCHP leadership delivered daily organization-wide updates via online meeting platforms to ensure that all employees were informed of the latest developments. Dialogue was encouraged, and areas of uncertainty were

openly discussed. These sessions also served to build and sustain community, foster a shared sense of purpose, and provide emotional support to staff members who were grappling with the uncertain and frightening realities of a rapidly evolving pandemic.

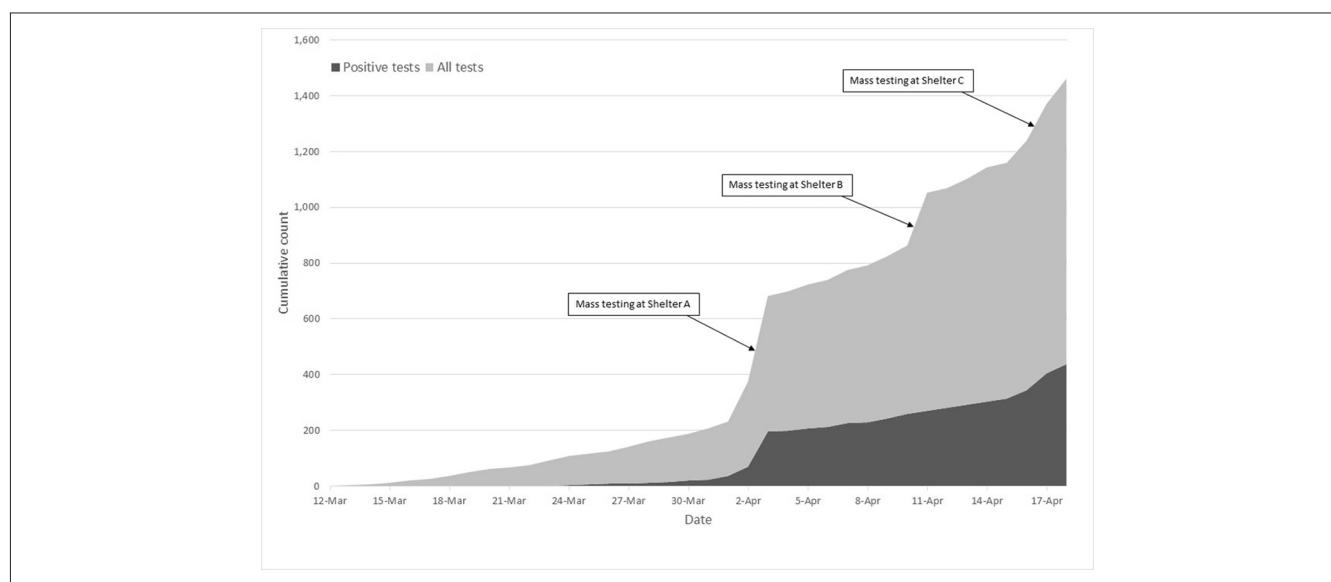
## Outcomes

BHCHP and its community partners deployed the COVID-19 care model on March 12, 2020. In the first 2 weeks of operation, 118 homeless and marginally housed people underwent PCR testing for SARS-CoV-2. Of these, 8 (6.8%) were positive.

In the third week of the response, disease surveillance activities led to the identification of an emerging cluster of 22 people with COVID-19 at a single large shelter in Boston. This finding prompted universal PCR testing of 408 remaining shelter residents during a 2-day span that uncovered a 36% prevalence of SARS-CoV-2 infection, as described elsewhere.<sup>7</sup> Most (88%) infected people identified through this universal testing reported no symptoms, and none had a positive symptom screen according to the algorithm previously described.

Overall, 1297 people underwent PCR testing for SARS-CoV-2 during the first 6 weeks of operations, of whom 429 (33.1%) had a positive test result (Figure 5). From March 20 to April 18, a total of 395 adults experiencing homelessness were diagnosed with COVID-19.

These surveillance efforts informed the need for several adaptations to the response model and COVID-specific care venues (Table).



**Figure 5.** Cumulative counts of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) polymerase chain reaction tests and positive results among homeless and marginally housed adults in Boston, March 12–April 18, 2020. The total number of tests ( $n = 1462$ ) exceeds the number of unique people tested ( $n = 1297$ ) because some people were tested more than once.

1. *De-emphasis on symptom screening:* Symptom screening at community sites continued when possible to identify people meriting expedited testing; however, it was undertaken with an understanding of its limited sensitivity for identifying subclinical disease and was deprioritized in the overall care model to direct resources and efforts elsewhere. In its place, as of May 2020, mass PCR testing was being pursued at selected shelters with higher levels of confirmed COVID-19 activity and at other sites when resources permit.
2. *Cessation of exposure screening and quarantining:* Given the high prevalence of SARS-CoV-2 infection discovered during the shelter outbreak, BHCHP shifted from COVID-19 exposure screening to operating under the assumption of “universal exposure.” This shift obviated the need for quarantining exposed people and allowed the quarantine tent to be used as another isolation venue for symptomatic people awaiting PCR results.
3. *Reduction of contact tracing efforts:* As the number of new COVID-19 cases among homeless people rapidly increased, BHCHP scaled back its contact tracing efforts, again based on the assumption of universal exposure across large congregate living environments. This shift freed up considerable personnel time to focus on other aspects of the response.
4. *Expansion of care sites:* The surge in COVID-19 cases identified during the shelter outbreak required an immediate expansion of isolation and management sites, particularly for people with minimal or no symptoms who did not require hospitalization but were not allowed to stay in a shelter. In response, the original 17-bed COVID-19 care unit at BHCHP’s medical respite facility was quickly expanded to 52 beds. Simultaneously, dozens more beds became available in reopened segments of previously shuttered health care facilities, and funding from the city and state enabled the rapid construction of a field hospital inside the Boston Convention and Exhibition Center containing 500 additional beds for homeless and marginally housed people with COVID-19 (Figures 6-8).

## Lessons Learned

Our disease surveillance activities suggested that about 10% of Boston’s estimated homeless adult population contracted COVID-19 during a 4-week period.<sup>1</sup> Private space to quarantine or recover from such an illness is a privilege not currently afforded to all. A community health center for people experiencing homelessness, working in close partnership with municipal leaders, public health agencies, and homeless service providers, rapidly deployed a COVID-19 care model



**Figure 6.** Boston Hope field hospital for coronavirus disease 2019 (COVID-19)-positive people experiencing homelessness in Boston, Massachusetts. Photo taken April 10, 2020.

that has reached a substantial number of people in the target population. This experience highlights a number of important lessons:

- Homeless-tailored health centers are well-poised to serve as key agencies in collaborative municipal responses to COVID-19 among people experiencing homelessness.
- Disease surveillance efforts deployed in parallel with clinical programming can play a crucial role in guiding community-based response efforts.



**Figure 7.** Patient care corridor in Boston Hope field hospital for coronavirus disease 2019 (COVID-19)-positive people experiencing homelessness in Boston, Massachusetts. Photo taken April 9, 2020.



**Figure 8.** Patient pods in Boston Hope field hospital for coronavirus disease 2019 (COVID-19)-positive people experiencing homelessness in Boston, Massachusetts. Photo taken April 10, 2020.

- Given the fluidity of the COVID-19 pandemic, maintaining flexibility in the usage and staffing of various elements of the care model—while still adhering to the core principles of the response effort—is vital.
- The high number of asymptomatic SARS-CoV-2 infections and the potential for rapid spread in congregate settings support the need for proactive, universal COVID-19 testing strategies in this population.
- Widespread COVID-19 testing efforts in this population must be paired with sufficient spaces for isolation and management of newly discovered cases.
- No illness more clearly illustrates the immense health risks of homelessness than COVID-19. Efforts to reduce widespread homelessness in the United States should remain a cornerstone of public health.

### Acknowledgments

The authors thank Nora Sporn, MA, MPH, for her assistance with data compilation.

### Declaration of Conflicting Interests

The authors declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this

article: Dr Baggett receives royalties from UpToDate for authorship of a topic review on homeless health care.

### Funding

The authors received no financial support with respect to the research, authorship, and/or publication of this article.

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# A National Measurement Framework to Assess and Improve Sickle Cell Care in 4 US Regions

Public Health Reports  
2020, Vol. 135(4) 442-451  
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DOI: 10.1177/0033354920935068  
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## Abstract

**Objectives:** Coordinated measurement strategies are needed to inform collaborative approaches to improve access to and quality of care for persons with sickle cell disease (SCD). The objective of our study was to develop a multilevel measurement strategy to assess improvements in access to and quality of care for persons with SCD in 4 US regions.

**Methods:** From 2014 through 2017, regional grantees in the Sickle Cell Disease Treatment Demonstration Program collected administrative and patient-level electronic health record (EHR) data to assess quality improvement initiatives. Four grantees—covering 29 US states and territories and an SCD population of 56 720—used a collective impact model to organize their work. The grantees collected administrative data from state Medicaid and Medicaid managed care organizations (MCOs) at multiple points during 2014–2017 to assess improvements at the population level, and local patient-level data were abstracted from site-level EHRs at regular intervals to track improvements over time.

**Results:** Administrative data were an important source of understanding population-level improvements but were delayed, whereas patient-level data were more sensitive to small-scale quality improvements.

**Conclusions:** We established a shared measurement approach in partnership with Medicaid and Medicaid MCO stakeholders that can be leveraged to effectively support quality improvement initiatives for persons with SCD in the United States.

## Keywords

sickle cell disease, measurement, quality improvement, collective impact, administrative data

Sickle cell disease (SCD) affects approximately 100 000 persons in the United States, leads to more than 83 000 hospitalizations, costs \$488 million annually, and is the most commonly detected genetic disorder in the nation.<sup>1–3</sup> SCD is a group of disorders, in which red blood cells become sickle shaped and lead to acute and chronic clinical complications.<sup>4</sup> Since medical advances in the 1980s, SCD childhood mortality has decreased as much as 68% (from 2.42 per 100 000 in 1999–2002 to <0.78 per 100 000 in 1983–1986 among children aged 0–3 y),<sup>5,6</sup> but persons with SCD have limited access to comprehensive care, compared with access for other genetic disorders, such as cystic fibrosis.<sup>7</sup>

Access to high-quality health care is critical to prevent complications and early SCD-related mortality, yet many persons with SCD are unable to obtain quality care. For example, hydroxyurea, the only drug approved by the US

Food and Drug Administration to treat SCD until the approval of L-glutamine in 2017 and the approvals of Adakveo and Oxbryta in November 2019,<sup>8</sup> is often underprescribed because of concerns among health care providers and patients about potential toxicity.<sup>9</sup> Another example of limited access to high-quality health care is the inadequate number of knowledgeable health care providers; patients with SCD often seek specialty care in emergency departments, which is costly, or from primary care providers who may not have experience treating SCD.

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The SCD Treatment Demonstration Program (SCDTDP), funded by the Maternal and Child Health Bureau of the Health Resources and Services Administration, has 3-year funding cycles.<sup>10-12</sup> In each previous funding cycle, grantees developed measures to assess improvements in quality of care for persons with SCD. During the 2014-2017 funding cycle, grantees and a group of experts developed and piloted a measurement strategy that captured data and described progress in improving clinical performance at the regional, state, and practice levels. One objective of the 2014-2017 funding cycle was to develop a multilevel measurement strategy to assess improvements in access to and quality of care for persons with SCD in 4 US regions. This article describes the work of the national coordinating center (NCC), the National Institute for Children's Health Quality, and the regional coordinating centers (RCCs), as well as lessons learned and recommendations.

## Methods: Components of the Measurement Strategy

### History of the SCDTDP

In response to disparities in access to effective SCD treatment strategies, Congress authorized a demonstration program in the Sickle Cell Treatment Act of 2003.<sup>13-15</sup> The goals of the program are to (1) improve care coordination and service delivery for persons living with SCD, (2) improve access to services, and (3) improve and expand patient and health provider education.

For the 2014-2017 funding cycle, the Health Resources and Services Administration established a regional collaborative model that organized efforts across regional networks to reach a broad portion of the SCD population and coordinate improvement efforts. The Health Resources and Services Administration selected 4 grantees to become RCCs to create networks across states that covered 6 of the 10 Health

Resources and Services Administration regions, with the potential to affect an estimated 56 720 persons with SCD. Each regional network was led by an RCC using a hub-and-spoke model.<sup>16</sup> The networks comprised academic medical centers, state Medicaid offices, Medicaid managed care organizations (MCOs), federally qualified health centers, and community-based organizations. The 4 RCCs are Sickle Cell Improvement Across the Northeast Region Through Education, in Baltimore, Maryland; Sickle Treatment and Outcomes Research in the Midwest, in Cincinnati, Ohio; the Pacific Sickle Cell Regional Collaborative, in Oakland, California; and the Heartland Sickle Cell Disease Treatment Network, in St Louis, Missouri (Figure).

Each RCC created a regional learning collaborative focused on 3 high-leverage, interrelated aims to maximize collaboration within and across regions. These aims are to (1) increase the number of health care providers treating patients with SCD, (2) increase the number of health care providers prescribing hydroxyurea, and (3) increase the number of patients obtaining care from health care providers knowledgeable about SCD. The NCC provided infrastructure to operationalize a collective impact model, support the RCCs' collaborative networks, and serve as a data hub.

The SCDTDP regional model used the collective impact model—an approach to facilitating coordination and collaborative work that includes the following key components for successful implementation: a common agenda, a shared measurement system, mutually reinforcing activities, continuous communication, and a backbone support organization.<sup>17</sup> The work of the Health Resources and Services Administration aligned with the work of other federal agencies, such as the 2014 expert panel report of the National Heart, Lung, and Blood Institute, on evidence-based treatment and management of SCD, which highlighted underused disease-modifying treatments.<sup>6</sup> The expert panel report included strong evidence and recommendations for appropriate treatment guidelines for using hydroxyurea.<sup>6</sup> Hydroxyurea, approved by the US Food

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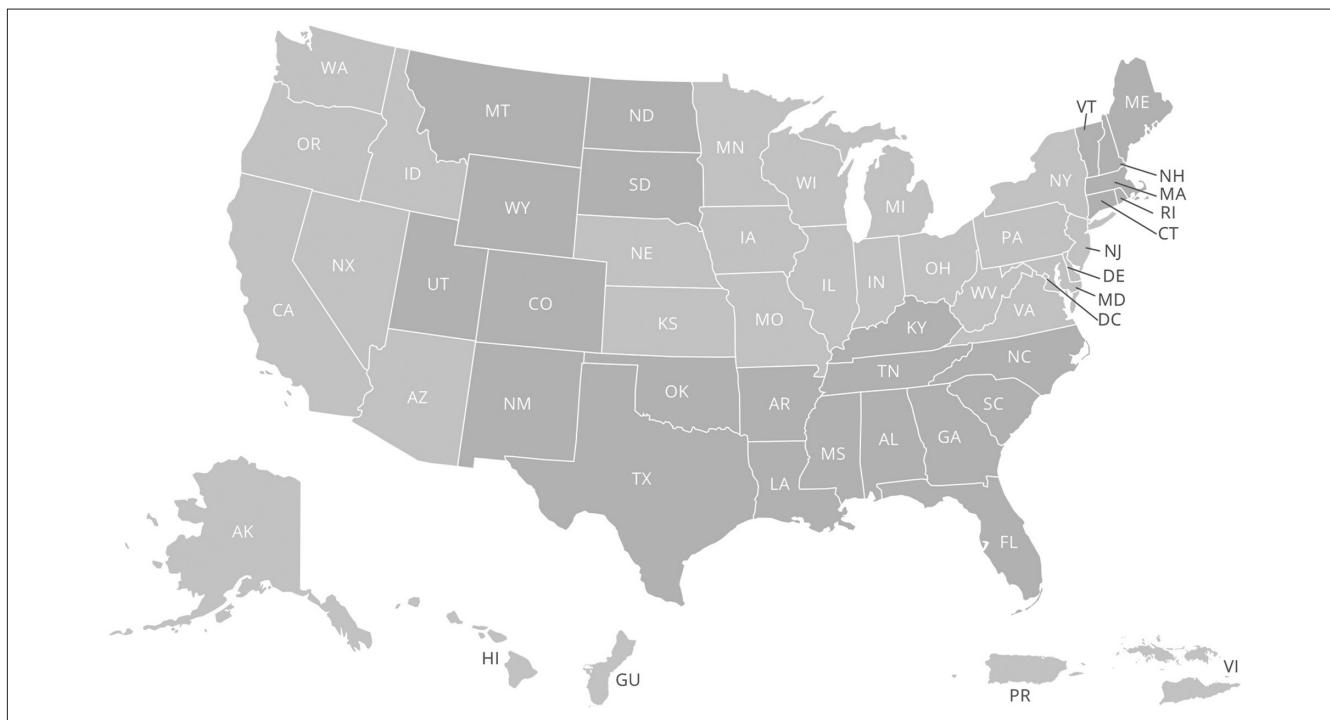
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**Figure.** Twenty-nine states and territories included in the 2014-2017 Sickle Cell Disease Treatment Demonstration Program in green with the 4 Regional Coordinating Centers and the National Coordinating Center in Boston. The 4 regions are represented in green with the following regional coordinating centers: Sickle Cell Improvement Across the Northeast Region Through Education, in Baltimore, Maryland; Sickle Treatment and Outcomes Research in the Midwest, in Cincinnati, Ohio; the Pacific Sickle Cell Regional Collaborative, in Oakland, California; and the Heartland Sickle Cell Disease Treatment Network, in St Louis, Missouri. Please see online version for reference to color.

and Drug Administration for use by adults and children with SCD, reduces the frequency of acute chest syndrome and painful episodes and can reduce mortality.<sup>18,19</sup>

To demonstrate progress toward SCSTDTP aims at the local, state, and regional levels, the program needed a shared measurement strategy. The quality improvement (QI) metrics for previous funding cycles of the SCSTDTP were based on small (~20 patients per month) samples designed to inform local QI initiatives, whereas the aims of the 2014-2017 funding cycle needed metrics to assess improvements at a regional population level. In November 2014, representatives from the 4 RCCs and the NCC, federal partners, and other experts convened a meeting, a data summit, to develop a shared measurement strategy. They prioritized building a framework that would use data to demonstrate the effect of the SCSTDTP on the number of persons with SCD and progress toward achieving the 3 project aims. The data summit attendees considered various data sources, including local registries, electronic health records (EHRs), and administrative data. In considering patient privacy, technical complexity, population size, and project resources, experts recommended collaboration with state Medicaid offices and Medicaid MCOs, because this approach was most likely to support project aims 1 and 2. For project aim 3, experts

recommended a separate qualitative evaluation strategy to understand regional efforts in health care provider education.<sup>11</sup> This study describes the measurement strategy for aims 1 and 2. This project was approved by the NCC's institutional review board (IRB).

### Administrative Data

An analysis of hospital claims data suggested that approximately two-thirds of persons with SCD are insured by Medicaid.<sup>2</sup> Therefore, state Medicaid claims data are population-based and comprehensive. State-level Medicaid data span multiple health care provider types and allow for analysis across pediatric and adult health care providers, including specialty and primary care. Some state Medicaid programs are managed by MCOs, so the strategy would need to include collaboration with both types of organizations; the data requests from the organizations are the same and hereinafter are referred to collectively as Medicaid/MCO. Although state-to-state differences exist, systems of common nomenclature and coding of Medicaid data exist to help standardize claims data across states and regions, reducing the need for a new standardization process in a national initiative. During the data summit, RCC teams and

**Table 1.** Administrative data measures included in a multilevel measurement strategy to assess improvements in access to and quality of care for persons with sickle cell disease in 4 US regions, Sickle Cell Disease Treatment Demonstration Program, funding cycle 2014-2017<sup>a</sup>

Aim	Measure Concept	Measure	Data Sources
Increase the number of health care providers treating persons with SCD	Number of health care providers who have seen same patient with SCD for ≥2 outpatient visits, excluding urgent visits and acute-care visits; providers would include hematologists, primary care providers, family physicians, physician assistants, nurse practitioners, and obstetricians/gynecologists	Number of providers who saw ≥1 patient aged <18 with SCD ≥2 times in the past 12 months Number of providers in plan who saw ≥1 adult patient with SCD ≥2 times in the past 12 months Number of providers who saw any patient with SCD ≥2 times in the past 12 months Number of children with SCD who had ≥2 outpatient visits in the past 12 months Number of adults with SCD who had ≥2 outpatient visits in the past 12 months	Medicaid claims data from Medicaid managed care organizations or state Medicaid records
Increase the number of health care providers prescribing hydroxyurea	Number of health care providers whose SCD patient(s) filled prescription for hydroxyurea during a specified time period; prescribers would include hematologists, primary care physicians, physician assistants, and nurse practitioners	Number of providers who prescribed hydroxyurea to a child with SCD ≥1 time in the past 12 months Number of providers who prescribed hydroxyurea to an adult with SCD ≥1 time in the past 12 months Number of providers in plan who prescribed hydroxyurea ≥1 time in the past 12 months Number of children with SCD who filled a prescription for hydroxyurea ≥1 time in the past 12 months Number of adults with SCD who filled a prescription for hydroxyurea ≥1 time in the past 12 months	• Medicaid claims data from Medicaid managed care organizations or state Medicaid records • Data on filled prescription from Medicaid claims data

Abbreviation: SCD, sickle cell disease.

<sup>a</sup>The 4 regions are represented by the following regional coordinating centers: Sickle Cell Improvement Across the Northeast Region Through Education, in Baltimore, Maryland; Sickle Treatment and Outcomes Research in the Midwest, in Cincinnati, Ohio; the Pacific Sickle Cell Regional Collaborative, in Oakland, California; and the Heartland Sickle Cell Disease Treatment Network, in St. Louis, Missouri.

measurement experts suggested that state-level Medicaid claims data had the potential to monitor QI efforts by providing quarterly data that could not be obtained from national sources because of substantial lags in data access. Therefore, experts recommended that state Medicaid/MCOs report data quarterly.

The NCC and RCCs developed administrative data measures on the basis of project aims, literature review, evidence-based practice and guidelines for quality SCD care, previously developed metrics, expert opinion, and measurement strategies proposed by the RCCs.<sup>20-25</sup> Content experts and grantees evaluated all measures through a

modified Delphi technique, a structured process used to achieve expert consensus through multiple rounds of feedback (Table 1).<sup>26</sup>

The expert group determined that MCOs might be incentivized to participate in this collaborative effort by the potential cost savings provided by improvements in the availability and quality of SCD care for their enrollees. The program used MCO data for comparison across MCOs and to inform descriptive uptake of patient care initiatives (eg, health care providers seeing patients ≥2 times annually) and treatments (eg, use of hydroxyurea) among the various data sources.

**Table 2.** Measures from patient-level electronic health records included in a multilevel measurement strategy to assess improvements in access to and quality of care for persons with sickle cell disease in 4 US regions, Sickle Cell Disease Treatment Demonstration Program, funding cycle 2014-2017<sup>a</sup>

Category	Measure Concept	Measure
Aim 1: Increase the number of health care providers treating persons with SCD	Has a primary care provider	Percentage of SCD patients who have a primary care provider
Aim 2: Increase the number of health care providers prescribing hydroxyurea	Hydroxyurea use Not using hydroxyurea	Percentage of SCD patients aged ≥9 months prescribed hydroxyurea Reasons given by SCD patients for not using hydroxyurea
Individual characteristics	Genotype	Distribution of SCD genotypes among patient population
Health care use	ED/day hospital visits  Day hospital visits  SCD-related ED/day hospital visits  Hospital admissions  SCD-related hospital admissions  ED visits	Average number of ED/day hospital visits for pain that did not result in a hospital admission per SCD patient in the past 12 months  Average number of day hospital visits that did not result in a hospital admission per SCD patient in the past 12 months  Average number of SCD-related ED/day hospital visits per SCD patient in the past 12 months  Average number of hospital admissions per SCD patient in the past 12 months (categorical)  Average number of hospital admissions per SCD patient in the past 12 months (continuous)  Average number of SCD-related hospital admissions per SCD patient in the past 12 months  Average number of ED visits that did not result in a hospital admission per SCD patient in the past 12 months

Abbreviations: ED, emergency department; SCD, sickle cell disease.

<sup>a</sup>The 4 regions are represented by the following regional coordinating centers: Sickle Cell Improvement Across the Northeast Region Through Education, in Baltimore, Maryland; Sickle Treatment and Outcomes Research in the Midwest, in Cincinnati, Ohio; the Pacific Sickle Cell Regional Collaborative, in Oakland, California; and the Heartland Sickle Cell Disease Treatment Network, in St. Louis, Missouri.

### Patient-Level EHR Data

The second component of the measurement strategy was patient-level EHR data collected by each RCC at the level of health care provider and institution (Table 2). The RCCs designed the EHR database to complement the state- and regional-level measures. Whereas administrative data are available several months to years after being collected, EHR data provide immediate, real-time patient-level data and are more sensitive than administrative data in driving improvement efforts.

The multistep process of creating and using patient-level EHR data began with leveraging existing SCD resources, including the PhenX Toolkit (consensus measures for Phenotypes and eXposures),<sup>27</sup> and previous SCDDP measures. Frequent conversations between the NCC and RCCs aligned measure definitions, data collection specifications, and reporting processes (eg, Medicaid cross-references, data dictionaries, and Research Electronic Data Capture).<sup>28</sup> RCCs shared lessons learned about state-level IRB and data use agreements. The process allowed RCCs to learn from each

other's successes and challenges, while ensuring data consistency across regions. The RCCs reviewed patient records, including EHR progress notes and local patient registries, after obtaining patient consent, to collect relevant data during the study period. All RCCs used a customized online data collection platform, the National Institute for Children's Health Quality Collaboratory, to report, annotate, and compare reported measures on anonymous, aggregated data across regions.

### Results

The 2014-2017 SCDDP captured data on 8714 children and adults with SCD in the EHR data, and these data were available as soon as EHR reviews were completed. During the same period, data on 21 873 patients were captured in the SCDDP administrative data. Using the administrative data and the EHR data together, RCCs were able to assess improvement on a population level and a more granular level in 2 critical domains: (1) access to care (ie, health care practices and health care

providers seeing persons with SCD) and (2) provision of a hydroxyurea prescription.

### Administrative Data

RCCs obtained baseline administrative data from 28 of the 29 US states and territories, as well as at least 1 quarterly data update from 7 of those states.

RCCs and states worked with state Medicaid/MCOs to establish standard algorithms and data requests to obtain the SCD measures from Medicaid administrative claims databases. The program used Medicaid/MCO data collection requests to monitor changes, document improvements in care, and provide data for state- and regional-level educational activities. Aggregate data obtained by the RCCs on health care provider encounters with patients with SCD and hydroxyurea prescriptions were stored in local databases, and RCCs submitted these data to the NCC quarterly for each state Medicaid/MCO in their region.

The RCCs recognized the need to build systems and infrastructure to manage data received from states. Staff member time and expertise were necessary for cleaning, analyzing, and compiling data from the state data sets before submitting them to the NCC. State data sets were large and complex, requiring extensive work using analytic applications in regions that received nonaggregated data. For non-aggregated data, personnel who had statistical programming experience or experience working with Medicaid data were required to manage and prepare the data for the NCC. RCCs collected Medicaid/MCO administrative claims data in most states in their regions (Table 3). When statewide data could not be obtained from either source, the inability was often due to resource or funding issues.

### Patient-Level EHR Data

We obtained patient-level EHR data from 26 sites and ≥1 quarterly data update from 16 of those sites, allowing the RCCs to use these baseline data for state team learning, QI, and immediate assessment of improvements in project aims 1 and 2.

Although RCCs aimed to create common measures, they were unable to define and collect data uniformly for some measures. The lack of common measures and uniform data collection caused difficulties in creating and comparing data across regions. In addition, the RCCs developed the approach for using patient-level EHR data after they had designed the initial, administrative data-focused project measurement strategy. By then, resources were limited, and time was limited for data collection, entry, and standardization of the final submitted aggregated patient-level EHR data. The RCCs experienced setbacks while obtaining data use agreements and IRB approvals (eg, a single IRB process covering multiple entities and a local IRB process covering 1 entity have different timelines), but eventually, the RCCs were able to

obtain consent and enroll patients without offering incentives (ie, the Pacific RCC obtained consent from 407 of 417 families approached for participation) and gather data on most or all network-wide EHR measures. In the Heartland, all 4 states submitted EHR data: Iowa, Kansas, Missouri, and Nebraska. In the Midwest region, 5 states submitted EHR data: Illinois, Indiana, Michigan, Minnesota, and Ohio. In the Northeast region, 8 states submitted EHR data: Delaware, District of Columbia, Maryland, New Jersey, New York, Pennsylvania, Virginia, and West Virginia. In the Pacific region, 7 states submitted EHR data: Alaska, Arizona, California, Idaho, Nevada, Oregon, and Washington. However, the consistency of reporting by state, period, and measure varied.<sup>11</sup>

### Discussion

To demonstrate the QI outcomes of a treatment demonstration program, administrative data can be useful, although the time (ie, potential 3-year time delay) and funding limitations for infrastructure development at the state level need to be carefully considered. Patient-level EHR data provide a complementary data source for driving real-time improvement at the local and health care provider levels. Developing patient-level EHR measures collaboratively between the RCCs and NCC using a collective impact model facilitated cross-regional learning. For example, the adoption of similar data collection methods and instruments across regions was critical in ensuring comparable measures and reducing burden through sharing best practices.

Although population-level and patient-level data are both needed, the work of the SCSTD RCCs and NCC demonstrates the need to have an overall measurement strategy that aligns both administrative data and data at the level of health care providers, health care organizations, public health entities, and patients. In addition, rigorous methods are needed to ensure quality measures can be used equally at national, state, and site levels. These findings are reflected in the current landscape of national efforts to develop metrics to assess quality of care for SCD patients across agencies, including the National Heart, Lung and Blood Institute's Sickle Cell Disease Implementation Consortium and the Agency for Healthcare Research and Quality's Pediatric Quality Measurement Program.

Administrative data for SCD have strengths and limitations for determining clinical use and identifying health care providers caring for persons with SCD. Administrative data can be useful for SCD surveillance and to better understand where patients receive clinical care. They can be used to measure access and use on a national scale for a rare disease. However, administrative data are not currently available in real time, making it difficult to link to ongoing QI activities, which require continuous, current data to inform change.

**Table 3.** Administrative data collection details including source, time range, and barriers to data collection for the Sickle Cell Disease Treatment Demonstration Program, funding cycle 2014-2017

Region	State/Source (State Medicaid or Medicaid MCO)	Timepoint/Date Range	Barriers
Heartland	Iowa <sup>a</sup> : Illinois Medicaid	2014 through second quarter 2016	State reported resource constraints that precluded its ability to collect data despite RCC offers to fund data collection
	Kansas: Medicaid	2014	—
	Missouri <sup>b</sup> : Medicaid; Illinois Medicaid	2014 through second quarter 2016	—
	Nebraska	Data not submitted	State reported resource constraints that precluded its ability to collect data despite RCC offers to fund data collection
Midwest	Illinois <sup>b</sup> : Medicaid	Third quarter 2014 through second quarter 2016	—
	Indiana: Medicaid	Third quarter 2014 through second quarter 2015	—
	Michigan: Medicaid	First quarter 2014 through third quarter 2016	—
	Minnesota	Data not submitted	—
	Ohio: Medicaid	2015	—
	Wisconsin	Data not submitted	—
	Delaware	Data not submitted	Cost prohibitive (\$30 000)
Northeast	District of Columbia: AmeriHealth MCO, Trusted MCO, Health Services for Children with Special Needs (HSCSN) MCO	Third quarter 2015 (AmeriHealth and Trusted) Third quarter 2014 through third quarter 2015 (HSCSN)	—
	Maryland: Medicaid	First quarter 2015 through second quarter 2016	—
	New Jersey: Horizon MCO	First quarter 2014 through first quarter 2016	—
	New York	Data not submitted	—
	Pennsylvania	Data not submitted	No contact person
	Puerto Rico	Data not submitted	No funding; red tape
	US Virgin Islands	Data not submitted	No contact person
	Virginia MCO	Data suppressed <sup>c</sup>	Low numbers and differences in measure definitions
	West Virginia	Data not submitted	Small numbers
	Alaska: Fee for Service (FFS)	Third quarter 2014 through third quarter 2016	—
Pacific	Arizona	Did not participate	—
	California: MCO and FFS	Third quarter 2014 through third quarter 2015	—
	Guam	Did not participate	—
	Hawaii	Did not participate	—
	Idaho: Medicaid	2014	—
	Nevada: Medicaid	Third quarter 2014 through second quarter 2015	—
	Oregon: MCO and FFS combined	Third quarter 2013 through third quarter 2016	—
	Washington: MCO and FFS	Third quarter 2014 through third quarter 2015	—

Abbreviations: —, none noted; FFS, fee for service; MCO, managed care organization; RCC, regional coordinating center.

<sup>a</sup>The Iowa and Missouri data from the Illinois Medicaid office.

<sup>b</sup>Includes data from patients living in Indiana, Iowa, Missouri, and Wisconsin, but receiving care from providers in Illinois.

<sup>c</sup>Virginia MCO data were received but suppressed due to low numbers and differences in measure definitions.

We found challenges in the standardization of administrative data despite a centrally developed set of clearly defined measure specifications and a data dictionary. The MCO partner organizations interpreted the measure definitions in various ways (eg, definitions of “provider” could include transport services, pharmacies, or durable medical equipment in some states). In addition, the methods for successfully obtaining Medicaid data in 1 state do not necessarily translate to another state. For example, cost, timeliness, and availability of claims data may vary among state agencies and MCOs. Some states rely on third-party MCOs, academic centers, or claims processing firms to administer claims, and extra care and resources (eg, a statistical programmer with experience using Medicaid data) are required to ensure that collected data are comparable across states and regions. Lessons for establishing a data collection strategy *de novo* ranged from the administrative data challenges to delays in obtaining individual state IRB approvals and data use agreements.

Although Medicaid data provide a record of care received, clinical information is limited, and no information on care needed is provided. RCCs also found that the quality of Medicaid data varied; for example, some data indicated incorrect diagnosis codes. Another limitation of MCO data requests is that some MCOs with research institutes require that their personnel are granted co-principal investigator status with salary support and authorship agreements before agreeing to provide data. A final limitation was that some MCOs had too few SCD claims to warrant the time required to set up the data request.

Initially, the NCC and RCCs also pursued the idea of collecting national administrative data directly through the Centers for Medicare & Medicaid Services’ Research Data Assistance Center and through a contracted supplier of Centers for Medicare & Medicaid Services data outputs. Unfortunately, given the cost (approximately \$150 000 per annum) and a substantial lag in data access (ie, several years between when an event takes place, when a claim is made, and when these data become available in the national data system), they decided that although access to these measures long term would be an asset to understanding SCD at a national level, resources were insufficient to contract with the Research Data Assistance Center during the 2014-2017 funding cycle.<sup>11</sup>

The collection of administrative data and the collection of EHR data posed different challenges. Many challenges arose from the retroactive alignment of data collection and analysis strategies developed locally to drive site-level QI. Furthermore, the consent and IRB approval process created challenges and delays, because patient-level EHR data were not included in the original project measurement strategy or required grant funding. Finally, because of limited resources, the EHR data included only patients from specific sites, leaving major gaps in a broad understanding of the reach and effectiveness of the SCDDTP. Much of the SCD population

receives care outside the specialty centers that contributed EHR data.

A major limitation of this measurement strategy was that the expert group, NCC, and RCCs developed quality measures via a modified Delphi method that were not otherwise validated or tested for feasibility. Using a modified Delphi method was a way to ensure timely buy-in from all stakeholders so that data collection could commence as quickly as possible. In addition, the project timeline necessitated a short turnaround time that did not allow for additional feasibility and validity testing.

A strategy to address the measurement concerns would be to create a population-based national data registry for persons with SCD. Registries can have different purposes—research and population-based disease management, surveillance, and QI—and can be sponsored by a government agency, nonprofit organization, health care facility, or private company. However, to establish an SCD registry, many questions need to be answered in collaboration with a broad range of stakeholders, including registry objectives, type of data collected, patient identification, data access, funding sources, and, most importantly, how a registry would benefit stakeholders including patients, families, health care providers, and researchers.

## Practice Implications

SCD requires an effective, simple, shared measurement approach because of the small numbers of SCD patients and the complexity of care delivery. To drive QI efforts in future SCDDTP funding cycles, patient-level EHR measures will be used, and RCCs have a structure for collectively developing additional measures as needed. This expanded data set will provide high-quality data, encourage use of existing systems and common metrics, and increase the ability of data to validate key processes and outcomes at regional and national levels. Medicaid data will not be used because of the cost, time, and effort required to access these data and the inconsistencies in data accuracy.

RCCs implemented real-time quality metrics to assess whether the QI interventions led to improvements in access to quality and care (aim 1) and increased use of hydroxyurea (aim 2). These interventions included telehealth-based approaches and expanding collaborative networks to include government partners and other stakeholders. RCCs developed education activities (eg, publications, presentations, clinical decision-making tools) for health care providers and patient education materials (eg, brochures, shared decision-making tools) to increase the use of hydroxyurea. Further details and a compendium of tools and resources can be found in the 2017 congressional report.<sup>11</sup>

By targeting a limited number of well-defined metrics and building partnerships with stakeholders invested in improving care and experienced with managing complex data, the SCDDTP established a shared measurement approach that

can be leveraged, and improved, to effectively support national improvement initiatives for SCD.

### Acknowledgments

The authors thank Susan T. Paulukonis, MA, MPH; Karen Kalinyak, MD; Michael Rowland, MPH; Rosalyn W. Stewart, MD, MS, MBA; and John J. Strouse, MD, MPH, for their contributions to the development of the measurement strategy, data collection, submission, and analysis for the SCDTDP.

### Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the Health Resources and Services Administration, Maternal and Child Health Bureau, US Department of Health and Human Services, contract no. HHSN50201 400026C, Sickle Cell Disease Treatment Demonstration Program.

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# Social Network Analysis of Patient Movement Across Health Care Entities in Orange County, Florida

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## Abstract

**Objective:** Multidrug-resistant organisms (MDROs) are continually emerging and threatening health care systems. Little attention has been paid to the effect of patient transfers on MDRO dissemination among health care entities in health care systems. In this study, the Florida Department of Health in Orange County (DOH-Orange) developed a baseline social network analysis of patient movement across health care entities in Orange County, Florida, and regionally, within 6 surrounding counties in Central Florida.

**Materials and Methods:** DOH-Orange constructed 2 directed network sociograms—graphic visualizations that show the direction of relationships (ie, county and regional)—by using 2016 health insurance data from the Centers for Medicare & Medicaid Services, which include metrics that could be useful for local public health interventions, such as MDRO outbreaks.

**Results:** We found that both our county and regional networks were sparse and centralized. The county-level network showed that acute-care hospitals had the highest influence on controlling the flow of patients between health care entities that would otherwise not be connected. The regional-level network showed that post–acute-care hospitals and other facilities (behavioral hospitals and mental health/substance abuse facilities) served as the primary controls for flow of patients between health care entities. The most prominent health care entities in both networks were the same 2 acute-care hospitals.

**Practice Implications:** Social network analysis can help local public health officials respond to MDRO outbreak investigations by determining which health care facilities are the main contributors of dissemination of MDROs or are at high risk of receiving patients with MDROs. This information can help epidemiologists prioritize prevention efforts and develop county- or regional-specific interventions to control and halt MDRO transmission across a health care network.

## Keywords

SNA, network analysis, patient transfers, baseline SNA, social network analysis

The field of public health is continuously evolving with new technologies, changing health care systems, globalization, and broader societal transformations.<sup>1,2</sup> In response, public health officials are using numerous tools to analyze and visualize complex data to answer important health questions (eg, about disease propagation) to protect the health of the community.<sup>3,4</sup> Social network analysis is an emerging analytical tool in public health that describes the connections of persons, partnerships, disease transmission, and interorganizational structure of health systems.<sup>4</sup> Social network analyses visually describe the existence and strengths of relationships of participants in a network. These visualizations are depicted through sociograms (ie,

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drawings of points connected by lines).<sup>5</sup> The points in the network (nodes) represent the persons or organizations of interest. The lines that connect nodes (edges) represent the relationship between nodes. In a directed sociogram, arrows are also used to connect nodes and show direction from a source node to a receiving node.

In applied public health, social network analyses have been used to understand disease transmission for HIV/AIDS, sexually transmitted infections, tuberculosis, and severe acute respiratory syndrome.<sup>4</sup> Other approaches in applied public health have examined health communication, health behaviors, partnerships, and community collaboration.<sup>4,6-10</sup> Social network analyses allow public health officials to assess the relationships of interest through strengths of connections rather than common variables (eg, type, location, size, population served). However, social network analyses have not traditionally been used by public health officials at local health departments. Explanations for the scarcity of application are not fully understood, but on the basis of our experience, we posit that training and resources for local public health officials are lacking.

Multidrug-resistant organisms (MDROs) are continually emerging and threatening health care systems by increasing health care-associated morbidity, mortality, and costs.<sup>11,12</sup> Efforts to control transmission of MDROs are a top priority for public health officials and are directed toward enhancing infection control practices within a health care entity. Although reinforcing infection control practices within a health care entity has been successful in halting the transmission of MDROs, little attention has been paid to understanding the effect of patient transfers on MDRO dissemination in a county's health care infrastructure.<sup>12</sup>

Understanding that patient transfers play an integral role in the health care infrastructure, we saw a meaningful application of social network analyses to local health department operations.<sup>13</sup> Health care entities in the same region or county are often connected through the patients they share.<sup>10</sup> Patients are transferred among health care entities for various reasons, such as health insurance providers, specialty medical procedures, referrals from physicians, or improved social support.<sup>10,13-15</sup> In this study, the Florida Department of Health in Orange County developed a baseline social network analysis of patient movement across health care entities countywide and regionally to learn how each health care entity contributes to the health care infrastructure. Central Florida's health care system is complex because it services an estimated 1.35 million persons and approximately 72 million tourists annually.<sup>16</sup> Understanding how each health care entity contributes to the health care infrastructure can assist us in guiding targeted MDRO intervention strategies and identifying facilities at risk for receiving or discharging a patient with an MDRO.

## Materials and Methods

### Data Collection

We received data on health care transfers for Orange County from the 2016 100% Medicare claims and Minimum Data Set files, provided as part of a collaboration with the Centers for Disease Control and Prevention (CDC) Division of Healthcare Quality Promotion. This work was conducted under a data-use agreement between CDC and Centers for Medicare & Medicaid Services (CMS) and was determined by CDC's Human Research Protection Office to be exempt from the regulations governing the protection of human subjects in research.

The data set includes health care entity attribute variables, which distinguish the location of each facility (eg, entity CMS identification number, entity state location, entity county location, entity name, national provider identifier [NPI], CMS provider identification, and postal ZIP codes of service). In addition, the data set identifies patient transfers between health care facilities through the source and destination provider identification, NPI (ie, source and destination), postal ZIP code (ie, source and destination), and number of Medicare fee-for-service beneficiaries (patients) shared between the discharge facility and receiving facility. Adhering to the CDC Division of Healthcare Quality Promotion's data-use agreement, the data set is coded with “–9” if the facility transferred or discharged ≤10 patients.

We used 2 data categories, provider ID and postal ZIP code, to fully identify the health care entities. Once we identified the entities, we were able to obtain data on additional descriptive statistics and understand the magnitude of the social connections/network. To maintain the anonymity of the entities, we labeled each with the letter “X” and a corresponding number as they appeared in the data set (ie, entity 1 is labeled X1). The health care entities represented in the data set comprised acute-care hospitals, post-acute-care hospitals (ie, long-term acute-care hospitals and rehabilitation hospitals), skilled nursing facilities, and other facilities (ie, mental health and behavioral hospitals, substance abuse rehabilitation facilities, and mental health facilities).

### Network Analysis

We managed data by using R-dplyr version 0.7.5.<sup>17</sup> Network visualizations and statistics were conducted using RStudio package R-statnet version 2016.9.<sup>18,19</sup> In 2018, we constructed 2 directed networks to understand county and regional influences in Orange County's health care system. The county sociogram includes all CMS-certified health care entities (ie, acute-care hospitals, post-acute-care hospitals, skilled nursing facilities, and other) located in Orange County, Florida. To understand the role of surrounding county entities on our county network, we constructed a regional sociogram. The regional network includes all the

CMS-certified health care entities located in Orange County plus entities that are geographically located in the 6 surrounding counties (Brevard, Osceola, Lake, Polk, Seminole, and Volusia). Patients shared in the networks were transferred from 1 to 365 days of the health insurance claim.

We created network visualizations by using the Fruchterman-Reingold 1991 layout (ie, force-directed graph drawing algorithm).<sup>20</sup> Each health care entity is represented by a node in both networks. The health care entities (nodes) are categorized by facility type (ie, acute-care hospitals, post-acute-care hospitals, skilled nursing facilities, and other) and have weighted edges depicting the volume of patients transferred. To control for fluctuation of patient volume across entities that transferred  $\leq 10$  patients, we valued the weighted edges as the midpoint (weight = 5). Intrafacility transfers were represented by a weighted edge from the node back into itself (self-loop).

In this study, we primarily focused on metrics that may be most useful for targeted MDRO reduction interventions or active case finding during an MDRO outbreak. Information flow depends on individual and group network properties. Thus, we calculated cohesion<sup>21</sup> (ie, density), magnitude of influence<sup>21</sup> (ie, centralization), and central importance of each entity<sup>21</sup> (ie, centrality) for each network and the individual node. Measures of centralization include the extent to which 1 or a few health care entities influence the network by serving as a connector between 2 health care entities<sup>21</sup> (ie, betweenness) and the extent to which 1 or a few health care entities influence the network by having the most connections<sup>21</sup> (ie, degree). Measures of centrality include degree (total number of connections<sup>21</sup>) indegree (ie, number of connections received<sup>21</sup>/outdegree (ie, number of connections sent/discharged,<sup>21</sup> and flow betweenness (ie, betweenness that incorporates all possible pathways weighted with patients). In addition, we calculated node-based measures for the edge metrics to understand the effect each entity contributed toward the health care infrastructure. These descriptive statistics included degree, betweenness, thickness (ie, weighted), and direction (ie, indegree/outdegree). Nodes are described by the facility type, the total number of beds in the health care entity, and the total number of transfers. Density and centrality network measures have been identified as potentially the most informative network measures in the examination of public health systems.<sup>22,23</sup> These measures provide us with the baseline understanding of the influences of each health care entity in our system.

## Results

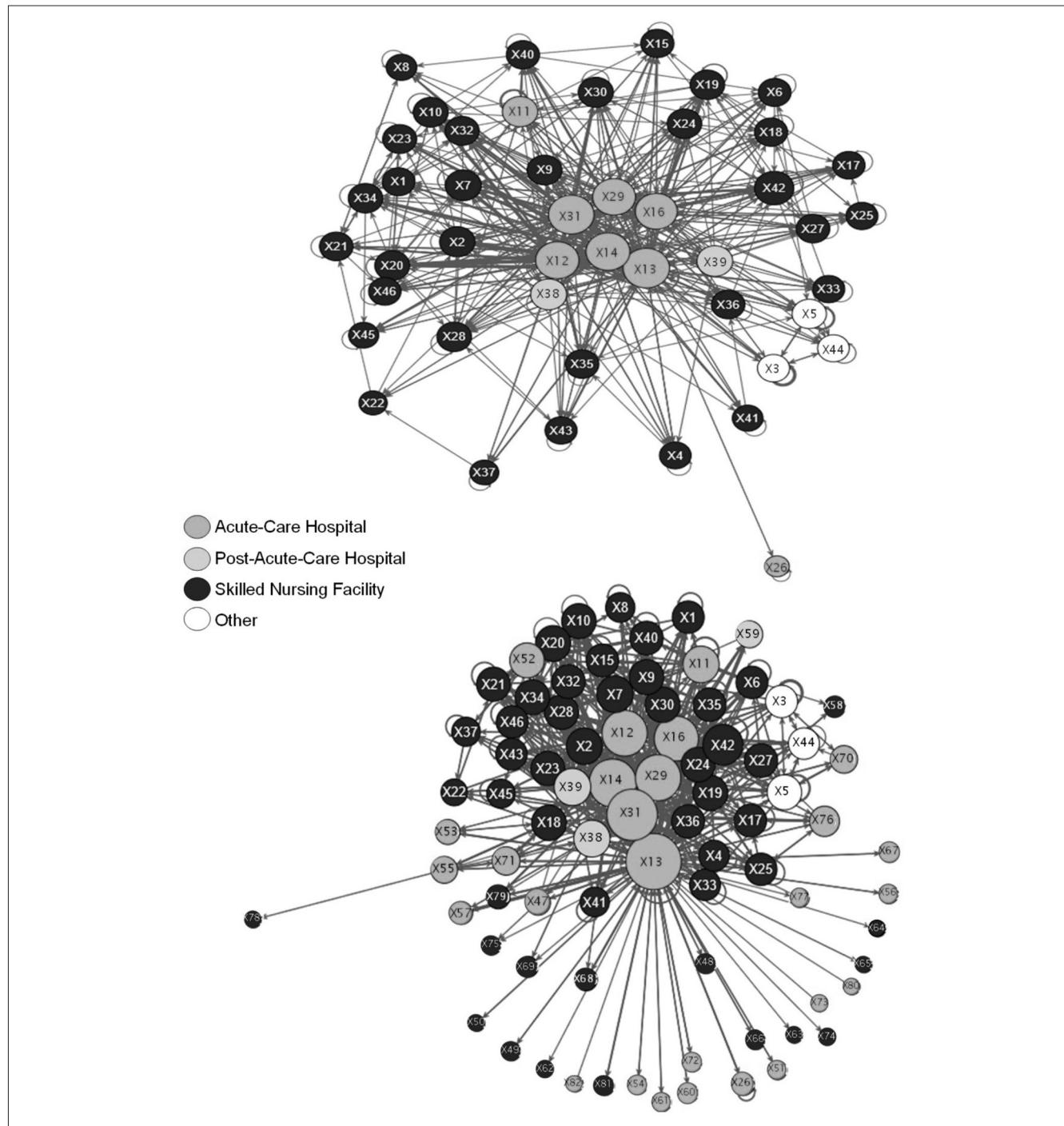
The Orange County network consisted of 46 health care entities (Figure), and the regional network consisted of 82 health care entities (Figure). Of the 46 health care entities in the Orange County network, 8 were acute-care hospitals, 2 were post-acute-care hospitals, 33 were skilled nursing facilities,

and 3 were other facilities. The Orange County network was sparse, with a density of 0.28 and a reciprocity of  $r = 74$  (edgewise reciprocity; Table 1), indicating that there is a high proportion of edges reciprocated (ie, mutual sharing of patients). Centralization by indegree, outdegree, and betweenness revealed that the Orange County network was centralized (indegree = 0.78, outdegree = 0.78, betweenness = 0.86). The regional network consisted of 27 acute-care hospitals, 3 post-acute-care hospitals, 49 skilled nursing facilities, and 3 other facilities. Similar to the Orange County network, the regional network was sparse (density = 0.11), with a high proportion of edges reciprocated (edgewise reciprocity  $r = 74\%$ ; Table 1). The regional network was centralized (indegree = 0.79, outdegree = 0.88, betweenness = 0.79) by 1 health care entity. Neither network displayed fragmentation, because no isolates or components (health care entities not connected to the network) were identified.

Node-level descriptive statistics for Orange County health care entities are described with a labeling scheme (Table 2). The number of beds at acute-care hospitals in the Orange County network ranged from 100 to 1366 (median = 266), and the number of patients shared across the network ranged from 15 (entity no. X26) to 6538 (entity no. X13) (median = 2025). Post-acute-care hospitals had a range of 35–40 beds (median = 38) and shared a range of patients from 188 (entity no. X38) to 240 (entity no. X39) (median = 214) across the network. The number of beds at skilled nursing facilities ranged from 39 to 420 (median = 120), and the total number of patients shared across the network ranged from 46 (entity no. X22) to 886 (entity no. X20) (median = 219). Other facilities had a range of 90–174 beds (median = 112) and shared a range of patients from 106 (entity no. X44) to 309 (entity no. X3) (median = 259) across the network.

Centrality measures further identify the heterogeneity across health care entities (Table 3). In Orange County, at acute-care hospitals, the weighted indegree (ie, patients being admitted) ranged from 10 (entity no. X26) to 4403 (entity no. X13) (median = 1202), and the weighted outdegree (ie, patients being discharged) ranged from 10 (entity no. X26) to 4947 (entity no. X13) (median = 1384). The median number of patients discharged from post-acute-care hospitals (median weighted outdegree = 121) was higher than the median number of patients admitted into post-acute-care hospitals (median weighted indegree = 96), whereas skilled nursing facilities in the Orange County network admitted more patients (median weighted indegree = 123) than they discharged (median weighted outdegree = 83). Other health care entities in the Orange County network had a median weighted indegree and outdegree of 173 (Table 3). In addition, acute-care hospitals played an integral role in controlling the flow of patients between health care entities that would not otherwise be connected (flow betweenness centrality = 0 [entity no. X26] – 1980 [entity no. X13]).

In the regional network, of the types of entities, acute-care hospitals received and transferred the highest number of



**Figure.** Directed social networks of patient transfers through (A) County (Orange County, Florida) and (B) Regional (central Florida) Centers for Medicare & Medicaid Services–accepting health care entities, 2016. Each node (circle) depicts a health care entity; the size of the node depicts the total degree, defined as the overall volume of connections that exist for each health care entity ( $\text{indegree} + \text{outdegree}$ )<sup>0.3</sup>, edges (lines) are weighted with a log reduction (divided by 50) of the volume of patients shared between facilities, arrows depict the direction of patients being shared, curved lines depict loops (an entity shared patients with itself), and length of lines depict the speed of patient movement. Administrative data from the 2016 100% Medicare claims and Minimum Data Set files, provided as part of a collaboration with the Centers for Disease Control and Prevention Division of Healthcare Quality Promotion.

patients (weighted indegree range = 0-5608; weighted outdegree range = 10-6259; Table 3). However, the other facilities

group (median weighted indegree = 188; median weighted outdegree = 189) and post-acute-care hospitals (median

**Table 1.** Directed sociogram attributes of patient transfers through CMS<sup>a</sup>-accepting health care facilities, stratified by county level (Orange County, Florida) and regional level (Central Florida), November 2016

Attribute	County	Regional
Network size, <sup>b</sup> no.	46	82
Total edges, <sup>c</sup> no.	600	736
Dyad count, <sup>d</sup> no.	2116	6724
Density <sup>e</sup>	0.28	0.11
Reciprocity "weighted edges," <sup>f</sup> %	74	74
Indegree centralization <sup>g</sup>	0.78	0.79
Outdegree <sup>h</sup>	0.78	0.88
Betweenness <sup>i</sup>	0.86	0.79

Abbreviation: CMS, Centers for Medicare & Medicaid Services.

<sup>a</sup>Administrative data from the 2016 100% Medicare claims and Minimum Data Set files, provided as part of a collaboration with the Centers for Disease Control and Prevention Division of Healthcare Quality Promotion.

<sup>b</sup>Network size is the total number of nodes (circles) in the sociogram(s) (network visualization).

<sup>c</sup>Total edges are the number of lines that connect nodes to each other in the sociogram(s).

<sup>d</sup>Dyads are the total number of node pairs that exist in the network.

<sup>e</sup>Density is the ratio of observable edges (physical lines that are observed connecting nodes in the network) to potential edges (total number of connections that could have connected nodes together) in a network.<sup>19</sup>

<sup>f</sup>Reciprocity is the proportion of dyad(s) (pairs of health care entities) that are mutually linked.<sup>19</sup>

<sup>g</sup>Indegree centralization is the extent to which 1 or a few health care entities influence the network by receiving a substantially higher amount of connections from other health care entities within the network.<sup>19</sup>

<sup>h</sup>Outdegree centralization is the extent to which 1 or a few health care entities influence the network by sending a substantially higher amount of connections to other health care entities within the network.<sup>19</sup>

<sup>i</sup>Betweenness is the extent to which 1 or a few health care entities influence the network by creating a bridge between health care entities within the network.<sup>19</sup>

weighted indegree = 146; median weighted outdegree = 124) consistently shared patients across the network. Also, in the regional network, post-acute-care hospitals served as the primary controls in the health care system (flow betweenness centrality median = 396).

## Discussion

Social network analyses provide a flexible framework for analyzing the association of health care entities in a community. The network visualizations allow public health officials to identify critical stakeholders and facilitate discussions to implement targeted interventions.<sup>10,23</sup> We developed and analyzed 2 directed networks (ie, county and regional) to understand the actors and influences in our health care infrastructure. Our analysis demonstrated a centralized network (indegree = 0.78, outdegree = 0.78, betweenness = 0.86) in Orange County, with 6 acute-care hospitals (entities no.

X12-X14, X16, X29, X31) serving as the most prominent facilities for controlling the flow of patients. When we expanded the analysis regionally, the centralization measures were constant (indegree = 0.79, outdegree = 0.88, betweenness = 0.79), but the influential facilities that shared a consistent number of patients shifted from acute-care hospitals to post-acute-care hospitals and the other facilities group. Centralization by degree and betweenness measures are important because they indicate which health care entities in a network may have the greatest influence on changes within the network.

The network of Orange County was not tightly knit (density = 0.28), and comparatively, the regional network was more sparse (density = 0.11). This finding was not unexpected because larger networks tend to have lower densities than smaller networks.<sup>24</sup> Although this sparseness could be viewed as a positive, because it could translate into lower rates of disease transmission, it could also be viewed as a negative, because it could result in slower rates of information dispersal and intervention implementation. The node-level analysis revealed that with 46 facilities, we could reach 8231 beds in our network. The most influential entities in the county network, excluding intrafacility transfers, were X13 and X31. Both facilities admitted the most patients (weighted indegree: X13 = 1581; X31 = 815) and discharged the most patients (weighted outdegree: X13 = 2125; X31 = 1068) in the county. Although X13 and X31 were the most active health care entities in the county, X13, X31, X14, and X12 all had a similar amount of control (flow betweenness centrality: X13 = 1980, X31 = 1728, X14 = 1440, X12 = 1241) based on the total volume of patients shared between health care entities. When we included intrafacility transfers, both X13 (weighted indegree = 4403, weighted outdegree = 4947) and X31 (weighted indegree = 1832, weighted outdegree = 2085) were the most active and controlling health care entities in the county. Although, overall, acute-care hospitals were the most prominent health care entities in the county network, skilled nursing facilities and other facilities also provided contributions, albeit moderate contributions, to the network. In particular, X42 (skilled nursing facility) and X7 (other facility) were the most active health care entities among their facility types (weighted indegree: X42 = 341, X7 = 437; weighted outdegree: X42 = 211, X7 = 299) by admitting and discharging the highest volume of patients. The information gained from the baseline county network provide us with reason to apply our network when we are in need of communicating information or applying countywide infection control interventions.

Post-acute-care hospitals admit patients with chronic critical illnesses that require specialized care (eg, mechanical ventilation), have multiple comorbidities, and have high rates of antibiotic use.<sup>25</sup> These complex treatment plans and prolonged hospitalization courses place patients at post-acute-care hospitals at risk of being colonized with MDROs.<sup>25</sup> Our baseline regional network identified that our

**Table 2.** Characteristics of facilities in a county-level network of patient transfers through CMS<sup>a</sup>-accepting health care facilities, Orange County, Florida, November 2016

Facility Type <sup>b</sup>	No. of Beds	Total No. of Patients Shared	Indegree Centrality <sup>c</sup>	Outdegree Centrality <sup>d</sup>	Flow Betweenness Centrality <sup>e</sup>
Acute-care hospital					
X11	120	329	11	14	299
X12	295	2549	31	37	1241
X13	1366	6538	48	48	1980
X14	320	2588	37	36	1440
X16	211	1500	27	31	1022
X26	100	15	2	2	0
X29	237	1311	27	37	1038
X31	866	2900	42	45	1728
Other					
X3	90	309	6	9	140
X5	174	259	11	10	257
X44	112	106	8	6	149
Post-acute-care hospital					
X38	35	188	8	19	335
X39	40	240	6	20	290
Skilled nursing facility					
X1	103	152	9	8	108
X2	120	411	12	13	261
X4	118	152	8	6	51
X6	180	139	10	7	142
X7	120	719	13	14	229
X8	120	113	7	5	104
X9	60	194	12	11	245
X10	120	499	10	13	200
X15	120	140	10	8	142
X17	228	226	9	7	136
X18	116	219	11	7	157
X19	120	509	11	11	209
X20	120	886	11	12	218
X21	138	235	8	11	248
X22	40	46	4	4	90
X23	60	310	12	8	202
X24	120	211	13	9	199
X25	120	110	8	7	89
X27	120	179	9	10	117
X28	420	261	12	10	152
X30	168	399	14	10	199
X32	120	330	13	7	149
X33	120	81	9	6	72
X34	120	367	12	10	209
X35	180	237	9	10	174
X36	120	133	9	10	138
X37	39	98	5	4	50
X40	120	300	10	8	157
X41	115	86	6	6	45

(continued)

**Table 2.** (continued)

Facility Type <sup>b</sup>	No. of Beds	Total No. of Patients Shared	Indegree Centrality <sup>c</sup>	Outdegree Centrality <sup>d</sup>	Flow Betweenness Centrality <sup>e</sup>
X42	120	532	25	17	291
X43	180	170	9	6	58
X45	120	146	7	4	39
X46	80	247	9	7	78

Abbreviation: CMS, Centers for Medicare & Medicaid Services.

<sup>a</sup>Administrative data from the 2016 100% Medicare claims and Minimum Data Set files, provided as part of a collaboration with the Centers for Disease Control and Prevention Division of Healthcare Quality Promotion.

<sup>b</sup>The health care entities represented in the data set comprised acute-care hospitals, post-acute-care hospitals (ie, long-term acute-care hospitals and rehabilitation hospitals), skilled nursing facilities, and other facilities (ie, mental health and behavioral hospitals, substance abuse rehabilitation facilities, and mental health facilities).

<sup>c</sup>Indegree centrality is the number of connections a health care entity receives from other health care entities across the network.

<sup>d</sup>Outdegree centrality is the number of connections a health care entity sends to other health care entities across the network.

<sup>e</sup>Flow betweenness centrality is the frequency with which a health care entity serves as a connector within the network that incorporates all possible pathways weighted with patients.

**Table 3.** County-level (Orange County, Florida) and regional (Central Florida) sociogram of CMS<sup>a</sup>-accepting facility-level centrality measures, 2016

Facility Type <sup>b</sup>	Centrality Measures				
	Median Indegree Centrality (Range)	Median Weighted Indegree <sup>c</sup> (Range)	Median Outdegree Centrality (Range)	Median Weighted Outdegree <sup>d</sup> (Range)	Median Flow Betweenness Centrality <sup>e</sup> (Range)
County (n = 46)					
Acute-care hospital (n = 8)	29 (2-48)	1202 (10-4403)	37 (2-48)	1384 (10-4947)	1140 (0-1980)
Post-acute-care hospital (n = 2)	7 (6-8)	96 (71-121)	20 (19-20)	121 (117-124)	313 (290-335)
Skilled nursing facility (n = 33)	10 (4-25)	123 (26-550)	8 (4-17)	83 (20-348)	149 (39-291)
Other (n = 3)	8 (6-11)	173 (66-206)	9 (6-10)	173 (55-236)	149 (140-257)
Regional (n = 82)					
Acute-care hospital (n = 27)	2 (0-73)	73 (0-5608)	3 (1-80)	115 (10-6259)	30 (0-5393)
Post-acute-care hospital (n = 3)	8 (4-10)	146 (111-311)	19 (4-20)	124 (117-246)	396 (24-413)
Skilled nursing facility (n = 49)	9 (1-25)	95 (11-574)	7 (0-17)	73 (0-359)	103 (0-466)
Other (n = 3)	9 (7-12)	188 (77-224)	10 (6-11)	189 (55-252)	238 (195-363)

Abbreviation: CMS, Centers for Medicare & Medicaid Services.

<sup>a</sup>Administrative data from the 2016 100% Medicare claims and Minimum Data Set files, provided as part of a collaboration with the Centers for Disease Control and Prevention Division of Healthcare Quality Promotion.

<sup>b</sup>The health care entities represented in the data set comprised acute-care hospitals, post-acute-care hospitals (ie, long-term acute-care hospitals and rehabilitation hospitals), skilled nursing facilities, and other facilities (ie, mental health and behavioral hospitals, substance abuse rehabilitation facilities, and mental health facilities).

<sup>c</sup>Weighted indegree is the volume of patients a given health care entity received from other health care entities in the network.

<sup>d</sup>Weighted outdegree is the volume of patients a given health care entity sent to other health care entities in the network.

<sup>e</sup>Flow betweenness centrality is the frequency with which a health care entity serves as a connector within the network that incorporates all possible pathways weighted with patients.

post-acute-care hospitals may be largely affected through admissions or may directly influence the dispersal of patients with MDROs across the network. Thus, this analysis allowed us to readily identify important facilities in MDRO outbreaks and direct our efforts toward targeted interventions in preventing and containing MDROs.

## Practice Implications

State and local health departments have a unique and eminent position in assessing emerging trends or gaps in disease prevention and are a consistent facilitator when health care communication between facilities shifts.<sup>26,27</sup> As MDROs increasingly emerge and are transferred across our health care system, we need to be vigilant and strategic to contain and halt transmission. A lack of coordination and communication between health care facilities may increase the risk of MDRO acquisition.<sup>28</sup> More recently, public health authorities have served as the lead in coordinating and alerting facilities of MDROs and outbreaks in a community.<sup>28</sup> Public health officials can use social network analyses to identify and address gaps in communication across the health care network. Moreover, social network analyses can help determine the direction of transmission between facilities and indicate which health care entities are at an increased risk for receiving a patient with an MDRO.<sup>12</sup> Once identified, local public health officials can prioritize facilities at high risk for outbreaks and develop county- or regional-specific interventions. Access to analysis platforms to perform social network analyses is a potential limitation for public health officials. However, the R software environment that we used for statistical computing and graphics is free, which allows for low-cost reproducibility for any health department.

## Limitations

Our study had several limitations. First, the data set provided was collected from the CMS billing system, which is limited to patients insured by CMS and facilities that accept CMS health insurance. Thus, proportional selection bias of the total patient volume shared across the facilities may have been introduced, leading to an underestimation of the effect of patient transfers. However, although the volume of patients may have been underestimated, we captured 94% of the acute-care hospitals, post-acute-care hospitals, and skilled nursing facilities located in Orange County.<sup>29</sup> Finally, closeness centrality is a metric we would have found most useful at the county level, because it is associated in communication sociograms with the speed of information dissemination. Closeness centrality allows for the shortest paths (geodesic distance) between entities to be determined on a close-knit network. However, our networks were not tightly knit, and the metric would have been ill-defined.<sup>20</sup>

## Conclusion

To better understand the associated connectiveness of health care entities as it relates to their shared patients, we created this baseline social network analysis of patient movement. In our county, acute-care hospitals served as the main entities, but post-acute-care hospitals and other facilities (mental health/substance abuse facilities) were most influential in patient flow in our regional network. Patients are transferred across health care entities for several reasons, and their infections and conditions travel with them. This knowledge and understanding can have a substantial effect on our response to MDRO outbreak investigations, developing targeted infection control interventions, preventing the spread of MDRO infections, and dispersing information.

Future social network analyses should include eigenvector centrality to capture the importance of entities in the network that can have a substantial effect on propagation of information, interventions, or spread of pathogens. Analyzing the transitivity of a community's health care infrastructure can assist health departments in outbreak situations to identify clusters. As part of this analysis, we created a social network analysis toolkit to provide local and state health departments with guidance in the construction of social networks.<sup>21</sup>

## Acknowledgments

The authors acknowledge Prabasaj Paul, PhD, MPH, and Hannah Wolford, MSPH, for their role in abstracting the analytic data sets. In addition, the authors thank Sarah Dee Gieger, PhD, MS, Rachel Slayton, PhD, MPH, Karen Elliott, MPH, and Taylor Langston, MPH, for their valuable comments and suggestions on earlier drafts.

## Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the National Association of County and City Health Officials, grant no. 2017-121401.

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# Trends in Indicators of Injection Drug Use, Indian Health Service, 2010-2014: A Study of Health Care Encounter Data

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## Abstract

**Objectives:** Hepatitis C virus (HCV) and HIV transmission in the United States may increase as a result of increasing rates of opioid use disorder (OUD) and associated injection drug use (IDU). Epidemiologic trends among American Indian/Alaska Native (AI/AN) persons are not well known.

**Methods:** We analyzed 2010-2014 Indian Health Service data on health care encounters to assess regional and temporal trends in IDU indicators among adults aged ≥18 years. IDU indicators included acute or chronic HCV infection (only among adults aged 18-35 years), arm cellulitis and abscess, OUD, and opioid-related overdose. We calculated rates per 10 000 AI/AN adults for each IDU indicator overall and stratified by sex, age group, and region and evaluated rate ratios and trends by using Poisson regression analysis.

**Results:** Rates of HCV infection among adults aged 18-35 increased 9.4% per year, and rates of OUD among all adults increased 13.3% per year from 2010 to 2014. The rate of HCV infection among young women was approximately 1.3 times that among young men. Rates of opioid-related overdose among adults aged <50 years were approximately 1.4 times the rates among adults aged ≥50 years. Among young adults with HCV infection, 25.6% had concurrent OUD. Among all adults with arm cellulitis and abscess, 5.6% had concurrent OUD.

**Conclusions:** Rates of HCV infection and OUD increased significantly in the AI/AN population. Strengthened public health efforts could ensure that AI/AN communities can address increasing needs for culturally appropriate interventions, including comprehensive syringe services programs, medication-assisted treatment, and opioid-related overdose prevention and can meet the growing need for treatment of HCV infection.

## Keywords

American Indian/Alaska Native, injection drug use, hepatitis C, HIV, opioid use disorder

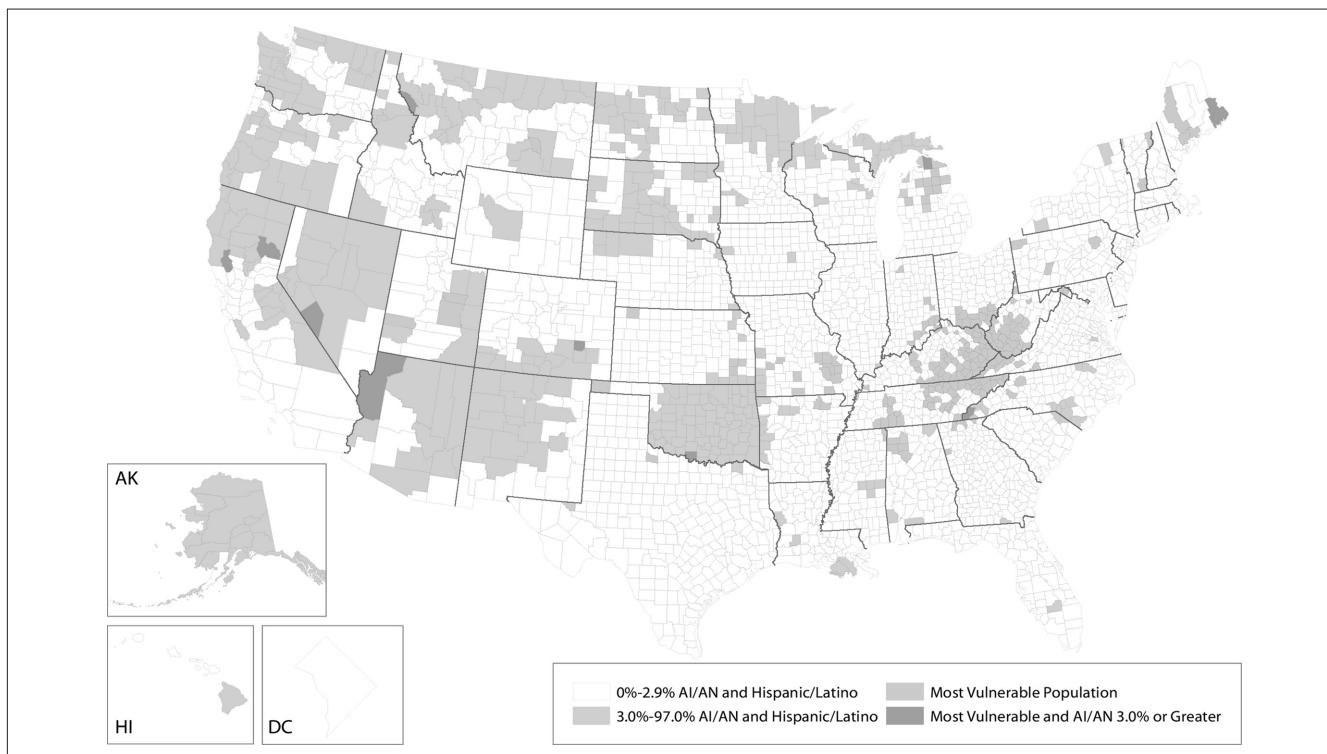
The risk for hepatitis C virus (HCV) and HIV infection in the United States has increased in parallel with increases in opioid use disorder (OUD) and injection drug use (IDU) in urban and rural areas.<sup>1-5</sup> National hepatitis C surveillance data indicated a steeper increase in the number of acute cases of HCV infection among American Indian/Alaska Native (AI/AN) persons than among other racial/ethnic groups during 2001-2016<sup>6</sup> and that the number of opioid-related overdose deaths increased more among AI/

AN persons than among other nonwhite groups.<sup>7,8</sup> However, compared with non-Hispanic white Appalachian communities with high numbers of cases of acute HCV

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**Figure 1.** Representation of American Indian/Alaska Native (AI/AN) and Hispanic/Latino population, as a percentage of county population, by county, in 2010, and 220 counties deemed as most vulnerable to rapid dissemination of HIV or hepatitis C virus infection among persons who inject drugs in the United States, 2012–2013. Data on 220 most vulnerable counties from Van Handel et al.<sup>9</sup> Data on American Indian/Alaska Native population from the 2010 US Census.<sup>11</sup>

infection and opioid-related overdose deaths,<sup>3,9,10</sup> AI/AN populations have received little public health attention. A landmark county-level vulnerability analysis of HIV and HCV infections among persons who inject drugs, conducted by Van Handel et al, showed vulnerability in 220 US counties, but few of these vulnerable counties had an AI/AN population of at least 3.0% (Figure 1).<sup>9,11</sup> An in-depth evaluation of IDU in AI/AN communities can inform infectious disease and opioid-related overdose prevention efforts and promote appropriate resource allocation to support interventions.<sup>12</sup>

No recognized *International Classification of Diseases, Ninth Revision, Clinical Modification* (ICD-9-CM) code

for IDU exists.<sup>13</sup> Therefore, data on the risk of HCV and HIV transmission associated with IDU via administrative data must rely on proxy indicators, such as diagnoses known to be common among persons who inject drugs, from surveys, health care databases, and communities.<sup>9</sup> Collectively, high rates of these indicators in a geographic region may signal increased risk for IDU. We sought to assess temporal trends and regional differences in rates of HCV infection, arm cellulitis and abscess, OUD, and opioid-related overdose to help inform national or regional prevention programs for AI/AN persons at the highest risk for unsterile IDU-associated spread of blood-borne pathogens.

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## Methods

### Data Source

We analyzed data from the Indian Health Service (IHS) administrative health care inpatient discharge and outpatient visit database. We accessed data through an existing Centers for Disease Control and Prevention–IHS data-use agreement, which permits geographic analyses of data at the regional and national level only.<sup>5,14</sup> The Indian health system supported by IHS serves IHS (federal), tribal, and urban (I/T/U) facilities and consists of 45 hospitals and more than 300 health centers in 37 US states, mainly primary care clinics in rural areas that are either federally or tribally operated<sup>15</sup> and contracted out-of-network health facilities, as needed.<sup>15</sup> Electronic health records at I/T/U facilities and some contracted care records are collected at the national level and maintained by the IHS National Patient Information Reporting System (NPIRS) using the National Data Warehouse.<sup>16</sup> NPIRS includes all inpatient discharge and outpatient visit records for services to patients eligible for IHS health care. We considered all AI/AN persons receiving care at I/T/U facilities or contracted care. NPIRS provides an annual denominator for the IHS user population, defined as the unduplicated count (by residence) of AI/AN registrants who have had an inpatient, ambulatory, or dental encounter with the Indian health system during the previous 3 years; these denominator data are provided only as aggregate counts by location, age, and sex.

### Study Design

We analyzed NPIRS data from 2010 through 2014 and limited our analyses to data on adults aged  $\geq 18$  years. For study outcomes, we counted each diagnosis at its first documented instance during the 2010–2014 analysis period, to avoid overcounting diagnoses for chronic diseases, such as HCV infection, for which a diagnosis may have been recorded on multiple occasions. We defined HCV infection, arm cellulitis and abscess, OUD, and opioid-related overdose as indicators of IDU on the basis of the associations of these factors with IDU in previous studies.<sup>3,10,17–19</sup> These indicators of IDU, the outcomes in our analyses, were defined by using ICD-9-CM codes and included the following: HCV infection (070.41, 070.44, 070.51, 070.54, 070.70, 070.71), OUD (304.00–304.03, 304.70–304.73, 305.50–305.53), opioid-related overdose (poisoning) (965.00–965.02, 965.09, 970.1, E850.0–E850.2), and arm cellulitis and abscess (682.3).<sup>13</sup>

We limited analyses of HCV infection to adults aged 18–35 to exclude older persons whose chronic HCV infection might be unrelated to recent IDU. Analyses of OUD, arm cellulitis and abscess, and opioid-related overdose included all adults aged  $\geq 18$  years. OUD included opioid-type dependence, combinations of opioid-type drug with any other drug, and opioid use. Opioid-related overdose was

defined as poisoning by opium, methadone, other opiates and related narcotics, heroin, or opiate antagonists. We also included accidental poisoning by heroin, methadone, and other opiates and related narcotics. Although drugs are injected at many anatomical locations, we chose the code for arm cellulitis and abscess because skin and soft-tissue infections of the arm are a common complication of unsterile injection, whereas skin and soft-tissue infections of the lower extremities are a common complication of diabetes and peripheral vascular disease.<sup>14,20,21</sup> We excluded adults with arm cellulitis and abscess from the numerator if they had an ICD-9-CM code indicating diabetes diagnosis (249, 250, 357.2, 362.0, 366.41, 648.0, 648.8, V45.85, V53.91, V65.46) in NPIRS on or before (since 2001) their first encounter for arm cellulitis or abscess. We considered several additional indicators of IDU, including endocarditis and osteomyelitis, but we eventually excluded them because of an insufficient number of these diagnoses to support analyses.

### Statistical Analysis

For each IDU indicator, we counted the number of adults with that diagnosis during 2010–2014, overall and stratified by sex, age group, and region; NPIRS contains a unique patient registration identifier that allows the de-duplication of data on persons with  $>1$  health care encounter with the same diagnoses, so that a person was counted only once in the numerator (first recorded diagnosis) during the study period. We calculated denominators by summing the NPIRS annual denominators during the study period. We determined sex, age group, and region from a person's first visit during the study period for each IDU indicator. We also counted the number of persons with concurrent IDU indicators (ie, when a person met requirements for  $\geq 2$  IDU indicators during the study period). We categorized geographic regions as described elsewhere.<sup>5,22</sup> We calculated rates of each IDU indicator for 2010–2014 combined per 10 000 AI/AN adults to compare the burden between strata by using IDU indicator counts and the corresponding aggregation of NPIRS annual denominators; we used Poisson regression analysis to calculate rate ratios (RRs) and 95% confidence intervals (CIs).

We performed a trend analysis to examine changes over time in the number of adults with IDU indicators who used the IHS system. We calculated annual rates per 10 000 AI/AN adults by using the number of adults in each calendar year with a diagnosis for each IDU indicator as the numerator and the corresponding NPIRS annual denominators. We calculated unadjusted average annual percentage change and used Poisson regression analysis to evaluate trends over time. For all analyses, we used SAS version 9.4<sup>23</sup> and set significance at  $P < .05$ .

The project relied on preexisting de-identified data and was approved by the Centers for Disease Control and Prevention and IHS institutional review board processes and federal regulations for the protection of human subjects.

## Results

### Demographic and Regional Comparisons

The rate of reported HCV infections across all regions was 19.5 per 10 000 AI/AN adults aged 18-35 ( $n = 4548$ ; Table 1). Among AI/AN adults aged 18-35, the rate of HCV infection was higher among women than men (RR = 1.28). By region, the rate of HCV infection in the East was 3.81 times the rate in the Southwest, which had the lowest rate, and the rate of HCV infection in the Northern Plains West was 3.63 times the rate in the Southwest. The overall rate of OUD was 39.2 per 10 000 AI/AN adults aged  $\geq 18$  ( $n = 20759$ ). Compared with rates of OUD in the Southwest, rates of OUD were higher in the East (RR = 4.62), Northern Plains East (RR = 3.30), West (RR = 3.22), Alaska (RR = 2.04), and Northern Plains West (RR = 1.56) and lower in the Southern Plains (RR = 0.88). The overall rate of arm cellulitis and abscess was 33.3 per 10 000 AI/AN adults aged  $\geq 18$  ( $n = 17664$ ). The overall rate of opioid-related overdose was 3.5 per 10 000 AI/AN adults aged  $\geq 18$  ( $n = 1879$ ). Opioid-related overdose was slightly more common among women than among men, and the relative rates of opioid-related overdose in all groups aged  $< 50$  were similarly higher, at approximately 1.4 times the rate in groups aged  $\geq 50$ .

### Concurrent Indicators

Among the 4548 AI/AN adults aged 18-35 with a diagnosis of HCV infection, 25.6% ( $n = 1165$ ) had a concurrent diagnosis of OUD and 6.9% ( $n = 315$ ) had a concurrent diagnosis of arm cellulitis and abscess (Table 1). Among the 17664 AI/AN adults aged  $\geq 18$  with a diagnosis of arm cellulitis and abscess, 5.6% ( $n = 982$ ) had a concurrent diagnosis of OUD. By region, the largest percentage of adults aged 18-35 with  $\geq 1$  IDU indicator was in the East (8.3%; 1694 of 20372); a greater percentage of men (4.3%; 12219 of 286908) than women (4.1%; 12839 of 316289) had  $\geq 1$  IDU indicator (Table 2).

### Trend Analysis

The annual rate of diagnoses of HCV infection per 10 000 AI/AN adults aged 18-35 increased significantly from 25.5 in 2010 to 35.1 in 2014, an average 9.4% increase per year ( $P < .001$ ; Figure 2). The annual rate of OUD diagnoses per 10 000 AI/AN adults aged  $\geq 18$  increased significantly from 47.1 in 2010 to 72.2 in 2014; an average 13.3% increase per year ( $P < .001$ ). The annual rate of arm cellulitis and abscess diagnosis per 10 000 AI/AN adults aged  $\geq 18$  decreased significantly from 38.4 in 2010 to 32.0 in 2014; an average 4.2% decrease per year ( $P < .001$ ). We found no significant change in the annual rate of opioid-related overdose during the study period.

## Discussion

In this analysis of a large database of outpatient and inpatient health care encounters among adult AI/AN patients at I/T/U facilities, the rates of HCV infection and OUD increased during 2010-2014. Our findings on HCV infection, based on ICD-9-CM codes, show a rate of 19.5 diagnoses per 10 000 adults for 2010-2014, in line with other studies reporting higher rates of HCV infection in the AI/AN population than in other racial/ethnic groups and an increase in rates of hospitalizations related to HCV infections among AI/AN persons over time.<sup>6,22</sup> Resources for treating and curing HCV infection in I/T/U facilities are inadequate<sup>12</sup>; therefore, this vulnerable population is at an even higher risk than other racial/ethnic populations of further rapid HCV transmission and hepatitis C sequelae, including end-stage liver disease, cirrhosis, hepatic cancer, and death.<sup>24</sup> The rate of concurrent diagnoses of HCV infection and OUD in our study was 5.0 per 10 000 AI/AN adults, consistent with the documented correlation between HCV infection and IDU in the overall US population.<sup>10</sup> Finding novel methods for gauging IDU levels in AI/AN communities is particularly important to ensure sufficient access to culturally appropriate interventions, syringe services programs, medication-assisted treatment, and opioid-related overdose prevention (eg, access to naloxone). Syringe services programs and medication-assisted treatment are effective interventions to prevent HCV transmission, but access to these programs is limited for AI/AN persons.<sup>25,26</sup> Although some tribes have already implemented syringe services programs, our analysis provides impetus and a framework for additional tribes and others, such as tribal epidemiology centers and tribal serving organizations, to conduct their own data analysis and needs assessment, which may point to a need for establishing or expanding syringe services programs for AI/AN persons.<sup>27</sup>

IHS has implemented opioid-prescribing guidelines<sup>28</sup> consistent with the *CDC Guideline for Prescribing Opioids for Chronic Pain*<sup>29</sup> and has expanded access to medication-assisted treatment and naloxone.<sup>30</sup> Our regional analyses can inform the geographic focus of resources, including access to medication-assisted treatment and naloxone.<sup>16,28,30</sup> Methamphetamine use, including injection, is common in many AI/AN communities<sup>31</sup> and might heighten the risk for introducing HIV into networks of persons who inject drugs if bridging or mixing occurs with the networks of men who have sex with men who use methamphetamines; methamphetamine is also increasingly combined with opioid injection.<sup>32-34</sup> Finally, the increase over time in rates of HCV infection and OUD suggests a need to screen and provide treatment for injection-related blood-borne pathogens such as HCV and HIV.<sup>12</sup>

Few studies have documented OUD among AI/AN persons; among 400 tribal members interviewed in 2009 on a rural Midwestern reservation, nearly 20% reported nonmedical use of OxyContin in the previous year.<sup>35</sup> Our study found

**Table 1.** Number (rate per 10 000 adults) of American Indian/Alaska Native adults aged  $\geq 18$  years with a health care encounter who had an injection drug use (IDU) indicator diagnosis, National Patient Information Reporting System (NPIRS), Indian Health Service (IHS), 2010-2014<sup>a</sup>

Characteristic	HCV Infection, <sup>b</sup> No. (Rate per 10 000 Adults)	Rate Ratio (95% CI)	Arm Cellulitis and Abscess, <sup>c</sup> No. (Rate per 10 000 Adults)	Rate Ratio (95% CI)	Opioid Use Disorder, <sup>c</sup> No. (Rate per 10 000 Adults)	Rate Ratio (95% CI)	Opioid-Related Overdose, <sup>c</sup> No. (Rate per 10 000 Adults)	Rate Ratio (95% CI)
Total <sup>d</sup>	4548 (19.5)	— <sup>e</sup>	17 664 (33.3)	— <sup>e</sup>	20 759 (39.2)	— <sup>e</sup>	1879 (3.5)	—
Sex <sup>f</sup>								
Male	1888 (17.0)	1.00 [Reference]	9385 (38.1)	1.00 [Reference]	9493 (38.6)	1.00 [Reference]	808 (3.3)	1.00 [Reference]
Female	2660 (21.7)	1.28 (1.20-1.35)	8279 (29.2)	0.77 (0.74-0.79)	11 265 (39.7)	1.03 (1.00-1.06)	1071 (3.8)	1.15 (1.05-1.26)
Age, y <sup>f</sup>								
18-29	— <sup>e</sup>	— <sup>e</sup>	7178 (42.8)	2.11 (2.02-2.19)	8356 (49.8)	2.46 (2.36-2.56)	642 (3.8)	1.37 (1.21-1.54)
30-39	— <sup>e</sup>	— <sup>e</sup>	4026 (39.2)	1.93 (1.85-2.02)	5428 (52.9)	2.61 (2.50-2.73)	402 (3.9)	1.40 (1.22-1.60)
40-49	— <sup>e</sup>	— <sup>e</sup>	3024 (33.6)	1.66 (1.58-1.74)	3548 (39.5)	1.95 (1.86-2.04)	361 (4.0)	1.43 (1.25-1.64)
$\geq 50$	— <sup>e</sup>	— <sup>e</sup>	3436 (20.3)	1.00 [Reference]	3427 (20.2)	1.00 [Reference]	474 (2.8)	1.00 [Reference]
Region <sup>f</sup>								
Alaska	435 (20.4)	1.94 (1.73-2.18)	3247 (69.4)	2.74 (2.61-2.86)	2215 (47.4)	2.04 (1.94-2.15)	290 (6.2)	1.78 (1.55-2.04)
East	295 (40.0)	3.81 (3.34-4.35)	671 (37.6)	1.48 (1.37-1.61)	1911 (107.1)	4.62 (4.38-4.88)	78 (4.4)	1.25 (0.99-1.59)
Northern Plains East	338 (22.2)	2.11 (1.86-2.40)	653 (18.1)	0.71 (0.66-0.77)	2763 (76.5)	3.30 (3.14-3.46)	109 (3.0)	0.87 (0.71-1.06)
Northern Plains West	1130 (38.1)	3.63 (3.32-3.96)	2776 (43.4)	1.71 (1.63-1.79)	2318 (36.3)	1.56 (1.49-1.65)	354 (5.5)	1.59 (1.39-1.81)
Southern Plains	1037 (20.3)	1.94 (1.77-2.12)	4074 (33.9)	1.34 (1.28-1.39)	2453 (20.4)	0.88 (0.84-0.93)	279 (2.3)	0.67 (0.58-0.77)
Southwest	841 (10.5)	1.00 [Reference]	4532 (25.4)	1.00 [Reference]	4140 (23.2)	1.00 [Reference]	623 (3.5)	1.00 [Reference]
West	472 (16.4)	1.56 (1.40-1.75)	1711 (25.7)	1.01 (0.96-1.07)	4959 (74.6)	3.22 (3.09-3.35)	146 (2.2)	0.63 (0.53-0.75)
Concurrent IDU indicators <sup>g</sup>								
HCV infection <sup>h</sup>	— <sup>e</sup>	— <sup>e</sup>	— <sup>e</sup>	— <sup>e</sup>	— <sup>e</sup>	— <sup>e</sup>	— <sup>e</sup>	— <sup>e</sup>
Arm cellulitis and abscess <sup>i,j</sup>	315 (1.3)	— <sup>e</sup>	— <sup>e</sup>	— <sup>e</sup>	— <sup>e</sup>	— <sup>e</sup>	— <sup>e</sup>	— <sup>e</sup>
Opioid use disorder <sup>i</sup>	1165 (5.0)	— <sup>e</sup>	982 (1.9)	— <sup>e</sup>	— <sup>e</sup>	— <sup>e</sup>	— <sup>e</sup>	— <sup>e</sup>
Opioid- related overdose <sup>i</sup>	65 (0.3)	— <sup>e</sup>	96 (0.2)	— <sup>e</sup>	509 (1.0)	— <sup>e</sup>	— <sup>e</sup>	— <sup>e</sup>

Abbreviation: HCV, hepatitis C virus.

<sup>a</sup>Data source: National Patient Information Reporting System.<sup>16</sup>

<sup>b</sup>Rates for HCV infection were calculated for adults aged 18-35 at the time of their health care encounter in 2010-2014. The total denominator, 2334 662, is the sum of the IHS NPIRS annual denominators, restricted to persons aged 18-35 years, from 2010-2014. See the Methods section for the description of denominators.

<sup>c</sup>Rates for arm cellulitis and abscess, opioid use disorder, and opioid-related overdose were calculated for adults aged  $\geq 18$  years at the time of their health care encounter in 2010-2014. The total denominator, 5 297 475, is the sum of the NPIRS annual denominators, restricted to persons aged  $\geq 18$  years, from 2010-2014. See the Methods section for the description of denominators.

<sup>d</sup>Total number of persons meeting the criteria for the IDU indicator specified in the column header.

<sup>e</sup>Cell is empty for one of the following reasons: (1) statistic cannot be calculated, (2) characteristic is not applicable, or (3) a comparison is already recorded.

<sup>f</sup>Data on sex, age, and region were captured from the first health care encounter in which the person met the criteria for the IDU indicator specified in the column header.

<sup>g</sup>For this section of the analysis on concurrent IDU indicators, data were captured for having an IDU indicator if a person (1) met the age criteria for the specified diagnosis, (2) had that diagnosis at any point during the study period, and (3) met the criteria specified in the column header.

<sup>h</sup>Diagnosed while the person was aged 18-35 years.

<sup>i</sup>Diagnosed while the person was aged 18-35 years when combined with data in the HCV Infection column and diagnosed while aged  $\geq 18$  years when combined with data in the columns for arm cellulitis and abscess, opioid use disorder, and opioid-related overdose.

<sup>j</sup>Data for arm cellulitis and abscess were counted only for persons with no diabetes diagnosis in the IHS data (since 2001) on or before the first diagnosis of arm cellulitis or abscess during the study period.

**Table 2.** Percentage of American Indian/Alaska Native adults aged 18-35 years having each combination of injection drug use indicators, overall and by region and sex, Indian Health Service, 2010-2014<sup>a</sup>

Indicator	Region						Sex			Total <sup>b</sup>	Cumulative <sup>c</sup>
			Northern Plains East	Northern Plains West	Southern Plains	Southwest	West	Male	Female		
	Alaska	East									
Total <sup>d</sup>	55 101	20 372	42 677	77 126	142 644	189 385	75 906	286 908	316 289	603 211 <sup>e</sup>	603 211 <sup>e</sup>
No IDU indicators <sup>f</sup>	51 959 (94.3)	18 678 (91.7)	40 372 (94.6)	73 163 (94.9)	138 168 (96.9)	184 017 (97.2)	71 796 (94.6)	274 689 (95.7)	303 450 (95.9)	578 153 <sup>e</sup> (95.9)	578 153 <sup>e</sup> (95.9)
≥1 IDU indicator <sup>f</sup>	3142 (5.7)	1694 (8.3)	2305 (5.4)	3963 (5.1)	4476 (3.1)	5368 (2.8)	4110 (5.4)	12 219 (4.3)	12 839 (4.1)	25 058 (4.2)	25 058 (4.2)
1 IDU indicator, no. (%) <sup>g</sup>											
Opioid use disorder	996 (31.7)	987 (58.3)	1600 (69.4)	1010 (25.5)	1235 (27.6)	1685 (31.4)	2696 (65.6)	4833 (39.6)	5376 (41.9)	10 209 (40.7)	12 039 (48.0)
Arm cellulitis	1469 (46.8)	326 (19.2)	283 (12.3)	1616 (40.8)	2044 (45.7)	2500 (46.6)	773 (18.8)	4863 (39.8)	4148 (32.3)	9011 (36.0)	9834 (39.2)
HCV infection	226 (7.2)	78 (4.6)	205 (8.9)	858 (21.7)	863 (19.3)	670 (12.5)	314 (7.6)	1352 (11.1)	1862 (14.5)	3214 (12.8)	4548 (18.1)
Opioid-related overdose	91 (2.9)	13 (0.8)	27 (1.2)	123 (3.1)	67 (1.5)	230 (4.3)	41 (1.0)	277 (2.3)	315 (2.5)	592 (2.4)	893 (3.6)
2 IDU indicators, no. (%) <sup>g</sup>											
HCV infection and OUD	138 (4.4)	172 (10.2)	99 (4.3)	186 (4.7)	115 (2.6)	128 (2.4)	128 (3.1)	375 (3.1)	591 (4.6)	966 (3.9)	1165 (4.6)
OUD and arm cellulitis	95 (3.0)	59 (3.5)	40 (1.7)	45 (1.1)	66 (1.5)	58 (1.1)	99 (2.4)	231 (1.9)	231 (1.8)	462 (1.8)	635 (2.5)
HCV infection and arm cellulitis	12 (0.4)	—	11 (0.5)	52 (1.3)	38 (0.8)	24 (0.4)	12 (0.3)	69 (0.6)	83 (0.6)	152 (0.6)	315 (1.3)
OUD and opioid-related overdose	46 (1.5)	12 (0.7)	16 (0.7)	27 (0.7)	20 (0.4)	44 (0.8)	25 (0.6)	108 (0.9)	82 (0.6)	190 (0.8)	251 (1.0)
HCV infection and opioid-related overdose	—	—	—	—	—	—	—	7 (0.1)	7 (0.1)	14 (0.1)	65 (0.3)
Arm cellulitis and opioid-related overdose	8 (0.3)	—	—	9 (0.2)	—	6 (0.1)	—	14 (0.1)	19 (0.1)	33 (0.1)	58 (0.2)
3 IDU indicators, no. (%) <sup>g</sup>											
HCV infection, OUD, and arm cellulitis	36 (1.1)	36 (2.1)	13 (0.6)	22 (0.6)	16 (0.4)	13 (0.2)	15 (0.4)	63 (0.5)	88 (0.7)	151 (0.6)	160 (0.6)
HCV infection, OUD, and opioid-related overdose	13 (0.4)	—	6 (0.3)	7 (0.2)	—	—	—	15 (0.1)	24 (0.2)	39 (0.2)	48 (0.2)
OUD, arm cellulitis, opioid-related overdose	—	—	—	—	—	—	—	5 (0.04)	8 (0.1)	13 (0.1)	22 (0.1)

(continued)

**Table 2.** (continued)

Indicator	Region						Sex		Total <sup>b</sup>	Total Cumulative <sup>c</sup>
	Alaska	East	Northern Plains East	Northern Plains West	Southern Plains	Southwest	West	Male		
			—	—	—	—	—	—		
HCV infection, arm cellulitis, opioid-related overdose	—	—	—	—	—	—	—	—	—	12 (0.1)
All 4 IDU indicators, no. (%) <sup>d</sup>	—	—	—	—	—	—	—	—	5 (0.04)	9 (0.04)
HCV infection, OUD, arm cellulitis, opioid-related overdose	—	—	—	—	—	—	—	—	9 (0.04)	9 (0.04)

Abbreviations: —, data suppressed because <5 persons had diagnosis; HCV, hepatitis C virus; IDU, injection drug use; OUD, opioid use disorder.

<sup>a</sup>Data source: National Patient Information Reporting System.<sup>16</sup>

<sup>b</sup>The total number of persons who were in only the specified category. For example, the 3214 persons with HCV infection did not have any other indicator, and the 151 persons with HV infection, OUD, and arm cellulitis did not have opioid-related overdose.

<sup>c</sup>This is the total that had the specified indicator, but they could have also been classified into another category. For example, 4548 persons had HCV infection. These persons could have been classified into the category of HCV infection alone, or they could also have been classified into the categories of HCV infection and arm cellulitis, HCV infection and OUD, and so forth.

<sup>d</sup>Total number of Indian Health Service users aged 18-35 with a health care encounter (inpatient hospitalization, emergency department visit, or outpatient clinical visit) in 2010-2014.

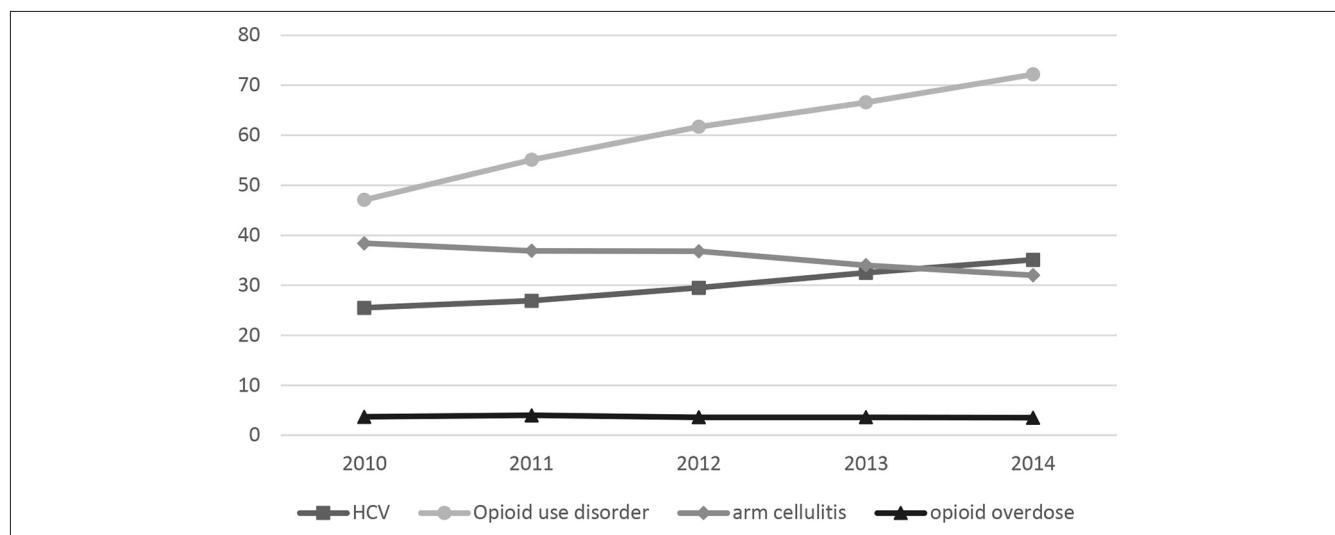
<sup>e</sup>Information on sex was missing from 14 persons.

<sup>f</sup>Percentages are based on total numbers.

<sup>g</sup>Percentages are based on number of persons with  $\geq 1$  IDU indicator.

that OUD was common, with increasing rates over time and substantial regional differences. However, trends in opioid-related overdose were stable, which was unexpected given that national data for AI/AN persons show increasing rates of opioid-related overdose.<sup>36,37</sup> Our discrepant findings may be

due to inadequate capture of data on fatal overdose events in the health records database for persons outside health care settings and misclassification of OUD as other injury events in medical records.<sup>38</sup> In addition, synthetic opioids such as fentanyl are associated with the largest increase in



**Figure 2.** Overall national annual rates (per 10 000 adults) of diagnoses among American Indian/Alaska Native persons for hepatitis C virus (HCV) infection, opioid use disorder, arm cellulitis and abscess, and opioid-related overdose, Indian Health Service, 2010-2014. Rates of diagnoses represent 1 health care encounter per person per year. Data for HCV infections are for adults aged 18-35; all other data are for adults aged  $\geq 18$ . Arm cellulitis was counted only among adults with no diabetes on or before the health care encounter for arm cellulitis visit (since 2001). Data source: National Patient Information Reporting System.<sup>16</sup>

opioid-related overdose deaths in the US general population.<sup>39</sup> The use of synthetic opioids is also affecting AI/AN persons,<sup>40,41</sup> but the availability of these drugs may have varied by community or region and been potentially lower in AI/AN communities than in the US general population during our study period.

Unlike rates of HCV infection and OUD, rates of arm cellulitis and abscess decreased during 2010-2014. Historical rates of hospitalization for skin and soft-tissue infection are higher among AI/AN persons than among other racial/ethnic groups, and the decrease in rates of arm cellulitis and abscess found in our study could be related to non-IDU factors, such as interventions that address the high rates of skin and soft-tissue infection.<sup>42</sup> Examining rates of arm cellulitis and abscess in the context of a concurrent IDU-related diagnosis of HCV infection or OUD is expected to increase the specificity of arm cellulitis and abscess as an indicator of IDU. Other studies relied on a single diagnosis, such as acute HCV infection or endocarditis, as a starting point for approximating county levels of IDU and then used multiple indicators.<sup>9,43</sup> Acute HCV infection is not a reliable measure for study in NPIRS because it is often asymptomatic and not recorded; other frequently used indicators, such as endocarditis, are not commonly managed in the IHS system.

Our assessment of the rates of HCV infection and OUD among AI/AN persons, whose tribal areas are not defined by US counties, suggests that the relatively high burden of these conditions among AI/AN persons, compared with other racial/ethnic populations, may not have been apparent in national county-level analyses that used acute HCV infection as an indicator across racial/ethnic populations.<sup>9</sup> The landmark county-level vulnerability study by Van Handel et al, which relied on acute HCV infection as an indicator, identified 220 US counties at risk for rapid spread of HIV and HCV infection via IDU and brought attention to areas that had few existing public health resources to spur mobilization of HIV and HCV infection prevention efforts.<sup>9</sup> Although the vulnerability analysis by Van Handel et al differed substantially from our study in objectives and methodology, some of the outcomes in our study are consistent with those in the vulnerability analysis, and we expected them. However, our study resulted in several unexpected outcomes; we identified regions not previously considered vulnerable, at least not for AI/AN populations. For example, the burden of HCV infection and OUD in the East in our study was consistent with the burden described by Van Handel et al. However, in our study, by region, Northern Plains West had the second highest rate of HCV infection and Northern Plains East had the second highest rate of OUD. On the basis of the vulnerability analysis, we did not expect either of these outcomes. Rates of OUD were also unexpectedly high in the West. Our findings add to the national data on IDU risk, illustrate the value of exploring a range of approaches and data sources, and provide evidence to support the need for broader distribution of opioid-related

prevention and treatment resources beyond the most vulnerable counties previously identified.<sup>9,44</sup>

The rise of HCV infection and OUD in AI/AN communities is deeply rooted in many social determinants of health that may manifest themselves in other substance use disorders, such as alcohol and methamphetamine use. Historical trauma is a well-documented factor associated with substance use disorders among many AI/AN persons who are raised in intergenerational traumas, such as forced removals like the Trail of Tears and mandatory boarding school attendance.<sup>45</sup> Resilience in the face of these traumas is an important strength in AI/AN communities and can help tribes identify culturally appropriate solutions unique to each tribe's needs. For example, OUD treatments might need to be adapted to preserve unique cultural holistic and traditional healing practices. In exploring the cultural and logistic considerations for implementing medication-assisted treatment in tribal communities, Venner et al observed that using medication (eg, buprenorphine/naloxone) for treatment conflicted with some traditional healing practices that require a person not to take medications. This conflict has considerable implications for the delivery of medication-assisted treatment in AI/AN communities.<sup>4</sup>

### Limitations

Our study had several limitations. First, we did not include all infectious disease complications of IDU in our analysis. We did not consider hepatitis B or HIV infections because the prevalence of HCV infection is higher than the prevalence of hepatitis B or HIV infection in persons who inject drugs.<sup>46-48</sup> We excluded adults aged >35 with HCV infection to limit the influence of chronic HCV infection among baby boomers (born 1945-1965) who are screened according to the Centers for Disease Control and Prevention recommendations.<sup>49,50</sup> Second, our data do not represent all AI/AN persons living in the United States, so our results cannot be generalized outside our study populations. Not all persons who identify as AI/AN use IHS-funded health care; 5.2 million adults and children in the United States self-identified as AI/AN in the 2010 US Census,<sup>51</sup> but only 1.2 million AI/AN adults were represented in our NPIRS analysis (which includes only members of the 573 federally recognized tribes who use IHS-provided care). Consequently, AI/AN adults who did not have a health encounter with the Indian health system in the past 3 years were not included in our analysis, and data on any health care encounter or diagnosis made outside Indian health I/T/U facilities or contracted care were not captured. Finally, restrictions on geographic analysis of IHS data required aggregating our analytic findings into large regions with sociodemographically and culturally diverse characteristics. Regional results must be interpreted cautiously to avoid generalizations about persons living in these large and diverse regions. Despite these limitations, our analysis adds important information about the relative burden of

and increasing trends in HCV infection and OUD among the population of AI/AN persons served by I/T/U facilities and should be considered in public health planning and resource allocation.

## Conclusion

Each tribal community in the United States has unique characteristics and will determine its own approach to addressing IDU among its members. Interested tribes could initiate exploration of tribe-specific data that are researched, analyzed, and disseminated internally, so that they can define their own data and program needs. However, our data offer compelling evidence for tribes already seeing anecdotal increases in IDU and, along with national data, could be used to support culturally appropriate interventions such as comprehensive syringe services programs, access to medication-assisted treatment, and opioid-related overdose prevention as well as to bolster treatment capacity for the rising number of IHS patients infected with HCV. Our analysis showed concerning trends in HCV infection and OUD among AI/AN persons and identified regional hotspots in which few counties were identified as vulnerable in a national vulnerability assessment.<sup>9</sup> These data reinforce the need for continued public health action to avert further IDU-related consequences and can help tribes allocate resources and plan policies to improve opioid-related overdose prevention and harm reduction in AI/AN communities.

## Disclaimer

The findings and conclusions in this article are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention or the Indian Health Service.

## Acknowledgments

We appreciate thoughtful insights from Vickie L. Bradley, Secretary, Public Health and Human Resources Eastern Band of Cherokee Indians, and Ginger Southard, Program Manager, Syringe Services Eastern Band of Cherokee Indians, who informed interpretations in this article. We also thank Melissa M. Smith, in the Geospatial Research, Analysis and Services Program at the Centers for Disease Control and Prevention, for assistance in preparation of the map.

## Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The authors declared no financial support with respect to the research, authorship, and/or publication of this article.

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# Geovisualization and Spatial Analysis of Infant Mortality and Preterm Birth in Ohio, 2008-2015: Opportunities to Enhance Spatial Thinking

Public Health Reports  
2020, Vol. 135(4) 472-482  
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DOI: 10.1177/0033354920927854  
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## Abstract

**Objectives:** Geovisualization and spatial analysis are valuable tools for exploring and evaluating the complex social, economic, and environmental interactions that lead to spatial inequalities in health. The objective of this study was to describe spatial patterns of infant mortality and preterm birth in Ohio by using interactive mapping and spatial analysis.

**Methods:** We conducted a retrospective cohort study using Ohio vital statistics records from 2008-2015. We geocoded live births and infant deaths by using residential address at birth. We used multivariable logistic regression to adjust spatial and space-time cluster analyses that examined the geographic clustering of infant mortality and preterm birth and changes in spatial distribution over time.

**Results:** The overall infant mortality rate in Ohio during the study period was 6.55 per 1000 births; of 1 097 507 births, 10.3% ( $n = 112\,552$ ) were preterm. We found significant geographic clustering of both infant mortality and preterm birth centered on large urban areas. However, when known demographic risk factors were taken into account, urban clusters disappeared and, for preterm birth, new rural clusters appeared.

**Conclusions:** Although many public health agencies have the capacity to create maps of health outcomes, complex spatial analysis and geovisualization techniques are still challenging for public health practitioners to use and understand. We found that actively engaging policymakers in reviewing results of the cluster analysis improved understanding of the processes driving spatial patterns of birth outcomes in the state.

## Keywords

GIS, geospatial analysis, spatial clusters, infant mortality, preterm birth, program planning, spatial thinking

Geographic information systems (GIS) have become ubiquitous in public health.<sup>1-4</sup> Most state health departments routinely use GIS; the extent to which it is used at the local level varies, however, with many local health departments citing GIS as an area for workforce development.<sup>5,6</sup> Training public health practitioners in geospatial technologies does not necessarily enable them to understand the patterns and processes that shape multiscale patterns of health, unless they also learn to think spatially. Spatial thinking involves understanding relationships within and between spatial structures, and a wide variety of visualizations (from drawings to computer models) provides the means to communicate about them.<sup>7</sup> In public health, spatial thinking permits researchers and practitioners to comprehend the relative locations of complex

social, economic, environmental, and demographic interactions that produce patterns of health and disease. Spatial thinking and reasoning skills are not routinely integrated into public health curricula in institutions of higher education, however, despite being even more valuable today than previously because of the widespread use of geospatial technologies.

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In 2016, the state of Ohio began using data analytics, including geospatial analysis and geovisualization, in new ways to better understand how to identify women at risk for poor birth outcomes and to inform initiatives addressing infant mortality. Geovisualization is a process by which tools such as GIS and mapping are used to support analysis of complex geospatial data in an interactive and comprehensible way. This effort was in response to the high infant mortality rate in Ohio, which consistently ranks 45th in the nation. Although rates in Ohio have decreased considerably since the early 1990s, from a high of 9.8 per 1000 live births in 1990 to 7.2 per 1000 live births in 2017, rates have stagnated since 2013. Furthermore, racial disparities (between African American and non-Hispanic white populations) in infant mortality in Ohio persist: African American infants die at nearly 3 times the rate as non-Hispanic white infants (15.6 vs 5.3 per 1000 births in 2017).<sup>8</sup> Spatial variation in infant mortality also exists across Ohio, driven by racial segregation and social and structural inequalities in access to health care, quality housing, environmental conditions, employment and educational opportunities, and perceived racism and discrimination.<sup>9,10</sup>

Recognizing that a coordinated effort, grounded in Ohio-specific data, was needed to address sociospatial inequalities in birth outcomes, the Ohio Department of Health, the Ohio Department of Medicaid, and the Ohio Department of Higher Education jointly established the Infant Mortality Research Partnership (IMRP), a collaboration between state health agencies and researchers at institutions of higher education in Ohio. One objective of this government-academic partnership was to use GIS and geospatial analysis to map small-area estimates of infant mortality and preterm birth, find areas with higher-than-expected rates, and examine the placement and effect of various initiatives that address birth outcomes. One such initiative is the Ohio Equity Institute (OEI), a collaboration between the Ohio Department of Health and local partners that targets community-specific causes of infant mortality in 9 OEI-designated counties (Figure 1).<sup>11</sup> The Ohio Department of Health selected these 9 counties because they collectively accounted for 59% of all infant deaths in the state and programs in these counties would be likely to have the greatest effect on preterm birth and infant mortality. Although the methods used by IMRP are not new<sup>14,15</sup> (numerous studies examine spatial patterns of preterm birth<sup>16,17</sup> and infant mortality),<sup>18-21</sup> what is new is

the partnership's objective to increase state capacity for spatial thinking. IMRP challenged policymakers to examine spatial patterns in birth outcomes and reframe policy questions in terms of the interrelationship between health and complex social and economic issues.

The objectives of this study were to (1) evaluate spatial patterns of infant mortality and preterm birth in Ohio and (2) examine changes in these outcomes over time, especially in OEI counties with programs that targeted reductions in these outcomes.

## Methods

### Data Sources

We conducted a retrospective cohort study of the spatial distribution of infant mortality and preterm birth in Ohio. We extracted data from the Ohio linked birth certificate and death certificate files for births that occurred from January 1, 2008, through December 31, 2015. We limited the sample to births with a gestation of >20 weeks. Although the medical literature generally agrees that 23 weeks is the lowest threshold for viability, we included earlier births because we were interested in the spatial patterns of mortality rather than individual determinants of early birth, and we did not want to risk biasing these spatial patterns with more stringent exclusion criteria. We defined preterm births as births occurring before 37 weeks of gestation (among births with a gestation of >20 weeks). We collected data on maternal age, race/ethnicity (non-Hispanic white, non-Hispanic black, non-Hispanic other, Hispanic, or unknown), education (<high school diploma, high school diploma or equivalent, some college, bachelor's or advanced degree, or unknown), and address at birth from the birth records. The Ohio linked birth-death certificate files contained data on 1 132 756 births, 118 149 preterm births, and 8352 infant deaths during the study period.

We geocoded records by using the address at birth with a 95% successful match rate. Examination of ungeocoded records suggested there were proportionally more rural records and post office boxes than geocoded records. We assigned coordinates for latitude and longitude to a census tract, which we used as the unit of analysis for the study. We excluded data on 3470 births to mothers residing outside the state. We excluded an additional 33 779 records from the

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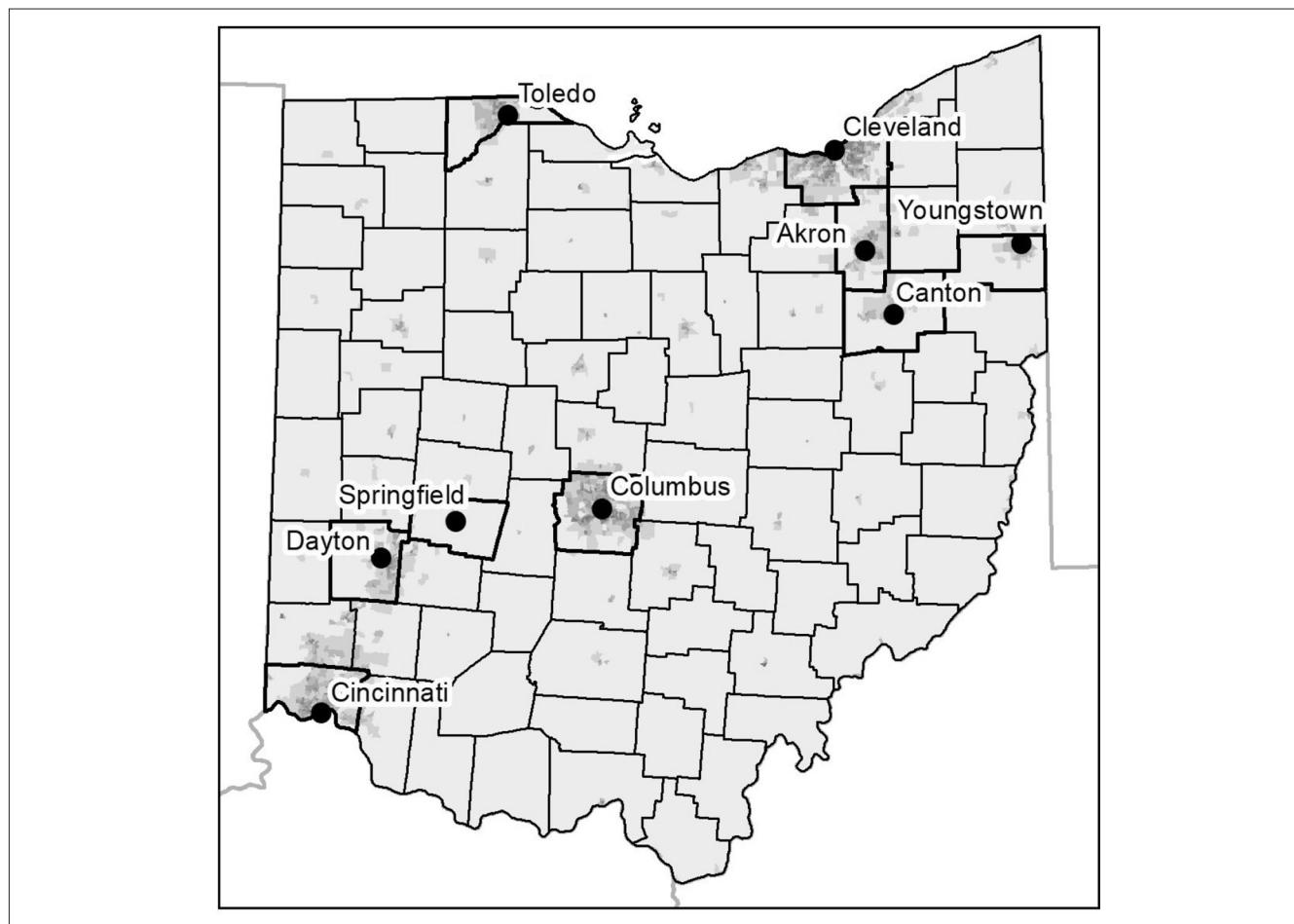
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**Figure 1.** Major cities in Ohio and the 9 corresponding Ohio Equity Institute (OEI) counties. OEI comprises local programs that target community-specific causes of infant mortality.<sup>11</sup> Map background shows population density (the darker the shade, the higher the density), and the thick black outline indicates OEI counties. Data source: Author analysis of US Census Bureau cartographic boundary files<sup>12</sup> and 2014-2017 American Community Survey data.<sup>13</sup>

final analysis because they were not matched during the geocoding process. The final sample included 1 097 507 births, 112 552 preterm births, and 7193 infant deaths from all 2946 census tracts in Ohio.

We produced maps by using the US Census Bureau cartographic boundary files for state, county, and census tract boundaries.<sup>12</sup> We obtained additional population data by census tract from the 2013-2017 American Community Survey.<sup>13</sup>

This project was reviewed and approved by The Ohio State University Institutional Review Board (approval no. 2016B0291).

### Statistical Methods

We generated several sets of descriptive maps of infant mortality and preterm birth by using spatial empirical Bayes smoothing methods. We used smoothing methods because small-area estimates typically result in unstable rates. Rate

smoothing is a technique used to (1) stabilize rates based on small numbers and (2) reduce extreme values in rates caused by various population sizes.<sup>22</sup> We used a technique that computes a weighted average between the raw rate for each census tract and the local average (based on a first-order queen's contiguity weights matrix), with weights proportional to the underlying population of births. We applied this method to all census tracts in Ohio. The method results in various levels of adjustment: rates in areas with a large population may have little adjustment, whereas rates in areas with small populations may have considerable adjustment. We implemented this technique in GeoDa version 1.12.1<sup>23</sup>; details of this technique are described elsewhere.<sup>24</sup> To display data on the descriptive maps, we applied a quantile classification system, which divides data into groups so that the total number of areas included in each class are approximately equal.

We used Kulldorff's space and space-time scan statistics to identify groups of census tracts with higher-than-expected

rates of infant mortality and preterm birth (high rates only, ie, hotspots).<sup>25,26</sup> This method creates a large number of overlapping circular windows, centered on each census tract in the study area, which are allowed to vary in size to include a minimum of 1% to a maximum of 30% of the population at risk (ie, births). The number of observed and expected cases of infant mortality or preterm birth inside and outside each circle is tabulated and used to calculate a log likelihood ratio test statistic. The circle with the maximum likelihood is the most likely cluster, that is, the cluster with a significantly higher number of observed cases than the number of cases expected given the underlying population of births. We applied the discrete Poisson model using counts of infant mortality or preterm birth (cases) and total births (population denominator) in each census tract. We ran models with alternative maximums (up to 50% of the population at risk), but we found that models >30% identified similar clusters with the same set of core tracts. We evaluated significance by using standard Monte Carlo methods using 999 random replicas of the data set. We reported only clusters with a *P* value < .05. We also computed relative risks (RRs), calculated as the observed number of cases divided by the expected number of cases within the cluster, divided by the observed-over-expected cases outside the cluster. For space-time scan statistics, we used the same model parameters and set the minimum time aggregation to 1 month and the maximum to the entire study period. We used this maximum because we wanted to account for temporally persistent spatial clusters.

We conducted 2 cluster analyses. In the unadjusted analysis, we calculated the expected number of infant mortality or

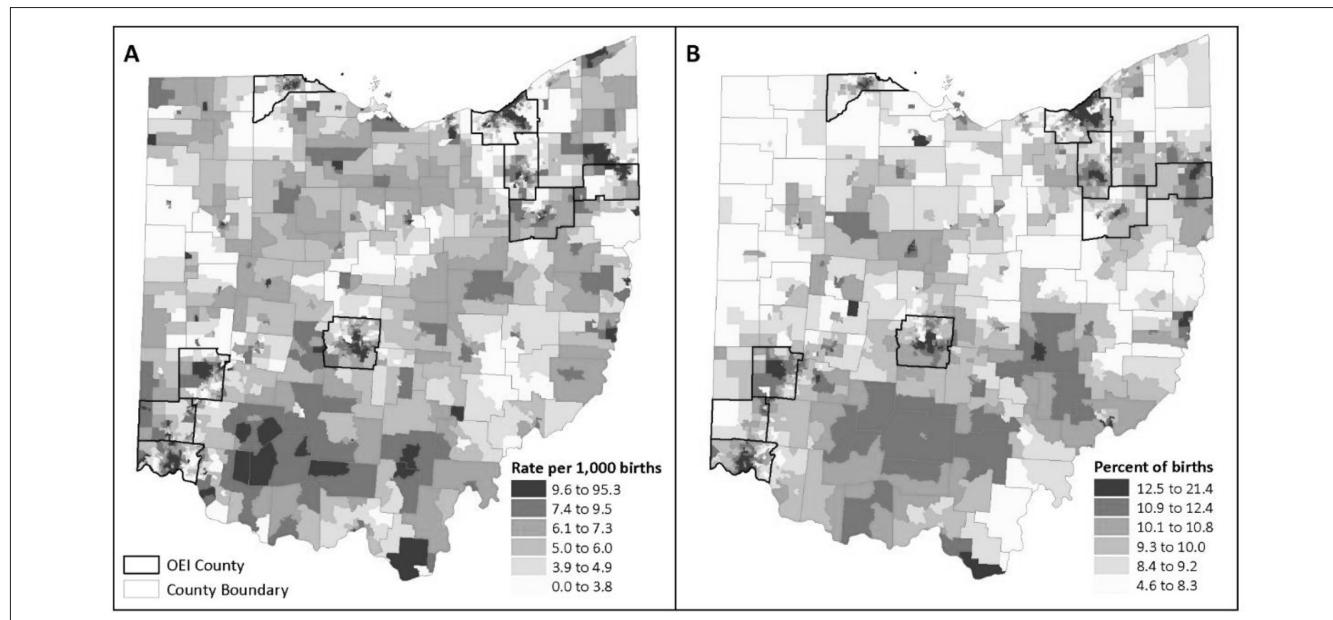
preterm birth events in a census tract by multiplying the total number of births in the census tract by the statewide rate. In the adjusted analyses, we calculated the expected number of events by using the predicted probabilities of infant mortality or preterm birth derived from a multivariable regression model containing maternal demographic characteristics that have an uneven spatial distribution: age, race/ethnicity, and education.<sup>27,28</sup> This extra step allowed us to examine whether the observed clusters were due to the underlying characteristics of the birth population (eg, maternal age, race/ethnicity, or education) or some other factor not included in the multivariate model. We cleaned data and conducted the analysis in R version 3.4.2,<sup>29</sup> SAS version 9.4,<sup>30</sup> and SaTScan,<sup>31</sup> and we created maps in ArcMap version 10.6.<sup>32</sup>

## Results

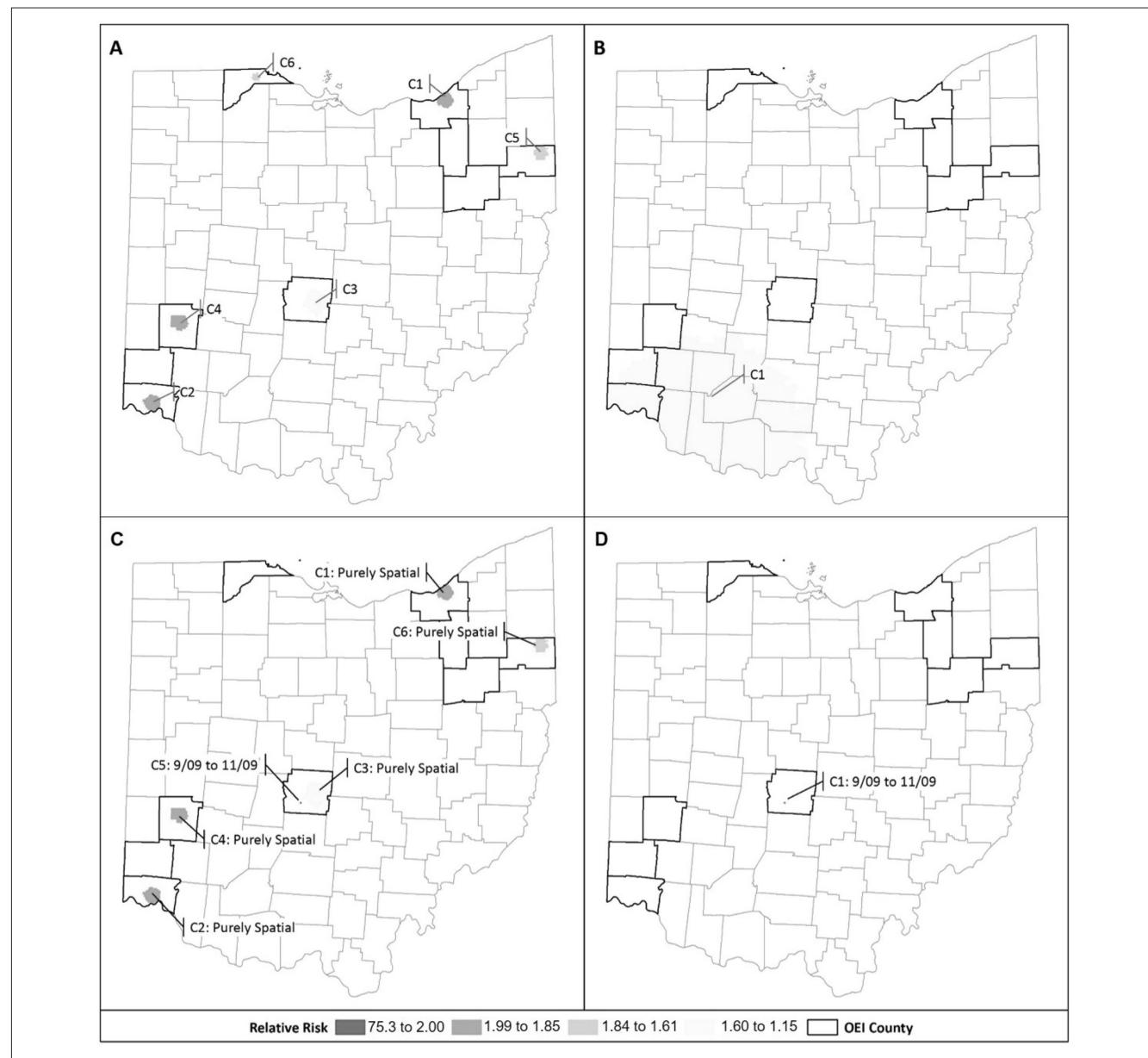
Both infant mortality and preterm birth were centered on the urban areas of the state (Figure 2). We identified a region of high rates of infant mortality in the rural southern counties to the east of Cincinnati and Dayton. We also identified a band of high rates that ran along rural Appalachia from south to southeast.

### Infant Mortality

The unadjusted spatial cluster analysis of infant mortality (Figure 3A and Table 1) indicated 5 significant clusters



**Figure 2.** Empirical Bayes smoothed rate maps for (A) infant mortality and (B) preterm births as a percentage of all births in Ohio, 2008-2015. The Ohio Equity Institute (OEI) comprises local programs that target community-specific causes of infant mortality in 9 counties.<sup>11</sup> Map classes were developed by using a quantile classification system. Data source: Author analysis of Ohio Department of Health linked birth-death certificate files and US Census Bureau cartographic boundary files.<sup>12</sup>



**Figure 3.** Clusters (indicated by “C”) of infant mortality, birth cohort 2008-2015 in Ohio, resulting from the (A) spatial unadjusted model; (B) spatial model, adjusted for maternal age, race/ethnicity, and education; (C) space–time unadjusted model; and (D) space–time model, adjusted for maternal age, race/ethnicity, and education. The adjusted space–time model resulted in 1 cluster (C1), in which the relative risk of infant mortality was 75.3. The Ohio Equity Institute (OEI) comprises local programs that target community-specific causes of infant mortality in 9 counties.<sup>11</sup> Data source: Author analysis of Ohio Department of Health linked birth–death certificate files and US Census Bureau cartographic boundary files.<sup>12</sup>

centered on 6 major urban areas in Ohio (Cincinnati, Cleveland, Columbus, Dayton, Toledo, and Youngstown). Relative risks ranged from 1.52 to 1.94, indicating a 52% to 94% greater risk of death among infants born in these clusters than among infants born elsewhere in the state. When we adjusted these clusters for maternal age, race/ethnicity, and education (Figure 3B and Table 1), all the urban clusters disappeared, but we found a cluster (C1) spanning Cincinnati and the rural area

to the east, indicating a higher-than-expected number of deaths given the age and race distribution of the population of births in that area ( $RR = 1.17; P = .01$ ).

The unadjusted space–time analysis of infant mortality (Figure 3C and Table 1) indicated that nearly all clusters were temporally persistent, meaning that the higher-than-expected number of infant deaths in these areas occurred across the entire study period. The clusters were again centered on 6

**Table 1.** Unadjusted and adjusted spatial and spatiotemporal cluster results for infant mortality, birth cohort 2008-2015 (N = 1 097 507 births), Ohio<sup>a</sup>

Cluster Number <sup>b</sup>	Date	Observed No. of Cases	Expected No. of Cases	Relative Risk	Log Likelihood Ratio	P Value <sup>c</sup>
<b>Spatial Analysis</b>						
Unadjusted (Figure 2A)						
Cluster 1	—	368	198	1.90	59.91	.001
Cluster 2	—	359	198	1.86	54.82	.001
Cluster 3	—	466	314	1.52	33.67	.001
Cluster 4	—	137	71	1.94	24.25	.001
Cluster 5	—	127	70	1.84	19.29	.001
Cluster 6	—	87	48	1.81	12.51	.01
Adjusted (Figure 2B)						
Cluster 1	—	1432	1261	1.17	13.52	.01
<b>Spatiotemporal Analysis</b>						
Unadjusted (Figure 2C)						
Cluster 1	2008-2015	368	198	1.90	60.12	.001
Cluster 2	2008-2015	359	197	1.86	55.01	.001
Cluster 3	2008-2015	466	314	1.52	33.54	.001
Cluster 4	2008-2015	137	71	1.95	24.37	.001
Cluster 5	September–November 2009	6	0	67.78	19.38	.01
Cluster 6	2008-2015	127	69	1.84	19.30	.01
Adjusted (Figure 2D)						
Cluster 1	September–November 2009	6	0	75.34	20.01	.002

Abbreviation: —, not applicable.

<sup>a</sup>Data sources: US Census Bureau cartographic boundary files<sup>12</sup> and Ohio Department of Health linked birth–death certificate files.

<sup>b</sup>Cluster numbers correspond to the numbers on maps in Figure 3.

<sup>c</sup>P values generated through Monte Carlo replications of the log likelihood ratio test statistic; P < .05 was considered significant.

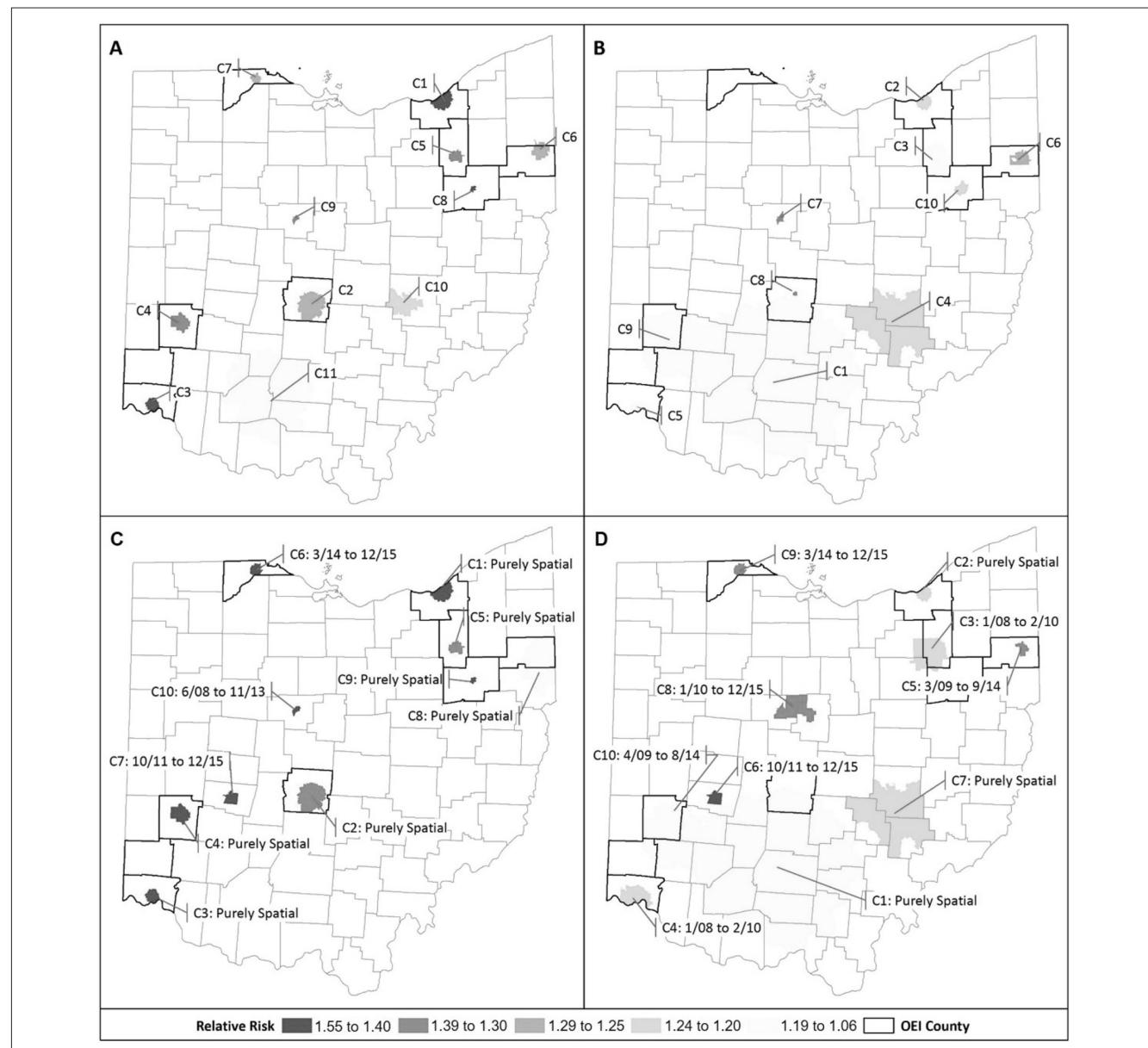
major urban areas of the state (Cincinnati, Cleveland, Columbus, Dayton, Toledo, and Youngstown), where the RR ranged from 1.52 to 67.78. In the space–time analysis adjusted for maternal age, race/ethnicity, and education (Figure 3D and Table 1), all clusters disappeared except for a cluster (Cluster 1) in south Columbus (RR = 75.3; P = .001).

### Preterm Birth

The unadjusted spatial cluster analysis (Figure 4A and Table 2) indicated 8 clusters of preterm birth in 8 urban areas (Akron, Canton, Cincinnati, Cleveland, Columbus, Dayton, Toledo, and Youngstown). Three small rural areas east of Cincinnati and north and east of Columbus also had a higher-than-expected risk. Relative risks ranged from 1.14 to 1.43, indicating that infants born in these clusters had a 14% to 43% greater risk of preterm birth than infants born outside these clusters. When we adjusted for maternal age, race/ethnicity, and education (Figure 4B and Table 2), we found a reduction in RRs in all urban clusters. The 2 rural clusters to the east (C4) and south (C1) of Columbus became much larger, essentially covering the entire rural Appalachian

region in the southeast portion of the state. These 2 areas had higher-than-expected rates given the age and racial/ethnic distribution of mothers who gave birth in these areas.

Similar to the space–time analysis of infant mortality, the space–time analysis of preterm birth indicated that most clusters of preterm birth were temporally persistent. The space–time clusters in Akron, Canton, Cincinnati, Cleveland, Columbus, Dayton, and Youngstown were nearly identical to the spatial clusters and spanned the entire study period (Figure 3C and Table 2). The cluster of preterm births in Toledo (C6) occurred in the last 2 years of the study period (March 2014 through December 2015), and a small cluster of preterm births to the east of Dayton (C7) occurred in the last 4 years of the study period (November 2011 through December 2015). The small cluster of preterm births to the north of Columbus (C10) occurred primarily during the early part of the study period (June 2008 through November 2013). When we adjusted for maternal characteristics, we observed changes in the timing of the clusters in the urban areas (Figure 3D). The 2 other spatial clusters of preterm births identified in the adjusted analysis were in rural Appalachia (C1 and C7), indicating a higher-than-expected number of



**Figure 4.** Cluster analysis of preterm birth, birth cohort 2008-2015 in Ohio, resulting from the (A) spatial unadjusted model; (B) spatial model, adjusted for maternal age, race/ethnicity, and education; (C) space-time unadjusted model; and (D) space-time model, adjusted for maternal age, race/ethnicity, and education. The Ohio Equity Institute (OEI) comprises local programs that target community-specific causes of infant mortality in 9 counties.<sup>11</sup> Data source: Author analysis of Ohio Department of Health linked birth-death certificate files and US Census Bureau cartographic boundary files.<sup>12</sup>

preterm births given the age and racial/ethnic distribution of mothers who gave birth in these regions.

## Discussion

Various statewide and community-based initiatives exist to reduce infant mortality in Ohio. By using geospatial analysis techniques, the IMRP explored the complex sociospatial relationships that are key to understanding spatial

inequalities in infant mortality and preterm birth. Through a series of quarterly presentations and community-based workshops, the partnership presented results to a wide range of organizations engaged in health and human services. Partners were challenged to think critically about the spatial patterns observed in maps and question the social, economic, environmental, and structural factors that might influence those patterns. Here, we discuss our results in light of conversations with state and local partners.

**Table 2.** Unadjusted and adjusted spatial and spatiotemporal cluster results for preterm birth, birth cohort 2008-2015 (N = 1 097 507 births), Ohio<sup>a</sup>

Cluster Number <sup>b</sup>	Date	Observed No. of Cases	Expected No. of Cases	Relative Risk	Log Likelihood Ratio	P Value <sup>c</sup>
<b>Spatial Analysis</b>						
Unadjusted (Figure 3A)						
Cluster 1	—	6259	4462	1.43	336.36	.001
Cluster 2	—	7176	5763	1.26	169.94	.001
Cluster 3	—	3012	2165	1.40	150.86	.001
Cluster 4	—	1792	1292	1.39	87.46	.001
Cluster 5	—	2123	1608	1.33	75.94	.001
Cluster 6	—	1590	1265	1.26	38.97	.001
Cluster 7	—	1543	1231	1.26	37.02	.001
Cluster 8	—	440	312	1.41	23.35	.001
Cluster 9	—	466	348	1.34	18.21	.001
Cluster 10	—	707	574	1.23	14.33	.01
Cluster 11	—	1381	1217	1.14	10.72	.048
Adjusted (Figure 3B)						
Cluster 1	—	11 574	10 406	1.13	69.98	.001
Cluster 2	—	3813	3150	1.22	67.44	.001
Cluster 3	—	4205	3716	1.14	32.01	.001
Cluster 4	—	1243	1005	1.24	26.40	.001
Cluster 5	—	2564	2220	1.16	25.86	.001
Cluster 6	—	1033	823	1.26	24.93	.001
Cluster 7	—	542	401	1.35	22.41	.001
Cluster 8	—	536	406	1.32	19.13	.002
Cluster 9	—	8759	8245	1.07	17.00	.003
Cluster 10	—	641	523	1.23	12.54	.01
<b>Spatiotemporal Analysis</b>						
Unadjusted (Figure 3C)						
Cluster 1	2008-2015	6259	4459	1.43	133.73	.001
Cluster 2	2008-2015	7176	5766	1.26	169.22	.001
Cluster 3	2008-2015	3012	2161	1.40	152.26	.001
Cluster 4	2008-2015	1792	1290	1.40	88.15	.001
Cluster 5	2008-2015	2123	1608	1.33	76.12	.001
Cluster 6	March 2014–December 2015	566	367	1.55	46.49	.001
Cluster 7	October 2011–December 2015	492	335	1.47	32.35	.001
Cluster 8	2008-2015	2354	1995	1.18	31.14	.001
Cluster 9	2008-2015	440	312	1.41	23.38	.001
Cluster 10	June 2008–November 2013	374	264	1.42	20.13	.003
Adjusted (Figure 3D)						
Cluster 1	All years	11574	10407	1.12	69.77	.001
Cluster 2	2008-2015	3813	3149	1.22	67.65	.001
Cluster 3	July 2008–November 2012	2279	1873	1.22	41.97	.001
Cluster 4	January 2008–February 2010	2098	1736	1.21	35.89	.001
Cluster 5	March 2009–September 2014	618	447	1.38	29.33	.001
Cluster 6	October 2011–December 2015	492	344	1.43	28.17	.001
Cluster 7	January 2008–December 2015	1243	1005	1.24	26.42	.001
Cluster 8	January 2010–July 2015	532	384	1.39	25.69	.001
Cluster 9	March 2014–September 2015	498	363	1.37	22.65	.001
Cluster 10	April 2009–August 2014	5679	5248	1.09	18.04	.047

Abbreviation: —, not applicable.

<sup>a</sup>Data sources: US Census Bureau cartographic boundary files<sup>12</sup> and Ohio Department of Health linked birth-death certificate files.<sup>b</sup>Cluster numbers correspond to the numbers on maps in Figure 4.<sup>c</sup>P values generated through Monte Carlo replications of the log likelihood ratio test statistic; P < .05 was considered significant.

In our study, infant mortality in Ohio showed a clear urban pattern. The Ohio Department of Health chose the OEI counties based on county-level aggregate data on infant deaths, and our spatial cluster analysis supports the selection of these 9 counties. County-level geographic analysis is good for large-scale policy decisions, but this type of analysis masks important within-county spatial variation. Many local health organizations engaged in the IMRP (eg, the Franklin County OEI) do not have the data or analytic capacity to develop census tract-level maps of birth outcomes. Our partners expressed surprise at the geographic location of some of the clusters, and they used the results of our analyses to consider various choices about resource distribution, where to target programs and interventions, and with which community organizations to partner. The maps also fostered conversations about the reasons for large-scale and small-scale inequalities, the availability of health services, neighborhood safety, housing opportunities, and homelessness.

Adjusting clusters for maternal age, race/ethnicity, and education resulted in the disappearance of many of the urban clusters of infant mortality. These results allowed us to discuss how urban residence does not increase the risk of infant mortality, *per se*; instead, the pattern reflects the concentration in urban centers of populations at highest risk of poor birth outcomes. Partners discussed needs specific to urban populations, programs that work well in urban communities, and the characteristics of successful programs in these communities.

That the clusters of preterm birth did not disappear entirely after adjustment for maternal characteristics was also discussed. Although some of the excess risk in these areas was explained by the concentration of the population at highest risk of poor birth outcomes, the persistence of many urban clusters implies that other factors contribute to clustering. We discussed social and environmental risk factors for preterm birth, many of which are described in the scientific literature (eg, air pollution,<sup>33,34</sup> crime,<sup>35,36</sup> neighborhood physical/social disorder).<sup>37</sup> This discussion challenged the partnership to think about complex spatial interactions and social structures in urban areas that collectively affect maternal and child health.

Representatives from state health agencies were particularly interested in the rural clusters of infant mortality and preterm birth identified in the adjusted analyses. Although the overall population living in these areas is small compared with the populations in urban areas targeted by the OEI and other state-level programs, state partners saw these rural clusters as a way to expand the OEI program into rural communities.

The space-time analysis was challenging for the partnership to understand. The temporally persistent clusters of infant mortality indicated that the spatial extent of infant mortality did not decrease over time. We saw little evidence of improvement in Ohio's urban areas. Partners were, understandably, disappointed with this finding. When we adjusted the space-time clusters for maternal age, race/ethnicity, and

education, we saw a pattern similar to the pattern in the spatial analysis, suggesting that clusters were concentrated among young, poorly educated, African American mothers during the entire study period. Essentially, these maternal characteristics explain both the spatial pattern and the temporal persistence of infant mortality in urban areas. One partner suggested these findings implied that they should continue to focus on their target population (low-income, urban, African American mothers).

The unadjusted space-time analysis of preterm birth also suggested that few changes in preterm birth rates occurred over time. But the adjusted space-time analysis tells a different story. The temporal extent of most of the clusters changed quite a bit, which likely reflects changing demographic characteristics. These results stimulated discussions about whether the geographic location of communities at high risk of poor birth outcomes has gradually changed as a result of gentrification, suburbanization of poverty, and changes in the housing market. Cities in Ohio have changed demographically during the past 10 years; these changes have been driven by changes in urban economies and gentrification. In some areas, the low-income population is gradually being displaced from traditional urban communities.<sup>38</sup> Columbus and Cincinnati have particularly low rates of unemployment and high rates of urban growth, whereas Cleveland has consistently lagged in economic growth.<sup>39</sup> Partners discussed how the space-time clusters of preterm birth may reflect this dynamic. In addition, the 2 temporally persistent clusters in rural Appalachia reflect the ongoing economic crisis and entrenched population at high risk of poor birth outcomes in this region of the state. Local partners in particular were concerned about whether these processes are shifting the location of their target populations such that target populations may reside in new areas of a city or in rural counties bordering major metropolitan regions. Understanding changes in the geographic distribution of the population at risk of poor birth outcomes is critical for the success of programs tailored to this population.

### Limitations

This study had several limitations. First, the geographic boundaries of the clusters detected in this study are approximations of the "true" clusters, especially because births were aggregated to census tracts. Although we know the general location of a cluster, we are uncertain about its exact boundaries. Furthermore, as with any ecological analysis, we cannot say that the entire population living in the cluster area has the same risk for giving birth to a preterm infant or having an infant die within the first year of life. Women have varying levels of risk, and these risks depend on their individual characteristics, behaviors, and family histories. Second, this geographic analysis uses residence at birth. Studies have shown that 10%-30% of women change residence between conception and birth.<sup>40,41</sup> However, most of these moves appear to be

local (eg, within the same city or county), and the characteristics of women who move are similar to those who do not move.<sup>42</sup> Caution should be exercised when interpreting the results of geographic studies that use maternal residential address at delivery, especially if trying to ascribe the case of a cluster to a local program or event. Finally, it is important to keep in mind that because infant death is a rare event, the power of the statistical test may be too low to detect small clusters, especially in rural areas. This issue is likely compounded by the fact that records lost during the geocoding process (because the address could not be geocoded) were more likely to occur in rural areas.

## Conclusions

Our study used data from a large, socioeconomically diverse population during a 7-year period to understand the dynamics of infant mortality and preterm birth in a state that has focused considerable public health resources toward reducing poor birth outcomes. One strength of our analysis was that it allowed for detection of changes over time as various maternal and child health initiatives were implemented in areas across the state. Furthermore, a strong government-academic partnership fostered a productive, iterative process by which statistical analyses and results were discussed and refined throughout the study to best meet the needs of state and local public health entities. Geovisualization and spatial analysis are excellent tools for engaging public health practitioners in spatial thinking. Results of spatial analyses can stimulate important discussions about the social and spatial determinants of health and the complex processes that lead to spatial inequalities. Although the original goal of the IMRP spatial analysis was to examine the spatial patterns of infant mortality and preterm birth and the effect of the OEI programs, we found that results led state and local organizations to think critically about the causes and consequences of spatial patterns and what they might mean for the future of outreach efforts, programs, and policies.

## Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

This research was funded by a grant from the Ohio Department of Medicaid, Ohio Department of Health, and the Ohio Department of Higher Education. Any opinions, findings, and conclusions expressed in this article are those of the authors and do not necessarily reflect the views of these agencies.

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# Persistent Disparities in Cervical Cancer Screening Uptake: Knowledge and Sociodemographic Determinants of Papanicolaou and Human Papillomavirus Testing Among Women in the United States

Public Health Reports  
2020, Vol. 135(4) 483-491  
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DOI: 10.1177/0033354920925094  
[journals.sagepub.com/home/phr](http://journals.sagepub.com/home/phr)



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## Abstract

**Objectives:** Cervical cancer is the second-most common type of cancer among women aged 15-44, and racial, ethnic, and economic disparities exist in survival rates despite widely available screening tests and early treatment options. The objective of this study was to describe the association among knowledge, sociodemographic characteristics, and cervical cancer screening, with the goal of developing interventions to prevent cervical cancer in populations at risk of the disease.

**Methods:** In 2017, we conducted a nationwide survey of women in the United States aged  $\geq 18$  who had ever received a Papanicolaou (Pap) test ( $N = 630$ ). We conducted t tests and one-way analysis of variance to determine sociodemographic differences (age, education, race, ethnicity, income, type of health insurance) in knowledge about cervical cancer screening (Pap test and human papillomavirus [HPV] test). We used logistic regressions to define significant determinants of cervical cancer screening behaviors in the previous 5 years.

**Results:** Of 629 respondents, 407 (64.7%) had an annual household income  $<\$30\,000$ , and 322 of 536 (60.1%) respondents had government-provided health insurance. Of 630 women who had ever had a Pap test, 425 (67.5%) had an HPV test. Hispanic and non-Hispanic white women were more likely than Hispanic and non-Hispanic black women (odds ratio [OR] = 2.49; 95% CI, 1.12-4.54;  $P = .02$ ) and women with government-provided health insurance (OR = 1.91; 95% CI, 1.08-3.37;  $P = .03$ ) were more likely than women with private health insurance to have received a Pap test in the previous 5 years. Knowledge of HPV was a significant predictor of having received an HPV test in the previous 5 years (OR = 1.37; 95% CI, 1.22-1.54;  $P < .001$ ).

**Conclusion:** Disparities in cervical cancer screening among sociodemographic groups of women suggest the need for targeted interventions to improve knowledge about Pap and HPV tests.

## Keywords

cervical cancer screening, Pap test knowledge, human papillomavirus (HPV), HPV knowledge, high-risk populations

Worldwide, cervical cancer is the second-most common type of cancer among women aged 15-44.<sup>1</sup> More than 11 000 diagnoses of cervical cancer occur annually in the United States despite the availability of a vaccine for oncogenic types of human papillomavirus (HPV) and 2 cervical cancer screening tests, the Papanicolaou (Pap) test for detecting pre-cancerous lesions and a molecular HPV test for detecting high-risk HPV infections (ie, HPV infections that can cause cancer).<sup>1</sup> Advancements in HPV testing and clinical

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protocols during the past decade have resulted in several changes in gynecological practice. Currently, cervical cancer screening guidelines recommend a Pap test every 3 years for average-risk women aged 21-65. Women aged 30-65 are advised to receive a Pap test alone every 3 years, a high-risk HPV test alone every 5 years, or co-testing (a high-risk HPV test and a Pap test) every 5 years.<sup>2-4</sup> Despite the longstanding history of both tests, women in all sociodemographic groups have poor knowledge about them,<sup>5-8</sup> and the barriers to cervical cancer screening are numerous.<sup>9</sup> The *Healthy People 2020* target for cervical cancer screening among women aged 21-65 is 93%.<sup>10</sup> No group of women in the United States has achieved this goal.<sup>11</sup> The most recent national data, from 2015, showed that 84.4% of non-Hispanic black women, 82.7% of non-Hispanic white women,<sup>12</sup> 81.4% of women aged 21-44, and 80.6% of women aged 45-65 had received cervical cancer screening in the previous 3 years.<sup>13</sup>

The incidence of cervical cancer among Hispanic women (9.3 per 100 000 persons) and non-Hispanic black women (8.1 per 100 000 persons) is disproportionately high compared with the incidence of cervical cancer among non-Hispanic white women (7.2 per 100 000 persons).<sup>14</sup> This disparity has been attributed to lack of screening, and lack of screening has been attributed to unequal access to health care.<sup>15</sup> In addition, although data on cervical cancer screening disparities are limited, cervical cancer mortality is high among women who have a low income and low educational attainment, and women without health insurance are less likely than women with health insurance to undergo cervical cancer screening.<sup>16</sup> These social determinants of health are important factors to consider because they influence preventive behaviors.<sup>17</sup> One way to address persistent disparities is through communicative processes. Communicative processes can be used to build knowledge, a well-established predictor of behavior.

In this study, we explored the knowledge and sociodemographic determinants of cervical cancer screening behaviors among women in the United States to identify groups for targeted preventive interventions. Despite the success of cervical cancer screening in detecting precancerous lesions and high-risk HPV infections, not every woman has equal access to these preventive services. Research can help to overcome difficult-to-budge barriers (low income and low levels of education) and misunderstanding about changing guidelines so that all women have equal access to preventive services. Consistent with the Theory of Reasoned Action,<sup>18,19</sup> our research model examined knowledge of Pap testing and HPV as representative of behavioral beliefs. These beliefs about the outcomes and value of a behavior, along with beliefs about norms concerning the behavior, are posited by the Theory of Reasoned Action to predict intentions and health behaviors. Contemporary applications of the Theory of Reasoned Action usually focus on the relationship between intention and behavior.<sup>20</sup> Thus, we expected to find a racial disparity

in knowledge about Pap tests and HPV and that women with greater knowledge about Pap tests and HPV would engage in cervical cancer screening behavior more regularly than women with less knowledge.

The primary objective of this study was to provide findings on cervical cancer screening knowledge and behavior that correspond with the incorporation of HPV screening in addition to Pap screening in national guidelines.<sup>16,21</sup> Our investigation was novel in its inclusion of Pap test and HPV knowledge measures as determinants of the 2 cervical cancer screening behaviors and its use of sampling strategies that ensured representation of women with sociodemographic characteristics (eg, race, ethnicity, income) associated with a high risk of cervical cancer and low rates of cervical cancer screening.<sup>8,9,15,21</sup>

## Methods

### Data

The data for this study came from a larger survey project in which data were collected in June 2017 through a Qualtrics online survey assessing cervical cancer screening knowledge, behaviors, experiences, and preferences for communication in a national sample of women in the United States who had a Pap test at least once in their lifetime. The study team worked directly with Survey Sampling International to determine the methods and goals for recruitment and data collection. Survey Sampling International sent email invitations to members of its US panel who met our study's target demographic group: women aged  $\geq 18$  and able to read English. The survey oversampled 3 groups to ensure representation of populations with high rates of cervical cancer: black women (20% of sample), Hispanic women (20% of sample), and women whose annual household income was  $\leq \$30\,000$  (20% of sample). We excluded 27 women who identified as Asian ( $n = 3$ ), American Indian/Alaska Native ( $n = 3$ ), or "other" ( $n = 21$ ) from the comparison and regression analyses because of their small numbers. Of 737 panelists who met the eligibility criteria and opened the survey, 60 opted out, 14 did not complete more than one-third of the survey, and 33 had never had a Pap test; 630 women who had ever had a Pap test completed the survey. The study was approved by the institutional review board of Indiana University–Purdue University Indianapolis.

### Measures

To conduct the tests for association between cervical cancer screening knowledge and cervical cancer screening behavior, we defined cervical cancer screening behavior as having received a Pap or HPV test in the previous 5 years. To ensure women knew what they were being asked about, explanations of the purpose and procedure of each test accompanied

each behavior question. Women who did not remember if they had had either test in the previous 5 years were considered as not having engaged in cervical cancer screening behavior. We controlled for sociodemographic determinants and redefined the variables to achieve adequate cell frequencies, given the sample size ( $N = 630$ ). We tested Hispanic ethnicity as a dichotomous variable. We transformed race into a dichotomous variable (Hispanic and non-Hispanic white and Hispanic and non-Hispanic black). Cross-tabulation between race and ethnicity showed that 8 of 130 black women and 82 of 472 white women identified as Hispanic, which would not allow for reliable comparison between groups defined by race and ethnicity together. We recoded the original 6 categories of education into 4 categories:  $\leq$ high school diploma, some college, 2-year college degree, and  $\geq$ 4-year college degree. We recoded the original 12 categories of annual household income (in \$10 000 intervals) into a dichotomous variable ( $<\$30 000$  and  $\geq\$30 000$ ) as an indicator of risk for cervical cancer occurrence.<sup>15</sup> We recoded the original 5 answers to the question on how often participants considered cost when making decisions about their health care into 3 categories:  $\leq$ half the time, most of the time, and always. For type of health insurance, we combined direct-purchase and employer-provided health insurance into 1 category (private health insurance), which yielded a dichotomous variable: government-provided health insurance and private health insurance. We tested age and knowledge scores as continuous variables.

We measured Pap test knowledge and HPV knowledge separately by using a 7-item sum scale adapted from similar scales.<sup>21-24</sup> For each topic, participants were asked to read statements about Pap tests (eg, "You only need a Pap test if you have symptoms," "It tests for pregnancy") and HPV (eg, "HPV is sexually transmitted," "HPV is relatively rare") and indicate whether they believed each statement was true or false or they did not know. To calculate the overall knowledge scores, we recoded the correct answer for each item as 1 and other responses as 0, and we summed the items on a scale ranging from 0 to 7. We then adjusted the scale to range from 1 to 8.

### Statistical Analysis

First, we used descriptive statistics to understand the socio-demographic characteristics (ie, race, ethnicity, age, annual household income, education level, and type of health insurance) of the populations who had received a Pap test or an HPV test in the previous 5 years. Then, we conducted independent-samples  $t$  tests (comparing race, ethnicity, income level, and type of health insurance) and one-way analysis of variance (comparing levels of education and age groups) to compare knowledge scores for Pap test and HPV. We used the Tukey honest significant difference post hoc tests to determine conservative difference mean estimates between mean knowledge values across multiple groups based on education and age. Lastly, we conducted statistical

analyses by using SPSS version 24.0 to estimate the odds of receiving cervical cancer screening in the previous 5 years based on sociodemographic characteristics and knowledge.<sup>25</sup> Significance was set at  $P < .05$ .

## Results

Among 630 women who had ever had a Pap test, 483 (76.7%) women had had a Pap test in the previous 5 years and 425 (67.5%) had ever had an HPV test (Table 1). Of these 425 women, 197 (46.4%) had had an HPV test in the previous 5 years. The age range of survey participants who had ever had a Pap test ( $N = 630$ ) was 25 to 66 (mean [SD] = 48.9 [10.5]); 407 of 629 (64.7%) women reported an annual household income  $<\$30 000$ ; 537 of 630 (85.2%) had health insurance. Of the 536 women who indicated type of health insurance, 322 (60.1%) had government-provided health insurance. By race (including both Hispanic and non-Hispanic), of 630 respondents, 472 (74.9%) were white and 131 (20.8%) were black; by ethnicity, of 628 respondents, 116 (18.5%) were Hispanic.

### Sociodemographic Differences in Pap Test and HPV Knowledge

Pap test knowledge scores were significantly higher among Hispanic and non-Hispanic white women (mean score = 6.1) than among Hispanic and non-Hispanic black women (mean score = 5.7) ( $t = 3.20$ ;  $P = .002$ ) (Table 2). Although HPV knowledge scores were also higher among Hispanic and non-Hispanic white women (mean score = 5.7) than among Hispanic and non-Hispanic black women (mean score = 5.3), the difference was not significant. Both Pap test and HPV knowledge scores were higher among non-Hispanic women than among Hispanic women, but the differences were not significant. Women aged 55-64 had significantly higher Pap test knowledge scores (mean score = 6.2) than women aged 25-34 (mean score = 5.5) ( $F = 4.44$ ;  $P = .004$ ), yet the inverse was true for HPV knowledge scores. Women aged 25-34 had significantly higher HPV knowledge scores (mean score = 5.9) than women aged 55-64 (mean score = 5.2) ( $F = 5.07$ ;  $P = .002$ ). Pap test and HPV knowledge scores were significantly higher among women with an annual household income  $\geq\$30 000$  (mean score = 6.3) than among women with an annual household income  $<\$30 000$  (mean score = 5.8) ( $t = -3.77$ ;  $P < .001$ ). HPV knowledge was significantly higher among women who had an HPV test in the previous 5 years (mean score = 6.4) than among women who did not (mean score = 5.2) ( $t = 6.34$ ;  $P < .001$ ). Women who received a Pap test in the previous 5 years had higher Pap test knowledge scores than women who did not, but the difference was not significant.

Tukey honest significant difference post hoc tests showed that women who had  $\geq$ 4-year college degree had significantly higher HPV knowledge scores (mean score = 6.2) than women who had some college (mean score = 5.5;  $P = .001$ ) or  $\leq$ high

**Table 1.** Sociodemographic characteristics of a sample of women aged 18-66 who reported having a Pap test or an HPV test at least once (N = 630), United States, June 2017<sup>a</sup>

Characteristic	Ever Had a Pap Test (n = 630)		Ever Had an HPV Test (n = 425)	
	No. of Respondents to Survey Question <sup>b</sup>	Value <sup>c</sup>	No. of Respondents to Survey Question <sup>b</sup>	Value <sup>c</sup>
Knowledge score, mean (SD) <sup>d</sup>	613	6.0 (1.4)	420	5.7 (2.2)
Age, mean (SD), y	617	48.9 (10.5)	414	47 (10.4)
Annual household income, \$				
<30 000	629	407 (64.7)	425	283 (66.6)
≥30 000		222 (35.3)		142 (33.4)
Race, including Hispanic and non-Hispanic				
White	630	472 (74.9)	425	308 (72.5)
Black		131 (20.8)		99 (23.3)
Other <sup>e</sup>		27 (4.3)		18 (4.2)
Ethnicity				
Hispanic	628	116 (18.5)	423	89 (21.0)
Non-Hispanic		512 (81.5)		334 (79.0)
Education				
≤High school diploma	629	206 (32.8)	424	128 (30.2)
Some college		168 (26.7)		119 (28.1)
2-year college degree		113 (18.0)		82 (19.3)
≥4-year college degree		142 (22.6)		95 (22.4)
Has health insurance				
Yes	630	537 (85.2)	425	371 (87.3)
No		93 (14.8)		54 (12.7)
Type of health insurance <sup>f</sup>				
Government-provided	536	322 (60.1)	370	226 (61.1)
Private		214 (39.9)		144 (38.9)
How often cost is considered when making health care decisions				
≤Half of the time	626	312 (49.8)	423	221 (52.2)
Most of the time		119 (19.0)		88 (20.8)
Always		195 (31.2)		114 (27.0)

Abbreviations: HPV, human papillomavirus; Pap, Papanicolaou; SD, standard deviation.

<sup>a</sup>Data source: A Qualtrics online survey assessing cervical cancer screening knowledge, behaviors, experiences, and preferences for communication in a national sample, conducted by the study team.

<sup>b</sup>Participants were not required to answer every item, and some women skipped questions.

<sup>c</sup>All values are number (percentage) unless otherwise indicated; percentages are based on the number of women who answered the question.

<sup>d</sup>Pap test knowledge and HPV knowledge were measured separately by using a 7-item sum scale adapted from similar scales.<sup>21-23</sup> For each topic, participants were asked to read statements about Pap tests and indicate whether they believed each statement was true or false or they did not know. The scale ranged from 1 to 8, with higher scores indicating greater knowledge.

<sup>e</sup>Three women identified as American Indian/Alaska Native, 3 as Asian, and 21 as "other" race. These women (n = 27) were excluded from subsequent analysis of knowledge by race and all regression analyses because of small numbers.

<sup>f</sup>One respondent who had health insurance did not indicate type.

school diploma (mean score = 5.3) ( $F = 4.7$ ;  $P = .003$ ), but we found no significant difference in Pap test knowledge based on education. We found no significant difference in knowledge of HPV or the Pap test based on type of health insurance.

### Determinants of Pap Test Behavior

We found no significant association between Pap test knowledge and behavior overall (Table 3). By sociodemographic

characteristics, we found significantly higher odds of receiving a Pap test in the previous 5 years among younger women (OR = 0.97; 95% CI, 0.94-0.99;  $P = .01$ ) compared with older women, among white women (OR = 2.49; 95% CI, 1.12-4.54;  $P = .02$ ) compared with black women, and among women with government-provided health insurance (OR = 1.91; 95% CI, 1.08-3.37;  $P = .03$ ) compared with women with private health insurance. Women with ≤high school

**Table 2.** Differences in knowledge of Pap test and HPV test in a sample of women aged 18-66 who reported having a Pap test at least once (N = 630), United States, June 2017<sup>a</sup>

Characteristic	Pap Test Knowledge <sup>b</sup>		HPV Knowledge <sup>b</sup>	
	Mean Score (95% CI or SD) <sup>c</sup>	t or F (P Value)	Mean Score <sup>c</sup> (95% CI or SD)	t or F (P Value)
Age, y				
25-34	5.5 (5.2-5.8) <sup>d</sup>	F = 4.44 (.004)	5.9 (5.4-6.3)	F = 5.07 (.002)
35-44	6.0 (5.7-6.2)		6.1 (5.7-6.4) <sup>d</sup>	
45-54	6.0 (5.8-6.2)		5.7 (5.3-6.1)	
55-66	6.2 (6.0-6.4) <sup>d</sup>		5.2 (4.9-5.5) <sup>d</sup>	
Education				
≤High school diploma	6.0 (5.8-6.2) <sup>d</sup>	F = 1.30 (.28)	5.3 (4.9-5.6)	F = 4.70 (.003)
Some college	5.9 (5.6-6.1) <sup>d</sup>		5.5 (5.1-5.8)	
2-year college degree	6.1 (5.8-6.3)		5.6 (5.2-6.0)	
≥4-year college degree	6.2 (5.9-6.4) <sup>d</sup>		6.2 (5.8-6.5)	
Annual household income, \$				
<30 000	5.8 (1.5)	t = -3.77 (<.001)	5.5 (2.2)	t = -2.02 (.04)
≥30 000	6.3 (1.3)		5.9 (2.2)	
Ethnicity				
Hispanic	5.8 (1.4)	t = -1.83 (.61)	5.4 (2.2)	t = -1.11 (.26)
Non-Hispanic	6.1 (1.4)		5.7 (2.3)	
Race <sup>e</sup>				
White	6.1 (1.4)	t = 3.20 (.002)	5.7 (2.2)	t = 1.92 (.06)
Black	5.7 (1.4)		5.3 (2.2)	
Type of health insurance				
Government-provided	6.1 (1.4)	t = 1.88 (.06)	5.6 (2.2)	t = 0.65 (.52)
Private	5.7 (1.5)		5.5 (2.5)	
Received a Pap test in previous 5 years				
Yes	6.1 (1.4)	t = 1.31 (.19)		—
No	5.9 (1.6)			
Received an HPV test in previous 5 years				
Yes			6.4 (1.7)	t = 6.34 (<.001)
No			5.2 (2.4)	

Abbreviations: HPV, human papillomavirus; Pap, Papanicolaou; SD, standard deviation.

<sup>a</sup>Data source: A Qualtrics online survey assessing cervical cancer screening knowledge, behaviors, experiences, and preferences for communication in a national sample, conducted by the study team.

<sup>b</sup>Pap test knowledge and HPV knowledge were measured separately by using a 7-item sum scale adapted from similar scales.<sup>21-23</sup> For each topic, participants were asked to read statements about Pap tests and indicate whether they believed each statement was true or false or they did not know. The scale ranged from 1 to 8, with higher scores indicating greater knowledge.

<sup>c</sup>One-way analysis of variance was used to test the differences in knowledge based on age groups and level of education. Independent-samples t tests were used to test the difference in knowledge scores based on race, ethnicity, income, type of health insurance, and cervical cancer screening behavior. Significance was set at the *P* < .05 level.

<sup>d</sup>Knowledge scores were significantly different among these groups, according to Tukey honest significant difference post hoc tests.

<sup>e</sup>White and black race includes both Hispanic and non-Hispanic ethnicities. Three women identified as American Indian/Alaska Native, 3 as Asian, and 21 as "other" race. These women (*n* = 27) were excluded from the comparison analyses based on race because of small numbers.

diploma were significantly less likely than women with ≥4-year college degree to have had a Pap test in the previous 5 years (OR = 0.30; 95% CI, 0.14-0.66; *P* = .002).

### Determinants of HPV Test Behavior

Knowledge about HPV was a significant predictor of receiving an HPV test in the previous 5 years (OR = 1.37; 95% CI, 1.22-1.54; *P* < .001). We found higher odds for

receiving an HPV test in the previous 5 years among younger women (OR = 0.98; 95% CI, 0.96-1.00; *P* = .047) compared with older women and among women with an annual household income ≥\$30 000 (OR = 0.53; 95% CI, 0.31-0.92; *P* = .02) compared with women with an annual household income <\$30 000. Race, type of health insurance, and education were not significantly associated with HPV test behavior.

**Table 3.** Determinants of cervical cancer screening behavior in previous 5 years in a sample of women aged 18-66 who reported having a Pap test at least once (N = 630), United States, June 2017<sup>a</sup>

Predictor	Pap Test in Previous 5 Years <sup>b,c</sup> (n = 482)	HPV Test in Previous 5 Years <sup>b,d</sup> (n = 333)
Knowledge score	1.07 (0.90-1.27) [.45]	1.37 (1.22-1.54) [<.001]
Age	0.97 (0.94-0.99) [.01]	0.98 (0.96-1.00) [.047]
Annual household income, \$		
<30 000	0.82 (0.47-1.42) [.47]	0.53 (0.31-0.92) [.02]
≥30 000	1.00 [Reference]	1.00 [Reference]
Ethnicity		
Non-Hispanic	0.80 (0.41-1.54) [.49]	0.97 (0.52-1.81) [.91]
Hispanic	1.00 [Reference]	1.00 [Reference]
Race (non-Hispanic and Hispanic) <sup>e</sup>		
White	2.49 (1.12-4.54) [.02]	1.56 (0.89-2.72) [.12]
Black	1.00 [Reference]	1.00 [Reference]
Education		
≤High school diploma	0.30 (0.14-0.66) [.002]	1.11 (0.57-2.17) [.75]
Some college	0.53 (0.23-1.22) [.13]	1.03 (0.53-2.04) [.92]
2-year college degree	0.46 (0.20-1.09) [.07]	0.94 (0.46-1.93) [.86]
≥4-year college degree	1.00 [Reference]	1.00 [Reference]
Health insurance		
Government-provided	1.91 (1.08-3.37) [.03]	1.38 (0.80-2.35) [.24]
Private	1.00 [Reference]	1.00 [Reference]
How often cost is considered when making health care decisions		
≤Half of the time	0.98 (0.55-1.72) [.93]	0.74 (0.41-1.33) [.31]
Most of the time	1.30 (0.60-2.82) [.50]	0.87 (0.43-1.78) [.70]
Always	1.00 [Reference]	1.00 [Reference]
Constant	24.00	0.51

Abbreviations: HPV, human papillomavirus; Pap, Papanicolaou.

<sup>a</sup>Data source: A Qualtrics online survey assessing cervical cancer screening knowledge, behaviors, experiences, and preferences for communication in a national sample, conducted by the study team.

<sup>b</sup>All values are odds ratio (95% CI) [P value]. P < .05 was considered significant.

<sup>c</sup>Pap test behavior model:  $\chi^2_{11} = 33.2$ ; P < .001.

<sup>d</sup>HPV test behavior model:  $\chi^2_{11} = 45.8$ ; P < .001.

<sup>e</sup>Three women identified as American Indian/Alaska Native, 3 as Asian, and 21 as "other" race. These women (n = 27) were excluded from these analyses because of small numbers.

## Discussion

Our study explored the knowledge and socioeconomic determinants of women's Pap and HPV testing behaviors in the 5 years before June 2017. Despite the success of cervical cancer prevention through screening and vaccination, in 2019, more than 13 000 new cervical cancer cases and 4000 deaths were estimated in the United States, which exceed annual averages.<sup>1</sup> After several iterations, guidelines were finalized for co-testing in 2018, which create new communicative and education challenges for women who receive a positive test result for HPV and need follow-up care. Our findings indicate that (1) racial and socioeconomic disparities in Pap test and HPV knowledge exist, (2) knowledge is a significant variable in cervical cancer screening behavior, and (3)

several demographic factors, including race, are strong determinants of cervical cancer screening behavior.

For Pap tests, knowledge and behavior were not related. However, HPV knowledge was a significant predictor of behavior; thus, women who knew more about HPV were more likely than women who knew less to have had an HPV test in the previous 5 years. Interestingly, though, the average HPV knowledge score among women who had ever had an HPV test was lower (average score, 5.7) than the average Pap test knowledge score among women who had ever had a Pap test (average score, 6.0). We also saw that HPV knowledge scores were lower among women who had not had an HPV test in the previous 5 years (average score, 5.2) than among women who had had an HPV test in the previous 5

years (average score, 6.4). This finding may indicate that new American College of Obstetricians and Gynecologists guidelines for education and revised protocols<sup>2</sup> are effective at improving knowledge and cervical cancer screening engagement, but the relative newness of the guidelines warrants more time to determine efficacy. Future research should continue to investigate the role of knowledge in predicting cervical cancer screening behavior, particularly as clinical recommendations and scientific developments change.

The lack of a significant association between Pap test knowledge and behavior may be best explained in terms of longevity of access to Pap tests. Pap tests have been routinely used in clinical practice for more than 60 years. Normative beliefs about Pap tests may be a stronger predictor of Pap test behavior than knowledge alone. Alternatively, HPV tests are a much newer approach to cervical cancer screening,<sup>5</sup> suggesting that increased knowledge about a previously little-known test is an important predictor of behavior. More research is needed on the role of knowledge in relation to subjective norms in predicting cervical cancer screening behaviors, especially because most Pap tests and HPV tests are now recommended to be given at the same time. Future work should continue to explore whether traditional health behavior models such as the Theory of Reasoned Action and the Theory of Planned Behavior, which privilege the role of knowledge and normative beliefs in predicting a single health behavior, are appropriate for understanding and predicting how various types of knowledge may predict related (and, often, simultaneous) health behaviors.

Cervical cancer screening behavior is less common among women without health insurance than among women with health insurance. Cervical cancer screening behavior also declines as age (and risk for cervical cancer occurrence) increases.<sup>11</sup> In our study, younger women were more likely than older women to have received a Pap test in the previous 5 years, but Pap test knowledge increased with age. This finding may highlight the emphasis on annual screening appointments among older women; although annual screening appointments are no longer recommended, less frequent Pap tests inherently yield less exposure to Pap test information. Younger women were also more likely to have gotten an HPV test than older women, which is consistent with the relationship between age and HPV knowledge, perhaps reflecting the effectiveness of several mass-media campaigns for the HPV vaccine.

Sociodemographically, women with an annual household income  $\geq \$30\,000$  had 2 times higher odds than women with an annual household income  $<\$30\,000$  of cervical cancer screening behavior and higher knowledge scores; women with  $\geq 4$ -year college degree had 3.3 times higher odds than women with  $\leq$ high school diploma of cervical cancer screening behavior and higher knowledge scores, and women with government-provided health insurance had 1.4 times higher odds than women with private health insurance of cervical cancer screening behavior and higher knowledge scores.

Previous research noted affordability and accessibility as the fundamental tenets of health care reform in the past decade, and an annual household income  $<\$30\,000$  continues to be a barrier to cervical cancer screening.<sup>26</sup> We can assume an increase in government-provided health insurance coverage rates since the passage of the Affordable Care Act in 2010, which may have contributed to this counterintuitive finding on cervical cancer screening behavior. In addition, a 2018 report on cervical cancer screening trends among 42 million women in the United States with private health insurance during 2003-2014 showed a decline in cervical cancer screening rates; the report also demonstrated the prevalence of cervical cancer screening behavior based on medical insurance claims was lower than the prevalence based on self-reported data.<sup>27</sup> Future research should continue to examine the role of health care coverage and socioeconomic status as determinants of cervical cancer screening behavior.

Race is a significant determinant in health disparities, and our findings demonstrate a large disparity between white and black women. White women in our sample had almost 2.5 times higher odds than black women of having had a Pap test in the previous 5 years. They also had higher Pap test and HPV knowledge scores. Future work must address this continuing disparity by designing interventions that ensure timely Pap and HPV education and testing behaviors among women with low levels of education, as well as low-income and black women. Previous research provided a mixed-methods approach to understanding normative beliefs in the black population, and continued efforts could shed light on persistent cultural barriers to cervical cancer screening.<sup>28</sup>

### Limitations

Our study had several limitations. First, our cross-sectional, quantitative study design lacked nuance and depth in understanding the relationship between knowledge and behavior for cervical cancer screening. For example, instead of viewing knowledge as a determinant of screening behavior, the act of engaging in cervical cancer screening behavior and receiving Pap and HPV test results may have influenced women's knowledge about the tests themselves as well as HPV. Second, although the study design intended to represent women with characteristics that reflect populations at high risk for cervical cancer, the online format of the survey limited participation to women who had access to the necessary technology, which inherently eliminated a portion of the at-risk population from our study sample. In addition, because participants were on Survey Sampling International's national panel, the sample was not truly random. A larger, randomly selected sample is needed in the future to estimate the odds of cervical cancer screening behaviors more accurately. Third, self-report of cervical cancer screening behaviors may be unreliable and has been shown to be inflated compared with behaviors documented in health insurance claims records.<sup>27</sup> Future research

could include clinical or health insurance claims records to supplement self-reported data for more reliable results. Before the new cervical cancer screening guidelines, HPV tests were used only as follow-up tests to abnormal findings from a Pap test, so patients often lacked control over whether they received an HPV test, and the current HPV testing data may not represent a person's actual cervical cancer screening behavior decision. Lastly, because of a low response rate from Hispanic women, which inhibited a statistically robust comparison, we did not test ethnicity as a determinant of cervical cancer screening behavior. Future research should continue addressing the nuance of disparities in cervical cancer screening behavior.

## Conclusions

This study provides critical data on cervical cancer screening rates among populations at risk of cervical cancer and offers an in-depth look at how various knowledge and sociodemographic variables may predict these screening behaviors. Interventions addressing cervical cancer screening disparities may benefit from this detailed look at sociodemographic determinants of screening uptake, particularly with the addition of HPV testing to guidelines. Racial and ethnic minority populations may differ in the way they use cancer screening services, and public health programs should aim to improve cervical cancer screening rates in these populations. To develop an appropriate intervention targeting women in populations at risk of cervical cancer, further research is needed to understand the cultural implications on preventive health care use.

## Disclaimer

The findings and conclusions in this article are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

## Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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# Health Literacy and Health Behaviors Among Adults With Prediabetes, 2016 Behavioral Risk Factor Surveillance System

Public Health Reports  
2020, Vol. 135(4) 492-500  
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DOI: 10.1177/0033354920927848  
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## Abstract

**Objectives:** Evidence is needed for designing interventions to address health literacy-related issues among adults with prediabetes to reduce their risk of developing type 2 diabetes. This study assessed health literacy and behaviors among US adults with prediabetes and the mediating role of health literacy on health behaviors.

**Methods:** We used data from the 2016 Behavioral Risk Factor Surveillance System (BRFSS) ( $N = 54\,344$  adults). The BRFSS health literacy module included 3 questions on levels of difficulty in obtaining information, understanding health care providers, and comprehending written information. We defined low health literacy as a response of “somewhat difficult” or “very difficult” to at least 1 of these 3 questions. Respondents self-reported their prediabetes status. We included 3 health behavior indicators available in the BRFSS survey—current smoking, physical inactivity, and inadequate sleep, all measured as binary outcomes (yes/no). We used a path analysis to examine pathways among prediabetes, health literacy, and health behaviors.

**Results:** About 1 in 5 (19.0%) adults with prediabetes had low health literacy. The rates of physical inactivity (31.0% vs 24.6%,  $P < .001$ ) and inadequate sleep (38.8% vs 33.5%,  $P < .001$ ) among adults with prediabetes were significantly higher than among adults without prediabetes. The path analysis showed a significant direct effect of prediabetes and health literacy on health behaviors. The indirect effect of prediabetes through health literacy on health behaviors was also significant.

**Conclusion:** BRFSS data from 2016 showed that rates of low health literacy and unhealthy behaviors were higher among adults with prediabetes than among adults without prediabetes. Interventions are needed to assist adults with prediabetes in comprehending, communicating about, and managing health issues to reduce the risk of type 2 diabetes.

## Keywords

prediabetes, health behaviors, health literacy, path model

More than 88 million US adults aged  $\geq 18$  (1 in 3) have prediabetes,<sup>1</sup> but 80% of them do not know they have it.<sup>2</sup> Adults with prediabetes are at high risk of type 2 diabetes (the most common type of diabetes), heart disease, and stroke.<sup>2</sup> To prevent prediabetes from progressing to type 2 diabetes, maintaining a healthy weight and adopting healthy behaviors are critical. One determinant of self-care behavior in type 2 diabetes is health literacy.<sup>3</sup> Adequate health literacy may increase individuals’ capacity to take responsibility for their health and the health of their family members.<sup>4</sup>

Health literacy is defined as the degree to which a person has the capacity to obtain, process, and understand basic health information and services needed to make appropriate

health decisions.<sup>5</sup> Thus, health literacy includes not only the components of general literacy—such as oral literacy, print literacy, and numeracy—but also the ability to obtain and use

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information for health-related decision making. Health literacy depends not only on the skills of a person but also on the communication skills of others, especially health care workers, and on the values of health care systems, such as whether intervention programs are in place to help those with low levels of health literacy.<sup>6</sup>

Health literacy is a national priority because limited health literacy costs the US health care system \$106 to \$238 billion each year.<sup>7</sup> Healthy People 2020 goals called for substantial improvements in levels of health literacy to advance the health of the US population.<sup>8</sup> The US Department of Health and Human Services released the National Action Plan to Improve Health Literacy in 2010 with a goal to provide all persons in the United States with access to accurate and actionable health information, deliver person-centered health information and services, and support lifelong learning and skills to improve health status.<sup>9</sup>

A growing body of literature shows that a low level of health literacy is associated with an increase in the number of hospitalizations and emergency department visits, poor self-care and adherence to medications, poor comprehension of medical terminology, poor communication with health care providers, unhealthy behaviors, and poor health outcomes.<sup>3,10,11</sup> One study in China showed that the prevalence of low health literacy was higher among adults with prediabetes than among adults without prediabetes, especially among adults with low education levels.<sup>12</sup> However, little research has been conducted to understand the role of health literacy among adults with prediabetes in the United States. Thus, the potential link between health literacy and health behaviors among adults with prediabetes is unclear. Health care providers and researchers have little evidence with which to design interventions (eg, improving communication for better understanding of medical instructions) to address health literacy-related issues among adults with prediabetes to reduce their risk of developing type 2 diabetes. The aim of this study was to describe health literacy and health behaviors among adults with prediabetes and assess the mediating role of health literacy on health behaviors.

## Methods

### Data Source

We used data for this analysis from the 2016 Behavioral Risk Factor Surveillance System (BRFSS).<sup>13</sup> The BRFSS is a random-digit-dialed telephone survey of adults aged  $\geq 18$  residing in the United States. The BRFSS collects self-reported information on various health behaviors and preventive health practices. The survey instrument includes core questions (administered in every state and US territory) and optional modules (administered in some states and territories). The variables of interest in this analysis were from 2 optional modules: (1) the health literacy module, in which 14 states and territories participated, and (2) the prediabetes

module, in which 27 states and territories participated. Among them, 8 states (Alabama, Alaska, Illinois, Iowa, Louisiana, Mississippi, Nebraska, and Virginia), as well as the District of Columbia and Puerto Rico, participated in both modules. The study sample included 54 344 adults who participated in both modules. Because this study was a secondary analysis of a publicly available data set, it did not require institutional review board review.

### Measurement

**Prediabetes status (independent variable).** Prediabetes status was defined by the response to the question, "Have you ever been told by a doctor or other health professional that you have prediabetes or borderline diabetes?" We classified respondents as having prediabetes if they answered yes; otherwise, we classified respondents as not having prediabetes. Respondents with diabetes were not asked the prediabetes question and were excluded from this analysis.

**Health literacy (mediator variable).** The Centers for Disease Control and Prevention developed a 3-question health literacy module,<sup>14</sup> which was offered as an optional module in the 2016 BRFSS. The 3 questions were (1) "How difficult is it for you to get advice or information about health or medical topics if you need it?" (indicated as "difficulty in obtaining information" hereinafter); (2) "How difficult is it for you to understand information that doctors, nurses, and other health professionals tell you?" (indicated as "difficulty in understanding doctors" hereinafter); and (3) "In general, how difficult is it for you to understand written health information?" (indicated as "difficulty in understanding written information" hereinafter).

We first coded the 3 health literacy variables as binary outcomes by combining the responses "somewhat difficult" and "very difficult" into 1 category—having difficulty (yes)—and by combining "very easy" and "somewhat easy" into 1 category—not having difficulty (no). We treated other responses—"don't know/not sure" and "refused"—as missing. In addition, we also treated the responses "I don't look for health information" in Question 1 and "I don't pay attention to written health information" in Question 3 as missing. Our preliminary analysis showed a significant correlation among these 3 measures of health literacy (all  $P < .001$ ). Given the study objective, we decided to combine the 3 variables into 1 variable: a respondent was classified as having low health literacy if a yes answer was recorded to any of the 3 questions; the respondent was classified as not having low health literacy if a no answer was recorded to all 3 questions.

**Health behaviors (outcome/dependent variables).** We included 3 health behavior-related variables available in the 2016 BRFSS core questionnaire as binary outcome variables—current smoking, physical inactivity, and inadequate sleep.

We selected these variables because smoking,<sup>15</sup> physical inactivity,<sup>16</sup> and inadequate sleep<sup>17,18</sup> are all risk factors for type 2 diabetes. We categorized smoking status as current smokers (ie, everyday smoker or some-day smoker) vs not current smokers (ie, former smoker or never smoker). We coded physical inactivity according to the following yes/no question: "During the past month, other than your regular job, did you participate in any physical activities or exercises such as running, calisthenics, golf, gardening, or walking for exercise?" We coded inadequate sleep according to the question, "On average, how many hours of sleep do you get in a 24-hour period?" We classified respondents who reported <7 hours as having inadequate sleep.<sup>17</sup> Otherwise, we classified respondents as not having inadequate sleep. We did not include variables on dietary intake because the 2016 BRFSS did not include questions on these topics.

### Covariates

Consistent with previous research,<sup>19-21</sup> we included the following variables as covariates: age, sex (male/female), race/ethnicity (non-Hispanic white, non-Hispanic black, Hispanic, other), formal education (<high school graduate, high school graduate, ≥some college), and annual household income (<\$15 000, \$15 000-\$24 999, \$25 000-\$34 999, \$35 000-\$49 999, ≥\$50 000). We also included marital status (married or living with a partner vs other [divorced, widowed, separated, or never married]) as an indicator of social support and having health insurance (yes/no) as an indicator of health care access.

### Statistical Analysis

We used Pearson  $\chi^2$  and *t* tests where appropriate to test for associations between sample characteristics and prediabetes status and between low health literacy and health behaviors. Then, using path analysis,<sup>22</sup> we assessed pathways among prediabetes, health literacy, and the 3 health behaviors. A single path analysis model included prediabetes as the independent variable, low health literacy as the mediator variable, the 3 health behaviors as the dependent variables, and covariates. We calculated the total effect of prediabetes on the 3 health behaviors as the sum of direct and indirect effects. We converted the coefficients to adjusted odds ratios (aORs) for easy interpretation.

The BRFSS survey uses dual sampling frames and disproportionate stratified sampling to achieve a population-based probability sample. Thus, we used survey procedures in analysis to account for geographic and telephone number stratification and analysis weights. We conducted data analyses by using Stata version 14.<sup>23</sup> Significance was set at  $P < .05$ .

### Results

Adults with prediabetes were significantly older than adults without prediabetes (mean age, 53.3 vs 45.3;  $P < .001$ ) (Table 1). Adults with prediabetes were also significantly more likely than adults without prediabetes to have health insurance ( $P = .04$ ) and to be married or living with a partner ( $P = .02$ ). Non-Hispanic black adults and Hispanic adults were significantly more likely than non-Hispanic white adults to have prediabetes ( $P < .001$ ); adults with an annual household income <\$35 000 were also significantly more likely to have prediabetes than adults with higher incomes ( $P < .001$ ). Overall, adults with prediabetes were significantly more likely than adults without prediabetes to have low health literacy (19.0% vs 14.9%;  $P < .001$ ). The proportions of adults who had difficulty in obtaining information (7.9% vs 5.4%;  $P < .001$ ), understanding health care professionals (10.1% vs 7.0%;  $P < .001$ ), and understanding written information (9.3% vs. 7.3%;  $P < .001$ ) were significantly higher among adults with prediabetes than among adults without prediabetes.

The proportion of adults who were physically inactive was significantly higher among adults with prediabetes than among adults without prediabetes (31.0% vs 24.6%;  $P < .001$ ) (Figure 1). The proportion of adults who reported inadequate sleep was also significantly higher among adults with prediabetes (38.8% vs 33.5%;  $P < .001$ ). We found no difference in smoking status (18.5% vs 17.7%;  $P = .44$ ) by prediabetes status.

### Path Analysis

The path analysis generated information on direct effects, indirect effects, total effects, and coefficients for covariates. The direct effect of prediabetes on low health literacy was significant ( $\beta = 0.034$ ;  $P = .003$  for all) in all 3 models (Figure 2A-C). The direct effect of low health literacy on current smoking was significant ( $\beta = 0.059$ ;  $P < .001$ ), and the direct effect of prediabetes on current smoking was also significant ( $\beta = 0.028$ ;  $P < .001$ ) (Figure 2A).

The direct effect of prediabetes on physical inactivity was significant ( $\beta = 0.031$ ;  $P = .02$ ), as was the direct effect of low health literacy on physical inactivity ( $\beta = 0.064$ ;  $P < .001$ ) (Figure 2B). Lastly, the direct effects of both prediabetes ( $\beta = 0.070$ ;  $P < .001$ ) and low health literacy ( $\beta = 0.075$ ;  $P < .001$ ) on inadequate sleep were significant (Figure 2C).

The indirect effect of prediabetes (ie, through low health literacy) on all 3 health behavior variables was also significant: current smoking ( $\beta = 0.002$ ;  $P < .001$ ), physical inactivity ( $\beta = 0.002$ ;  $P = .01$ ), and inadequate sleep ( $\beta = 0.003$ ;  $P < .001$ ).

In the analysis of the total effects of prediabetes on the 3 health behaviors from the path model, we found that adults with prediabetes, compared with adults without prediabetes,

**Table 1.** Descriptive statistics of the study sample (54 344 adults aged  $\geq 18$ ), by prediabetes status, 2016 Behavioral Risk Factor Surveillance System (BRFSS) survey<sup>a</sup>

Variables	Has Prediabetes (n = 5701)	Does Not Have Prediabetes (n = 48 643)	P Value <sup>b</sup>
Age, weighted mean, y	53.3 (52.6-54.1)	45.3 (45.1-45.6)	<.001
Female	53.6 (51.2-55.9)	51.8 (51.0-52.6)	.16
Race/ethnicity			<.001
Non-Hispanic white	57.0 (54.7-59.3)	61.6 (60.8-62.3)	
Non-Hispanic black	19.9 (18.1-21.9)	16.5 (15.9-17.1)	
Hispanic	18.2 (16.4-20.2)	16.6 (16.0-17.2)	
Other	4.9 (3.8-6.2)	5.4 (5.0-5.9)	
Has health insurance	90.5 (88.8-91.9)	88.6 (88.0-89.1)	.04
Education level			.11
<High school graduation	13.9 (12.2-15.8)	13.3 (12.7-14.0)	
High school graduation	30.9 (28.8-33.2)	28.8 (28.0-29.5)	
≥Some college	55.2 (52.8-57.5)	57.9 (57.1-58.7)	
Annual household income, \$			<.001
<15 000	13.7 (12.2-15.4)	12.4 (11.9-13.0)	
15 000-24 999	20.3 (18.2-22.5)	17.8 (17.1-18.4)	
25 000-34 999	11.3 (9.7-13.1)	9.6 (9.1-10.1)	
35 000-49 999	13.4 (11.8-15.0)	13.3 (12.7-13.9)	
≥50 000	41.4 (38.9-43.9)	47.0 (46.1-47.8)	
Married/living with a partner	52.4 (50.1-54.7)	49.3 (48.5-50.1)	.02
Low health literacy <sup>c</sup>			<.001
Difficulty in obtaining information	7.9 (6.5-9.5)	5.4 (5.0-5.8)	<.001
Difficulty in understanding health care professionals	10.1 (8.6-11.8)	7.0 (6.6-7.5)	<.001
Difficulty in understanding written information	9.3 (7.9-11.1)	7.3 (6.9-7.8)	<.001

<sup>a</sup>Variables of interest were from 2 optional modules in the 2016 BRFSS survey: (1) the health literacy module, in which 14 states and territories participated, and (2) the prediabetes module, in which 27 states and territories participated. All values are weighted percentage (95% CI) unless otherwise indicated. Data source: Centers for Disease Control and Prevention.<sup>13</sup>

<sup>b</sup>Determined by  $\chi^2$  or t test;  $P < .05$  was considered significant.

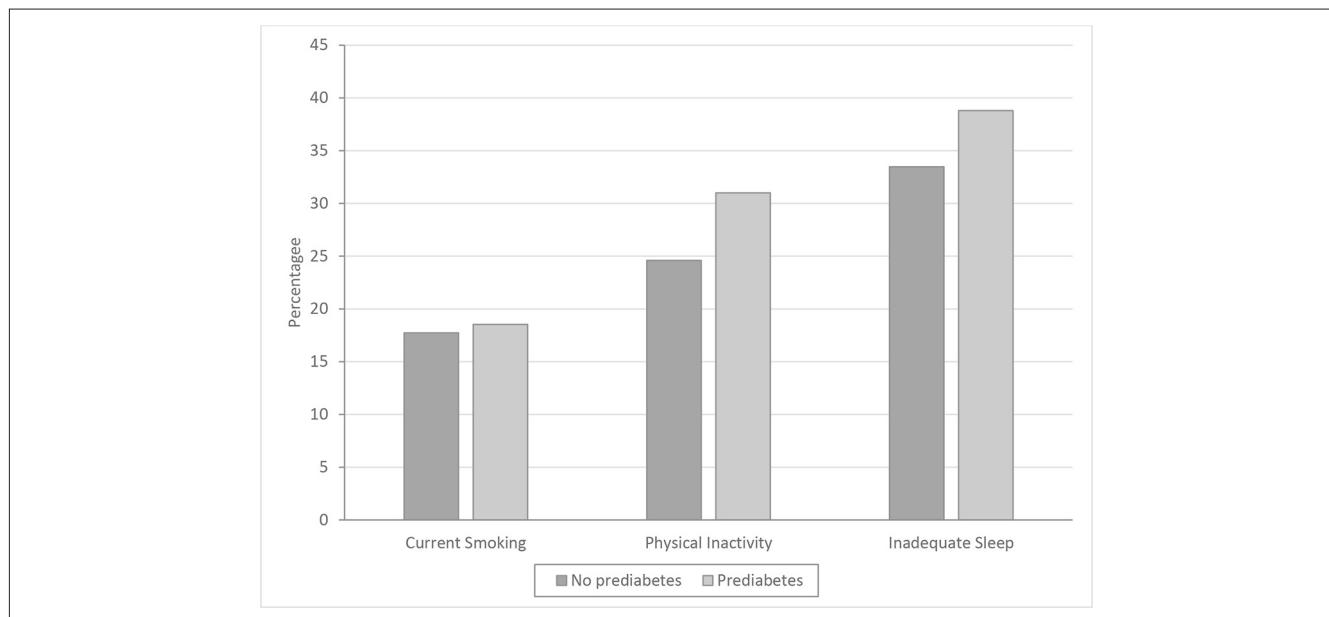
<sup>c</sup>The BRFSS health literacy module included 3 questions on levels of difficulty in obtaining information, understanding health care providers, and comprehending written information. Low health literacy was defined as a response of "somewhat difficult" or "very difficult" to at least 1 of these 3 questions.

were more likely to be current smokers ( $aOR = 1.03$ ; 95% CI, 1.01-1.05), to be physically inactive ( $aOR = 1.03$ ; 95% CI, 1.01-1.06), and to get inadequate sleep ( $aOR = 1.08$ ; 95% CI, 1.05-1.11) (Table 2).

The significant results for the covariates were similar to significant results for the 3 health behavior outcomes (Table 2). Women were less likely to be current smokers ( $aOR = 0.96$ ; 95% CI, 0.95-0.97) and more likely to be physically inactive ( $aOR = 1.04$ ; 95% CI, 1.03-1.06) than men; adults with health insurance ( $aOR = 0.92$ ; 95% CI, 0.90-0.95) were less likely than adults without health insurance to be current smokers; non-Hispanic black adults ( $aOR = 0.94$ ; 95% CI, 0.92-0.96) and Hispanic adults ( $aOR = 0.83$ ; 95% CI, 0.81-0.85) were less likely than non-Hispanic white adults to be current smokers; and Hispanic adults were more

likely than non-Hispanic white adults to be physically inactive ( $aOR = 1.03$ ; 95% CI, 1.01-1.05). As education levels increased, adults were less likely to be current smokers and less likely to be physically inactive ( $P < .001$ ), and adults with an annual household income  $\geq \$25 000$  were less likely than adults with an annual household income  $< \$15 000$  to be current smokers and less likely to be physically inactive ( $P < .001$ ).

In summary, the path analysis results confirmed the mediating role of low health literacy: (1) prediabetes status among adults was significantly associated with the 3 health behaviors (total effect); (2) prediabetes status was significantly associated with low health literacy levels among adults; (3) controlling for prediabetes, low health literacy was significantly associated with the 3 health behaviors among adults;



**Figure 1.** Health behaviors reported by respondents (54 344 adults aged  $\geq 18$ ), by prediabetes status, 2016 Behavioral Risk Factor Surveillance System survey.<sup>13</sup> Current smokers were defined as everyday smokers or some-day smokers; not current smokers were defined as former smokers or never smokers. Physical inactivity was coded according to the following yes/no question: “During the past month, other than your regular job, did you participate in any physical activities or exercises such as running, calisthenics, golf, gardening, or walking for exercise?” Inadequate sleep was coded according to the question, “On average, how many hours of sleep do you get in a 24-hour period?” Those who reported  $<7$  hours were classified as having inadequate sleep.<sup>17</sup>

and (4) the relationship between prediabetes and the 3 health behaviors among adults was reduced (ie, the direct effect) when we controlled for low health literacy (ie, the indirect effect), with a significant indirect effect.

## Discussion

To our knowledge, our study is the first to use population-based national survey data to assess health literacy and health behaviors among adults with prediabetes and to examine the pathways among prediabetes, low health literacy, and health behaviors. Our results showed that, compared with adults without prediabetes, adults with prediabetes had lower health literacy and were more likely to be current smokers, to get inadequate sleep, and to be physically inactive.

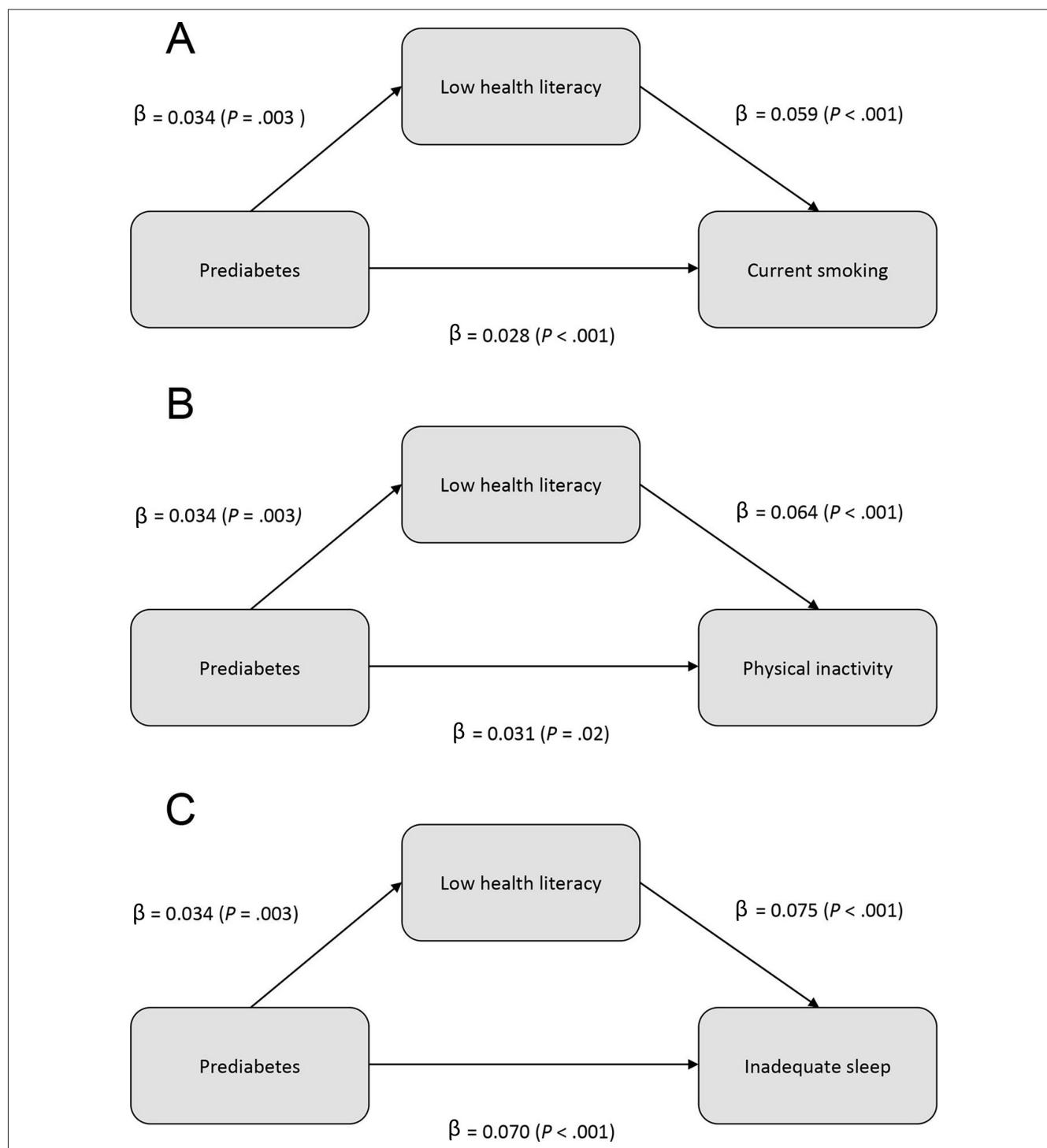
We showed that almost 1 in 5 adults with prediabetes had low health literacy. The rate of low health literacy among adults with prediabetes (19.0%) was 4.1 percentage points higher than among adults without prediabetes (14.9%). These findings indicate that many adults with prediabetes may not be able to read and comprehend essential health-related materials (eg, prescription bottles, appointment slips, self-care protocols) and may lack the capacity to take responsibility for their health and their family’s health.

Health literacy is not just the result of individual capacities but also the health literacy-related demands and complexities of the health care system.<sup>6,24</sup> Potential

communication barriers between patients and health care providers created by low health literacy may lead to poor self-care and adherence to medications.<sup>25,26</sup> To assist persons with low health literacy, programs and interventions such as visual aids and counseling could be implemented to increase comprehension of prescription labels and ensure medication safety and adherence.

The BRFSS survey first included the health literacy module as an optional module in 2016; these data will provide a baseline for tracking the prevalence of low health literacy. Because of differences in defining and measuring health literacy,<sup>27,28</sup> it is difficult to directly compare our results with the results of other studies. In addition, few population-based studies on health literacy exist, and it is difficult to compare results from populations that differ by geography, health status, and demographic characteristics. To our knowledge, the only other existing national study of health literacy is the 2003 National Assessment of Adult Literacy,<sup>29</sup> which found that more than one-third of US adults had basic (22%) or below-basic (14%) health literacy and would have difficulty managing common health-related tasks.

One might expect that adults with prediabetes would engage in healthy lifestyles because of their risk of developing type 2 diabetes. However, our study results showed that a larger proportion of adults with prediabetes than adults without prediabetes were physically inactive (31.0% vs.



**Figure 2.** Results of path analysis in a study ( $N = 54\,344$  adults aged  $\geq 18$ ) on health literacy and health behaviors among adults with prediabetes, 2016 Behavioral Risk Factor Surveillance System survey.<sup>13</sup> (A) Relationship among prediabetes, low health literacy, and current smoking. (B) Relationship among prediabetes, low health literacy, and physical inactivity. (C) Relationship among prediabetes, low health literacy, and inadequate sleep. Low health literacy was defined as answering “somewhat difficult” or “very difficult” to any of the 3 questions on obtaining information, understanding physicians, and understanding written information. Current smokers were defined as everyday smokers or some-day smokers; not current smokers were defined as former smokers or never smokers. Physical inactivity was coded according to the following yes/no question: “During the past month, other than your regular job, did you participate in any physical activities or exercises such as running, calisthenics, golf, gardening, or walking for exercise?” Inadequate sleep was coded according to the question, “On average, how many hours of sleep do you get in a 24-hour period?” Those who reported  $<7$  hours were classified as having inadequate sleep.<sup>17</sup> Arrows indicate a direct effect.

**Table 2.** Results from the total effects path model in a study (N = 54 344 adults aged ≥18) on health literacy and health behaviors among adults with prediabetes, 2016 Behavioral Risk Factor Surveillance System survey<sup>a</sup>

Variables	Model I (Dependent Variable Is Current Smoking <sup>b</sup> )	Model II (Dependent Variable Is Physical Inactivity <sup>c</sup> )	Model III (Dependent Variable Is Inadequate Sleep <sup>d</sup> )
Diabetes status			
Has prediabetes	1.03 (1.01-1.05) [.01]	1.03 (1.01-1.06) [.01]	1.08 (1.05-1.11) [≤.001]
Does not have prediabetes	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]
Health literacy level <sup>e</sup>			
Does not have low health literacy	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]
Has low health literacy	1.06 (1.04-1.09) [≤.001]	1.07 (1.04-1.09) [≤.001]	1.08 (1.05-1.11) [≤.001]
Age	1.00 (0.998-0.999) [≤.001]	1.00 (1.002-1.003) [≤.001]	1.00 (0.998-0.999) [≤.001]
Sex			
Male	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]
Female	0.96 (0.95-0.97) [≤.001]	1.04 (1.03-1.06) [≤.001]	0.99 (0.98-1.01) [.46]
Race/ethnicity			
Non-Hispanic white	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]
Non-Hispanic black	0.94 (0.92-0.96) [≤.001]	1.02 (1.00-1.04) [.06]	1.10 (1.07-1.13) [≤.001]
Hispanic	0.83 (0.81-0.85) [≤.001]	1.03 (1.00-1.05) [.04]	1.00 (0.97-1.03) [.89]
Other	0.96 (0.93-1.00) [.03]	1.02 (0.99-1.06) [.25]	0.99 (0.95-1.04) [.65]
Health insurance status			
Does not have health insurance	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]
Has health insurance	0.92 (0.90-0.95) [≤.001]	0.97 (0.94-1.00) [.08]	0.99 (0.96-1.02) [.45]
Education			
<High school graduation	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]
High school graduation	0.95 (0.92-0.98) [≤.001]	0.94 (0.90-0.97) [≤.001]	1.01 (0.97-1.04) [.77]
≥Some college	0.89 (0.86-0.92) [≤.001]	0.86 (0.84-0.90) [≤.001]	1.01 (0.97-1.05) [.64]
Annual household income, \$			
<15 000	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]
15 000-24 999	0.98 (0.96-1.01) [.26]	0.96 (0.93-0.99) [.005]	0.99 (0.96-1.03) [.75]
25 000-34 999	0.96 (0.93-0.99) [.01]	0.92 (0.89-0.96) [≤.001]	0.98 (0.95-1.02) [.43]
35 000-49 999	0.95 (0.92-0.98) [≤.001]	0.88 (0.85-0.91) [≤.001]	0.97 (0.93-1.00) [.06]
≥50 000	0.89 (0.86-0.91) [≤.001]	0.82 (0.79-0.84) [≤.001]	0.96 (0.93-0.99) [.02]
Marital status			
Divorced, widowed, separated, or never married	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]
Married/living with a partner	0.96 (0.95-0.98) [≤.001]	1.01 (1.00-1.03) [.08]	0.98 (0.96-1.00) [.02]
R <sup>2</sup>	16.3	17.6	12.3
Standardized root mean squared residual	<.001	<.001	<.001

<sup>a</sup>All values are adjusted odds ratio (95% CI) [P value] unless otherwise indicated. Variables of interest were from 2 optional modules in the 2016 Behavioral Risk Factor Surveillance System (BRFSS) survey: (1) the health literacy module, in which 14 states and territories participated, and (2) the prediabetes module, in which 27 states and territories participated. Data source: Centers for Disease Control and Prevention.<sup>13</sup>

<sup>b</sup>Current smokers were defined as everyday smokers or some-day smokers; not current smokers were defined as former smoker or never smokers.

<sup>c</sup>Physical inactivity was coded according to the following yes/no question: "During the past month, other than your regular job, did you participate in any physical activities or exercises such as running, calisthenics, golf, gardening, or walking for exercise?"

<sup>d</sup>Inadequate sleep was coded according to the question, "On average, how many hours of sleep do you get in a 24-hour period?" Those who reported <7 hours were classified as having inadequate sleep.<sup>17</sup>

<sup>e</sup>The BRFSS health literacy module included 3 questions on levels of difficulty in obtaining information, understanding health care providers, and comprehending written information. Low health literacy was defined as a response of "somewhat difficult" or "very difficult" to at least 1 of these 3 questions.

24.6%) and got inadequate sleep (38.8% vs 33.5%). To prevent prediabetes from developing into type 2 diabetes, adults with prediabetes should be encouraged to exercise, quit smoking, and get adequate sleep.<sup>15-18</sup> The National Diabetes Prevention Program has been proven to help persons make the lifestyle changes needed to prevent or delay type 2 diabetes. A loss of a modest amount of body weight (ie, 5%-7%) and regular physical activity (ie, ≥150 minutes per week of brisk walking or similar activity) greatly reduce the risk of type 2 diabetes.<sup>30</sup>

The path analysis results showed important direct and indirect effects of having prediabetes on low health literacy and then unhealthy behaviors. Low health literacy is consistently associated with increases in hospitalizations and use of emergency care, decreases in use of preventive care, and a poor ability to interpret labels and health messages.<sup>3,10</sup> As such, programs that target improvements in health literacy could help to promote positive health behaviors among adults with prediabetes. Medical instructions and patient education material should be written at a sixth-grade or lower reading level, preferably including pictures and illustrations. Health care providers should be mindful that most patients are unwilling to admit that they do not understand medical instructions.<sup>31</sup>

### Limitations

This study had several limitations. First, health literacy data were self-reported, and self-reported data can be subject to bias (eg, social desirability bias). Respondents to the BRFSS survey may have had undiagnosed prediabetes, which would have led to misclassification. Also, we treated data from respondents who answered “I don’t look for health information” in Question 1 and “I don’t pay attention to written health information” in Question 3 as missing. These respondents may have had limited health literacy. Second, we could not assess other health behaviors, such as dietary intake, because these data were not available in the BRFSS. Third, health behaviors were treated as outcomes in our study. Therefore, we could not test whether unhealthy behaviors might lead to prediabetes; that pathway was beyond the scope of this study. Fourth, the 3-item health literacy questionnaire was administered as an optional module, thereby limiting generalizability of findings to other states and territories. Finally, having low health literacy did not completely mediate the relationship between prediabetes and health behaviors—the ratio of indirect effect to total effect was small. Other factors, such as self-efficacy, likely contributed to this relationship.<sup>32</sup>

### Conclusion

We found that adults with prediabetes had lower levels of health literacy and were more likely to practice unhealthy behaviors than adults without prediabetes. Health literacy

plays an important role in the relationship between prediabetes and health behaviors. Intervention programs can target this modifiable factor to improve health behaviors and prevent prediabetes from developing into type 2 diabetes. Adults with low levels of health literacy, particularly those in low-resource communities, may not understand that physical inactivity and inadequate sleep can lead to type 2 diabetes. It is of public health importance to improve the health literacy level of these adults so that this population can adequately comprehend, communicate about, and manage health issues to reduce the risk of type 2 diabetes.

### Acknowledgments

We presented the results of our study at the annual meeting of the 2019 American Public Health Association in Philadelphia, Pennsylvania, November 2-6, 2019.

### Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

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# State Trends in HIV Testing Among US Adults Aged 18-64 Years, 2011-2017

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Public Health Reports  
2020, Vol. 135(4) 501-510  
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DOI: 10.1177/0033354920931833  
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## Abstract

**Objectives:** HIV testing identifies persons living with HIV and can lead to treatment, decreased risk behaviors, and reduced transmission. The objective of our study was to describe state-level trends in HIV testing in the general US adult population aged 18-64 years, for both ever tested for HIV and tested for HIV in the previous 12 months.

**Methods:** Using 2011-2017 Behavioral Risk Factor Surveillance System data, we estimated the percentage of the state population, plus the District of Columbia, aged 18-64 years ever tested for HIV and tested for HIV in the previous 12 months. The 50 states and the District of Columbia were grouped according to the estimated prevalence of HIV in 2011. We used orthogonal contrasts to calculate P values for linear trends.

**Results:** The percentage of the population ever tested for HIV increased significantly in 23 states during 2011-2017, whereas the percentage tested for HIV in the previous 12 months increased significantly in 8 states. In 2017, the mean percentage ever tested for HIV in states with a high prevalence of HIV was 8.6 percentage points higher than the mean percentage in states with a low prevalence of HIV (48.5% vs 39.9%); the mean increase in the percentage ever tested was highest (11.4%) in states with a low prevalence of HIV.

**Conclusion:** Enhanced efforts by states to make HIV testing simple, accessible, and routine are needed to reduce the number of persons who are not aware of their infection.

## Keywords

state HIV testing, HIV screening, HIV testing trends, prevention

Approximately 1.1 million persons are living with HIV infection in the United States, of whom 86% have received a diagnosis and are aware of their HIV infection.<sup>1</sup> The percentage of persons aware of their HIV infection (with relative standard error <30%) varies across the 50 states and the District of Columbia, ranging from 81.8% in Louisiana to 92.4% in Pennsylvania.<sup>1</sup> Overall, persons living with undiagnosed HIV infection account for approximately 38% of HIV transmissions.<sup>2</sup> HIV testing is key to reducing HIV transmissions, by increasing awareness of HIV serostatus that can lead to treatment, decreased risk behaviors, and viral suppression.<sup>3-8</sup> A key strategy in the proposed initiative, Ending the HIV Epidemic: A Plan for America, is to diagnose all HIV infections as early as possible by making HIV testing simple, accessible, and routine.<sup>9</sup>

In 2006, the Centers for Disease Control and Prevention (CDC) released revised recommendations for HIV testing, which recommended screening for persons aged 13-64 years

at least once in health care settings (ie, routine HIV screening) and at least yearly screening for persons at increased risk of HIV infection (eg, gay, bisexual, and other men who have sex with men [MSM]; persons who inject drugs).<sup>7</sup> Routine HIV screening is more effective than risk-based testing in identifying persons with HIV, results in earlier

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diagnosis of HIV infection, and destigmatizes HIV testing.<sup>7,10,11</sup> In 2013, the US Preventive Services Task Force (USPSTF) revised its HIV testing recommendation to include routine HIV screening of all adolescents and adults aged 15-65 years, thus more closely aligning with CDC recommendations.<sup>12</sup> This revision was an important change insofar as private and public health insurers base their coverage and payments on USPSTF recommendations.<sup>12</sup>

Implementation of routine HIV screening in health care settings is not consistent across states. For example, at the end of January 2011, 5 states had laws that were not compatible with CDC's recommendation for routine HIV screening.<sup>13</sup> In 2014, only 1 state had incompatible laws, and these laws became compatible in early 2018.<sup>14</sup> As of 2014, 34 states and the District of Columbia covered routine HIV screening under their Medicaid programs.<sup>15</sup> In a comparison of states that had expanded Medicaid by December 2015 with states that had not expanded Medicaid, the probability of an HIV test increased by 5% over time for low-income, nonelderly adults in expansion states and did not increase in nonexpansion states.<sup>16</sup>

Other factors shown to influence HIV testing at the state level include the amount of federal funding for HIV testing<sup>17,18</sup> (as federal funding increases, testing increases) and the percentage of the population residing in urban areas (as the percentage of persons in urban areas increases, testing increases).<sup>19</sup>

In 2017, nearly half (45.9%) of US adults aged 18-64 years reported having ever been tested for HIV and 1 of 7 (14.8%) reported having been tested in the previous year.<sup>20</sup> Although published studies describe national trends in HIV testing overall and for population subgroups (by age, sex, race/ethnicity, and HIV risk behavior),<sup>20,21</sup> less information is available on state trends in HIV testing. State HIV testing estimates have been reported by individual states. However, none of CDC's state HIV prevention progress reports reported trends for all 50 states or the District of Columbia.<sup>22-25</sup>

The objective of our study was to describe state-level trends in HIV testing in the general US adult population aged 18-64 years, for both ever tested for HIV and tested for HIV in the previous 12 months. Monitoring trends in state HIV testing is important for understanding where progress is likely being made toward incorporating HIV screening as part of routine clinical care. Each state has an important role in contributing toward national goals and monitoring progress in key indicators—reducing the number of new HIV infections, increasing knowledge of HIV seropositive status, and increasing viral suppression.

## Methods

### Data Sources

The Behavioral Risk Factor Surveillance System (BRFSS) is a state-based, annual, cross-sectional telephone survey of

persons aged ≥18 years that collects information on health risk behaviors, preventive health practices, and health care access among noninstitutionalized US adults.<sup>26</sup> BRFSS completes 400 000 interviews annually in all 50 states, the District of Columbia, and 3 US territories. Respondents' data are weighted to generalize sampled adults to the adult general population and provide national and state estimates. Before 2011, BRFSS was conducted by using random-digit-dialing sampling of landline telephones only. In 2011, BRFSS began including respondents who received 100% of their calls on a cell phone, in addition to respondents using a landline telephone. Because of this change in methodology, we did not include pre-2011 data in our analysis.<sup>27</sup> The median response rates for all states and territories in 2017 for both cell phones and landline telephones was approximately 45%.<sup>28</sup>

### Inclusion Criteria

BRFSS interviewers asked respondents if they had ever been tested for HIV, excluding tests that were part of a blood donation, and the date of their last HIV test. We included in our analysis respondents who met the following criteria: (1) resided in the 50 states or the District of Columbia in 2011-2017, (2) reported a valid age (ie, 18-64), (3) reported a yes or no response for having ever been tested, and (4) had a valid or imputable date (ie, year provided) of their most recent test. For the purpose of this analysis, we restricted respondents to adults aged 18-64 to match the age range in the CDC HIV testing guidelines.<sup>7</sup> For records with a most recent HIV test date in the preceding calendar year but an unknown or missing month, we assigned the month of June, and we categorized interviews conducted through June of the following year as having a test in the previous 12 months. This process resulted in counting approximately half of the tests in the previous year with an unknown month as taking place in the 12 months before the survey, which we would expect, assuming that HIV testing is uniformly distributed throughout the year. We used date of last HIV test and interview date to calculate the estimated number and percentage of adults aged 18-64 years who had been tested for HIV in the previous 12 months.

### Data Analysis

We estimated the percentage of the state population ever tested for HIV and tested for HIV in the previous 12 months during 2011-2017. We completed all statistical analyses in SAS version 9.4<sup>29</sup> and SUDAAN<sup>30</sup> to account for the complex sample design of BRFSS and incorporated analysis weights provided. We measured each outcome as a weighted percentage (and 95% confidence intervals [CIs]) of persons tested. For each state, we used orthogonal contrasts in SUDAAN to calculate *P* values for linear trends for ever tested for HIV and tested in the previous 12 months. A significant linear trend indicated that testing increased or decreased

during the study period; a nonsignificant linear trend suggested stable rates or no clear pattern of change. We used the significance threshold of  $P < .01$ .

To quantify the magnitude of linear trends during 2011-2017, we calculated estimated annual percentage change (EAPC). Using the assumption of linearity on the log scale (ie, assuming a constant rate of change), we calculated the EAPC as the difference in the model-predicted prevalence for each year divided by the baseline prevalence.<sup>31</sup> The EAPC quantifies the rate of change over time, as well as the direction of change: a positive EAPC corresponds to an increasing trend, whereas a negative EAPC corresponds to a decreasing trend; a slope of 0 implies no change between the beginning and ending points. We calculated EAPCs to quantify change, and we used the method of contrasts to test for the significance of that change (ie,  $P$  values refer to the significance of the linear trend, not the EAPC). The significance of trends generally leads to the same conclusions despite the different underlying assumptions of contrasts and EAPC. The relationship between EAPC and  $P$  values may not be monotonic (eg, a larger EAPC may not necessarily result in a smaller  $P$  value); a smaller  $P$  value may be due to the differing sizes of subpopulations.

We grouped states by HIV prevalence based on HIV prevalence in 2011<sup>32</sup> to reflect similarities in the prevalence of HIV and the amount of CDC funding for HIV testing. We expected to see higher rates of HIV testing in areas with a high prevalence of HIV because of more CDC funding in those areas.<sup>17</sup> We defined the following categories of prevalence: high prevalence,  $\ge 20\,000$  persons living with HIV infection; medium prevalence, 4000-19 999 persons living with HIV infection; low-medium prevalence, 1000-3999 persons living with HIV infection; and low prevalence,  $<1000$  persons living with HIV infection. We used HIV prevalence rather than incidence to group states because incidence estimates are not stable for all states, whereas prevalence data are available for every state and are used by CDC to determine state funding levels.

We conducted all analyses using data from publicly available data sets; institutional review board approval was not required.

## Results

### Ever Tested for HIV

In 2017, among the 50 states, the percentage of persons aged 18-64 years reporting having ever been tested for HIV ranged from 26.5% (Utah) to 56.6% (New York) (Figure 1 and Table 1). The percentage ever tested in 2017 was  $\ge 19$  percentage points higher in the District of Columbia than in any state, and it was  $>50\%$  in 7 states (Delaware, Florida, Georgia, Maryland, New York, North Carolina, and Virginia).

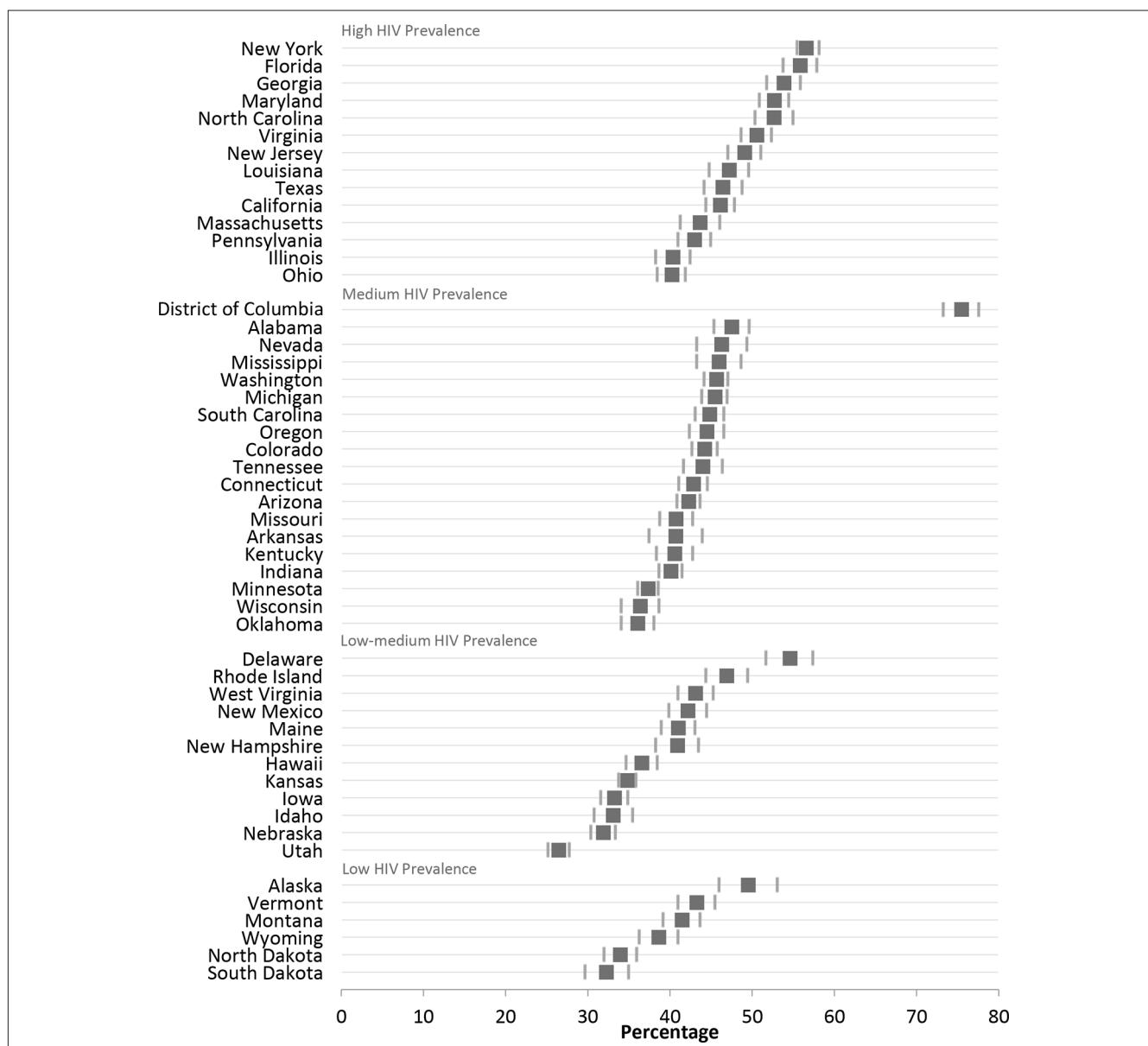
We found a significant linear trend during 2011-2017 in 24 states for persons ever tested for HIV (Table 1). Of these 24 states, 23 had a significant increase in the percentage ever tested for HIV (EAPC range = 0.39% [Washington] to 1.60% [West Virginia]), and 1 state (Tennessee) had a significant decline in the percentage ever tested for HIV (EAPC =  $-0.77\%$ ;  $P = .003$ ). In 2017, the mean percentage ever tested for HIV in states with a high prevalence of HIV was 8.6 percentage points higher than the mean percentage in states with a low prevalence of HIV (48.5% vs 39.9%); however, the low-prevalence states had the greatest relative percentage change (11.4%) (Table 2). For the categories of medium and low-medium prevalence, the relative percentage change in the 23 states that had a significant increase in the percentage ever tested for HIV during 2011-2017 was twice as high as the relative percentage change in all states combined (medium prevalence: 10.6% [23 states] vs 5.3% [all states]; low-medium prevalence: 16.7% [23 states] vs 7.6% [all states]) (Table 3).

### Tested for HIV in the Previous 12 Months

In 2017, among the 50 states, the percentage of adults tested in the previous 12 months ranged from 6.5% (Utah) to 22.4% (Georgia) (Figure 2 and Table 3). The percentage of adults tested in the previous 12 months was  $\ge 18\%$  percentage points higher in the District of Columbia than in any state. The percentage of adults tested in the previous 12 months was  $>20\%$  in 3 states (Florida, Georgia, and New York). We found a significant positive linear trend during 2011-2017 (EAPC range = 0.33 [Minnesota] to 0.71 [Florida]) in the percentage of adults tested in the previous 12 months in 8 states: Florida, Georgia, Indiana, Michigan, Minnesota, New Hampshire, Oregon, and West Virginia (Table 3); we found no significant declines. In 2017, the mean percentage of adults tested in the previous 12 months was 6.1 percentage points higher in states with a high prevalence of HIV infection than in states with a low prevalence of HIV infection (16.5% vs 10.4%); however, the low-prevalence states had the greatest relative percentage change (18.0%) (Table 2). Comparing the 8 states that had a significant increase in the percentage of adults tested in the previous 12 months during 2011-2017 with all 50 states and the District of Columbia, we found that the relative percentage in the 8 states with a significant increase was nearly 3 times higher in each prevalence category (high prevalence: 26.1% [8 states] vs 8.6% [all states]; medium prevalence: 34.4% [8 states] vs 11.9% [all states]; low-medium prevalence: 35.8% [8 states] vs 12.6% [all states]) (Table 2).

## Discussion

The percentage of the population ever tested for HIV increased significantly in 23 states during 2011-2017, whereas the percentage tested for HIV in the previous 12 months increased in



**Figure 1.** Percentage of US adults aged 18-64 years ever tested for HIV, by state and HIV prevalence, Behavioral Risk Factor Surveillance System, 2017. Categories of prevalence were based on data for 2011 from the Centers for Disease Control and Prevention<sup>32</sup>: high prevalence, ≥20 000 persons living with HIV infection; medium prevalence, 4000-19 999; low-medium prevalence, 1000-3999; and low prevalence, <1000. Error bars indicate 95% confidence intervals. Data source: Centers for Disease Control and Prevention.<sup>26</sup>

8 states. HIV testing in the previous 12 months is useful for interpreting trends in the number of HIV diagnoses. However, other data are needed to assess the extent to which testing in the previous 12 months includes persons at high risk of HIV infection who should be tested/retested at least annually per the 2006 testing recommendations.<sup>7,33</sup>

Progress has been made for both ever-tested and tested for HIV in the previous 12 months nationally,<sup>20</sup> but in our analysis, progress varied by state. Accelerated testing is needed to diagnose HIV infections among persons unaware of their infection. CDC analyses published in 2017 suggested that without

increased testing, an infection could be undiagnosed for many years and that 1 in 2 persons had been living with HIV for ≥3 years before an infection had been diagnosed.<sup>34,35</sup> Ideally, HIV is diagnosed within months of infection, rather than years later. Increasing routine HIV testing and narrowing the time frames between testing, diagnoses, and treatment are essential to stopping HIV. Testing is particularly important in states where the percentage of diagnosed HIV infections is below the National HIV/AIDS Strategy target of 90%.<sup>1,36</sup>

Increasing the percentage of persons tested for HIV will require that more health care providers implement both the

**Table 1.** Percentage of US adults aged 18-64 years ever tested for HIV, by state and level of prevalence,<sup>a</sup> Behavioral Risk Factor Surveillance System, 2011-2017<sup>b</sup>

State	2011	2012	2013	2014	2015	2016	2017	P Value for Linear Trend <sup>c</sup>	EAPC <sup>d</sup>
High HIV prevalence									
California	43.8 (42.5-45.0)	43.5 (42.1-45.0)	45.9 (44.3-47.5)	45.0 (43.3-46.8)	44.9 (43.5-46.3)	44.7 (43.2-46.2)	46.1 (44.4-47.9)	.04	0.30
Florida	51.3 (49.5-53.1)	51.3 (49.0-53.6)	50.6 (49.0-52.2)	51.3 (49.5-53.1)	50.9 (48.9-52.9)	55.1 (53.7-56.5)	55.8 (53.8-57.9)	<.001	0.79
Georgia	51.1 (49.2-52.9)	49.8 (47.7-52.0)	48.9 (47.1-50.8)	49.2 (47.1-51.3)	49.6 (47.1-52.2)	50.6 (48.4-52.8)	53.9 (51.8-55.9)	.06	0.37
Illinois	37.0 (34.7-39.4)	35.2 (33.0-37.5)	38.9 (36.6-41.2)	33.3 (31.2-35.5)	36.9 (34.8-39.0)	38.7 (36.6-40.8)	40.4 (38.3-42.5)	.01	0.53
Louisiana	49.4 (47.5-51.2)	50.0 (47.9-52.0)	49.0 (46.3-51.8)	49.4 (47.6-51.3)	47.7 (45.3-50.2)	50.8 (48.0-53.6)	47.2 (44.8-49.6)	.32	-0.20
Maryland	53.4 (51.6-55.2)	51.8 (50.0-53.6)	50.0 (48.3-51.7)	50.7 (48.7-52.7)	52.2 (49.8-54.6)	52.7 (51.3-54.2)	52.7 (50.9-54.5)	.69	0.07
Massachusetts	45.5 (44.1-46.9)	42.9 (41.7-44.2)	43.9 (42.3-45.5)	43.1 (41.6-44.7)	44.7 (42.9-46.5)	45.1 (43.2-47.0)	43.7 (41.3-46.1)	.92	-0.02
New Jersey	45.0 (43.5-46.5)	44.6 (43.2-46.0)	42.7 (41.1-44.2)	41.5 (40.0-43.1)	46.4 (44.6-48.3)	47.2 (45.0-49.5)	49.1 (47.1-51.1)	<.001	0.76
New York	50.4 (48.4-52.3)	49.7 (47.5-51.9)	54.0 (52.2-55.7)	52.4 (50.4-54.3)	55.3 (53.7-56.8)	55.3 (53.9-56.7)	56.6 (55.0-58.2)	<.001	1.12
North Carolina	47.7 (45.9-49.6)	48.7 (47.3-50.2)	48.3 (46.6-50.1)	49.0 (47.2-50.7)	50.0 (48.2-51.9)	48.1 (46.2-49.9)	52.7 (50.4-55.0)	.003	0.55
Ohio	38.8 (37.0-40.5)	35.8 (34.4-37.3)	37.0 (35.4-38.7)	35.2 (33.4-37.1)	36.4 (34.5-38.4)	40.1 (38.4-41.8)	40.2 (38.5-41.9)	.006	0.45
Pennsylvania	38.2 (36.6-39.9)	38.4 (37.1-39.7)	38.5 (37.0-40.0)	36.7 (35.1-38.4)	40.5 (38.3-42.7)	40.1 (38.2-42.0)	43.0 (41.0-45.0)	<.001	0.69
Texas	42.9 (41.2-44.7)	43.8 (42.1-45.6)	43.3 (41.4-45.1)	40.5 (38.9-42.1)	46.0 (44.0-47.9)	44.0 (41.9-46.1)	46.5 (44.2-48.8)	.01	0.48
Virginia	48.9 (46.7-51.2)	46.6 (44.7-48.4)	47.3 (45.5-49.1)	46.4 (44.7-48.1)	48.7 (46.9-50.5)	50.7 (49.1-52.4)	50.6 (48.7-52.4)	.005	0.53
Medium HIV prevalence									
Alabama	48.4 (46.4-50.4)	48.3 (46.4-50.2)	44.8 (42.5-47.1)	44.8 (42.9-46.8)	44.5 (42.6-46.5)	45.2 (43.2-47.2)	47.5 (45.4-49.7)	.10	-0.34
Arizona	40.9 (38.0-43.8)	39.9 (37.5-42.2)	43.2 (39.8-46.6)	39.3 (37.5-41.1)	41.3 (39.2-43.5)	41.8 (39.7-43.9)	42.3 (40.9-43.7)	.31	0.23
Arkansas	40.6 (37.7-43.6)	36.8 (34.5-39.2)	36.8 (34.4-39.3)	40.1 (37.4-42.8)	44.0 (40.8-47.2)	40.0 (36.8-43.2)	40.7 (37.5-44.0)	.09	0.49
Colorado	41.8 (40.2-43.3)	40.5 (39.1-41.9)	42.1 (40.7-43.4)	39.5 (38.1-40.9)	43.8 (42.0-45.5)	42.1 (40.7-43.5)	44.2 (42.7-45.8)	.002	0.44
Connecticut	43.6 (41.5-45.8)	40.1 (38.3-41.9)	42.3 (40.3-44.4)	41.5 (39.6-43.5)	43.2 (41.5-44.9)	42.8 (41.1-44.5)	42.9 (41.1-44.6)	.44	0.14
District of Columbia	73.5 (70.9-76.0)	72.1 (68.9-75.1)	77.2 (74.7-79.6)	74.7 (71.8-77.4)	75.7 (72.0-78.9)	75.9 (73.6-78.1)	75.5 (73.3-77.6)	.08	0.44
Indiana	35.8 (34.0-37.6)	35.0 (33.4-36.6)	35.6 (34.0-37.2)	35.2 (33.7-36.8)	38.4 (36.1-40.8)	36.7 (35.0-38.4)	40.1 (38.7-41.5)	<.001	0.68
Kentucky	35.2 (33.3-37.1)	36.6 (34.8-38.3)	36.9 (35.1-38.7)	38.2 (36.3-40.1)	41.3 (39.1-43.6)	37.7 (35.9-39.6)	40.6 (38.4-42.8)	<.001	0.79
Michigan	41.3 (39.6-43.0)	40.4 (38.8-42.0)	41.1 (39.7-42.6)	40.0 (38.4-41.7)	41.3 (39.7-42.9)	41.3 (39.9-42.7)	45.5 (43.9-47.0)	.001	0.51
Minnesota	31.9 (30.6-33.2)	32.4 (31.0-33.7)	32.4 (30.8-34.1)	30.6 (29.5-31.7)	35.0 (33.8-36.2)	33.9 (32.8-35.0)	37.4 (36.1-38.6)	<.001	0.77
Mississippi	43.7 (41.9-45.5)	45.5 (43.5-47.5)	47.8 (45.6-49.9)	43.9 (41.3-46.6)	47.3 (44.9-49.7)	47.9 (45.6-50.3)	46.0 (43.3-48.7)	.07	0.41
Missouri	38.3 (36.2-40.5)	39.0 (36.9-41.1)	37.3 (35.2-39.4)	36.5 (34.4-38.7)	38.9 (36.8-41.0)	39.8 (37.6-42.2)	40.7 (38.8-42.8)	.06	0.38
Nevada	45.7 (42.8-48.7)	45.1 (42.6-47.6)	44.8 (41.7-48.0)	44.7 (41.6-47.9)	45.7 (42.1-49.3)	44.2 (41.6-46.9)	46.3 (43.3-49.4)	.92	0.03
Oklahoma	35.5 (33.7-37.3)	35.6 (33.9-37.3)	35.1 (33.4-36.9)	28.8 (27.3-30.5)	33.0 (30.9-35.2)	33.3 (31.4-35.3)	36.1 (34.1-38.1)	.33	-0.19
Oregon	40.6 (38.5-42.7)	39.9 (37.7-42.2)	42.7 (40.5-44.9)	41.0 (38.7-43.3)	44.0 (41.8-46.3)	43.4 (41.4-45.5)	44.5 (42.4-46.6)	<.001	0.71
South Carolina	40.7 (39.0-42.4)	41.8 (40.2-43.4)	42.7 (41.0-44.4)	43.3 (41.7-44.9)	43.4 (41.7-45.1)	43.7 (42.0-45.5)	44.8 (43.1-46.6)	<.001	0.60
Tennessee	46.4 (42.9-49.9)	46.4 (44.3-48.5)	49.5 (47.1-52.0)	45.0 (42.4-47.6)	42.1 (39.5-44.7)	42.9 (40.6-45.3)	44.0 (41.7-46.4)	.003	-0.77
Washington	42.8 (41.2-44.5)	40.4 (39.1-41.7)	43.0 (41.5-44.5)	40.9 (39.2-42.6)	42.7 (41.3-44.0)	41.7 (40.4-43.0)	45.7 (44.2-47.1)	.01	0.39
Wisconsin	32.4 (30.0-34.9)	34.5 (32.2-36.9)	36.8 (34.4-39.2)	32.9 (30.9-35.0)	34.5 (32.3-36.8)	33.4 (31.2-35.7)	36.4 (34.1-38.7)	.24	0.26
Low-medium HIV prevalence									
Delaware	51.8 (49.3-54.3)	50.2 (47.9-52.5)	48.0 (45.6-50.3)	45.6 (42.9-48.4)	49.2 (46.3-52.1)	50.7 (47.9-53.5)	54.6 (51.7-57.4)	.13	0.36
Hawaii	36.1 (34.1-38.2)	35.0 (33.1-36.9)	36.4 (34.4-38.3)	36.4 (34.4-38.4)	34.9 (33.0-36.9)	35.6 (33.7-37.5)	36.6 (34.7-38.5)	.83	0.04
Idaho	33.5 (31.2-35.8)	33.0 (30.4-35.7)	34.4 (32.1-36.8)	33.0 (30.7-35.4)	34.1 (31.7-36.5)	34.4 (32.0-36.8)	33.1 (30.8-35.5)	.84	0.05
Iowa	31.6 (30.0-33.3)	30.8 (29.2-32.5)	31.5 (29.7-33.3)	29.3 (27.6-31.0)	32.7 (30.6-34.8)	31.8 (30.0-33.6)	33.3 (31.6-34.9)	.08	0.28
Kansas	34.4 (33.4-35.5)	35.6 (34.2-37.1)	35.8 (34.8-36.7)	31.0 (29.8-32.2)	33.8 (32.8-34.8)	32.2 (30.8-33.6)	34.9 (33.8-35.9)	.01	-0.29
Maine	37.2 (35.8-38.6)	36.8 (35.4-38.3)	38.0 (36.3-39.9)	37.1 (35.4-38.9)	38.2 (36.3-40.1)	39.6 (37.6-41.5)	41.0 (39.0-43.1)	<.001	0.61
Nebraska	30.8 (29.7-31.8)	30.9 (29.8-32.1)	31.9 (30.5-33.4)	30.8 (29.5-32.1)	31.9 (30.4-33.4)	31.8 (30.3-33.4)	31.9 (30.4-33.4)	.14	0.19
New Hampshire	36.7 (34.7-38.8)	36.4 (34.5-38.5)	36.2 (34.2-38.2)	36.3 (34.1-38.6)	38.8 (36.6-41.0)	39.1 (36.8-41.4)	40.9 (38.3-43.5)	.001	0.72
New Mexico	39.1 (37.4-40.8)	38.8 (37.3-40.5)	41.0 (39.1-42.9)	37.9 (35.9-39.9)	39.3 (37.0-41.7)	39.8 (37.4-42.2)	42.2 (39.9-44.5)	.08	0.33
Rhode Island	40.9 (38.8-43.0)	40.3 (38.0-42.5)	41.7 (39.6-43.9)	41.1 (38.9-43.4)	43.5 (41.0-46.0)	45.0 (42.5-47.6)	46.9 (44.4-49.5)	<.001	1.03
Utah	27.4 (26.2-28.7)	25.8 (24.6-27.1)	28.3 (27.1-29.5)	24.0 (23.0-25.0)	26.8 (25.5-28.0)	25.5 (24.2-26.9)	26.5 (25.2-27.8)	.14	-0.18
West Virginia	32.6 (30.7-34.6)	35.4 (33.5-37.3)	37.8 (36.0-39.7)	37.3 (35.5-39.2)	42.7 (40.9-44.7)	41.0 (39.3-42.7)	43.1 (41.0-45.3)	<.001	1.60
Low HIV prevalence									
Alaska	47.0 (44.3-49.8)	48.0 (45.6-50.4)	49.1 (46.6-51.5)	45.9 (43.4-48.3)	48.7 (45.5-51.9)	45.6 (42.2-49.1)	49.5 (46.0-53.1)	.78	0.08

(continued)

**Table 1.** (continued)

State	2011	2012	2013	2014	2015	2016	2017	P Value for Linear Trend <sup>c</sup>	EAPC <sup>d</sup>
Montana	37.1 (35.3-38.9)	36.5 (34.8-38.2)	37.2 (35.6-38.9)	37.2 (35.1-39.3)	40.4 (38.1-42.8)	38.5 (36.3-40.9)	41.5 (39.2-43.7)	<.001	0.73
North Dakota	29.5 (27.5-31.6)	30.2 (28.0-32.4)	31.0 (29.1-32.9)	30.4 (28.2-32.6)	30.6 (28.4-32.9)	32.4 (30.4-34.5)	33.9 (32.0-36.0)	.002	0.62
South Dakota	29.3 (27.0-31.8)	29.5 (27.7-31.4)	31.2 (28.9-33.5)	26.5 (24.4-28.8)	29.3 (27.0-31.8)	30.4 (27.8-33.1)	32.3 (29.7-35.0)	.19	0.31
Vermont	37.8 (35.9-39.7)	35.4 (33.5-37.4)	36.3 (34.4-38.3)	36.6 (34.8-38.3)	39.9 (37.9-41.9)	43.7 (41.6-45.9)	43.3 (41.0-45.5)	<.001	1.29
Wyoming	34.0 (32.0-36.0)	35.8 (33.3-38.3)	34.2 (32.1-36.3)	31.6 (29.1-34.3)	37.2 (34.6-40.0)	38.5 (35.7-41.3)	38.6 (36.3-41.0)	<.001	0.80

Abbreviation: EAPC, estimated annual percentage change.

<sup>a</sup>Categories of prevalence were based on data for 2011 from the Centers for Disease Control and Prevention<sup>32</sup>: high prevalence, ≥20 000 persons living with HIV infection; medium prevalence, 4000-19 999; low-medium prevalence, 1000-3999; and low prevalence <1000.

<sup>b</sup>Data source: Centers for Disease Control and Prevention.<sup>26</sup> All values are percentage (95% confidence interval) unless otherwise indicated. Data include the District of Columbia.

<sup>c</sup>Orthogonal contrasts were used to calculate P values for linear trends; *P* < .01 was considered significant.

<sup>d</sup>EAPC was calculated as the difference in the model-predicted prevalence for each year divided by baseline prevalence.

CDC and USPSTF recommendations for routine HIV screening of adolescents and adults. In addition, HIV testing in populations and neighborhoods with high rates of HIV infection will continue to be important in identifying persons living with HIV who are unaware of their infection. Testing in these populations and neighborhoods will also present an opportunity to provide prevention services (eg, preexposure prophylaxis) to persons who receive a negative test result for HIV. Routinely monitoring the implementation of HIV testing programs will help address any gaps or issues and ultimately improve these programs. State testing efforts can be supported by existing HIV campaigns that encourage adolescents and adults to get tested and health care providers to increase routine testing in health care settings (eg, CDC's Let's Stop HIV Together).<sup>37</sup> Increasing the amount of routine

testing is likely to result in an increase in both ever tested and tested in the previous 12 months.

### Limitations

This study had several limitations. First, we could not assess state trends in HIV testing by race/ethnicity or age because the sample sizes for each state varied, and many states were missing data as a result of unstable estimates. In addition, the distribution of racial/ethnic populations and age groups varied by state. These differences in state populations could explain some of the differences in HIV testing found in our study. Second, we could not assess trends related to reported HIV risk behaviors because of small numbers of survey respondents at the state level. In addition, the question about

**Table 2.** Average percentage of ever tested and percentage of tested in the previous 12 months for HIV, by prevalence category,<sup>a</sup> for all states and states with significant positive trends, 2011-2017<sup>b</sup>

Testing	All States				States With a Significant Increase in Testing			
	No. of States	Mean in 2011, %	Mean in 2017, %	Relative Change, %	No. of States	Mean in 2011, %	Mean in 2017, %	Relative Change, %
<b>Ever tested for HIV</b>								
High	14	46.0	48.5	5.4	7	45.7	49.7	8.7
Medium	19	42.1	44.3	5.3	8	38.7	42.8	10.6
Low-medium	12	36.0	38.7	7.6	4	36.9	43.0	16.7
Low	6	35.8	39.9	11.4	4	34.6	39.3	13.7
Total	51	41.0	43.6	6.3	23	39.8	44.3	11.4
<b>Tested for HIV in the previous 12 months</b>								
High	14	15.2	16.5	8.6	2	17.3	21.9	26.1
Medium	19	12.8	14.3	11.9	4	8.8	11.8	34.4
Low-medium	12	9.4	10.6	12.6	2	8.2	11.2	35.8
Low	6	8.8	10.4	18.0	0	—	—	—
Total	51	12.2	13.6	11.5	8	10.8	14.2	31.0

Abbreviation: —, does not apply.

<sup>a</sup>Categories of prevalence were based on data for 2011 from the Centers for Disease Control and Prevention<sup>32</sup>: high prevalence, ≥20 000 persons living with HIV infection; medium prevalence, 4000-19 999; low-medium prevalence, 1000-3999; and low prevalence <1000.

<sup>b</sup>Data source: Centers for Disease Control and Prevention.<sup>26</sup> Data include the District of Columbia.

**Table 3.** Percentage of US adults aged 18-64 years tested for HIV in the previous 12 months, by state and level of prevalence,<sup>a</sup> Behavioral Risk Factor Surveillance System, 2011-2017<sup>b</sup>

State	2011	2012	2013	2014	2015	2016	2017	P Value <sup>c</sup>	EAPC <sup>d</sup>
High HIV prevalence									
California	12.9 (12.0-13.8)	12.7 (11.7-13.7)	13.3 (12.1-14.7)	12.9 (11.7-14.3)	14.5 (13.5-15.5)	13.5 (12.5-14.6)	14.3 (13.1-15.6)	.02	0.24
Florida	16.9 (15.5-18.5)	15.7 (14-17.6)	16.0 (14.8-17.3)	17.8 (16.3-19.5)	17.3 (15.7-18.9)	18.4 (17.2-19.6)	21.4 (19.5-23.3)	<.001	0.71
Georgia	17.7 (16.2-19.4)	18.1 (16.3-20.1)	17.2 (15.7-18.8)	18.2 (16.5-20.0)	18.7 (16.6-20.9)	17.4 (15.7-19.3)	22.4 (20.5-24.3)	.005	0.47
Illinois	12.3 (10.5-14.3)	9.4 (8.1-11.0)	10.4 (8.9-12.1)	11.1 (9.7-12.8)	11.0 (9.6-12.6)	11.1 (9.8-12.6)	12.6 (11.2-14.2)	.22	0.19
Louisiana	18.7 (17.0-20.4)	17.5 (15.7-19.4)	19.5 (17.1-22.3)	20.1 (18.4-21.8)	18.9 (16.9-21.1)	18.7 (16.3-21.4)	19.1 (17.1-21.3)	.58	0.11
Maryland	20.5 (18.8-22.3)	19.4 (17.7-21.1)	16.4 (15.0-17.8)	17.9 (16.2-19.8)	18.6 (16.6-20.8)	19.1 (17.8-20.4)	19.5 (18.0-21.1)	.82	-0.04
Massachusetts	11.8 (10.8-12.9)	11.5 (10.7-12.4)	13.4 (12.2-14.6)	11.4 (10.3-12.6)	11.0 (9.9-12.2)	10.8 (9.6-12.1)	11.2 (9.8-12.9)	.11	-0.19
New Jersey	14.5 (13.4-15.7)	14.3 (13.3-15.4)	12.3 (11.2-13.4)	12.8 (11.7-13.9)	15.4 (13.9-16.9)	13.7 (12.2-15.3)	15.5 (14.0-17.1)	.18	0.17
New York	20.1 (18.5-21.9)	18.2 (16.5-20.0)	21.6 (20.0-23.2)	20.3 (18.6-22.0)	22.2 (20.8-23.6)	20.4 (19.3-21.6)	21.0 (19.7-22.4)	.06	0.28
North Carolina	15.8 (14.3-17.4)	16.6 (15.5-17.9)	16.8 (15.4-18.3)	15.2 (13.8-16.7)	18.2 (16.6-19.8)	15.1 (13.7-16.6)	18.4 (16.5-20.4)	.19	0.20
Ohio	10.9 (9.6-12.2)	10.1 (9.1-11.2)	10.1 (9.0-11.3)	9.7 (8.5-11.2)	10.6 (9.2-12.2)	10.9 (9.7-12.2)	11.7 (10.5-12.9)	.16	0.17
Pennsylvania	10.8 (9.8-12.0)	11.1 (10.2-12.0)	11.5 (10.4-12.6)	10.9 (9.7-12.1)	12.3 (10.8-13.9)	10.6 (9.5-11.9)	13.7 (12.3-15.2)	.01	0.28
Texas	14.2 (13.0-15.6)	13.7 (12.5-15.1)	13.3 (12.0-14.8)	12.1 (11.0-13.2)	15.0 (13.6-16.6)	13.7 (12.3-15.4)	15.4 (13.7-17.4)	.20	0.19
Virginia	15.9 (14.2-17.8)	14.6 (13.1-16.1)	15.0 (13.6-16.5)	14.8 (13.5-16.2)	15.3 (14.0-16.8)	15.3 (13.9-16.7)	15.3 (13.9-16.8)	.96	-0.01
Medium HIV prevalence									
Alabama	16.7 (15.1-18.5)	17.1 (15.5-18.9)	16.3 (14.4-18.4)	15.0 (13.6-16.6)	15.8 (14.2-17.4)	16.5 (14.9-18.3)	16.6 (14.9-18.4)	.63	-0.08
Arizona	11.5 (9.6-13.7)	10.2 (8.7-11.8)	10.4 (8.4-12.8)	12.0 (10.6-13.4)	11.8 (10.4-13.5)	9.9 (8.5-11.4)	12.2 (11.3-13.2)	.50	0.10
Arkansas	13.0 (10.8-15.6)	11.1 (9.6-12.9)	10.1 (8.6-11.9)	10.8 (9.0-12.8)	13.2 (10.9-15.8)	12.2 (10.0-14.8)	11.8 (9.7-14.3)	.74	0.07
Colorado	11.0 (10.0-12.2)	9.5 (8.6-10.4)	11.0 (10.1-12.0)	9.4 (8.5-10.4)	11.1 (9.9-12.4)	10.3 (9.4-11.3)	12.1 (11.1-13.3)	.07	0.19
Connecticut	12.5 (10.9-14.2)	10.7 (9.7-11.9)	11.7 (10.3-13.2)	10.9 (9.7-12.2)	11.2 (10.1-12.5)	11.7 (10.5-13.0)	13.1 (11.9-14.5)	.37	0.12
District of Columbia	38.6 (35.8-41.5)	39.4 (36.2-42.7)	42.0 (39.0-45.0)	39.5 (36.1-42.9)	42.7 (38.6-47.0)	42.4 (39.5-45.3)	40.7 (38.0-43.4)	.10	0.46
Indiana	8.8 (7.7-10.1)	8.6 (7.6-9.7)	9.1 (8.1-10.2)	9.0 (8.0-10.0)	10.3 (8.8-12.1)	9.1 (8.1-10.3)	11.5 (10.5-12.5)	.001	0.34
Kentucky	10.0 (8.8-11.4)	10.0 (8.9-11.4)	9.4 (8.3-10.7)	10.2 (8.8-11.7)	11.8 (10.2-13.6)	9.6 (8.5-10.9)	11.2 (9.8-12.8)	.17	0.17
Michigan	10.7 (9.6-11.9)	10.7 (9.6-12.0)	11.1 (10.1-12.3)	12.0 (10.8-13.4)	11.4 (10.2-12.6)	10.8 (9.8-11.9)	14.3 (13.1-15.7)	<.001	0.37
Minnesota	7.3 (6.6-8.1)	8.5 (7.7-9.5)	7.3 (6.5-8.3)	7.7 (7.0-8.4)	9.2 (8.4-10.0)	8.3 (7.6-9.0)	10.3 (9.4-11.2)	<.001	0.33
Mississippi	16.4 (15-17.9)	17.1 (15.4-19.0)	16.5 (14.9-18.4)	18.0 (15.7-20.6)	17.6 (15.7-19.7)	18.4 (16.4-20.6)	18.1 (15.9-20.6)	.09	0.30
Missouri	10.7 (9.3-12.2)	10.9 (9.5-12.4)	10.8 (9.4-12.4)	10.1 (8.7-11.8)	11.0 (9.6-12.6)	11.1 (9.6-12.8)	11.8 (10.4-13.2)	.32	0.13
Nevada	12.9 (10.8-15.3)	13.6 (11.9-15.6)	10.9 (9.0-13.1)	13.3 (11.0-15.9)	12.7 (10.3-15.6)	13.0 (11.2-15.1)	15.5 (13.3-18.0)	.15	0.31
Oklahoma	9.5 (8.3-10.8)	8.9 (7.8-10.0)	9.6 (8.5-10.9)	8.0 (7.0-9.0)	9.8 (8.3-11.4)	9.2 (7.9-10.7)	10.5 (9.1-12.1)	.27	0.14
Oregon	8.2 (6.9-9.7)	8.5 (7.2-10.1)	10.1 (8.7-11.8)	8.3 (7.0-9.7)	10.8 (9.3-12.4)	9.8 (8.5-11.2)	11.0 (9.7-12.5)	.003	0.37
South Carolina	13.4 (12.2-14.7)	14.2 (13.1-15.4)	14.3 (13.0-15.6)	14.1 (12.9-15.4)	14.7 (13.5-16.1)	14.0 (12.7-15.5)	16.4 (15.0-17.8)	.01	0.30
Tennessee	13.6 (11.0-16.8)	13.9 (12.3-15.7)	15.6 (13.6-17.8)	15.1 (13-17.6)	12.8 (11.0-14.9)	14.7 (12.8-16.8)	15.4 (13.6-17.5)	.51	0.15
Washington	10.1 (9.0-11.3)	8.6 (7.8-9.4)	10.5 (9.5-11.6)	10.2 (9.1-11.4)	10.0 (9.1-10.9)	9.1 (8.3-10.0)	11.3 (10.3-12.3)	.14	0.15
Wisconsin	8.6 (7.0-10.6)	9.7 (8.1-11.5)	9.2 (7.7-11.0)	7.6 (6.4-9.0)	8.3 (7.0-9.9)	7.2 (6.0-8.8)	8.7 (7.3-10.4)	.21	-0.20
Low-medium HIV prevalence									
Delaware	17.1 (15.0-19.3)	16.7 (14.9-18.8)	15.7 (13.9-17.8)	16.4 (14.1-19)	15.3 (13.1-17.8)	16.8 (14.6-19.3)	19.3 (16.9-22)	.29	0.22
Hawaii	9.4 (8.2-10.7)	8.2 (7.2-9.4)	9.7 (8.5-10.9)	9.7 (8.4-11.1)	9.7 (8.5-11.0)	9.5 (8.2-10.8)	11.1 (9.8-12.5)	.03	0.27
Idaho	7.2 (5.8-8.8)	8.0 (6.3-10.0)	7.7 (6.4-9.3)	7.8 (6.5-9.5)	6.5 (5.2-8.0)	6.2 (5.0-7.7)	7.5 (6.2-9.0)	.32	-0.13
Iowa	7.8 (6.8-8.9)	7.1 (6.1-8.2)	6.6 (5.6-7.7)	7.4 (6.4-8.6)	8.0 (6.7-9.4)	7.0 (6.0-8.2)	8.4 (7.4-9.6)	.26	0.12
Kansas	8.8 (8.1-9.5)	8.9 (7.9-9.9)	8.4 (7.8-9.1)	7.3 (6.6-8.1)	8.8 (8.1-9.5)	7.4 (6.6-8.4)	8.5 (7.8-9.2)	.08	-0.14
Maine	7.9 (7.0-8.9)	7.7 (6.8-8.7)	6.3 (5.4-7.3)	7.0 (6.0-8.2)	7.6 (6.4-9.0)	6.6 (5.6-7.8)	8.3 (7.0-9.8)	.93	0.01
Nebraska	8.0 (7.4-8.7)	7.8 (7.1-8.6)	6.8 (6.0-7.8)	7.3 (6.5-8.1)	7.5 (6.7-8.5)	7.1 (6.1-8.1)	7.7 (6.8-8.7)	.46	-0.07
New Hampshire	7.6 (6.3-9.0)	6.9 (5.7-8.2)	5.6 (4.6-6.8)	7.0 (5.6-8.5)	8.8 (7.4-10.4)	7.1 (5.9-8.5)	10.5 (8.6-12.7)	.002	0.44
New Mexico	10.9 (9.8-12.2)	10.1 (9.1-11.3)	9.5 (8.5-10.7)	11.2 (9.8-12.8)	10.5 (9.0-12.2)	10.9 (9.4-12.8)	12.4 (10.9-14.2)	.06	0.25
Rhode Island	12.8 (11.3-14.6)	12.5 (10.9-14.3)	9.9 (8.6-11.4)	11.8 (10.2-13.6)	13.2 (11.4-15.2)	13.2 (11.4-15.2)	15.2 (13.2-17.4)	.01	0.41
Utah	6.7 (5.9-7.5)	5.4 (4.8-6.2)	6.4 (5.7-7.2)	5.1 (4.6-5.7)	6.6 (5.9-7.4)	5.7 (4.9-6.5)	6.5 (5.8-7.4)	.91	0.01
West Virginia	8.9 (7.7-10.4)	8.0 (6.9-9.4)	8.6 (7.4-9.8)	7.2 (6.2-8.4)	10.9 (9.7-12.3)	9.7 (8.5-10.9)	11.9 (10.3-13.6)	<.001	0.50
Low HIV prevalence									
Alaska	12.4 (10.4-14.6)	12.8 (11.1-14.7)	12.9 (11.2-14.8)	12.0 (10.3-13.9)	12.6 (10.2-15.5)	13.4 (11-16.3)	16.3 (13.6-19.4)	.05	0.44
Montana	7.9 (6.8-9.1)	8.3 (7.3-9.4)	8.0 (7.0-9.1)	7.7 (6.5-9.1)	9.6 (8.2-11.3)	8.0 (6.7-9.5)	10.6 (9.1-12.3)	.01	0.30
North Dakota	8.5 (7.2-10.1)	6.9 (5.7-8.3)	7.4 (6.3-8.7)	7.0 (5.7-8.5)	7.5 (6.3-9.0)	8.2 (6.9-9.7)	8.9 (7.7-10.4)	.26	0.17
South Dakota	7.9 (6.6-9.5)	7.5 (6.5-8.7)	8.1 (6.7-9.6)	6.1 (5.1-7.4)	8.4 (6.9-10.3)	6.3 (5.0-7.9)	8.6 (6.9-10.5)	.91	0
Vermont	8.4 (7.2-9.8)	8.3 (7.1-9.7)	7.4 (6.3-8.7)	8.1 (7.1-9.3)	9.0 (7.8-10.5)	9.1 (7.7-10.7)	9.6 (8.2-11.1)	.07	0.23

(continued)

**Table 3.** (continued)

State	2011	2012	2013	2014	2015	2016	2017	P Value <sup>c</sup>	EAPC <sup>d</sup>
Wyoming	7.8 (6.6-9.1)	7.2 (5.8-8.9)	6.7 (5.5-8.1)	5.5 (4.2-7.1)	9.1 (7.4-11.1)	8.9 (7.1-11)	8.5 (7.2-10.0)	.04	0.30

Abbreviation: EAPC, estimated annual percentage change.

<sup>a</sup>High prevalence, ≥20 000 persons living with HIV infection; medium prevalence, 4000-19 999; low-medium prevalence, 1000-3999; and low prevalence <1000.

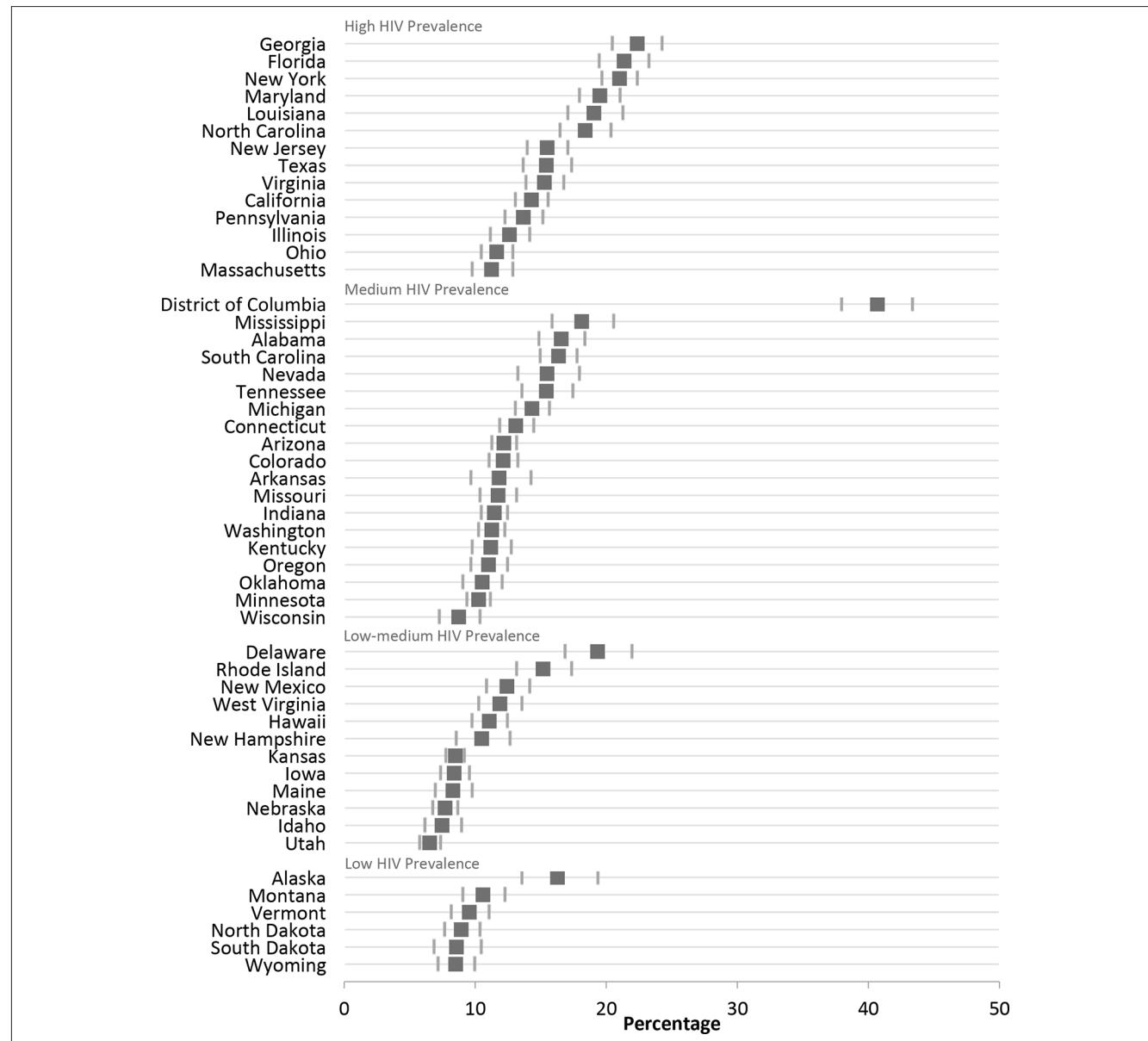
<sup>b</sup>All values are percentage (95% confidence interval) unless otherwise indicated.

<sup>c</sup>Orthogonal contrasts were used to calculate P values for linear trends; P < .01 was considered significant.

<sup>d</sup>EAPC was calculated as the difference in the model-predicted prevalence for each year divided by baseline prevalence.

HIV risk behaviors changed during the study period, and it was not asked annually; thus, we could not compare trends in

responses to this question. Finally, the BRFSS is based on self-reported data, which may be subject to recall bias,



**Figure 2.** Percentage of US adults aged 18-64 years tested for HIV in the previous 12 months, by state and HIV prevalence, Behavioral Risk Factor Surveillance System, 2017. Categories of prevalence were based on data for 2011 from the Centers for Disease Control and Prevention<sup>32</sup>: high prevalence, ≥20 000 persons living with HIV infection; medium prevalence, 4000-19 999; low-medium prevalence, 1000-3999; and low prevalence, <1000. Error bars indicate 95% confidence intervals. Data source: Centers for Disease Control and Prevention.<sup>26</sup>

whereby respondents may not remember being tested in previous years. This limitation could have resulted in an underestimation of testing.

## Conclusions

Routine HIV screening, repeat screening for persons likely to be at high risk for HIV, and targeted HIV testing efforts have reduced the number of persons with undiagnosed HIV infection.<sup>1</sup> Enhanced efforts by states to make HIV testing simple, accessible, and routine will contribute toward reaching national goals to end the HIV epidemic.

## Disclaimer

The findings and conclusions in this article are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

## Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

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# Disparities in Health Effects and Access to Health Care Among Houston Area Residents After Hurricane Harvey

Public Health Reports  
2020, Vol. 135(4) 511-523  
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DOI: 10.1177/0033354920930133  
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**and Jayajit Chakraborty, PhD<sup>4</sup>**

## Abstract

**Objectives:** Although research shows that public health is substantially affected during and after disasters, few studies have examined the health effects of Hurricane Harvey, which made landfall on the Texas coast in August 2017. We assessed disparities in physical health, mental health, and health care access after Hurricane Harvey among residents of the Houston–The Woodlands–Sugar Land, Texas, metropolitan statistical area (ie, Houston MSA).

**Methods:** We used structured survey data collected through telephone and online surveys from a population-based random sample of Houston MSA residents ( $n = 403$ ) collected from November 29, 2017, through January 6, 2018. We used descriptive statistics to describe the prevalence of physical health/mental health and health care access outcomes and multivariable generalized linear models to assess disparities (eg, based on race/ethnicity, socioeconomic status, disability) in health outcomes.

**Results:** Physical health problems disproportionately affected persons who did not evacuate (odds ratio [OR] = 0.41; 95% confidence interval [CI], 0.19-0.87). Non-Hispanic black persons were more likely than non-Hispanic white persons to have posttraumatic stress (OR = 5.03; 95% CI, 1.90-13.10), as were persons in households that experienced job loss post-Harvey (vs did not experience job loss post-Harvey; OR = 2.89; 95% CI, 1.14-7.32) and older persons (OR = 1.04; 95% CI, 1.01-1.06). Health care access was constrained for persons whose households lost jobs post-Harvey (vs did not lose jobs post-Harvey; OR = 2.73; 95% CI, 1.29-5.78) and for persons with disabilities (vs without disabilities; OR = 3.19; 95% CI, 1.37-7.45).

**Conclusions:** Our findings underscore the need to plan for and ameliorate public health disparities resulting from climate change-related disasters, which are expected to occur with increased frequency and magnitude.

## Keywords

health disparities, Hurricane Harvey, disaster, flooding

Hurricane Harvey made landfall on the Texas coast in August 2017. Harvey was an unprecedented tropical storm; total rainfall for the Houston, Texas, area was 36-48 inches.<sup>1</sup> Rainfall caused flooding across the Houston–The Woodlands–Sugar Land metropolitan statistical area (ie, Houston MSA), resulting in about \$125 billion in damages, making it the second costliest disaster in US history, after Hurricane Katrina in 2005.<sup>1</sup> Although research shows that public health is substantially affected during and after disasters,<sup>2-9</sup> few studies have examined the health effects of Harvey, none of which have been population based.

Persons in racial/ethnic minority groups, older persons, persons with disabilities or infirmities, and persons of low socioeconomic status (SES) disproportionately experience poor health outcomes after disasters occur.<sup>10-15</sup> Research on

Harvey found disparities in flood exposure based on race/ethnicity and SES.<sup>16-18</sup> For example, after a flood event in El Paso, Texas, non-US citizens (vs US citizens) and persons of Hispanic ethnicity (vs non-Hispanic white persons) were

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more likely to have physical health problems such as allergies, headaches, coughing and wheezing, and throat, nose, eye, and skin irritations.<sup>10</sup> A literature review published in 2012 concluded that men (vs women) and older persons (vs younger persons) tend to have a higher risk of physical health problems during and after flood events.<sup>2</sup> In addition, women and persons of low SES had an increased risk of having post-traumatic stress (PTS) after Hurricane Ike, which occurred in 2008.<sup>19</sup> In the El Paso study, non-US citizens were more likely to have mental health problems than US citizens.<sup>10</sup>

Public health issues resulting from Harvey have been inadequately documented in the literature. Studies have relied on small convenience samples of local residents. At a convention center in Houston, researchers found more than 200 evacuees seeking mental health treatment, many of whom had no access to needed medications.<sup>20</sup> Another study found that many persons who relocated to shelters after Harvey had high levels of anxiety as a result.<sup>21</sup> A survey of 41 persons in the Houston MSA found that hurricane exposure and property damage were associated with increased symptoms of PTS.<sup>22</sup> Although these studies identified health effects resulting from Harvey, they were not based on representative, population-based samples but instead were based on convenience samples. To advance knowledge of Hurricane Harvey's health effects, we conducted a population-based study based on a random sample of residents in the Houston MSA.

Our study addressed 2 research questions: (1) To what extent did Hurricane Harvey affect the physical health, mental health, and health care access of Houston MSA residents? and (2) How were factors of social vulnerability, disaster

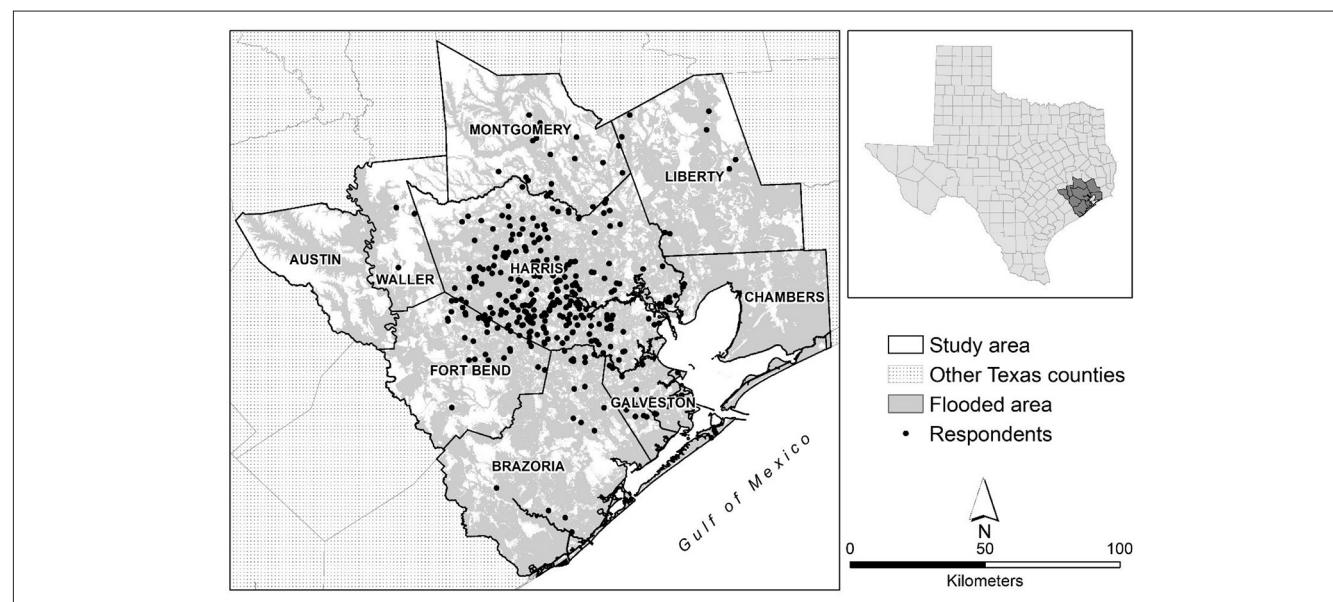
experiences, home site effects, and access to aid associated with physical health, mental health, and health care access outcomes among Houston MSA residents, during and soon after Hurricane Harvey?

## Methods

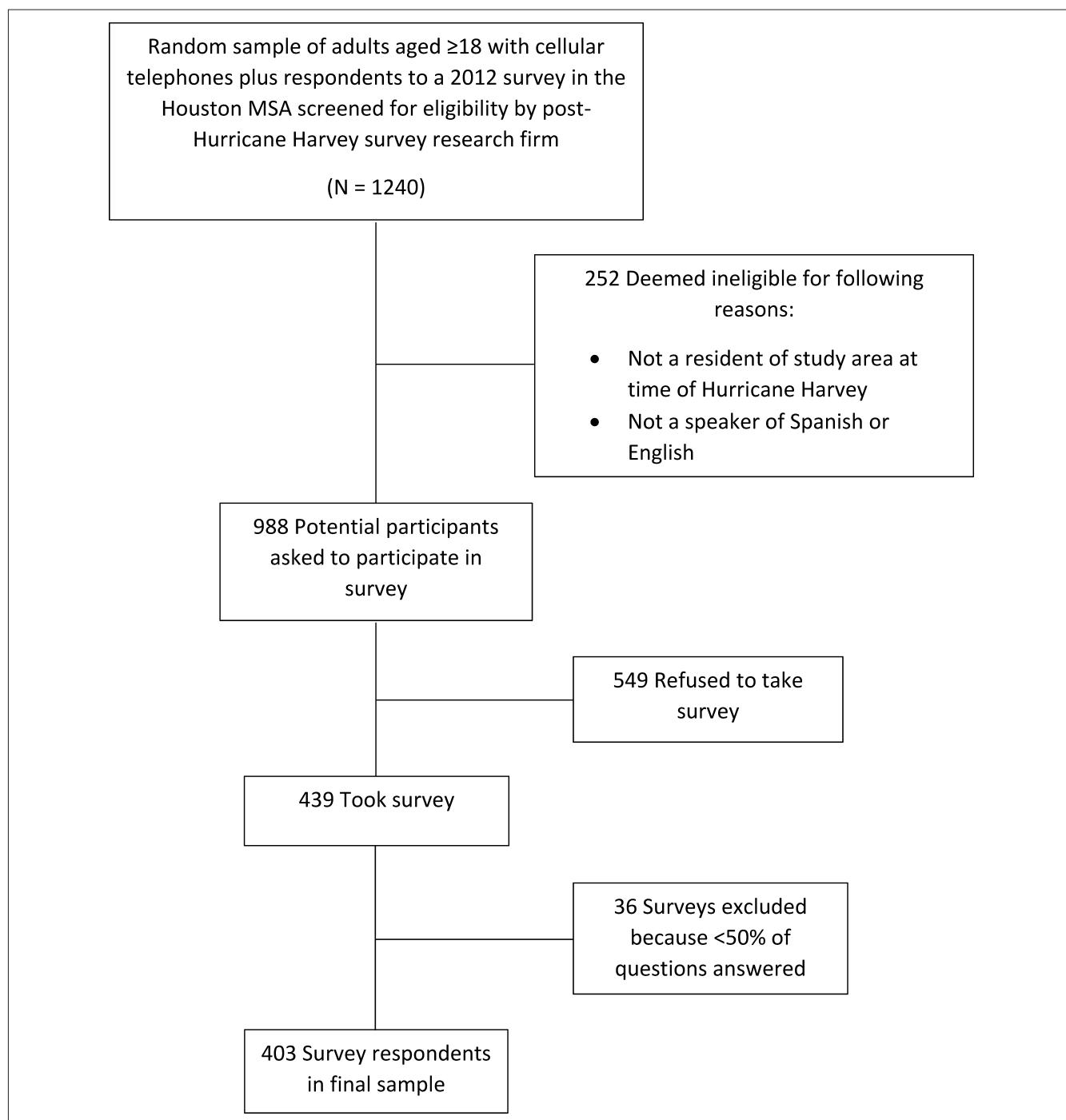
### Data Collection and Sample

We collected data through telephone and online surveys of a random sample of Houston MSA residents from November 29, 2017, through January 6, 2018. The sampling frame consisted of adults aged  $\geq 18$  with cellular telephones in the Houston MSA ( $n = 1240$ ). Using random-digit dialing within a random sample of cellular telephone numbers across this area, interviewers from a survey research firm screened respondents for eligibility, which was based on permanent residence in the Houston MSA at the time of Hurricane Harvey (August 25, 2017) and the ability to speak Spanish or English (Figure 1). Cellular telephone numbers were important because they allowed us to reach persons who had relocated (temporarily or permanently) because of Harvey.<sup>24</sup> Respondents could take the survey by cellular telephone in English or Spanish; the average time for survey completion was 46 minutes. We augmented the sample with completed surveys from respondents to a representative, probability-based survey focused on flood hazards conducted in 2012; we updated their contact information and recontacted them as part of our 2017 post-Harvey survey.<sup>25,26</sup>

Of 988 eligible respondents we contacted, 439 (44.4%) took the survey: 368 were new respondents from the cellular



**Figure 1.** Counties of the Houston–The Woodlands–Sugar Land, Texas, metropolitan statistical area, 2017. Data source: The flooded area is based on the Hurricane Harvey Inundation Footprint from the Federal Emergency Management Agency Region 6.<sup>23</sup>



**Figure 2.** Data collection process for a post–Hurricane Harvey survey in the Houston–The Woodlands–Sugar Land, Texas, metropolitan statistical area (ie, Houston MSA), 2017.

telephone sample and 71 were resurveyed respondents from the 2012 survey (Figure 2).<sup>25</sup> This calculation follows the American Association for Public Opinion Research Cooperation Rate 2 guidelines.<sup>27</sup> We excluded 36 respondents who did not complete at least 50% of the survey items relevant to this analysis, leaving a final sample of 403 survey respondents.

Survey respondents were generally representative of adult residents in the Houston MSA in terms of race/ethnicity, income, and age. The 2016 average annual household income for respondents was \$66 400, whereas the 2016 median annual household income for Houston MSA residents was \$61 708.<sup>28</sup> The survey sample was 34% non-Hispanic white, 38% Hispanic/Latino, and 19% non-Hispanic black. In the

Houston MSA in 2016, non-Hispanic white adults comprised approximately 36%, Hispanic/Latino adults comprised 37%, and non-Hispanic black adults comprised 17% of the adult population. The median age of survey respondents was 49.6; the average age for the adult population in the Houston MSA was 46.<sup>28</sup>

We adapted the survey instrument from previously administered post-flood disaster survey instruments.<sup>10,13,29-31</sup> Through the survey, we collected data from participants on health problems experienced during and after Harvey, lack of access to health care during and after Harvey, and other domains (ie, social vulnerability, disaster experiences, home site effects, and access to aid). We geocoded data on respondents' home addresses and integrated the data with Federal Emergency Management Agency (FEMA) estimates of the Harvey flood extent for areas surrounding their home sites.

### Dependent Variables

We included 3 dichotomous dependent variables: physical health problems, PTS, and lack of access to health care. We assessed data on physical health problems based on respondents' answers to 24 items about having physical health problems during or any time after Hurricane Harvey. We recoded the variable such that respondents who did not have any physical health problem were coded 0, and respondents who had at least 1 physical health problem were coded 1. We measured PTS by using the Post-Traumatic Stress Disorder Checklist-S (PCL-S),<sup>32</sup> a 17-item self-reported measure that includes questions about experiences that occurred at any time since Harvey. Responses to each item were on a 5-point Likert-type scale, where 1 = not at all, 2 = a little bit, 3 = moderately, 4 = quite a bit, and 5 = very much. Overall scores can range from 17 to 85. Although various thresholds have been used to screen persons for PTS,<sup>32</sup> we used a threshold of 40 based on previous studies assessing disaster-induced PTS.<sup>22,33</sup> Respondents with a PTS score <40 were coded as 0 (no or low PTS), and respondents with a PTS score ≥40 were coded as 1 (high PTS). For the lack of access to health care variable, we coded respondents who had continuous access to health care during or soon after Harvey as 0 and respondents who went without access to health care during or soon after Harvey as 1.

### Independent Variables

We classified independent variables into 4 domains: (1) social vulnerability, (2) disaster experiences, (3) home site effects, and (4) access to aid (Table 1).

**Social vulnerability.** We treated age as a continuous variable. Female respondents were the reference category (0), and male respondents were the response category (1). We operationalized race/ethnicity as a construct including

dichotomous variables for Hispanic, non-Hispanic black, and non-Hispanic multiple/other race (nonwhite); in the multivariable models, results for those variables are interpretable in reference to the non-Hispanic white group. We coded respondents born outside the United States as 0 and respondents born in the United States as 1. Annual household income in 2016 was a 10-category measure (<\$10 000, \$10 000-\$19 999, \$20 000-\$29 999, \$30 000-\$39 999, \$40 000-\$49 999, \$50 000-\$74 999, \$75 000-\$99 999, \$100 000-\$149 999, \$150 000-\$249 999, ≥\$250 000).

**Disaster experiences.** We coded respondents without a disability as 0 and respondents with a physical or emotional disability that influenced their ability to evacuate as 1. We coded respondents who did not evacuate as 0 and respondents who did evacuate as 1. Losing a job because of Harvey was a dichotomous variable: we coded respondents whose households did not experience job loss as 0 and respondents whose households did experience job loss as 1. We created a variable for unmet needs by summing responses to 10 checklist-type items (with yes = 1 and no = 0): you went without a comfortable place to sleep for some time; you went without adequate drinking water for some time; you went without adequate clothing for some time; you went without a bathroom for some time; you went without running hot water for some time; you went without electricity for some time; you went without adequate food for some time; you went without adequate transportation for some time; you lacked money for living expenses for some time; or you went without clean piped water for some time. We determined the extent of adverse events experienced by summing 12 checklist-type items: you saw someone drowning or in danger of drowning; you lost a pet or had to abandon one; you worried about crime; you had to perform a dangerous activity; you were stranded in an unsafe place during the disaster; you lost irreplaceable items such as photographs, family mementos or heirlooms, jewelry, or documents; you thought at least once that you might be injured or killed; you worried about family members or friends; you had to split up from household members; you were separated from your children; you experienced unsanitary living conditions; or you experienced crowded living conditions. We assessed personal exposures by summing 5 checklist-type items: you were present when major flooding or hurricane damage occurred; you were a victim of a crime; you smelled unpleasant chemical odors; you inhaled smoke from chemical fires; or you made physical or skin contact with chemicals or contaminants.

**Home site effects.** We derived the flood extent by using Harvey's Inundation Footprint, a cartographic product developed by the FEMA Region 6 Mitigation Division.<sup>23</sup> This raster map layer contains flood depth values for each grid pixel (3×3 m) in the study area and was used in recent Harvey studies.<sup>16-18</sup> Using ArcGIS Desktop version

**Table 1.** Survey question and summary statistics for variables analyzed among adult respondents ( $N = 403$ ) to a post-Hurricane Harvey survey in the Houston–The Woodlands–Sugar Land, Texas, metropolitan statistical area, 2017

Variable	Survey Question	No. of Respondents	Mean Value	No. (%) of Respondents With Missing Information for This Question
<b>Dependent variables</b>				
Physical health problems	Respondent was asked if he/she experienced 24 health problems (Table 2) during or any time after Hurricane Harvey			
	0 = No problems experienced	177	0.56	0
	1 = ≥1 problem experienced	226		
Posttraumatic stress	Respondent was asked 17 items related to posttraumatic stress symptoms from the Post-Traumatic Stress Disorder Checklist-S (PCL-S), <sup>32</sup> and a composite score (on a scale of 17–85) was calculated (Table 3)			
	0 = No, score <40	304	0.18	32 (8.0)
	1 = Yes, score ≥40	67		
Lack of access to health care	Respondent was asked if he/she went without access to health care or medical services for some time during or soon after Hurricane Harvey			
	0 = No	305	0.22	10 (2.5)
	1 = Yes	88		
<b>Social vulnerability</b>				
Age	In what year were you born?	377	49.6	26 (6.4)
Sex	Are you male or female?			
	0 = Female	220	0.44	7 (1.7)
	1 = Male	176		
Ethnicity	Are you Hispanic, Latino, or of Spanish origin?			
	0 = No	245	0.38	5 (1.2)
	1 = Yes	153		
Black or African American	Which of the following best describes your race?			
	0 = No, if not black or African American	319	0.20	8 (2.0)
	1 = Yes, if black or African American	76		
Multiple/other races	Which of the following best describes your race?			
	0 = No, if not multiple/other races	357	0.09	9 (2.2)
	1 = Yes, if not multiple/other races	37		
US born	Were you born in the United States?			
	0 = No	131	0.67	10 (2.5)
	1 = Yes	262		
Income	What was your total annual household income for the year 2016 before taxes?			
	1 = <\$10 000	367	4.89	36 (8.9)
	2 = \$10 000-\$19 999			
	3 = \$20 000-\$29 999			
	4 = \$30 000-\$39 999			
	5 = \$40 000-\$49 999			
	6 = \$50 000-\$74 999			
	7 = \$75 000-\$99 999			
	8 = \$100 000-\$149 999			
	9 = \$150 000-\$249 999			
	10 = ≥\$250 000			
<b>Disaster experiences</b>				
Evacuation disability	Because of a physical, mental, or emotional health condition, did you need any special assistance during Hurricane Harvey to evacuate your home and get to a safe place?			
	0 = No	364	0.07	10 (2.5)
	1 = Yes	29		

(continued)

**Table I.** (continued)

Variable	Survey Question	No. of Respondents	Mean Value	No. (%) of Respondents With Missing Information for This Question
Evacuated	Did you evacuate your home?			
	0 = No	302	0.23	13 (3.0)
	1 = Yes	88		
Lost job	Did you or anyone else in your household lose a job because of Hurricane Harvey?			
	0 = No	357 (0)	0.09	9 (2.2)
	1 = Yes	37 (1)		
Unmet needs <sup>a</sup>	Which of the following happened to you during or soon after Hurricane Harvey?			
	Sum of 10 measures (range, 0-10) <sup>a</sup>	393	2.73	10 (2.5)
Adverse events <sup>b</sup>	Which of the following happened to you during or soon after Hurricane Harvey?			
	Sum of 12 measures (range, 0-12) <sup>b</sup>	393	3.04	10 (2.5)
Personal exposures <sup>c</sup>	Which of the following happened to you during or soon after Hurricane Harvey?			
	Sum of 5 measures (range, 0-5) <sup>c</sup>	393	1.13	10 (2.5)
Home site effects				
Flood extent <sup>d</sup>	Proportion of area surrounding respondents' home (100-m radius) that flooded <sup>d</sup>	357	0.16	46 (11.4)
Level of home damage	Was the home you were living in at the time of Hurricane Harvey "not damaged at all," "damaged to a minor degree," "damaged to a limited degree," "seriously damaged," or "completely destroyed"?			
	1 = Not damaged at all	392	1.84	11 (2.7)
	2 = Minor damage			
	3 = Limited damage			
	4 = Serious damage			
	5 = Completely destroyed			
Square feet of mold	How much surface area in the home you lived in was covered by mold after Hurricane Harvey?			
	1 = 0	389	1.72	14 (3.5)
	2 = <10 square feet			
	3 = 10-25 square feet			
	4 = 25-100 square feet			
	5 = >100 square feet			
Access to aid				
Cleanup	After Hurricane Harvey, did you help clean or repair any flooded home sites?			
	0 = No	100	0.74	21 (5.2)
	1 = Yes	282		
Received social support <sup>e</sup>	Since Hurricane Harvey, how often did family members, friends, neighbors, or coworkers . . . ?			
	Sum of 8 measures (range, 8-32) <sup>e</sup>	394	15.4	9 (2.2)

<sup>a</sup>Unmet needs items were as follows: you went without a comfortable place to sleep for some time; you went without adequate drinking water for some time; you went without adequate clothing for some time; you went without a bathroom for some time; you went without running hot water for some time; you went without electricity for some time; you went without adequate food for some time; you went without adequate transportation for some time; you lacked money for living expenses for some time; or you went without clean piped water for some time.

<sup>b</sup>Adverse events items were as follows: you saw someone drowning or in danger of drowning; you lost a pet or had to abandon one; you worried about crime; you had to perform a dangerous activity; you were stranded in an unsafe place during the disaster; you lost irreplaceable items such as photographs, family mementos; you thought at least once that you might be injured or killed; you worried about family members or friends; you had to split up from household members; you were separated from your children; you experienced unsanitary living conditions; or you experienced crowded living conditions.

<sup>c</sup>Personal exposure items were as follows: you were present when major flooding or hurricane damage occurred; you were a victim of a crime; you smelled unpleasant chemical odors; you inhaled smoke from chemical fires; or you made physical or skin contact with chemicals or contaminants.

<sup>d</sup>Derived using the Federal Emergency Management Agency estimates of Harvey flood extent for areas surrounding respondents' home sites.<sup>23</sup>

<sup>e</sup>Social support items were as follows: suggest some action that you should take; give, loan, or offer you money or something else you needed; comfort you with a hug or another sign of affection; let you know they would be around if you needed them; express interest and concern in your well-being; offer or provide you with a place to stay; help you with cleaning up or improving your property; or bring you food or cook for you.

10.5.1,<sup>34</sup> we generated a flood extent value for each survey respondent by creating a circular buffer (100-m radius) around each geocoded home location and summing all flooded pixels (nonzero depth) areas within the buffer. Next, we divided the flooded area sum by the area of the circular buffer (square meters) to derive the proportion of the area surrounding the respondent's home that was flooded because of Harvey. The level of home damage was a self-reported measure ranging from 0 (not damaged at all) to 5 (completely destroyed). The square footage of mold present in the respondent's home was a self-reported measure ranging from 1 (none) to 5 (>100 ft<sup>2</sup>).

**Access to aid.** We coded respondents who did not help clean or repair flooded homes as 0 and respondents who did help clean or repair flooded homes as 1. We measured social support by summing respondents' answers to 8 questions about how often they received the following types of help from family, friends, neighbors, or coworkers: suggest some action that you should take; give, loan, or offer you money or something else you needed; comfort you with a hug or another sign of affection; let you know they would be around if you needed them; express interest and concern in your well-being; offer or provide you with a place to stay; help you with cleaning up or improving your property; or bring you food or cook for you.

## Data Analysis

To answer research question 1, we used descriptive statistics for the dependent variables and individual indicators comprising the physical health problems and PTS measures. To answer research question 2, we began by using multiple imputation, which is a best practice for reducing bias when analyzing data with missing values.<sup>35,36</sup> We tabulated the percentage of missing values for each variable in the original data set; the percentage of respondents with missing information for our analysis variables ranged from 0% for physical health problems to 11.4% for flood extent (Table 1). As is recommended, we performed multiple imputation to create 20 data sets with imputed values for all missing data points.<sup>10,18,37,38</sup> We specified all ordinal variables as continuous variables, which is recommended in the multiple imputation literature, because rounding imputed values to conform to discrete ordinal variable specifications results in more biased parameter estimates than treating ordinal variables as continuous in multivariable models.<sup>37,39-41</sup>

We used the multiple imputation data in binary logistic generalized linear modeling<sup>10</sup> to predict the 3 dichotomous dependent variables. The physical health model did not include social support as an independent variable because social support has not been previously linked to postdisaster physical health outcomes. Social support was included in the PTS model because evidence indicates that social

support protects against mental health problems (eg, depression, PTS) after disasters.<sup>42,43</sup> The PTS model did not include cleaning activities because these activities are not known to predict PTS. The access to health care model included only social vulnerability variables and having an evacuation disability. For each model, we used Akaike information criterion values to assess goodness of fit. Diagnostic testing indicated that the models were not affected by multicollinearity. We report pooled results from analyses of the 20 multiply imputed data sets for each of the 3 dependent variables. We conducted all analyses by using SPSS version 25.<sup>44</sup>

## Results

### Research Question 1

More than half of respondents (226 of 403, 56.1%) had  $\geq 1$  physical health problem (Table 1). On average, respondents had 3 physical health problems, and 45 (11.2%) respondents had  $\geq 10$  physical health problems. The most common physical health problems were allergies or hay fever (n = 132, 32.8%), headaches (n = 114, 28.3%), nose irritation (n = 110, 27.3%), and throat irritation (n = 107, 26.6%; Table 2). Sixty-seven of 371 (18.1%) respondents had PTS scores  $\geq 40$ . Of the 17 items on the PCL-S, having repeated, disturbing memories, thoughts, or images of Harvey was the most reported experience (n = 194 of 400, 48.5%; Table 3). Eighty-eight of 393 (22.4%) respondents reported going without access to health care during or soon after Harvey.

### Research Question 2

Respondents who evacuated after Harvey had 59% lower odds than those who did not evacuate of having  $\geq 1$  physical health problem (odds ratio [OR] = 0.41; 95% confidence interval [CI], 0.19-0.87). For each additional adverse event experience, respondents had 36% greater odds of reporting  $\geq 1$  physical health problem (OR = 1.36; 95% CI, 1.15-1.60). In addition, each scale unit increase in square feet of mold in the home resulted in a 39% increase in the odds of experiencing  $\geq 1$  physical health problem (OR = 1.39; 95% CI, 1.05-1.86; Table 4).

Each additional year in age was associated with a 4% increase in the odds of having a PTS score  $\geq 40$  (OR = 1.04; 95% CI, 1.01-1.06; Table 4). Being non-Hispanic black versus non-Hispanic white was associated with a 403% increase in the odds of having a PTS score  $\geq 40$  (OR = 5.03; 95% CI, 1.93-13.13). Having a household member experience job loss because of Hurricane Harvey was associated with a 189% increase in the odds of having a PTS score  $\geq 40$  (OR = 2.89; 95% CI, 1.14-7.32). Each additional adverse event experience during or soon after Hurricane Harvey resulted in a 28% increase in the odds of having a

**Table 2.** Physical health problems experienced by respondents to a post-Hurricane Harvey survey (N = 403) in the Houston–The Woodlands–Sugar Land, Texas, metropolitan statistical area, 2017

Physical Health Problem	No. (%) Affected
Allergies or hay fever	132 (32.8)
Headaches	114 (28.3)
Nose irritation	110 (27.3)
Throat irritation	107 (26.6)
More allergies or hay fever than before Hurricane Harvey	106 (26.3)
Eye irritation	88 (21.8)
More coughing or wheezing than before Hurricane Harvey	78 (19.4)
Lung or airway irritations or inflammation	60 (14.9)
Dizziness	52 (12.9)
Skin irritation	50 (12.4)
Missed work or school because of coughing or wheezing	48 (11.9)
Fever	46 (11.4)
Blurred vision	46 (11.4)
Diarrhea	44 (10.9)
Nausea	43 (10.7)
Asthma	36 (8.9)
More asthma attacks than before Hurricane Harvey	30 (7.4)
Vomiting	30 (7.4)
Athlete's foot	29 (7.2)
Gastrointestinal infection	15 (3.7)
Any other infectious disease	11 (2.7)
Food poisoning	7 (1.7)
West Nile virus	4 (1.0)
Hepatitis A	3 (0.7)

PTS score  $\geq 40$  (OR = 1.28; 95% CI, 1.08-1.53). A scale-unit increase in square feet of mold present in the home was associated with a 55% increase in the odds of having a PTS score  $\geq 40$  (OR = 1.55; 95% CI, 1.19-2.03).

Having a disability that interfered with evacuation was associated with a 219% increase in the odds of going without access to health care after Harvey (OR = 3.19; 95% CI, 1.37-7.45; Table 4). Also, having a household member experience job loss because of Harvey was associated with a 173% increase in the odds of going without access to health care (OR = 2.73; 95% CI, 1.29-5.78).

## Discussion

Descriptive statistics indicated the prevalent effects of Hurricane Harvey on the physical health, mental health, and lack of access to health care among residents of the Houston MSA. Physical health problems were prevalent in

more than half of the sample. PTS affected approximately one-fifth of the population, which manifested most frequently in having repeated or disturbing memories of the hurricane. Nearly one-quarter of respondents reported going without adequate health care services during or after Harvey. These results align with previous findings after Hurricane Katrina.<sup>45-47</sup>

Our multivariable statistical models clarified important predictors of the 3 health-related outcomes. Evacuating at any time was protective, whereas more adverse event experiences (vs fewer adverse event experiences) and greater mold exposure (vs less mold exposure) increased the odds of having physical health problems after Harvey. The protective effect of evacuation was likely due to the evacuated residents' absence during flooding, which reduced their odds of experiencing physical harm, highlighting the importance of evacuating during high-magnitude flood events. Adverse event experiences were also risk factors in the odds for greater severity of PTS, aligning with previous literature.<sup>10</sup> Increased surface area of mold present in one's home after Harvey was another substantial risk factor for greater severity of PTS. Studies have tested the relationship between mold exposure and mental health, but few have found significant relationships.<sup>48</sup> Exposure to mold may induce physical discomfort or respiratory distress, which could exacerbate the stress response. Also, exposure to mold can impair cognitive function.<sup>49</sup> Having a household member experience job loss because of Harvey played a substantial role in respondents' mental health, significantly increasing their odds of having PTS. Older age also had a significant effect on respondents' risk for PTS, which contradicts findings from most, but not all, postdisaster studies on PTS.<sup>13</sup> Non-Hispanic black persons were disproportionately affected by PTS, highlighting environmental justice issues associated with flooding in the Houston MSA. These findings are also consistent with previous studies on mental health and disasters.<sup>8,19,50,51</sup> Respondents whose households experienced job loss because of Harvey (vs households that did not experience job loss) and respondents whose disabilities made it difficult to evacuate (vs respondents without disabilities) faced greater odds of lacking access to health care after the event. These findings are concerning from a public health perspective. Disparate risks for populations with disabilities in the Houston MSA were also highlighted in a study that showed neighborhoods with higher (vs lower) proportions of residents with disabilities had more extensive flooding because of Harvey.<sup>17</sup>

## Limitations

Although our sample was generally representative of the Houston MSA population, the data had some limitations. First, measurement error inevitably propagates in self-reported data, which were the basis for this study.<sup>52</sup> Second, our analysis

**Table 3.** Posttraumatic stress symptoms experienced by respondents to a post–Hurricane Harvey survey (N = 403) in the Houston–The Woodlands–Sugar Land, Texas, metropolitan statistical area, 2017

Posttraumatic Stress Symptoms	No. of Respondents for This Question	No. (%) Affected “a Little Bit,” “Moderately,” “Quite a Bit,” or “Very Much”
Having repeated, disturbing memories, thoughts, or images of Hurricane Harvey	400	194 (48.5)
Being “super-alert,” watchful, or on guard	400	163 (40.8)
Feeling very upset when something reminded you of Hurricane Harvey	395	160 (40.5)
Avoiding thinking about or talking about Hurricane Harvey or avoiding having feelings related to it	397	148 (37.3)
Having repeated, disturbing dreams of Hurricane Harvey	398	122 (30.7)
Suddenly acting or feeling as if Hurricane Harvey was happening again—as if you were reliving it	401	120 (29.9)
Feeling jumpy or easily startled	401	116 (28.9)
Having trouble falling or staying asleep	397	114 (28.7)
Having difficulty concentrating	399	114 (28.6)
Feeling distant or cut off from other people	397	100 (25.2)
Feeling irritable or having angry outbursts	401	100 (24.9)
Having a loss of interest in activities that you used to enjoy	401	96 (23.9)
Having physical reactions—that is, heart pounding, trouble breathing, sweating—when something reminded you of Hurricane Harvey	397	95 (23.9)
Avoiding activities or situations because they reminded you of Hurricane Harvey	400	90 (22.5)
Having trouble remembering important parts of Hurricane Harvey	399	84 (21.1)
Feeling as if your future will somehow be cut short	399	82 (20.6)
Feeling emotionally numb or being unable to have loving feelings for those close to you	397	81 (20.4)

<sup>a</sup>Posttraumatic stress was measured by using the Post-Traumatic Stress Disorder Checklist-S (PCL-S),<sup>32</sup> a 17-item self-reported measure that includes questions about experiences that occurred at any time since Harvey. Responses to each item were on a 5-point Likert-type scale, where 1 = not at all, 2 = a little bit, 3 = moderately, 4 = quite a bit, and 5 = very much.

lacked the reference frame needed to attribute the health effects we documented directly to Harvey. For example, because we did not account for pre-Harvey health care access, we could not infer that Harvey exacerbated preexisting disparities in health care access. Thus, future postdisaster health research should seek to strengthen causal inferences using pre- and postevent designs and/or appropriate control groups. Finally, our PTS variable was not a diagnostic measure. It was a screening measure of PTS symptomatology based on a conventionally applied threshold.

## Conclusion

To our knowledge, this study is the first to use a population-based random sample to analyze the physical health, mental health, and health care access outcomes among residents in the Houston MSA after Hurricane Harvey. Using structured survey data allowed us to determine which residents were disadvantaged in physical health, mental health, and access to health care. Our results indicate that Harvey had substantial effects on Houston MSA

residents, highlighting racial/ethnic, age, and socioeconomic disparities, aligning with previous findings on environmental justice in the region.<sup>16,17,25,53-56</sup> This study indicates a need to enhance knowledge of the role of race/ethnicity and SES in creating population health vulnerabilities in order to improve public health interventions, as some residents’ social disadvantages were associated with post-disaster health disparities. Our findings also indicate the need for improvements to flood hazard mitigation and public health response efforts in the Houston MSA. Public health officials can use this information to provide health services to disadvantaged populations in future flood events to ameliorate disparities. These efforts have become essential as similar events are more likely to occur now rather than 20 years ago in the Houston MSA because of climate change.<sup>57</sup>

## Acknowledgments

The authors thank Mark English, the Hazard and Performance Analysis’s Geospatial Unit Lead with FEMA under Disaster Operations within the Mitigation Branch, for contributing to the

**Table 4.** Generalized linear models predicting physical health problems, posttraumatic stress, and lack of access to health care among respondents to a post-Hurricane Harvey survey (N = 403) in the Houston–The Woodlands–Sugar Land, Texas, metropolitan statistical area, 2017<sup>a</sup>

Variable	Has ≥1 Physical Health Problem	Posttraumatic Stress ≥40 <sup>b</sup>	Lack of Access to Health Care
<b>Social vulnerability</b>			
Age	1.01 (0.99-1.03) [.22]	1.04 (1.01-1.06) [.002]	1.00 (0.98-1.01) [.71]
Sex			
Female	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]
Male	0.74 (0.46-1.19) [.21]	0.80 (0.41-1.54) [.50]	0.83 (0.50-1.39) [.49]
Race/ethnicity			
Non-Hispanic white	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]
Hispanic	0.76 (0.35-1.64) [.48]	1.94 (0.65-5.80) [.24]	1.26 (0.56-2.84) [.58]
Non-Hispanic black	0.88 (0.43-1.79) [.73]	5.03 (1.93-13.13) [<.001]	1.57 (0.79-3.12) [.20]
Multiple/other races	1.34 (0.60-3.00) [.47]	1.11 (0.37-3.38) [.85]	2.04 (0.92-4.53) [.08]
Nativity			
Non-US-born	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]
US-born	1.31 (0.66-2.59) [.45]	0.83 (0.33-2.08) [.69]	1.79 (0.86-3.73) [.12]
Annual household income (2016)	0.98 (0.88-1.08) [.68]	0.96 (0.82-1.12) [.57]	0.95 (0.85-1.06) [.31]
<b>Disaster experiences</b>			
Needed assistance in evacuating because of a disability			
No	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]
Yes	1.35 (0.34-5.33) [.67]	0.70 (0.22-2.25) [.55]	3.19 (1.37-7.45) [.01]
Evacuated from home			
No	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]
Yes	0.41 (0.19-0.87) [.02]	0.69 (0.26-1.79) [.44]	—
Persons in household experienced job loss post-Harvey			
No	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]
Yes	1.11 (0.45-2.74) [.82]	2.89 (1.14-7.32) [.03]	2.73 (1.29-5.78) [.01]
Unmet needs			
Adverse event experiences	1.02 (0.91-1.15) [.72]	1.11 (0.96-1.28) [.15]	—
Personal exposures	1.36 (1.15-1.60) [<.001]	1.28 (1.08-1.53) [.01]	—
Flood extent	1.31 (0.95-1.81) [.10]	0.97 (0.63-1.48) [.88]	—
<b>Home site effects</b>			
Level of home damage	0.38 (0.08-1.87) [.23]	0.68 (0.06-8.20) [.76]	—
Square feet of mold	1.23 (0.88-1.71) [.23]	0.83 (0.55-1.25) [.37]	—
Helped clean up	1.39 (1.05-1.86) [.02]	1.55 (1.19-2.03) [<.001]	—
<b>Access to aid</b>			
Received social support	1.00 [Reference] 1.63 (0.95-2.79) [.08] —	1.00 [Reference] — 1.06 (0.99-1.12) [.09]	1.00 [Reference] — —

Abbreviation: —, not included in the model.

<sup>a</sup>All values are odds ratio (95% CI) [P value]. The Wald  $\chi^2$  test was used to determine significance; P < .05 was considered significant. Results are for analyses of multiply imputed data.

<sup>b</sup>Posttraumatic stress scores ranged from 17 (did not experience any symptoms at all) to 85 (experienced all symptoms very much).

creation of Harvey's Inundation Footprint, a data product used in our analysis.

### Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This research was funded by the US National Science Foundation (award no. 1841654). Any opinions, conclusions, or recommendations expressed in this article are those of the authors and do not necessarily reflect the views of the National Science Foundation.

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# Trends in Women With an HIV Diagnosis at Delivery Hospitalization in the United States, 2006-2014

Public Health Reports  
2020, Vol. 135(4) 524-533  
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DOI: 10.1177/0033354920935074  
[journals.sagepub.com/home/phr](http://journals.sagepub.com/home/phr)



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## Abstract

**Objectives:** The risk of mother-to-child HIV transmission can be reduced to  $\leq 0.5\%$  if the mother's HIV status is known before delivery. This study describes 2006-2014 trends in diagnosed HIV infection documented on delivery discharge records and associated sociodemographic characteristics among women who gave birth in US hospitals.

**Methods:** We analyzed data from the 2006-2014 National Inpatient Sample and identified delivery discharges and women with diagnosed HIV infection by using *International Classification of Diseases, Ninth Revision, Clinical Modification* codes. We used a generalized linear model with log link and binomial distribution to assess trends and the association of sociodemographic characteristics with an HIV diagnosis on delivery discharge records.

**Results:** During 2006-2014, an HIV diagnosis was documented on approximately 3900-4400 delivery discharge records annually. The probability of having an HIV diagnosis on delivery discharge records decreased 3% per year (adjusted relative risk [aRR] = 0.97; 95% CI, 0.94-0.99), with significant declines identified among white women aged 25-34 (aRR = 0.93; 95% CI, 0.88-0.97) or those using Medicaid (aRR = 0.93; 95% CI, 0.90-0.97); among black women aged 25-34 (aRR = 0.95; 95% CI, 0.92-0.99); and among privately insured women who were black (aRR = 0.96; 95% CI, 0.92-0.99), Hispanic (aRR = 0.92; 95% CI, 0.86-0.98), or aged 25-34 (aRR = 0.96; 95% CI, 0.92-0.99). The probability of having an HIV diagnosis on delivery discharge records was greater for women who were black (aRR = 8.45; 95% CI, 7.56-9.44) or Hispanic (aRR = 1.56; 95% CI, 1.33-1.83) than white; for women aged 25-34 (aRR = 2.33; 95% CI, 2.12-2.55) or aged  $\geq 35$  (aRR = 3.04; 95% CI, 2.79-3.31) than for women aged 13-24; and for Medicaid recipients (aRR = 2.70; 95% CI, 2.45-2.98) or the uninsured (aRR = 1.87; 95% CI, 1.60-2.19) than for privately insured patients.

**Conclusion:** During 2006-2014, the probability of having an HIV diagnosis declined among select sociodemographic groups of women delivering neonates. High-impact prevention efforts tailored to women remaining at higher risk for HIV infection can reduce the risk of mother-to-child HIV transmission.

## Keywords

HIV, delivery, perinatal, mother-to-child transmission, national estimates

Screening for HIV is an essential step to prevent mother-to-child (perinatal) transmission. When the HIV status of a mother is known before delivery, the risk of perinatal HIV transmission can be reduced from 25% to  $\leq 0.5\%$ <sup>1</sup> by appropriate antiretroviral treatment of the mother,<sup>2</sup> elective cesarean section,<sup>3,4</sup> avoidance of breastfeeding,<sup>5</sup> and administration of appropriate antiretroviral prophylaxis to an exposed newborn within hours after birth.<sup>2</sup> Successful reduction and, eventually, elimination of mother-to-child HIV transmission require coordinated efforts involving women with HIV infection, health care providers, case managers, social

workers, and public health professionals.<sup>6,7</sup> National estimates of women with HIV infection, diagnosed before or at

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delivery, and of their demographic and health insurance characteristics will help allocate appropriate resources,<sup>8</sup> inform guidance for policies on HIV testing, and monitor progress toward elimination of perinatal transmission.<sup>9</sup>

National trends in deliveries to women with HIV infection in the United States are not well described. Whitmore et al<sup>8</sup> used an indirect method and HIV surveillance data for 2006 from states with confidential name-based case reporting and estimated that 8700 infants were born to women with HIV infection nationwide. Ewing et al<sup>10</sup> used hospital discharge data for 2007 and 2011 and estimated that 5397 women in 2007 and 3855 women in 2011 with an HIV diagnosis gave birth in US hospitals. The objective of our study was to describe trends in the annual number and rate of deliveries to women with an HIV diagnosis that occurred in US hospitals during 2006-2014 by using a nationally representative sample of hospitalizations and a comprehensive list of HIV diagnosis codes.

## Methods

### Data

We analyzed data from the National (Nationwide) Inpatient Sample (NIS), Healthcare Cost and Utilization Project, Agency for Healthcare Research and Quality<sup>11</sup> for 2006-2014. In October 2015, the United States transitioned inpatient diagnosis coding from the *International Classification of Diseases, Ninth Revision, Clinical Modification* (ICD-9-CM) to the ICD-10-CM, which substantially shifted trends in hospital stays with certain medical conditions.<sup>12</sup> Because analyzing the effects of the transition in codes was beyond the scope of our analysis, we excluded data from 2015-2016 and focused on years that consistently used ICD-9-CM codes (ie, 2006-2014).

NIS represents more than 96% of all hospital discharges in the United States. Each year, NIS collects data on 7-8 million discharges, which, when weighted, represent 35-39 million discharges. These large numbers of discharges allow for analyses of rare conditions and special patient populations. For each hospital stay, NIS included up to 15 diagnoses during 2006-2008, up to 25 diagnoses during 2009-2013, and up to 30 diagnoses in 2014. NIS also included data on the primary expected health insurer and patient demographic characteristics.

In 2012, NIS changed its sampling strategy from selecting a random sample of 20% of US hospitals to sampling 20% of discharges across all US hospitals.<sup>11</sup> In addition, NIS switched from weights based on hospital admissions to weights based on discharges. The new sampling and weighting strategies reduced the width of confidence intervals (CIs) by half and resulted in a one-time drop in discharge counts by about 4%.<sup>11</sup> To make the discharge counts comparable across all years, we used the revised 2006-2011 NIS trend weights.<sup>13</sup> Because NIS is a publicly available database that

eliminates all patient identifiers, this study did not require institutional review board approval.

### Identification of Delivery Hospitalizations and HIV Diagnoses

Following methods described in previous studies,<sup>14,15</sup> we identified delivery discharges by using ICD-9-CM<sup>16</sup> and diagnosis-related group (DRG)<sup>17</sup> codes. Starting with 2007 data, NIS reported codes from DRG version 24 (DRG24), which could handle a maximum of 579 diagnoses, and Medicare Severity DRGs (MS-DRGs), which increased the number of DRGs by 207 (in effect since October 1, 2007).<sup>18,19</sup> Consequently, we used DRG24 to determine delivery discharges during 2006-2007 and MS-DRG to determine delivery discharges during 2008-2014 (Table 1). Alternatively, we identified a delivery discharge by the presence of discharge records with a set of ICD-9-CM codes.

To identify HIV diagnoses, we used Healthcare Cost and Utilization Project Clinical Classifications Software,<sup>20</sup> which defines HIV by the presence of discharge records with any of the ICD-9-CM diagnosis codes listed in Table 1. An HIV diagnosis could have been made at any point in the past or based on tests obtained during a hospitalization.

### Statistical Analyses

To account for the multilevel sampling design of NIS data, stratified on hospital characteristics, we used Stata version 14.0<sup>22</sup> command “svyset hosp\_nis [pw = discwt], strata(nis\_stratum)” to ensure that variance calculations accounted for the clustering of discharges within hospitals<sup>23</sup> when (1) estimating the annual weighted number of delivery hospitalizations and the annual weighted number of delivery discharges with an HIV diagnosis per 10 000 deliveries and (2) examining the association of patients’ sociodemographic characteristics with an HIV diagnosis on discharge records.

We used Stata command “mean2” to examine which sociodemographic characteristics of delivery discharges with and without an HIV diagnosis significantly changed from 2006 to 2014. To determine whether there was an increasing or decreasing trend in the probability of having an HIV diagnosis on discharge records during 2006-2014, we estimated crude relative risks (RRs) and 95% CIs by using a generalized linear model with log link and binomial distribution, where the dependent variable indicated the presence of delivery discharge records with ICD-9-CM codes indicating HIV. To examine the impact of potentially confounding effects, we then estimated the adjusted relative risk (aRR) for the temporal trend, where the set of covariates included patients’ sociodemographic characteristics listed and defined in Table 1. To account for interactions that represent differential trends in race/ethnicity and expected primary health insurer groups, we stratified the analyses within each category of race/ethnicity and expected primary health insurer

**Table 1.** Definitions of delivery discharges, HIV diagnoses, and dependent and independent variables for study on trends in deliveries among women with an HIV diagnosis in the United States, 2006-2014<sup>a</sup>

Item	Definition
Delivery discharge	<p>DRG codes<sup>14,15</sup></p> <ul style="list-style-type: none"> <li>Cesarean section: 370-371 (DRG24 codes 2006-2007); 765-766 (MS-DRG codes 2008-2014)</li> <li>Vaginal delivery: 372-375 (DRG24 codes 2006-2007); 767-768, 774-775 (MS-DRG codes 2008-2014)</li> </ul> <p>ICD-9-CM codes<sup>14,15</sup></p> <ul style="list-style-type: none"> <li>Outcomes of delivery: V27.x</li> <li>Normal delivery: 650</li> <li>Delivery with complications during pregnancy: 640.0x-649.8x, where x = 1 or 2</li> <li>Delivery with complications in the course of labor and delivery: 651.0x-676.9x, where x = 1 or 2</li> <li>Other maternal or fetal complications: 678.01, 678.11, or 679.0x-679.1x, where x = 1 or 2</li> </ul>
HIV diagnosis	<p>CCS diagnosis code 5 that includes the following ICD-9-CM codes<sup>20</sup></p> <ul style="list-style-type: none"> <li>HIV disease type 1 (HIV-1): 042.x<sup>21</sup></li> <li>HIV infection causing other specified conditions: 043.0-043.3 or 043.9</li> <li>HIV infection, unspecified: 044.0 or 044.9</li> <li>HIV infection type 2 (HIV-2)<sup>b</sup>: 079.53<sup>21</sup></li> <li>Nonspecific serologic evidence of HIV: 795.71 (positive result for a preliminary screening test, but HIV infection status is not yet confirmed)<sup>21</sup></li> <li>HIV infection, asymptomatic: V08.x</li> </ul>
Dependent variable	The presence of discharge records with HIV ICD-9-CM codes at delivery
Independent variables	
Year	Time trend (years)
Race/ethnicity	Race/ethnicity identifier categorized as white, black, Hispanic, Asian or Pacific Islander, Native American, other, or missing/invalid. In HCUP NIS, ethnicity takes precedence over race; therefore, white and black patients represent the non-Hispanic population. <sup>19</sup>
Age at delivery	Patient's age in years <sup>19</sup> categorized as 13-24, 25-34, and ≥35
Expected primary health insurer	Primary expected payer identifier <sup>19</sup> categorized as private health insurance (Blue Cross/Blue Shield, other commercial carriers, private health maintenance, and preferred provider organizations), Medicaid, Medicare, and other government insurance (eg, worker's compensation, CHAMPUS, CHAMPVA) combined with uninsured ("self-pay" and "no charge") <sup>c</sup>
Median annual household income	<p>Median annual household income for patient's zip code; varied by year<sup>19</sup></p> <ul style="list-style-type: none"> <li>2006: \$1-\$37 999; \$38 000-\$46 999; \$47 000-\$61 999; ≥\$62 000; missing/invalid</li> <li>2007: \$1-\$38 999; \$39 000-\$47 999; \$48 000-\$62 999; ≥\$63 000; missing/invalid</li> <li>2008: \$1-\$38 999; \$39 000-\$48 999; \$49 000-\$63 999; ≥\$64 000; missing/invalid</li> <li>2009: \$1-\$39 999; \$40 000-\$49 999; \$50 000-\$65 999; ≥\$66 000; missing/invalid</li> <li>2010: \$1-\$40 999; \$41 000-\$50 999; \$51 000-\$66 999; ≥\$67 000; missing/invalid</li> <li>2011: \$1-\$38 999; \$39 000-\$47 999; \$48 000-\$63 999; ≥\$64 000; missing/invalid</li> <li>2012: \$1-\$38 999; \$39 000-\$47 999; \$48 000-\$62 999; ≥\$63 000; missing/invalid</li> <li>2013: \$1-\$37 999; \$38 000-\$47 999; \$48 000-\$63 999; ≥\$64 000; missing/invalid</li> <li>2014: \$1-\$39 999; \$40 000-\$50 999; \$51 000-\$65 999; ≥\$66 000; missing/invalid</li> </ul>
Census region of hospital	Information was obtained from the American Hospital Association's Annual Survey of Hospitals <sup>19</sup> ; categorized as Northeast, Midwest, South, or West

Abbreviations: CCS, Clinical Classifications Software; CHAMPUS, Civilian Health and Medical Program of the Uniformed Services; CHAMPVA, Civilian Health and Medical Program of the Department of Veterans Affairs; DRG, diagnosis-related group; DRG24, DRG version 24; HCUP, Healthcare Cost and Utilization Project; ICD-9-CM, *International Classification of Diseases, Ninth Revision, Clinical Modification*; MS-DRG, Medicare Severity DRG; NIS, National (Nationwide) Inpatient Sample.

<sup>a</sup>Data source: National (Nationwide) Inpatient Sample, Healthcare Cost and Utilization Project, Agency for Healthcare Research and Quality for 2006-2014.<sup>11</sup>

<sup>b</sup>ICD-9-CM code for HIV-2 infection (079.53) used as an additional diagnosis to indicate cases of illness resulting from infection with HIV-2.<sup>21</sup> All other HIV-related ICD-9-CM diagnosis codes are assumed to be for HIV-1.<sup>21</sup>

<sup>c</sup>Because the unweighted number of delivery discharges with an HIV diagnosis in the category of government insurance did not exceed 10 discharges per year, we combined data for the categories of government insurance and uninsured.

**Table 2.** HIV diagnosis on discharge records at delivery, by HIV type and year, United States, 2006-2014<sup>a</sup>

HIV Diagnoses at Delivery	2006 (N = 4377), % (N = 5209), (N = 3960), (N = 4761), (N = 4587), (N = 3758), (N = 3750), (N = 3850), %	2007 (N = 5209), % (N = 4761), (N = 4587), (N = 3758), (N = 3750), %	2008 (N = 3960), % (N = 4761), (N = 4587), (N = 3758), (N = 3750), %	2009 (N = 4761), % (N = 4587), (N = 3758), (N = 3750), %	2010 (N = 4587), % (N = 3758), (N = 3750), %	2011 (N = 3758), % (N = 3750), %	2012 (N = 3750), % (N = 3850), %	2013 (N = 3850), % (N = 3915), %	2014 (N = 3915), % %
HIV disease type I (HIV-1) (ICD-9-CM code 042.x)	20.2	20.2	23.1	22.9	24.9	18.6	18.8	18.5	18.7
HIV-1 infection (ICD-9-CM code V08.x)	77.1	78.0	74.2	75.1	72.5	79.4	78.9	79.4	79.6
HIV infection type 2 (HIV-2) (ICD-9-CM code 079.53)	0.1	0.1	0.6	0.3	0.5	0.2	0.3	0.4	0.5
Positive preliminary test for HIV (ICD-9-CM code 795.71)	2.6	1.7	2.1	1.7	2.1	1.7	2.0	1.7	1.2

Abbreviations: ICD-9-CM, International Classification of Diseases, Ninth Revision, Clinical Modification; N, number of delivery hospitalizations.

<sup>a</sup>Data source: The National (Nationwide) Inpatient Sample, Healthcare Cost and Utilization Project, Agency for Healthcare Research and Quality for 2006-2014.<sup>11</sup>  
All results in this table (ie, number of discharges and percentages) represent weighted samples.

group by the remaining sociodemographic characteristics. For each stratified analysis, we estimated crude RRs and aRRs for the temporal trend in HIV diagnoses.

## Results

### Delivery-Related Hospitalizations by HIV Type, Health Insurance Status, and Demographic Characteristics

During 2006-2014, the distribution of ICD-9-CM codes and types of HIV diagnoses were stable (Table 2). Of the delivery discharges with an HIV diagnosis, most (72.5%-79.6%) had a diagnosis of asymptomatic HIV type 1 infection, and fewer than one-quarter (18.5%-24.9%) of discharges had a diagnosis of HIV type 1 disease. Few delivery discharges had a diagnosis of HIV type 2 (HIV-2) (0.1%-0.6%). A preliminary test for HIV was positive for 1.2% to 2.6% of women, but their HIV infection status was not yet confirmed at the time of hospital discharge.

The sociodemographic characteristics of women with and without an HIV diagnosis on their discharge records were mostly stable during 2006-2014 (Table 3). The percentage of patients aged  $\geq 25$  was consistently higher among women with an HIV diagnosis than among women without an HIV diagnosis on their discharge record. Of delivery discharges with an HIV diagnosis, 68.1% in 2006 and 68.5% in 2014 occurred among Medicaid recipients and 20.2% in 2006 and 21.3% in 2014 occurred among privately insured women. Of delivery discharges without an HIV diagnosis, 50.2% in 2006 and 50.7% in 2014 occurred among privately insured women and 42.4% in 2006 and 42.9% in 2014 occurred among Medicaid recipients. Women with an HIV diagnosis consistently represented more socially disadvantaged

populations: 41.0%-49.6% of delivery discharges with an HIV diagnosis and 26.8%-27.4% of delivery discharges without an HIV diagnosis were among women living in areas with the lowest median annual household income (first income quartile:  $\leq \$37\ 999$  in 2006,  $\leq \$39\ 999$  in 2014). In contrast, only 7.6%-9.2% of delivery discharges with an HIV diagnosis and 21.4%-22.2% of delivery discharges without an HIV diagnosis were among women living in areas with the highest median annual household income (fourth quartile:  $\geq \$62\ 000$  in 2006,  $\geq \$66\ 000$  in 2014).

The probability of having an HIV diagnosis on discharge records at delivery varied by race/ethnicity, age, health insurance status, annual household income, and census region (Table 3). The probability of having an HIV diagnosis, compared with not having an HIV diagnosis, was higher for women who were black (aRR = 8.45; 95% CI, 7.56-9.44) or Hispanic (aRR = 1.56; 95% CI, 1.33-1.83) than for women who were white; for women aged 25-34 (aRR = 2.33; 95% CI, 2.12-2.55) or  $\geq 35$  (aRR = 3.04; 95% CI, 2.79-3.31) than for women aged 13-24; for Medicaid recipients (aRR = 2.70; 95% CI, 2.45-2.98) or the uninsured (aRR = 1.87; 95% CI, 1.60-2.19) than for privately insured patients; for women residing in areas in the first income quartile (aRR = 1.90; 95% CI, 1.58-2.29) than for women residing in areas in the fourth income quartile; and for discharges recorded in the Northeast (aRR = 3.66; 95% CI, 2.55-5.26) or the South (aRR = 3.62; 95% CI, 2.50-5.25) than in the West.

### Estimated Number of Women With an HIV Diagnosis on Discharge Records

During 2006-2014, a total of 35.3 million delivery discharges (95% CI, 34.1-36.5 million) occurred in US hospitals, and 38 167 (95% CI, 33 523-42 809) had an HIV diagnosis on the

**Table 3.** Delivery discharges by HIV diagnostic status and relative risk of an HIV diagnosis at delivery, United States, 2006-2014<sup>a</sup>

Characteristic	HIV Diagnosis				No HIV Diagnosis				Crude RR (95% CI) (N = 35 246 928)	Adjusted <sup>d</sup> RR (95% CI) (N = 35 246 928)
	2006, % (N = 4377)	2014, % (N = 3915)	% Change From 2006 to 2014 <sup>b</sup>	P Value <sup>c</sup>	2006 (N = 4 135 547)	2014 (N = 3 801 320)	% Change From 2006 to 2014 <sup>b</sup>	P Value <sup>c</sup>		
Year	—	—	—	—	—	—	—	—	0.99 (0.96-1.02)	0.97 (0.94-0.99)
Race/ethnicity										
Non-Hispanic white	14.9	14.7	-0.2	.92	37.0	50.2	13.2	<.001	Reference	Reference
Non-Hispanic black	43.1	62.3	19.2	<.001	8.7	13.4	4.7	<.001	13.76 (12.30- 15.40)	8.45 (7.56-9.44)
Hispanic	14.4	10.7	-3.7	.26	20.2	19.4	-0.8	.67	2.03 (1.70-2.43)	1.56 (1.33-1.83)
Other	6.5	5.2	-1.3	.51	6.7	10.6	3.9	<.001	1.92 (1.64-2.25)	1.58 (1.34-1.87)
Missing/invalid data	21.1	7.0	-14.1	.002	27.4	6.4	-21.0	<.001	2.20 (1.75-2.78)	2.31 (1.84-2.89)
Age at delivery, y										
13-24	27.5	22.1	-5.4	.06	35.8	28.6	-7.2	<.001	Reference	Reference
25-34	55.7	59.4	3.7	.29	50.0	55.8	5.8	<.001	1.37 (1.25-1.51)	2.33 (2.12-2.55)
≥35	16.9	18.5	1.6	.43	14.2	15.6	1.4	.001	1.51 (1.38-1.65)	3.04 (2.79-3.31)
Expected primary health insurer										
Medicare	4.1	5.1	1.0	.30	0.5	0.7	0.2	<.001	12.60 (10.59- 14.99)	6.47 (5.45-7.67)
Medicaid	68.1	68.5	0.4	.91	42.4	42.9	0.5	.71	3.81 (3.42-4.25)	2.70 (2.45-2.98)
Private	20.2	21.3	1.1	.70	50.2	50.7	0.5	.79	Reference	Reference
Self-pay, no charge, other	7.5	5.1	-2.4	.26	6.9	5.7	-1.3	.08	2.79 (2.37-3.28)	1.87 (1.60-2.19)
Median annual household income for patient's zip code, \$ <sup>e</sup>										
1st quartile	49.6	41.0	-8.6	.02	26.8	27.4	0.6	.67	4.06 (3.17-5.20)	1.90 (1.58-2.29)
2nd quartile	21.7	23.1	1.4	.51	25.1	26.1	1.0	.32	2.02 (1.63-2.51)	1.45 (1.24-1.71)
3rd quartile	16.6	14.9	-1.7	.39	23.9	23.6	-0.3	.73	1.51 (1.25-1.81)	1.28 (1.11-1.49)
4th quartile	7.6	9.2	1.6	.45	22.2	21.4	-0.8	.62	Reference	Reference
Missing/invalid data	4.5	11.7	7.2	.003	2.0	1.5	-0.5	.18	14.42 (10.80- 19.27)	6.63 (4.99-8.80)
Census region										
Northeast	25.0	22.0	-3.0	.42	15.2	16.0	0.8	.43	6.06 (4.16-8.84)	3.66 (2.55-5.26)
Midwest	13.0	15.6	2.6	.46	22.3	21.3	-1.0	.39	2.50 (1.66-3.77)	2.07 (1.41-3.04)
South	53.8	56.4	2.6	.64	37.0	38.5	1.5	.45	6.07 (4.08-9.01)	3.62 (2.50-5.25)
West	8.2	6.0	-2.2	.35	25.5	24.2	-1.3	.46	Reference	Reference

Abbreviations: —, not applicable; RR, relative risk.

<sup>a</sup>N is number of delivery discharges. All results (ie, number of delivery discharges, frequencies, and RRs) represent weighted samples. Data source: National (Nationwide) Inpatient Sample, Healthcare Cost and Utilization Project, Agency for Healthcare Research and Quality for 2006-2014.<sup>11</sup>

<sup>b</sup>Percentage-point change.

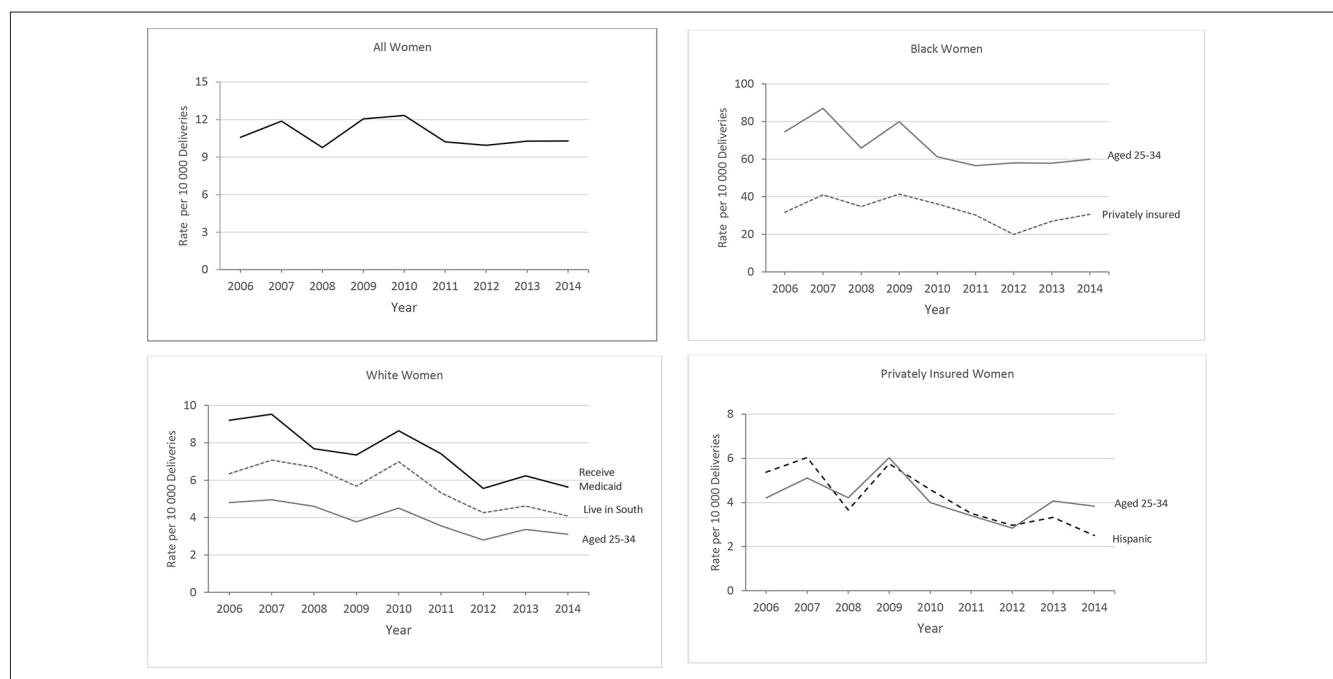
<sup>c</sup>Significant if P < .05; estimated by using Stata command mean.<sup>2</sup>

<sup>d</sup>In the adjusted model, the set of covariates included temporal trend and patients' sociodemographic characteristics (race/ethnicity, age at delivery, expected primary health insurer, median annual household income for patient's zip code, and census region).

<sup>e</sup>Income quartiles in 2006: 1st quartile, \$1-\$37 999; 2nd quartile, \$38 000-\$46 999; 3rd quartile, \$47 000-\$61 999; 4th quartile, ≥\$62 000. Income quartiles in 2014: 1st quartile, \$1-\$39 999; 2nd quartile, \$40 000-\$50 999; 3rd quartile, \$51 000-\$65 999; 4th quartile, ≥\$66 000.

record. Overall, the number of delivery hospitalizations was stable: 4.2 million (95% CI, 3.7-4.6 million) in 2006 and 3.8 million (95% CI, 3.6-4.0 million) in 2014. The number of delivery discharges with an HIV diagnosis was 4377 (95% CI, 3227-5527) in 2006 and 3915 (95% CI, 3410-4420) in 2014 (Table 2), and the rate per 10 000 deliveries among all women was 10.6 (95% CI, 8.1-13.1) in 2006 and 10.3 (95% CI, 9.0-11.6) in 2014 (Figure).

The crude RR for the temporal trend in an HIV diagnosis during 2006-2014 was not significant (0.99; 95% CI, 0.96-1.02) (Table 3), whereas the aRR for the temporal trend was significant (0.97; 95% CI, 0.94-0.99), implying heterogeneity in temporal trends in HIV diagnoses across sociodemographic groups. By sociodemographic group, we found homogenous declines with significant RRs and aRRs in discharges of white women, specifically those aged 25-34,



**Figure.** Rates of delivery discharges with an HIV diagnosis, United States, 2006-2014. All results represent weighted samples. Data source: National (Nationwide) Inpatient Sample, Healthcare Cost and Utilization Project, Agency for Healthcare Research and Quality for 2006-2014.<sup>11</sup>

Medicaid recipients, or those delivering in the South; of black women aged 25-34; and of privately insured women who were black, Hispanic, or aged 25-34 (Tables 4 and 5 and Figure).

## Discussion

In this study, we analyzed 2006-2014 data from the NIS to estimate the number of delivery discharges with an HIV diagnosis that occurred in US hospitals overall and by sociodemographic group. According to our findings, the probability of having an HIV diagnosis, adjusted for sociodemographic characteristics, declined on average 3% annually, with significant declines among some groups when stratified by race/ethnicity and primary payer. Overall, the probability of having an HIV diagnosis was greater among women who were black or Hispanic, aged  $\geq 25$ , Medicaid recipients or uninsured, residing in areas with the lowest median annual household income ( $\leq \$37\ 999$  in 2006,  $\leq \$39\ 999$  in 2014), or delivering in the Northeast and the South.

To our knowledge, this is the first US study to estimate the number of deliveries to women with an HIV diagnosis for each year during 2006-2014. Our estimates for 2007 and 2011 were somewhat lower than those published by Ewing et al<sup>10</sup> (whereas our study estimated 5209 women with an HIV diagnosis who delivered in 2007 and 3758 women in 2011, Ewing et al estimated 5397 women in 2007 and 3855 women in 2011) because we used a conservative definition of deliveries (ie, ICD-9-CM

diagnosis codes alone), whereas Ewing et al used a combination of ICD-9-CM diagnosis and procedure codes. However, our estimate for 2006 was approximately half as large as the estimate reported by Whitmore et al<sup>8</sup> (our study estimated 4377 deliveries to women with an HIV diagnosis in 2006, whereas Whitmore et al estimated 8700 infants born to women with HIV infection in 2006). Such a discrepancy was expected, because we included only women with diagnosed HIV infection, whereas Whitmore et al included women with both diagnosed HIV infection (ranging from 82.7% of women living with HIV in 2006<sup>24</sup> to 87.8% in 2014)<sup>25</sup> and undiagnosed HIV infection. In addition, we analyzed actual deliveries, including live births (about 99%) and stillbirths (1%),<sup>26</sup> whereas Whitmore et al<sup>27</sup> calculated pregnancy rates and assumed that all pregnancies resulted in live births. However, only about 65% of all pregnancies result with a live-born infant,<sup>28</sup> and the live-birth rates among HIV-positive and HIV-negative women were similar during 2006-2012.<sup>29</sup> After we adjusted our estimates to account for women with undiagnosed HIV infection and for the number of pregnancies that do not result in live births, we estimated 8142 (95% CI, 6003-10 282) pregnant women living with diagnosed or undiagnosed HIV infection in 2006, which is comparable to the estimate of 8700 women by Whitmore et al.<sup>27</sup>

The number of deliveries to women with an HIV diagnosis was also estimated in a 2017 article by Arab et al.<sup>30</sup> However, that study included only ICD-9 code 042.x (HIV disease type 1), which—as our study demonstrated—accounted for only

**Table 4.** Relative risk for temporal trends in an HIV diagnosis on discharge records at delivery by sociodemographic group, United States, 2006-2014<sup>a</sup>

Characteristic	White (N = 15 674 710)		Black (N = 15 674 710)		Hispanic (N = 10 918 152)	
	RR (95% CI)	aRR (95% CI)	RR (95% CI)	aRR (95% CI)	RR (95% CI)	aRR (95% CI)
Overall	0.95 (0.92-0.99)	0.94 (0.91-0.98)	0.97 (0.94-1.01)	0.97 (0.93-1.01)	0.97 (0.92-1.02)	0.97 (0.93-1.02)
Age at delivery, y						
13-24	0.97 (0.93-1.03)	0.98 (0.93-1.03)	0.99 (0.93-1.04)	0.99 (0.94-1.05)	0.97 (0.90-1.03)	0.98 (0.92-1.04)
25-34	0.94 (0.89-0.98)	0.93 (0.88-0.97)	0.99 (0.92-0.99)	0.95 (0.92-0.99)	0.97 (0.91-1.04)	0.98 (0.92-1.04)
≥35	0.95 (0.90-1.01)	0.94 (0.89-0.99)	0.98 (0.94-1.02)	0.97 (0.93-1.01)	0.93 (0.86-1.00)	0.93 (0.87-1.00)
Expected primary health insurer						
Medicaid	0.94 (0.90-0.98)	0.93 (0.90-0.97)	0.97 (0.94-1.01)	0.96 (0.93-1.01)	1.00 (0.94-1.07)	0.96 (0.93-1.04)
Private	0.96 (0.92-1.02)	0.97 (0.92-1.02)	0.95 (0.92-0.99)	0.96 (0.92-0.99)	0.91 (0.85-0.98)	0.92 (0.86-0.98)
Self-pay, no charge, other	0.95 (0.85-1.06)	0.95 (0.86-1.06)	1.00 (0.93-1.06)	1.00 (0.94-1.07)	0.92 (0.85-1.00)	0.93 (0.86-1.01)
Census region						
Northeast	0.95 (0.89-1.01)	0.95 (0.89-1.01)	0.98 (0.96-1.02)	0.97 (0.92-1.01)	1.00 (0.95-1.05)	0.97 (0.91-1.04)
Midwest	1.07 (0.99-1.15)	1.06 (0.99-1.13)	1.01 (0.95-1.07)	0.99 (0.93-1.06)	0.94 (0.80-1.11)	0.94 (0.80-1.11)
South	0.94 (0.89-0.99)	0.93 (0.88-0.98)	0.98 (0.93-1.03)	0.96 (0.92-1.01)	0.97 (0.90-1.03)	0.97 (0.91-1.03)
West	0.92 (0.79-1.06)	0.90 (0.78-1.03)	0.96 (0.83-1.11)	0.93 (0.82-1.08)	0.95 (0.77-1.18)	0.96 (0.77-1.19)

Abbreviations: aRR, adjusted relative risk; RR, relative risk.

<sup>a</sup>N is number of delivery discharges. All results (ie, number of delivery discharges and RRs of an HIV diagnosis on discharge records at delivery) represent weighted samples. In each stratified multivariate analysis, we adjusted for the remaining sociodemographic characteristics, such as patient's race/ethnicity, age at delivery, expected primary payer, medium annual household income for patient's zip code, and census region. Data source: National (Nationwide) Inpatient Sample, Healthcare Cost and Utilization Project, Agency for Healthcare Research and Quality for 2006-2014.<sup>11</sup>

18%-23% of deliveries to women with a diagnosis of HIV on their discharge records. In addition, the number of women who delivered infants in US hospitals reported by Arab et al was one-fifth of the number of registered births in the United States.

Arab et al estimated that 7.8 million women delivered infants in US hospitals during 2003-2011, whereas national vital statistics reports estimated that 37.3 million women delivered infants in US hospitals during that period,<sup>31</sup> indicating that

**Table 5.** Relative risk for temporal trends in an HIV diagnosis on discharge records at delivery, by expected primary health insurer, United States, 2006-2014<sup>a</sup>

Characteristic	Medicaid N = 15 153 246		Private N = 17 648 595		Self-Pay, No Charge, Other N = 2 210 933	
	RR (95% CI)	aRR (95% CI)	RR (95% CI)	aRR (95% CI)	RR (95% CI)	aRR (95% CI)
Overall	0.99 (0.96-1.03)	0.97 (0.93-1.00)	0.97 (0.94-1.00)	0.97 (0.94-0.99)	0.97 (0.93-1.01)	0.97 (0.94-1.02)
Age at delivery, y						
13-24	0.99 (0.95-1.03)	0.98 (0.94-1.02)	0.98 (0.93-1.03)	0.98 (0.93-1.03)	1.05 (0.97-1.14)	1.08 (0.98-1.18)
25-34	0.98 (0.94-1.02)	0.96 (0.93-1.00)	0.96 (0.93-0.99)	0.96 (0.92-0.99)	0.92 (0.87-1.00)	0.93 (0.89-0.99)
≥35	0.96 (0.92-1.00)	0.94 (0.91-0.99)	1.00 (0.96-1.04)	0.99 (0.95-1.04)	1.03 (0.93-1.13)	0.99 (0.91-1.07)
Census region						
Northeast	0.98 (0.93-1.02)	0.95 (0.91-1.00)	0.97 (0.91-1.03)	0.97 (0.92-1.02)	1.03 (0.97-1.11)	1.15 (1.06-1.25)
Midwest	0.97 (0.90-1.05)	0.98 (0.90-1.05)	1.02 (0.94-1.10)	1.04 (0.96-1.11)	1.04 (0.90-1.19)	1.02 (0.89-1.17)
South	1.00 (0.94-1.05)	0.96 (0.91-1.01)	0.96 (0.92-1.01)	0.95 (0.91-0.99)	0.96 (0.91-1.02)	0.93 (0.87-0.99)
West	1.00 (0.86-1.13)	0.96 (0.83-1.11)	0.93 (0.83-1.03)	0.92 (0.82-1.03)	0.90 (0.78-1.04)	0.89 (0.76-1.05)

Abbreviations: aRR, adjusted relative risk; RR, relative risk.

<sup>a</sup>N is number of delivery discharges. All results (ie, number of discharges and RRs of an HIV diagnosis on discharge records at delivery) represent weighted samples. In each stratified multivariate analysis, we adjusted for the remaining sociodemographic characteristics, such as patient's race/ethnicity, age at delivery, expected primary payer, median annual household income for patient's zip code, and census region. Data source: National (Nationwide) Inpatient Sample, Healthcare Cost and Utilization Project, Agency for Healthcare Research and Quality for 2006-2014.<sup>11</sup>

Arab et al likely reported unweighted results from the NIS data set.

Our findings on sociodemographic factors are consistent with previous analyses of deliveries to women with HIV infection<sup>10,29,30</sup> and of all US women living with diagnosed HIV infection.<sup>24,25,32,33</sup> Similar to those studies, our study identified a higher probability of diagnosed HIV infection on delivery discharges among non-Hispanic black women, Medicaid recipients, women living in areas with the lowest median annual household income, and women who delivered in the Northeast or South.

To our knowledge, our study is the first to examine temporal trends in diagnosed HIV infection at delivery by sociodemographic group and to demonstrate significant declines in RR of having an HIV diagnosis on discharge records among white women, specifically white women aged 25-34, receiving Medicaid, or delivering in the South; black women aged 25-34 or privately insured; privately insured Hispanic women; and privately insured women aged 25-34. Although the sociodemographic characteristics for most patients were well reported for all years, data on race/ethnicity were missing or invalid for a substantial percentage (21.1%) of delivery discharge records in 2006. In 2014, however, only 6.4% of data on race/ethnicity were missing or invalid. Improved reporting of race/ethnicity over time was predominantly due to an increasing number of states that make this information publicly available in their inpatient data sets<sup>34</sup> (during 2006-2007, 7 states did not report data on race/ethnicity for hospitalizations; during 2008-2014, 2 or 3 states did not report data on race/ethnicity). We observed that the geographic distribution of states with missing data on race/ethnicity was random and neighboring states, with comparable sociodemographic characteristics, reported race/ethnicity.<sup>34</sup> We also assessed temporal trends in HIV diagnoses by excluding states without race/ethnicity data available for all years during 2006-2014 and found similar RRs (aRR = 0.96; 95% CI, 0.93-0.99) compared with including states with race/ethnicity reported in any year (aRR = 0.97; 95% CI, 0.94-0.99) (Table 3). Combined, these findings support estimating race/ethnicity trends in women with an HIV diagnosis in this analysis.

The number of women with a diagnosis of HIV-2 on their discharge records was higher in our study than in previous studies. The most recent report of HIV-2 diagnoses in the United States, published in 2011, found 24 pregnant women with an HIV-2 diagnosis during 1987-2009, with most cases of HIV-2 reported during 2000-2009.<sup>35</sup> In contrast, our study estimated 123 (95% CI, 98-148) delivery discharges with a diagnosis of HIV-2 during 2006-2014, of which 46 (95% CI, 44-48) delivery discharges occurred during 2006-2009. The 2011 report may have underestimated the number of women with a diagnosis of HIV-2 as a result of inadequate data on test results and incomplete reporting of HIV-2 by laboratories and HIV surveillance programs.<sup>35</sup> In contrast, our study could have overestimated the number of women with diagnosed HIV-2 infection if some ICD-9-CM

diagnoses were not confirmed at the time of hospital discharge.

### Limitations

This analysis had several limitations. First, we almost certainly underestimated the actual number of deliveries among women with an HIV diagnosis, because NIS did not include 1.0%-1.5% of women who delivered outside a hospital.<sup>31,36</sup> Second, we underestimated the total number of delivery discharges with HIV infection (diagnosed and undiagnosed) because we did not have information on women with undiagnosed HIV infection. In addition, the proportion of women who lived with undiagnosed HIV infection declined from 17.3% in 2006<sup>24</sup> to 12.2% in 2014.<sup>25</sup> Thus, the rate of delivery discharges with HIV infection could have further decreased. Third, we had no information on whether women learned of their HIV status before delivery, which would have helped preventing the in utero and intrapartum mother-to-child transmission. However, a 2017 study in Florida documented that nearly 97% of mothers of HIV-exposed infants born during 2007-2014 were diagnosed with HIV before or during pregnancy.<sup>37</sup> Finally, NIS lacked mother-to-child linkages, which limited our ability to analyze trends in perinatal transmission of HIV among children delivered during 2006-2014.

Despite these limitations, our study contributes to the literature by synthesizing a comprehensive definition of an HIV diagnosis and a nationally representative sample to identify deliveries to all women with an HIV diagnosis in US hospitals from 2006 to 2014 overall and by sociodemographic group. Estimates of diagnosed HIV infection among women delivering infants are crucial for understanding trends and characteristics of mother-infant pairs that could benefit from prevention services.

### Conclusions

From 2006 to 2014, the probability of having an HIV diagnosis at delivery declined among several sociodemographic groups of women. High-impact prevention programs and interventions, tailored to sociodemographic groups in which rates of diagnosed HIV infection have not declined or the probability of an HIV diagnosis at delivery is higher than in other groups, can reduce the risk of mother-to-child HIV transmission by offering appropriate medical care before, during, and after delivery and by supporting adherence to antiretroviral treatment among women and infants exposed to HIV infection.

### Disclaimer

Preliminary findings from this research were presented at the 2019 National HIV Prevention Conference in Atlanta, Georgia, March 19, 2019. The findings and conclusions in this article are those of the authors and do not necessarily represent the official position of CDC.

## Acknowledgments

The authors thank the Division of Health Informatics and Surveillance's Partnership and Evaluation Branch at the Centers for Disease Control and Prevention (CDC) for technical assistance with Healthcare Cost and Utilization Project data.

## Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

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# A Statement of Commitment to Zero Tolerance of Harassment and Discrimination in Schools and Programs of Public Health

Public Health Reports  
2020, Vol. 135(4) 534-538  
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DOI: 10.1177/0033354920921816  
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## Abstract

The Association of Schools and Programs of Public Health convened a Task Force on Zero Tolerance of Harassment and Discrimination in 2019 to develop a policy statement and strategies for addressing harassment of all types in institutions offering public health education. We outline the premises and scholarly foundation for the development of the Statement of Commitment to Zero Tolerance of Harassment and Discrimination, the statement itself, and future plans for realizing the aspiration established in the statement. The development of this living document is predicated on the belief that it is the core responsibility of academic institutions to build the knowledge and that it is the responsibility of leaders, namely deans of schools of public health and directors of public health programs, to lead in building the shared knowledge and insist on the practices that create institutions for a better future free of harassment and discrimination. Our statement is informed by the knowledge that aggressions in the form of harassment and discrimination undermine the health and well-being of individuals, the public, and populations.

## Keywords

harassment, discrimination, education, leadership, universities

In 2019, the Association of Schools and Programs of Public Health (ASPPH) Board of Directors convened a task force charged with developing a statement of commitment to zero tolerance of sexual harassment and discrimination and proposing recommendations for further actions that ASPPH might take. The 9 Task Force on Zero Tolerance of Harassment and Discrimination (hereinafter, Task Force) members, who are recognized experts in their respective fields of public health, held various leadership positions at ASPPH-member schools and programs of public health.

The statement was developed through an iterative process with various ASPPH constituencies, including members of the board of directors, academic leaders from schools and programs of public health, members of the Diversity and Inclusion Advisory Committee, and members attending the 2019 annual ASPPH conference. A series of structured discussions and seminars were held in 2019 to empower school

and program members with the most recent empirical knowledge about matters of harassment and discrimination, to enable all to speak openly about this matter, and to ensure that all voices were heard. These seminars and discussions helped shape and direct the work of the Task Force to develop the statement.

ASPPH directed the Task Force to develop a statement of commitment to zero tolerance for discrimination and harassment to be ratified by all ASPPH-member schools and programs of public health. The Task Force undertook numerous

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activities to enact this work, including (1) data collection on published materials and the extant literature; (2) consideration and analysis of ideas that emerged from 2018 ASPPH meetings (annual meeting, sections meeting, leadership retreat) with leadership groups, faculty, and staff members that led to the development of the Task Force; and (3) consideration of initiatives related to sexual harassment being undertaken by the National Academies of Sciences, Engineering, and Medicine<sup>1</sup> and universities with schools and programs of public health. The Task Force met through monthly teleconferences from October 2018 through March 2019 and undertook drafting and editing between meetings.

After the statement was drafted, a series of feedback discussions were held with the ASPPH Board of Directors, the Diversity and Inclusion Committee, and the Diversity and Inclusion Section. The Task Force garnered detailed feedback; in response, the Task Force addressed feedback and modified the document accordingly. The response and the revised document were presented to the board of directors, leading to approval of the final statement in May 2019. Inherent in all discussions were the core responsibility of academic institutions to build the knowledge; that leadership sets the stage for a better future; that it is the responsibility of leaders, namely deans of schools of public health and directors of public health programs, to lead in building the shared knowledge and insist on the practices that create institutions for a better future free of harassment and discrimination; and that leaders have to take responsibility for identifying and solving structural inequalities while also holding all responsible to be part of building a culture for a better future.

## Premises

The Task Force undertook its work guided by a set of beliefs about issues of harassment and discrimination as follows:

1. Issues of harassment and discrimination continue to resurface because they are being treated like topics and not ways of life.
2. Harassment is rooted in discrimination; thus, we must commit to zero tolerance for discrimination.
3. Harassment is shaped by culture and identity.

4. Voices cannot be silenced out of fear of environmental discomfort if we are to effectively address harassment in our schools and programs.
5. Harassment is not confined to actions of male-identified persons on female-identified persons; thus, efforts must be all-encompassing.
6. Harassment and discrimination undermine individual and population health.

## The Statement

ASPPH and our member schools and programs are committed to eliminating harassment and discrimination in academic public health. It is essential to provide all our students, staff, faculty, and community partners with respectful and safe learning and working environments. We oppose acts of harassment and discrimination in all forms, while we simultaneously work toward developing schools and programs that are directed by cultural competence and humility, inclusivity, and diversity.

There should be zero tolerance for acts of harassment or discrimination in academic public health. As we aspire to apply this zero-tolerance mandate, we envision that the cultures of all of our schools and programs will be free of any forms of harassment and discrimination.

## Points of Understanding

ASPPH and our member organizations acknowledge that harassment and discrimination exist in academic medicine,<sup>2</sup> nursing,<sup>3</sup> and science and engineering,<sup>4</sup> as well as in many other branches of academia,<sup>5</sup> including academic public health. We affirm that the consequences of harassment and discrimination can include decreased performance by individuals, within organizations, and throughout society as a whole.<sup>6,7</sup>

We are concerned about the broad spectrum of harassing and discriminatory behavior. Rape and sexual assault reflect the criminal side of this spectrum; the physical and psychic violence experienced by survivors of these acts is most often horrific. We are also concerned about the other side of the spectrum, which includes all forms of harassment and

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discrimination that do not rise to the levels of criminal violence or civil rights violations (eg, microaggression, belittling, berating, and bullying).<sup>8,9</sup> These behaviors are also detrimental to the mental health of victims and to the cultures of communities and organizations. Furthermore, if not opposed, this type of conduct can lead to an impression that even more toxic forms of behavior may be tolerated.

ASPPH and our member organizations also acknowledge that harassment and discrimination have not been confined only to inappropriate actions taken by male-identified cisgender persons against female-identified cisgender persons.<sup>10</sup> We believe that harassment and discrimination may be understood as actions taken by those who abuse their power and privilege in settings that permit intolerant and unethical behavior.<sup>11</sup>

Universities are among the oldest institutions in human history that have been devoted to understanding and improving the human condition, by promoting student scholarship and engagement with society. As such, universities have a special obligation to address conditions that threaten to erode their values and missions and to negatively affect their climates and cultures. To paraphrase American psychologist Carl Rogers, human beings are driven to activate and express all of their capacities. If so, each person should have the right, particularly within our institutions of higher learning, to pursue those capacities in climates and cultures that are free of harassment and discrimination.

ASPPH and our member organizations affirm our obligation and commitment to eliminating harassment and discrimination within the public health academy, just as our colleagues have done in medicine and other fields.<sup>12,13</sup> Academic public health should not be left behind in this important work.<sup>14</sup>

### A Public Health Approach

As a group of public health professionals, ASPPH and its member organizations will be directed in our efforts by the tenets of public health: human rights, social justice, and health equity. We will take proactive steps to prevent harassment and discrimination from occurring in the first place. We will actively seek to understand the characteristics of our institutions and to address the power differentials that can enable harassing and discriminatory behavior within our organizations. We will work to change our cultures and systems to stop harassment and discrimination. We will focus efforts on developing institutional climates that foster inclusion for all persons.

Through ASPPH's Diversity and Inclusion Committee and Diversity and Inclusion Section, we can enable our members to (1) share best practices developed and implemented successfully at their own institutions; (2) develop new strategies for addressing harassment and discrimination, as new knowledge becomes available and our understandings evolve; (3) determine how best to implement new

approaches within their own organizations; and (4) empower organizational leaders by providing the tools needed to pursue approaches that are consistent with federal and local laws, as well as university bylaws and policies.

We envision the ongoing development of strategies that combat harassment and discrimination and become embedded in organizational cultures. We will encourage each member institution to enact zero-tolerance approaches that align with their respective federal and local laws and university policies. We expect that these approaches will change as laws, policies, and evidence evolve. Moreover, we anticipate that this Statement of Commitment to Zero Tolerance of Harassment and Discrimination will also evolve and change over time.

Recognizing that efforts to prevent and reduce sexual harassment and violence require a long-term process of culture change, ASPPH is committed to providing training to organizational leaders, faculty, and staff. The Diversity and Inclusion Committee and the Diversity and Inclusion Section will make recommendations to ASPPH members about appropriate training topics and instruments. We envision that this document will be analyzed and discussed throughout all segments of ASPPH and our member organizations. It is our intent that this process will allow leaders in the academic, research, and practice segments of public health to apply the document in ways that are most appropriate for their professional disciplines.

### Proposed Tenets for Developing Zero-Tolerance Strategies

We propose 5 tenets with supporting action items that can be used by organizations to develop zero-tolerance strategies toward harassment and discrimination.

#### *Antiharassment and Antidiscrimination Policies and Trainings*

- Develop policies on harassment and discrimination, as many institutions have already enacted.<sup>15-17</sup>
- Develop trainings that educate the academic community on current harassment and discrimination policies and procedures.
- Create trainings aimed at changing inappropriate behaviors, challenging biased norms and beliefs, and promoting respect and civility.
- Foster climates in which trainings are taken seriously and in which expectations for faculty, staff, and student participation and engagement are explicitly communicated.
- Identify, examine, and address policies, processes, and practices that have undermined institutional responsibility and accountability for addressing misconduct

and for promoting a culture that fosters aspirational achievement.

- Periodically update and publish information about institutional policies and trainings, to keep them in sync with the evolution of social conditions and to be sure they reach all faculty, students, and staff, considering the turnover that can occur in these populations.

### *Identifying and Reporting Harassment and Discrimination*

- Train persons to recognize harassment and discrimination.
- Promote bystander intervention in the event of any witnessed harassment or discrimination.
- Encourage and facilitate reporting by those who are subjected to harassment and discrimination, as well as by those who witness such acts.
- Empower persons to report acts of harassment and discrimination in real time.
- Provide safe ways, including with the use of technology, to report harassment and discrimination.
- Create a culture of accountability so that acts of harassment and discrimination do not go unpunished.

### *Protecting Victims of Harassment and Discrimination*

- Provide support, including resiliency training, for persons who are targets of harassment and discrimination.
- Follow institutional and legal policies and procedures when charges of harassment are made.
- Adopt mentoring networks that include peers and senior faculty to diffuse the hierarchical relationships between faculty and students that lead to power differentials.
- Create a system of accountability so that persons who harass and discriminate are not protected.
- Foster an environment in which it is safe to pursue difficult conversations without fear of retaliation.

### *Communicating and Transparency*

- State clearly and follow closely legal procedures that are in place to protect due process.
- Inform communities that persons will be held accountable for violating harassment and discrimination policies and procedures.
- Be as transparent as possible about how reports of sexual harassment are handled.

### *Shifting the Culture*

- Create systems to integrate values that emphasize diversity and respect.
- Commit to changes in the power dynamics at academic institutions.
- Address institutional norms that have been shaped by centuries of power and privilege held by a select few.
- Improve transparency and accountability.
- Create a pipeline of leaders who reflect the diversity of our society.
- Demonstrate zero tolerance for the use of words that are demeaning or disparaging or that seek to silence.

### **Implications**

The ideas outlined in the Statement of Commitment to Zero Tolerance for Harassment and Discrimination adopted by ASPPH and its constituent organizations will be manifested and realized through a set of initiatives. First, we will enact ongoing efforts for training, program development, and discussions at retreats and conferences. As evidenced by the development and adoption of the statement of commitment to eliminating harassment of any type in academic public health, ASPPH plans to implement a multipronged approach that includes training of staff and members to prevent harassment and to intervene when appropriate, developing policies that state ASPPH's position on harassment and discrimination, and collecting and disseminating resources that can be used by ASPPH-member schools and programs of public health as a primer on the issues and promising practices implemented within institutions.

Second, we will enable active sharing of best practices across institutions. The Task Force is working with the ASPPH Diversity and Inclusion Committee and Diversity and Inclusion Section to ensure that we serve the leadership, faculty, staff, and students of member schools and programs of public health by setting up mechanisms to share promising practices and proven strategies to achieve inclusion and ensure equity in public health education. One mechanism is the establishment of online communities to share information on strategic initiatives.

Third, we will consider and develop other strategies. The Task Force advocated for challenging the status quo and leading changes to achieve zero tolerance. The call is for schools and programs of public health to lead the way at their universities and colleges to implement proactive strategies and actions that will make a difference in higher education, research, and service.

In the end, the discipline of public health, as led by ASPPH and its constituent organizations, intends to lead the way on matters of harassment and discrimination. We will be vigilant in our efforts until such time as our society is free

from harassment and discrimination. This aspiration is the centerpiece of the statement we have proudly forged.

### Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The authors received no financial support with respect to the research, authorship, and/or publication of this article.

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# Age-Standardized Mortality of Persons on Probation, in Jail, or in State Prison and the General Population, 2001-2012

Public Health Reports  
2020, Vol. 135(4) 539  
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DOI: 10.1177/0033354920921815  
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The findings of Wildeman et al<sup>1</sup> about elevated mortality among persons in the criminal probation system are topical and compelling. We laud the authors' use of innovative methods to address the dearth of research about persons on probation—the largest group in the criminal justice system yet the group about which the least is known.

In their discussion of potential mortality risks in this population, the authors note that individual conditions (eg, mental illness) and community conditions (eg, exposure to firearms) may increase the risk of mortality. Although we agree, we believe the discussion overlooks crucial social and structural factors that disproportionately affect persons on probation. Persons with criminal records are subject to discrimination in housing and employment. Furthermore, depending on local policies, they may be ineligible for certain social services.<sup>2</sup> Although access to Medicaid among this population has improved with the Patient Protection and Affordable Care Act, many remain uninsured, and the process of reinstating suspended benefits after incarceration can be complex.<sup>3</sup> These social and structural issues work in tandem with those addressed by the authors to increase homelessness, poverty, lack of health care, and, ultimately,

heightened mortality risk among persons in the criminal probation system.

## Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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## Letter to the Editor

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Public Health Reports  
2020, Vol. 135(4) 540-541  
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DOI: 10.1177/0033354920935065  
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The article by Walley et al,<sup>1</sup> “The Contribution of Prescribed and Illicit Opioids to Fatal Overdoses in Massachusetts, 2013-2015,” concerns us. Our general experience in Cuyahoga County, Ohio, is similar to the experience of the authors in Massachusetts: illicit opioids are overtaking legal opioid pain relievers in overdose fatalities in our jurisdiction. However, the large percentage of opioid-related overdose deaths (21%) excluded by the authors because of inadequate toxicology testing is concerning. This percentage seems unacceptably high and substantially differs from our experience in Cuyahoga County. Our experience is that <5% of fatal overdose deaths are certified without at least the scope of toxicology testing described by the authors. This scope is considered adequate, not exhaustive, according to the National Association of Medical Examiners.<sup>2</sup> The article also did not clarify whether fentanyl testing was routinely performed; fentanyl was not among the drugs listed in the Methods section, but it did appear in the Results section. It would be a serious shortcoming if any of these “complete” screens lacked testing for fentanyl and its analogs, given the frequency with which fentanyl and its analogs show up in toxicology testing in decedents. In 2018, fentanyl and its analogs were involved in 67% of opioid-related fatalities.<sup>3</sup>

Of additional concern is the absence of any mention of the percentage of overdose decedents who underwent autopsy. The National Association of Medical Examiners recommends full autopsy for suspected overdose fatalities.<sup>2</sup> In some jurisdictions, performing an autopsy for all suspected overdose fatalities is difficult because of the burden placed on death investigation systems by the opioid crisis. It is a mistake, however, to substitute toxicology testing for autopsy as a routine practice in apparent overdose fatalities to determine the cause of death. The error rates from limited examination are unknown but may be substantial if other comorbidities are present.<sup>4</sup> It would be helpful to know the percentage of the decedents who underwent autopsy in the study by Walley et al.

The narrow view the authors took by focusing on active prescriptions at the time of death is troubling. These persons represented a small fraction of the general overdose cohort. The findings of Walley et al may create complacency about the relative importance of opioid pain relievers in the opioid crisis. The authors noted that the

percentage of fatal overdose victims who had a prescription for opioid pain relievers steadily increased with further “look back” during a 12-month period before death, ultimately rising to more than half of the decedents. In our experience in Cuyahoga County, approximately 60% to 65%<sup>5</sup> of our fentanyl-related overdose victims had a prescription for a legal controlled substance within 2 to 3 years of their death, and this trend persisted in 2018 (unpublished data, Cuyahoga County Medical Examiner’s Office, September 2019). That opioid pain relievers are minimal in illicit drug trade in Cuyahoga County is indirect evidence that the legal supply of opioid pain relievers is an important factor in the initiation and maintenance of substance abuse in our illicit drug-using populations. Persons who die of an illicit drug overdose may have been introduced to opioids through prescription opioid pain relievers, and when that supply was no longer available, they transitioned to using illicit drugs. This transition from prescription opioid pain relievers to illicit drugs does not necessarily imply that opioid pain relivers were neither overprescribed nor diverted. Shifting attention away from prescribed opioid pain relievers could have substantial negative public health consequences because they are a pathway to the use of illicit drugs. The pathways and transitions in addiction are complex and varied for each person, and it is beneficial to review data in addition to cause of death toxicology such as a death scene narrative to understand the complete picture.

### Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

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# Response to Letter to the Editor: The Contribution of Prescribed and Illicit Opioids to Fatal Overdoses in Massachusetts, 2013-2015

Public Health Reports  
2020, Vol. 135(4) 542-543  
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DOI: 10.1177/0033354920935076  
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We are grateful for the interest of Bhullar and Gilson from the Cuyahoga County Medical Examiner's Office in our article, "The Contribution of Prescribed and Illicit Opioids to Fatal Overdoses in Massachusetts, 2013-2015."<sup>1</sup> They expressed 3 concerns that we would like to address.

First, they were concerned about the proportion of deaths that were excluded because of inadequate toxicology. As we described in the Methods section, toxicology reports were available for analysis through the Chapter 55 database from June 1, 2013, through December 31, 2015. We excluded 21% of deaths from analysis because the toxicology results available to us in the database did not specify an opioid. For those reports that we excluded, we do not know whether further detail was absent because further testing was not conducted or because details on further testing were not entered into the database. In Table 1 of our article, we did compare the demographic characteristics of decedents who were included and decedents who were excluded to determine significant differences. Early during the study period, toxicology testing for fentanyl was included at the discretion of the medical examiner's office; later, during the study period, fentanyl was routinely included. Therefore, some samples earlier in the sampling window may not have been tested for fentanyl, and so our study may have underestimated the true prevalence of fentanyl-positive toxicology tests.

Second, the medical examiner's office decided when a full autopsy was done. Full autopsies were completed in 68% of the cohort in our study.

Third, Bhullar and Gilson were concerned about our focus on decedents with active opioid prescriptions at the time of death, because the focus may have minimized the relative importance of opioid analgesics in the opioid crisis. We acknowledged in our article that most persons (58%) who died of opioid-related overdose during our study period had received an opioid prescription in the year before death. Our analysis was not designed to identify the role of previous opioid prescriptions in the development of opioid use disorder but, rather, to examine the opioids present in toxicology at the time of death. A major strength of our study was that we explicitly looked at the proportion of decedents with prescribed opioids at the time of death and whether or not those

opioids were present in toxicology. We found that actively prescribed opioid prescriptions were often not detected in toxicology. Furthermore, toxicology tests showed that non-prescribed substances were present in >98% of opioid overdose decedents. These data support a focus on illicit opioids as the opioids most likely involved in the overdoses of Massachusetts decedents. Although opioid analgesic stewardship is a worthwhile focus to reduce unnecessary and risky opioid exposure, our data highlight the need to amplify harm-reduction services and the identification and treatment of persons with opioid use disorder to reduce the risk of dying from opioid overdose.

## Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

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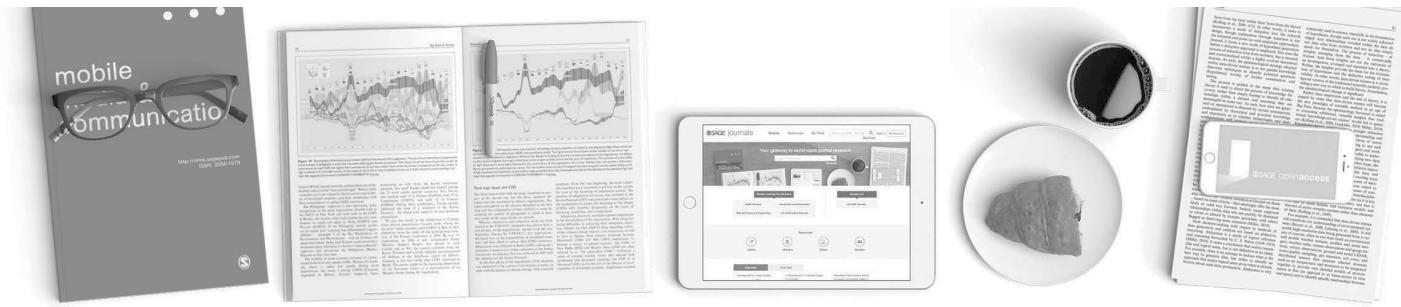
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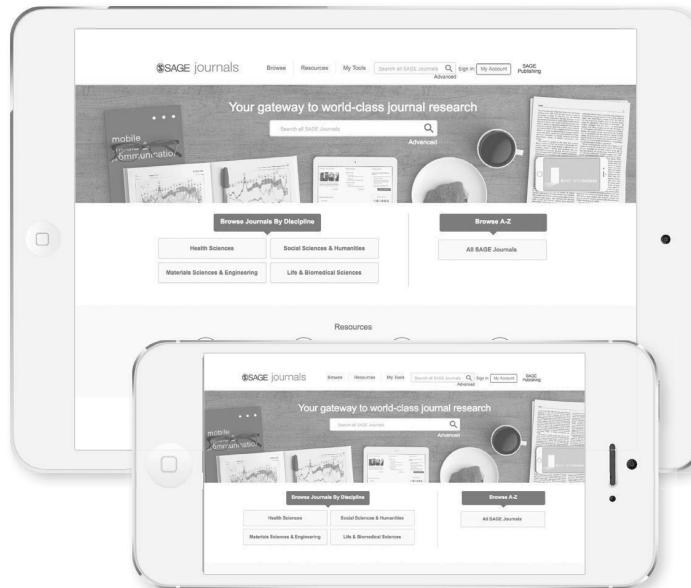
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